AN INVESTIGATION OF THE REHABILITATION NEEDS, DEVELOPMENT, AND PRELIMINARY OUTCOMES OF AN EDUCATION AND EXERCISE SELF-MANAGEMENT INTERVENTION FOR BREAST CANCER SURVIVORS

By

Anita Beutel

BSc Physiotherapy; MPhil Sports Physiotherapy

THESIS PRESENTED FOR THE DEGREE OF

DOCTOR OF PHILOSOPHY

IN PHYSIOTHERAPY

DEPARTMENT OF HEALTH AND REHABILITATION SCIENCES
FACULTY OF HEALTH SCIENCES

UNIVERSITY OF CAPE TOWN

JULY 2024

Supervisors:

Associate Professor Delva Shamley

Associate Professor Theresa Burgess

Associate Professor Nirmala (Niri) Naidoo

Declaration

I, Anita Beutel, hereby declare that the work on which this thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor part of it has been, is being, or is to be submitted for another degree in University of Cape Town or any other university.

This thesis is presented in fulfilment of the requirements for the degree of PhD in Physiotherapy.

I empower the University of Cape Town reproduce for the purposes of researcher either the whole or any portion of the contents in any manner whatsoever.

Signed by candidate

.....

Anita Beutel

17 July 2024

Acknowledgements

This thesis is dedicated to all the courageous breast cancer survivors whom it was my privilege to meet during this project. Thank you for opening my eyes to what life is like after breast cancer. You lead busy lives as mothers, wives, grandmothers, cancer survivors, and breadwinners. And still, you gave your time, insights, and efforts to help those who will be affected by the long-term effects of this disease after you. Your humility, dignity, and inner strength have been inspirational to this body of work.

Thank you to my three supervisors for your consistent, patient wisdom and guidance, which were instrumental to see this project through to completion. Special thanks to Associate Professor Theresa Burgess for planting the seed of this project. If you hadn't suggested it all those years ago, the thought of taking on this academic adventure would never have occurred to me!

Many thanks to the clinical breast cancer experts Dr Ian de Waal, Dr Alista Easton, Dr Corne van Eck, Dr Inarie Jacobs, and Dr Helena van Oers, for graciously donating your expertise to form the intervention handbook into something I hope we can be proud of. Grateful thanks to Portia Motsoeneng for validating the qualitative study results, and for assisting with screening and data extraction for the systematic review. Thanks also to the UCT Health Science Librarian Namhla Madini for facilitating the systematic review search, and to the UCT biostatisticians Grace Carmichael and Dr Innocent Karangwa for assisting with the meta-analysis.

Thank you to my family and friends who kept asking how it was going. Thanks to my parents for collecting all the handbooks from the printers and for sending off each one individually. Thank you to my wonderful husband and children, for your constant love, support, extreme patience, and belief in my abilities.

Finally, I thank God for giving me perseverance, resilience, and self-motivation, in abundance. Without these gifts, this thesis would not exist.

This work was supported by a Research Training Grant from the University of Cape Town.

"Investing in the health of women is an investment in the development of nations and their futures."- Emerita Professor Lynette Denny

Research Outputs

1. Motsoeneng, P. M., Beutel, A., Burgess, T. L., Naidoo, N., Stewart, A., & Shamley, D. (2022). Breast Cancer Rehabilitation Services in South Africa and Survivor Experience of These Services in Two Dedicated Cancer Units. J Cancer Res Immunooncol, 8, 145. Breast Cancer Rehabilitation Services in South Africa and Survivor Experience of These Services in Two Dedicated Cancer Units (researchgate.net)

2. The abstract of this thesis was presented online at the World Forum of Women in Science, held on 16 April 2024 in Rome, Italy. Presentation title: An investigation of the rehabilitation needs, development, and preliminary outcomes of an education and exercise self-management intervention for breast cancer survivors.

Abstract

The central premise of this thesis was that breast cancer (BC) survivors face debilitating long-term side effects (LTSEs) after completing their medical cancer treatment (MCT), such as persistent pain and upper limb dysfunction, cancer-related fatigue, a reduction in health-related quality of life (HRQoL), reduced physical function, weight gain, and lymphoedema. It was hypothesised that BC survivors may not receive education and support to manage these and other LTSEs. It was also hypothesised that LTSEs of BC treatment can be improved by an education and exercise self-management intervention (SMI).

Firstly, a qualitative study using focus group discussions was conducted to investigate the lived experience of LTSEs of BC treatment and the rehabilitation needs of survivors, in a semi-urban region of South Africa (SA). The findings of the qualitative study revealed that survivors were affected by LTSEs of MCT. These impacted their daily lives, and in some cases, the ability to provide for their families. Participants were unable to self-manage their symptoms as they had not been provided with information or rehabilitation for these sequelae of their cancer. Furthermore, many participants lacked support from cancer support organisations, and felt isolated. Transportation and financial challenges were identified, and survivors lived in geographically diverse areas. Attitudes towards and perspectives of participating in a rehabilitation intervention including an exercise component, were positive. However, specific exercise and rehabilitation preferences varied between participants. For example, some participants preferred to exercise in a group, while others preferred to exercise alone, or with a family member. Some participants preferred to receive survivorship information via email or through printed material, while others preferred to receive talks.

Second, a systematic review and meta-analysis was conducted to determine the effectiveness of SMIs including an exercise component, to improve LTSEs and physical activity, in BC survivors following the completion of MCT. The systematic review and meta-analysis presented in this thesis found that, as an alternative to supervised on-site interventions, SMIs including an exercise component are effective to improve LTSEs and increase physical activity, in early-stage BC survivors following MCT.

Third, the results of the qualitative study and the systematic review were used to inform the content and structure; and the Medical Research Council (MRC) guidelines for intervention development were used to inform the process of developing an education and exercise SMI. As patient-centred SMIs based on cognitive behavioural and self-management principles have shown promise in previous chronic disease management programmes, the new intervention ‘Survive and Thrive’ was informed by the abovementioned principles.

Content validation was established by obtaining feedback from a multidisciplinary team of five South African clinical BC experts and refining the intervention accordingly. An acceptability evaluation was conducted through a small qualitative study including three BC survivors. Alterations were made to the intervention according to the results of this study.

The final phase was a single-group, pre-test-post-test study to determine the feasibility, safety, and preliminary outcomes of the newly developed intervention, in early-stage BC survivors who had completed their MCT. The baseline findings of the intervention study suggest that prevalence and levels of pain and cancer-related fatigue were high, and HRQoL index scores and physical activity levels were low at baseline, compared to previous studies of BC survivors conducted in high-income countries. The intervention was feasible and safe to implement in this study. Furthermore, significant improvements were demonstrated post-intervention in terms of pain and fatigue prevalence, severity, and interference, HRQoL, self-efficacy, and exercise participation.

The findings of this thesis revealed that physical LTSEs were a significant problem for South African BC survivors, and that they were largely unaddressed by the standard of care. Further, the findings demonstrated that a resource-efficient SMI was feasible, safe, and potentially effective to improve patient-reported outcomes in South African BC survivors.

Contents

List of tables

List of figures

Abbreviations

AB	Anita Beutel
ACSM	American College of Sports Medicine
BC	Breast Cancer
BFI	Brief Fatigue Inventory
BMI	Body Mass Index
BPI	Brief Pain Inventory
CANSA	Cancer Association of South Africa
CDC	Centers for Disease Control and Prevention
DNA	Deoxyribonucleic Acid
DS	A/Prof Delva Shamley
DVD	Digital Video Disc
EQ-VAS	General Health Score of the EQ-5D-3L Questionnaire
EQ-5D-3L	EuroQol Group 5-Dimension 3-Level Self-Report Questionnaire
FGD	Focus Group Discussion(s)
HCP	Healthcare Practitioner
HIV	Human Immunodeficiency Virus
HRQoL	Health-Related Quality of Life
ICF	Informed Consent Form
IPAQ-SF	International Physical Activity Questionnaire – Short Form
Km	Kilometres
LMIC	Low- and middle income country. Plural: LMICs
LTSE	Long-Term Side Effect. Plural: LTSEs
MCT	Medical Cancer Treatment
MET	Metabolic Equivalent of Task
NCD	Non-Communicable Disease. Plural: NCDs
NICE	National Institute for Health and Care Excellence
NN	A/Prof Niri Naidoo
PA	Physical Activity

PICO	Population, Intervention, Comparator, Outcome
PM	Portia Motsoeneng
QALY	Quality-Adjusted Life Year
QoL	Quality of Life
R4R	Reach for Recovery
SA	South Africa
SE	Self-Efficacy
SE-6	Self-Efficacy for Managing Chronic Disease 6-Item Scale
SMI	Self-Management Intervention. Plural: SMIs
SMR	Stage of Motivational Readiness
SMRPA	Stage of Motivational Readiness for Physical Activity
TB	A/Prof Theresa Burgess
UK	United Kingdom
USA	United States of America
VAS	Visual Analogue Scale
WHO	World Health Organisation

Glossary of terms

Adhesive capsulitis	An inflammatory condition where the body forms excessive scar tissue or adhesions over the glenohumeral joint, causing stiffness, pain, and dysfunction of the shoulder [1].
Adjuvant therapy	The part of medical cancer treatment given after surgery to prevent a cancer recurrence, such as chemotherapy, radiation, endocrine therapy, and biological agents [2].
Aerobic exercise	Physical activity that uses large muscle groups, is continuous, and rhythmic in nature [3].
Anaemia	A condition where the body lacks enough red blood cells to carry oxygen to the tissues, defined in women by haemoglobin levels of less than 12 grams per decilitre of blood [4]. Cancer treatments, blood loss, or decreased red blood cell production may cause anaemia in cancer survivors. Symptoms of cancer-related anaemia include fatigue, pale skin, weakness, and shortness of breath. Anaemia most commonly presents at the time of diagnosis or during chemo- or radiotherapy but may develop later during the cancer trajectory [4].
Axillary web syndrome	This refers to a syndrome that may develop following axillary lymph node dissection (surgical removal of axillary lymph nodes) for breast cancer (BC), where fibrotic cord-like bands form in the axilla of a patient. Axillary web syndrome is self-limiting in most cases, however it causes significant upper limb morbidity [5].
Breast cancer survivor	A breast cancer survivor is someone who has been diagnosed with BC, from their cancer diagnosis until the end of their life [6]. However, throughout the literature, patients who have completed their primary medical cancer treatment consisting of surgery, combined with chemotherapy or radiation, or both, are referred to as breast cancer survivors [7-9]. Similarly, in this thesis, breast cancer survivors are patients who have completed primary medical cancer treatment.

Breast conservation surgery	Also known as breast conserving surgery, partial mastectomy, or lumpectomy. This is a surgical procedure where only the cancerous lump (tumour) is removed, leaving as much of the normal breast tissue intact as possible. Breast conservation surgery is recommended for early stage (I-III) BC [10].
Cancer	A group of diseases where abnormal cells grow and spread uncontrollably due to deoxyribonucleic acid (DNA) damage [11].
Cancer-related fatigue	Persistent physical, emotional, and mental exhaustion related to cancer and its medical treatment. Cancer-related fatigue is not relieved by resting or sleeping, and it interferes with usual daily activities [12, 13]. Both 'fatigue' and 'cancer-related fatigue' refer to cancer-related fatigue in this thesis.
Chronic diseases	Conditions such as heart disease, stroke, diabetes, obesity, metabolic syndrome, and some cancers. These result from years of leading an unhealthy lifestyle: a diet high in saturated fat, sugars and salt, smoking, drinking excessive alcohol and low physical activity [14]. After completion of primary medical cancer treatment, BC is regarded as a chronic disease [7].
Content validity	The extent to which an intervention is likely to be relevant and effective for its intent and for its target population [15].
Ductal carcinoma in situ	A non-invasive BC type situated within the milk ducts of the breast. The abnormal cells have not invaded the surrounding tissue. This is considered the earliest form of BC [16].
Endocrine therapy	Also known as hormone (blocking) therapy; endocrine therapy consists of systemic drugs taken to block the growth of hormone-sensitive tumours. This treatment is usually given for five to 10 years to prevent a cancer recurrence, in hormone receptor positive breast cancer [6].

Exercise	Physical activity which includes planned, structured, repetitive movement of the body done to improve physical fitness [17].
Exercise guidelines for cancer	The dosage of exercise recommended to improve survival, optimise health, and to reduce the risk of cancer recurrence. Survivors of BC are advised to exercise moderately for at least 150 minutes per week, and to include muscle strength training [18].
Exercise guidelines for cancer-related health outcomes	An effective exercise prescription to improve specific health outcomes in cancer survivors. For most outcomes, such as fatigue and health-related quality of life, at least 30 minutes of moderate exercise, three times per week for at least eight to 12 weeks is required to gain improvements. Aerobic and resistance training in combination is advised [18].
Flesch-Kincaid readability	This is an indication of how difficult text is to read and understand in English. Grade level means the average student in that grade can read the text in question. For example, grade level 8 means a student in grade 8 should be able to read the passage in question [19].
Physical function	Activities defined by an individual that are essential for the maintenance of quality of life or independence [20].
Health-related quality of life	The perceived physical or mental health of individuals with a medical disorder, causing symptoms or impairing their daily life [21].
Healthy lifestyle	Living life while maintaining a body weight within the normal range, exercising regularly, eating a nutritious diet, avoiding excessive alcohol, and not smoking. These factors reduce the risk of many lethal chronic diseases [22]. For BC survivors, leading a healthy lifestyle optimises overall survival, lowers the risk of a cancer recurrence, and helps to prevent and treat many long-term side effects (LTSEs) of cancer treatment [6, 7, 23].

Long-term physical side effects	Lingering sequelae of medical breast cancer treatment related to physical functioning, such as chronic pain and upper limb morbidity, cancer-related fatigue, lymphoedema, weight gain, and loss of fat-free mass [6, 24].
Lymphoedema	Breast cancer-related lymphoedema occurs when the network of lymph nodes and lymphatic vessels gets damaged by disease, surgery, or radiation. Protein-rich lymph accumulates in the interstitial spaces due to an imbalance between lymph fluid production and transport. This leads to upper limb swelling and multiple symptoms on the affected side [25].
Mastectomy	Breast cancer surgery where the entire breast is removed [10].
Medical cancer treatment	Medical cancer treatment (MCT) includes surgery, chemotherapy, and radiation, used separately, or combined [6]. Medical treatment depends on the stage, size, location and tumour characteristics [26]. After this primary MCT, endocrine therapy is often prescribed for several years if the tumour is hormone receptive [6].
Moderate exercise	Planned, structured, organised physical activities such as brisk walking, cycling on level ground and dancing, where one can talk, but not sing, during participation [17, 27].
Muscle strengthening	Exercises that increase muscle strength by making muscles work against a weight or force [3]
Non-communicable diseases	Diseases which cannot be transmitted directly from one person to another, such as most types of cancer, cardiovascular- and respiratory diseases [28].

Patient-reported outcomes	Feedback on a patient's health condition such as symptoms and quality of life coming directly from the patient, without external interpretation and using validated instruments [29].
Physical activity	Body movement produced by skeletal muscle contraction resulting in a substantial increase in energy expenditure [17]. While exercise is structured and planned physical activity performed with the goal of improving health, physical activity is a broader term which includes activities such as taking the stairs, gardening, or walking to work [17]. While these two terms are often used interchangeably throughout the literature, they will be referred to specifically wherever possible, in this thesis.
Rehabilitation	The aim of rehabilitation in BC is to restore function and independence in everyday life, while encouraging an active, healthy lifestyle [30]. These elements are essential to prevent cancer recurrence, reduce the risk of chronic diseases and to facilitate re-integration into society [31]. Rehabilitation has shown to be effective after cancer treatment to improve the physical function of survivors [30-32]. Maximising physical function has the added benefit of reducing the long-term load on healthcare systems [30].
Retention rate	The number of participants who remain in the study until the endpoint data collection, as a percentage of those recruited for baseline assessments [33].
Rotator cuff injury	Damage in the form of a tendinopathy, partial, or full tear of the group of muscles and tendons that move the shoulder joint [34]. This may be caused by trauma, overuse, and the ageing process. An injury to the rotator cuff muscles can cause shoulder pain, swelling, weakness, and limited range of motion of the arm [34].
Self-efficacy	A person’s belief in their ability to succeed in different situations [35].

Self-management	Active participation by the person in their recovery and rehabilitation, to minimise the consequences of their disease, and promote survival, health, and well-being. In cancer survivorship, self-management is the ability to manage health problems resulting from cancer [36].
Social cognitive theory	This theory of learning suggests that understanding, behaviour, and the environment are interrelated. The theory consists of motivational and self-regulatory mechanisms. The social cognitive theory explains the nature of bidirectional reciprocal influences through learning, symbolising, forethought, self-reflection, and self-regulation [37].
Stage of breast cancer	Staging relies on the tumour size (stage I is the smallest), whether the lymph nodes are affected and whether there is spread beyond the axilla. Non-invasive BC is stage 0. These cancers have not grown into the stroma and have not spread to other tissues [38]. In early invasive BC (stages I to III), there is no evidence of spread to distant parts of the body. Stage IV is metastatic (late stage) BC, where the cancer has spread to distant sites [38].
Survivorship	The period following medical BC treatment where survivors need support and follow-up care. This includes surveillance for recurrence or new cancer, management of symptoms after the end of MCT, evaluating the risk for and prevention of long-term side effects, assessment and provision of psychological support, and education on healthy lifestyle to reduce morbidity and mortality [6, 39].
Thyroid dysfunction	This is referred to when the thyroid gland, producing hormones that regulate vital body functions such as heart rate, body temperature and respiration, secretes too much (overactive thyroid) or too few hormones (underactive thyroid) [40].

Chapter 1. Introduction and thesis outline

1.1 Background and nature of the problem

Non-communicable diseases (NCDs) such as cancer, cardiovascular- and respiratory disease are the leading public health challenges worldwide, affecting people of all countries, regions, and age groups [28]. Non-communicable diseases make up a third of the global burden of disease, resulting in 41 million deaths each year. They disproportionally affect low- and middle income populations, where more than three quarters of deaths due to NCDs occur [28]. Because NCDs are typically of long duration, these largely preventable diseases are not only associated with life loss, but also with ill health, reduced quality of life, loss of income, and poor social development [28]. This places a strain on already disadvantaged people and economies of low- and middle income countries (LMICs), who are dealing with an increased burden of communicable diseases in parallel [41]. For example, South Africa (SA) is a middle income country with a growing burden of NCDs [42]. In 2016, NCDs caused 57.4% of deaths in this country [42].

Cancer is a major group of NCDs causing the second most deaths worldwide [43]. Breast cancer (BC) is the most common type of cancer in women[1]: over 12% of women will be diagnosed in their lifetime [45]. Previously regarded a disease of the developed world, almost 50% of cases and 70% of deaths now occur in LMICs [45, 46]. In Africa, BC is the most frequently diagnosed cancer, predominantly affecting younger women [47]. The African BC incidence increased from 92 600 cases and 50 000 deaths in 2008, to 168 690 cases and 74 072 deaths, in 2018 [48]. On this continent, the BC incidence is expected to double by the year 2050 [49]. This rising burden is partly explained by a lack of physical activity, overweight and obesity, and poor dietary choices, as lifestyles are becoming more urbanised [50].

Breast cancer survivors form the largest group of cancer survivors in the world, and this poses a substantial global disability burden [45]. Particularly for early-stage (non-metastatic) BC, which includes stage I, II, III, and ductal carcinoma in situ, the five-year survival rates in high-income countries are estimated to be between 70 and 99% [51].

[1] The author is aware of the distinction between biological sex and gender used in research. In this thesis, a gender-informed perspective is taken, where the term 'women' refers to persons who self-identify as females.

44. Rich-Edwards, J.W., et al., *Sex and Gender Differences Research Design for Basic, Clinical, and Population Studies: Essentials for Investigators.* Endocrine Reviews, 2018. **39**(4): p. 424-439.

There are no survival data by stage, for African countries [47]. However, for all breast cancers combined, including metastatic BC, the five-year survival rate of BC in SA is estimated at 62% [47]. Increased survival means that globally, there has been a shift in focus towards the health-related quality of life (HRQoL) of women after completing their primary Medical Cancer Treatment (MCT) [52]. In 2021, the World Health Organization (WHO) launched the Global Breast Cancer Initiative, marking a milestone to address this global health challenge. This initiative strives to support those affected by BC through three main pillars: health promotion, timely diagnosis, and comprehensive treatment and supportive care [53].

Indeed, supportive care is necessary after the completion of MCT, when patients commonly experience cumulative, debilitating long-term side effects (LTSEs) [24]. Up to 90% of cancer survivors experience LTSEs [54]. These may occur unexpectedly, during a time when frequent visits to the breast clinic have come to an end [24]. For example, persistent pain and upper limb morbidity, cancer-related fatigue, a decline in HRQoL and activities of daily living, weight gain, and lymphoedema [24, 26]. Breast cancer survivors face these and other health challenges for 10 years or more, after completing MCT [24, 55-57]. Long-term side effects of BC increase survivors' chances of developing secondary cancers, reduce their life expectancy and economic activity [52]. Low income, low levels of education, a lack of social support, obesity, and insufficient exercise, have been associated with more severe LTSEs during survivorship [58, 59].

Apart from functional limitations and physical impairment resulting from LTSEs with detrimental effects on their quality of life, affected women often have other chronic diseases of lifestyle, such as hypertension and type two diabetes mellitus [60]. After completing adjuvant MCT for BC, the commonly experienced LTSE weight gain, further increases the risk of developing chronic diseases [7]. Furthermore, chemotherapy may cause long-term damage to the heart (cardiotoxicity), which increases the risk of cardiovascular disease in survivors [61]. This multiple burden of LTSEs and comorbidities in BC survivors places a strain on those diagnosed and on the health system, creating new challenges for holistic health care and rehabilitation service delivery [62].

A healthy lifestyle is key to prevent cancer recurrence, chronic diseases of lifestyle, and to improve survival in BC survivors [23, 63, 64]. Moreover, robust evidence shows that interventions including exercise are effective to prevent and improve commonly occurring physical LTSEs [65-68].

Published exercise guidelines for cancer survivors exist, which have been refined to specify the frequency, intensity, time, and type of exercise needed to improve health-related outcomes associated with cancer and its treatments [18]. Despite this, research shows that only 10 to 20% of cancer survivors participate in regular exercise after their MCT [69]. Without intervention, exercise participation typically declines during MCT and rarely returns to pre-treatment levels [70].

South Africa (SA) has the highest identified incidence rate of BC on the African continent, and the incidence is increasing [45, 47]. In this country, many women are breadwinners for their families [71, 72]. Women using the public health system in SA do not typically have medical insurance [62]. They receive medical care through primary health clinics, served by the poorly resourced public health sector [73]. South African BC survivors may be less wealthy and more isolated in terms of access to health services, than most survivors in high-income countries [62, 74]. Furthermore, South African women who use public health facilities do not have access to routine screening programmes to detect BC [49]. Paired with inadequate public awareness of BC, this leads to delays in diagnosis and treatment, requiring more aggressive treatment regimens [75]. As a result, it can be argued that South African BC survivors may be disproportionately vulnerable to LTSEs following MCT [39]. While it is recognised that BC occurs commonly in both older and younger women, BC characteristics, treatment, and rehabilitation strategies differ between these age groups [76]. As most women with BC are aged between 18 and 70 [77], the focus of this thesis will be on adult women with BC.

The importance of rehabilitation in cancer is growing with the increasing number of cancer survivors, and considering the prevalence of LTSEs [78]. According to the National Cancer Institute Dictionary of Cancer Terms, cancer rehabilitation is defined as “a process to restore mental and / or physical abilities lost to injury or disease, to function in a normal or near-normal way” [79]. There is very little research regarding the experience of LTSEs, how these affect the lives of women, and their rehabilitation needs, in South African BC survivors. The management of LTSEs of BC is likely to rely on pharmacological agents, even though their effectiveness for this purpose is limited [7, 80]. This may place a further strain on the health system, causing unnecessary expenses and side effects [80, 81]. The WHO stipulates that women should receive rehabilitation interventions following MCT [53]. Yet, the standard of care in both public and private health facilities in SA does not provide education or rehabilitation interventions for BC survivors, following the completion of their MCT [39, 62, 74]. To fill this gap, a theoretical framework was adapted within which to explore the experience of LTSEs, their rehabilitation needs, the development, and subsequent evaluation of an intervention.

1.2 A theoretical framework for the management of LTSEs

This thesis is based on a modified conceptual framework for person-centred care [82], integrating the essential components of self-management [83] and cognitive behavioural principles [37].

The person-centred care model was deemed an appropriate foundation for this thesis as it strives to understand the person as a unique being, together with their context and individual preferences [82]. Thus, it refrains from reducing a person to just their diagnosis or symptoms [82]. This model, based on the biopsychosocial model, sees the person (BC survivor) as a holistic entity while respecting their right to self-determination [82]. Ensuring that people are involved in, and at the centre of the healthcare process, is regarded as key to developing high-quality care [84]. Conceptually, person-centred care requires researchers, healthcare providers, and patients to partner up, working together to create and deliver effective, efficient health interventions [82].

The process of exploring the experience and needs of survivors, and the subsequent development and evaluation of a person-centred intervention for women with early-stage BC after the completion of primary MCT, is presented in Figure 1. This thesis commenced by exploring women's experiences and needs (context), developing an intervention (process) accordingly, and then evaluating its outcomes [82]. Ideally, each element should be revisited in the future, as contextual needs may evolve, requiring adaptions or a novel process to produce favourable outcomes [85].

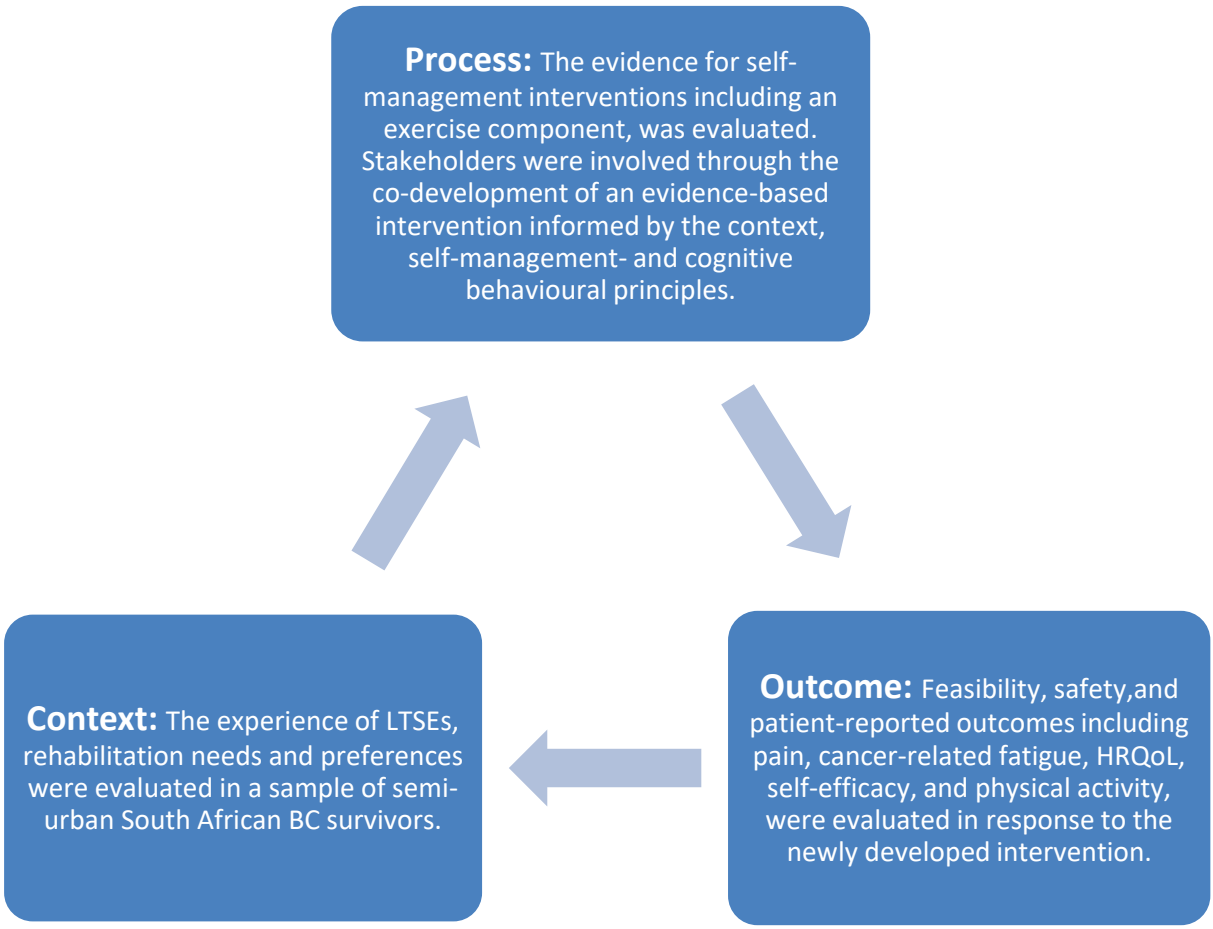


Figure 1: Theoretical framework of this thesis, adapted from the model of person-centred care [82].

1.3 Research setting: The South African health system

South Africa has a population of about 62 million people (2022 census data) [86]. The population consists of more women (51.5%) than men, and approximately 65% of people are aged between 15 and 64 years [86]. South Africa is a developing middle-income country characterised by persistent social, economic, and health service inequality [87]. This is owing to its legacy of apartheid, a system of institutionalised racial segregation which lasted from 1948 until 1994 [87]. The South African health system is two-tiered, consisting of a large, poorly funded public sector and a smaller, better resourced private sector [87]. According to the latest General Household Survey conducted in 2016, only 17 in 100 South Africans can afford medical insurance, which provides access to private health facilities [88]. Therefore, the great majority of the population are dependent on public healthcare, which is poorly funded, overburdened, and under-staffed [89]. Furthermore, the South African public health system is plagued by widespread inefficiencies, staff shortages, and suboptimal care levels and patient management [87].

Across the nine South African provinces presented in Figure 2, there are only nine specialised breast care units in the entire public health sector, serving BC patients and survivors from a vast geographical area [90, 91].

Despite its limitations, the South African health system strives to promote a primary health care approach, focusing on health promotion and preventive strategies. The focus is on community participation and on patient empowerment, with the aim of improving health outcomes and effective communication between healthcare providers and patients [92]. Therefore, it is within the scope of healthcare providers managing BC survivors after MCT to integrate this approach, empowering survivors with skills and knowledge to self-manage their LTSEs.

A tertiary hospital in the southernmost province called the Western Cape, in the Eden District (Figure 2) is the only public hospital including an active Oncology unit in this province, apart from the Cape Town Metropole, (situated in the far West of the province, 431 kilometres away). This hospital supports other district hospitals in rural and outlying sub-districts, serving patients from a predominantly low socio-economic background [93]. Oncology patients are referred here from the entire region, spanning an area of several hundred kilometres. For example, the distance between three outlying towns and the Oncology unit serving these towns is 164, 163 and 129 kilometres, respectively. Throughout SA, many cancer patients are served by healthcare facilities far away from their homes [94].

As most women diagnosed with early-stage BC will become long-term survivors [6, 59], it was necessary to gain an understanding of the experiences and rehabilitation needs of women in a relatively underserved, semi-urban to rural region of SA such as the Eden District, Western Cape. The researcher resided in this district, which provided an opportunity to conduct a study in this region.
The results informed the development of an intervention that could potentially translate to clinical practice, in LMICs. In the final phase of this project (Chapter 5), the intervention 'Survive and Thrive' was remotely delivered and evaluated, which allowed BC survivors to participate in the intervention from throughout the country. Participants in that study were from six South African provinces: Western Cape, Northern Cape, Eastern Cape, Gauteng, KwaZulu-Natal, and North West (Figure 2).

Figure 2: Map of South Africa showing its provinces and districts. Retrieved from South Africa Maps & Facts - World Atlas on 12 June 2024.

1.3.1 Problem statement

Physical LTSEs affect the HRQoL of BC survivors for years after the completion of primary MCT [24, 95]. Interventions including education and advocating exercise can ameliorate these debilitating health challenges [68, 96-98]. Breast cancer is the most commonly occurring cancer in SA [72]. However, many survivors in this geographically large country may be isolated from each other and from specialised breast clinics, which can compromise their access to survivorship care [99].

The experience of LTSEs and the rehabilitation needs of South African BC survivors, were unknown, and there seemed to be a lack of supportive interventions following the completion of MCT, for survivors in this country. Therefore, this thesis set out to explore this gap in research and in the provision of supportive care.

1.3.2 Research questions

This thesis addressed the following research questions:

- What is the experience of South African early-stage BC survivors in terms of physical LTSEs, once they have completed MCT; what are their rehabilitation needs; and their perspectives of exercise?
- How effective are SMIs including an exercise component, to manage commonly occurring physical LTSEs such as pain and fatigue, and to improve HRQoL, self-efficacy and physical activity, in early-stage BC survivors following MCT?
- Can an evidence-based, resource-efficient, acceptable intervention be developed in SA, meeting the needs of BC survivors?
- Is the new intervention feasible, safe, and potentially effective to improve commonly experienced LTSEs, HRQoL, self-efficacy, and physical activity; in South African early-stage BC survivors who have completed primary MCT?

1.3.3 Aims and objectives of this thesis

The broad aim of this thesis was to describe the development, implementation, and evaluation of an intervention to improve the self-management of commonly occurring physical LTSEs, and physical activity of South African BC survivors. The chapter-specific aims and their objectives were as follows:

Aim 1: To explore the lived experience of physical LTSEs, and to investigate the rehabilitation needs of BC survivors in a semi-urban setting in SA (Chapter 2). The specific objectives of aim 1 were to:

- Explore the lived experience of long-term physical side effects of MCT.
- Describe BC survivors' perspectives of exercise participation.
- Describe women's rehabilitation needs and preferences, regarding content, delivery, modes of exercise or activity, venue, frequency, healthcare provider or peer led.

Aim 2: To evaluate the effects of self-management interventions including an exercise component and utilising minimal clinical visits, on physical LTSEs and physical activity, in early-stage post-treatment BC survivors (Chapter 3).

The specific objectives of aim 2 were to:

- Determine if SMIs including an exercise component, utilising minimal clinical visits and equipment, are effective at improving LTSEs such as pain, cancer-related fatigue, body composition, HRQoL, self-efficacy, and physical activity.

- Determine if a suitable, effective SMI including exercise, and utilising minimal clinical visits, already existed that met the rehabilitation needs and preferences identified in Chapter 2.

Aim 3: To develop an intervention using published guidelines, based on the data from the preceding chapters, and to evaluate its content validity and acceptability (Chapter 4). The specific objectives of aim 3 were to:

- Develop an intervention based on the results of the qualitative study in Chapter 2, the systematic review in Chapter 3, and on current evidence-based cancer rehabilitation literature, using self-management [83] and social cognitive [37] principles.
- Establish the content validity of the developed intervention handbook, through the review and feedback by a South African multidisciplinary team of clinical BC experts.
- Evaluate and improve the acceptability of the new intervention, through a small qualitative study.

Aim 4: To evaluate if the newly developed intervention was feasible and safe to deliver, and if it was associated with improvements in commonly occurring physical LTSEs, physical activity, HRQoL, and self-efficacy (Chapter 5). The specific objectives of aim 4 were to:

- Describe the sample of BC survivors in terms of their socio-demographic characteristics, MCT details, and reported chronic medication use.
- Determine the feasibility of the intervention, based on pragmatic evidence-based feasibility criteria.
- Determine the safety of the intervention, based on the number of adverse events related to participation in the study.
- Determine if there was a significant difference in the following patient-reported outcome measures after participating in the new intervention for 12 weeks, compared to baseline:
    - Pain prevalence, severity and interference with function using the Brief Pain Inventory (BPI).
    - Self-efficacy using the Self-efficacy for Managing Chronic Disease 6-item Scale (SE-6).
    - Health Related Quality of Life (HRQoL) using the EQ-5D-3L questionnaire.
    - Physical activity levels using the IPAQ-SF (International Physical Activity Questionnaire Short Form).
    - The number of participants who met the minimum exercise guidelines for improving cancer-related health outcomes (at least 90 minutes of moderate activity per week [18]), using data from the IPAQ-SF.

- Hours per week spent sitting, using the 'sitting on weekdays' question from the IPAQ-SF.
- Fatigue prevalence, severity, and interference with function, using the Brief Fatigue Inventory (BFI).

1.3.4 Significance of this thesis

As per the Breast Health Global Initiative Global Summit, all BC survivors should receive supportive interventions after MCT [39]. There is a need for developing and implementing patient-centred, evidence-based management strategies for chronic diseases including cancer, in SA [60, 100-102]. Furthermore, the recent coronavirus pandemic has highlighted the need for BC survivorship interventions which do not require on-site clinical visits [95, 103]. It was hypothesised that a resource-efficient intervention including self-management, education, and exercise, could be developed for BC survivors. It was further hypothesised that such an intervention may benefit South African BC survivors regardless of their geographic location or socio-economic status, and that it may be feasible and safe to implement. Therefore, the significance of this project was that it aimed to address this gap in research and in the provision of supportive care.

1.3.5 Main outcome of this thesis

The main outcome of this thesis was the development and implementation of an education and exercise SMI, which is feasible, safe to deliver and potentially effective to improve LTSEs and physical activity, in South African early stage BC survivors following MCT.

1.4 Thesis outline

In this thesis, a series of studies were conducted sequentially and will be presented by chapter. In Chapter 2, the qualitative study: 'An investigation of the rehabilitation needs for physical long-term side effects of treatment in breast cancer survivors', is presented. In Chapter 3, 'Self-management interventions including an exercise component, for breast cancer survivors: a systematic review and meta-analysis', is presented. In Chapter 4, the development and acceptability of a self-management intervention for BC survivors, designed according to the data in the preceding chapters, is systematically described using published intervention development guidelines. In Chapter 5, a single group, pre-test post-test study to evaluate a supported self-management intervention for breast cancer survivors, is presented.

Finally, in Chapter 6, a discussion, summary, and conclusion are presented, including the clinical implications and applications of the research, and recommendations for future research.

Chapter 2. An investigation of the rehabilitation needs for physical long-term side effects of treatment, in breast cancer survivors.

2.1 Introduction

Rehabilitation needs arise when survivors do not have the capacity to recover from the sequelae of their cancer by themselves, and they require external resources to achieve wellbeing [104]. Understanding the experience of long-term side effects (LTSEs), and the rehabilitation needs and preferences of survivors after breast cancer (BC) treatment in South Africa (SA), is a critical first step towards the development of feasible, acceptable rehabilitation interventions [84]. The patient-centred model advocates that the needs and preferences of patients should be solicited to achieve optimal survivorship outcomes [105]. Equitable and collaborative intervention development between researchers, healthcare professionals and end-users is needed to improve outcomes and ultimately, to improve the quality of life of cancer survivors [84]. Therefore, the lived experience of LTSEs of BC; rehabilitation needs; and attitudes towards exercise participation of BC survivors were explored in this study to inform a patient-centred intervention for BC survivors.

2.2 Research question

What is the experience of South African early-stage BC survivors in terms of physical LTSEs, once they have completed medical cancer treatment (MCT); what are their rehabilitation needs; and their perspectives of exercise?

2.3 Research aim and objectives

2.3.1 Aims of this study

To explore the lived experience of physical LTSEs, and to investigate the rehabilitation needs of BC survivors in a semi-urban setting in SA.

2.3.2 Objectives of this study

- To explore the lived experience of long-term physical side effects of MCT.
- To describe BC survivors' perspectives of exercise participation.
- To describe women's rehabilitation needs and preferences, regarding content, delivery, modes of exercise or activity, venue, frequency, healthcare provider or peer led.

2.4 Methodology

2.4.1 Research design

Qualitative methodology offers an excellent in-depth exploration of experiences and needs, from the perspectives of patients [106]. Since the goal of qualitative research is "to produce a rich description and in-depth understanding of the phenomenon of interest, the cultural or lived experience of people in natural settings" [107], qualitative research was suitable to address the research question for this study. There are many qualitative research designs, such as phenomenology, ethnography, narrative enquiry, grounded theory, and qualitative descriptive. The design chosen for this study was the qualitative descriptive design [108]. This design is philosophic in tradition, drawing from naturalistic enquiry [108, 109]. Its scope is limited to producing a clear description of an experience or situation from the perspective of participants, without being bound to a particular theory or target phenomenon [109]. Further, a qualitative descriptive design is committed to discovering the nature of specific events or experiences, without producing a theory from the data generated. The results from a qualitative descriptive study are useful for providing information to develop new interventions [108]. Therefore, a descriptive approach was appropriate for this study as we were interested in how LTSEs are experienced by BC survivors; and in exploring their perceptions of exercise and intervention preferences.

Focus groups are widely used in healthcare research [110]. They are an excellent way to study what people think and why [111]. Focus groups have been selected above individual interviews for this study to allow conversation, agreement, and disagreement amongst participants, which stimulates sharing of experiences and opinions [112]. Open-ended questions from a semi-structured interview guide were used, and sessions were recorded. A rigorous, standardised approach was used to transcribe, translate, analyse, and report data. This study adhered to the Enhancing the Quality and Transparency of Health Research (EQUATOR) reporting guidelines for qualitative research (COREQ) [113]. The completed COREQ checklist is included in Appendix A.

2.4.2 Setting

The setting for this study was a public tertiary hospital in the Eden District, Western Cape, SA. Refer to Chapter 1, 1.3 Research setting: the South African health system.

2.4.3 Participants

2.4.3.1 Inclusion criteria

Inclusion criteria were as follows:

- Women aged between 18 and 70 years. Most women with BC are in this age range, and this is the age range in which most previous research has been conducted. Breast cancer in males is uncommon [114].
- Ductal carcinoma in situ, stage I, II or III BC following MCT: surgery with or without adjuvant therapy. Surgery and adjuvant therapy (chemotherapy and radiation) are major risk factors for LTSEs [24]. Stage IV (metastatic) BC treatment and rehabilitation strategies differ [32].
- Primary MCT completed within the last five years. Treatment-related side effects may persist for this period or present as late effects [55, 57, 115].
- Participants have completed primary MCT at least six months prior to their participation. This was to ensure that they had been exposed to living with LTSEs, and to allow for acute side effects of MCT to attenuate.
- Breast cancer survivors lived in the Western Cape, Eden District: Participants had to be able to attend a focus group discussion (FGD) at this hospital. They were reimbursed for their travel costs to attend a FGD at this facility.
- Breast cancer survivors were fluent in English, Afrikaans, or isiXhosa: the three most spoken languages in this region. This was to ensure that participants were to be able to converse with each other to share experiences and ideas.

2.4.3.2 Exclusion criteria

The exclusion criteria for this study were as follows:

- Other malignancies or metastatic disease, to ensure that reported experiences reflect lived experience of BC.
- Previous diagnoses of Alzheimer's disease, dementia, psychosis, schizophrenia, intellectual dysfunction, or organic brain syndrome, which may influence memory or the ability to communicate. This was to ensure the credibility of reported experiences, and that participants were able to participate in the research process and complete questionnaires reliably.

2.4.4 Sampling and recruitment of participants

Purposeful sampling was used for this study. Sampling and data collection continued until data saturation was achieved. Saturation was defined as the point when new data became redundant with data already collected: the same comments recurred and no new data was apparent [116]. Saturation was not defined by a preset number of FG discussions [117].

Using purposive sampling, participants were selected based on their alignment with the inclusion criteria listed above. The purposive strategy included survivors from a wide age range, with various cancer stages, and both early- and long-term survivors, who shared the commonality BC survivorship. This was to provide a sample that represented a variety of experiences and perspectives, to explore how LTSE during BC survivorship affected them within this framework. Participants were intentionally selected based on criteria relevant to the research question. This facilitated the gathering of in-depth information from targeted individuals who were most likely to provide valuable insights and to understand specific experiences, specifically LTSE of BC treatment. Leaflets advertising the study and outlining the inclusion criteria of prospective participants were placed in the waiting areas of a public hospital oncology unit and outpatient clinics in the Western Cape, Eden District (Appendix B). The information on the advertisements requested interested respondents to place their contact details in a sealed box marked 'Breast cancer and exercise research'. The researcher contacted interested women telephonically to confirm their eligibility to participate using the inclusion and exclusion criteria and invited them to attend a single FGD.

2.4.5 Instrumentation

A self-developed socio-demographic questionnaire (Appendix C) was used to obtain descriptive information about the study sample such as age, employment status, household income, and cancer treatment details. Questions were closely based on socio-demographic questionnaires previously used in qualitative BC survivorship research [118-121]. The questionnaire was validated during the first FGD. This allowed questions that were not well understood by participants, to be adapted following this first session to improve clarity. The question 'Are you taking hormone therapy' was misunderstood by some participants to mean hormone replacement therapy. The question was subsequently adapted to read: 'Are you taking hormone blocking medicine, such as Tamoxifen?' Further measurement instruments for this study included the researcher, the self-developed FGD guide (Appendix D) and a Philips DVT6010 digital audio-recorder.

The female researcher AB facilitated all FGD sessions. The researcher was trained by a qualitative researcher and co-supervisor NN for this purpose. In addition, DS, the primary supervisor and an experienced BC researcher, attended the first FGD via digital media. The researcher is an experienced clinician with a masters' degree in physiotherapy. The researcher did not know the study participants, at the time of inviting them to attend an FGD. The researcher may have been biased due to her interest in the research topic, and due to an endeavour to help improve the survivorship care offered to women with BC. To minimise this bias, the FGD guide was used (Appendix D).

Questions in the guide were aimed at exploring commonly experienced physical LTSEs of participants, and to assess participants' perspectives of exercise. In the final section of questions, rehabilitation preferences were explored. The guide was developed in collaboration with the supervisory team and based on previous qualitative studies in BC [118-120, 122]. The final section of questions regarding rehabilitation preferences, were unique to the context of this study. Credibility of the FGD guide was improved by running a pilot session (first FGD) and then refining the questions where needed. Each FGD was conducted in English and Afrikaans, the languages preferred by the participants of this study. All participants were able to understand and speak both these languages, even though many participants were most comfortable speaking Afrikaans. Such bilingualism, and often also multilingualism, is not unusual in SA [123]. In the Western Cape, the predominant population group are from a mixed ancestry referred to as 'coloured' [124]. Amongst the coloured population in the Western Cape, Afrikaans is the most frequently spoken mother tongue [125]. In this study, one participant reported that her home language was isiXhosa. However, she assured the researcher that she was able to understand English and Afrikaans and would be comfortable to converse in English during the FGD[2]. Four to five participants participated in each FGD to elicit a good discussion and varying opinions, while maintaining a familiar, comfortable atmosphere [116]. Once five participants had been scheduled to attend a FGD, another FGD was opened for the next consenting participants, until data saturation was reached. If a participant who had been scheduled for an FGD, was unable to attend on a specific day, they were offered attendance at the next FGD on a day and time that suited them.

2.4.6 Procedure

Ethical approval was obtained from the Human Research Ethics Committee of the Faculty of Health Sciences, University of Cape Town (Reference number 506/2019, Appendix E). Permission to conduct the study was granted from the Western Cape Department of Health and from the public tertiary hospital (Appendix F). The researcher contacted respondents to the leaflet advertising the study telephonically using the contact details they had placed in the sealed boxes. After confirming their eligibility to participate, the researcher invited the prospective participant to attend an FGD.

[2] South Africa is a country characterised by multilingualism. There are 11 official languages: English, which is widely used in public domains for commercial, educational and political purposes, Afrikaans, which has the widest geographical, racial, and demographic distribution, and nine further languages. 123. Posel, D. and J. Zeller, *Language shift or increased bilingualism in South Africa: Evidence from census data.* Journal of Multilingual and Multicultural Development, 2016. **37**(4): p. 357-370. 125. Wissing, D.P., *Afrikaans.* Journal of the International Phonetic Association, 2020. **50**(1): p. 127-140.

On the day of their FGD, the researcher explained the study purpose and procedure verbally; gave potential participants an opportunity to read the informed consent form (all participants were literate); to ask questions in case anything was not clear; and invited them to sign informed consent and the confidentiality agreement (Appendices G and H). The informed consent form, confidentiality agreement and the socio-demographic questionnaire were available on site in English and Afrikaans, as these were the languages in which this cohort of participants were fluent. Language preferences had been confirmed when contacting each participant to invite them to attend a FGD. Participants were requested to take part in all aspects of the study: to sign informed consent, complete the socio-demographic questionnaire, sign the confidentiality agreement, and to attend a single FGD. Non-participants were not permitted to be present during an FGD.

Once informed consent and the confidentiality agreements had been signed, participants completed the socio-demographic questionnaire. Only the study number was recorded on the questionnaire, to ensure participants' privacy. To protect anonymity, the researcher linked the names of participants to the study number via a master list (Appendix I). The researcher collected and stored the socio-demographic questionnaires as soon as they were completed. The researcher invited participants to assume pseudonyms if they preferred, however none did so. Before the start of each FGD, participants were reminded that they were to be audio-taped, and that their anonymity and confidentiality would be protected within the study. Although participants were requested to keep what was discussed in the FGD confidential, they were made aware that confidentiality within the group of participants could not be guaranteed. Participants who felt uncomfortable being audiotaped were free to withdraw.

The audio-recorded FGD started when all the socio-demographic questionnaires were completed. Women sat in a circle, to encourage openness and to foster a supportive environment. Each session commenced with refreshments, and a relaxed environment was created. At the start of an FGD, the researcher introduced herself, explained to the participants the reasons for doing the research: the lack of information available on LTSEs in South African BC survivors, and the possible need for an intervention to support women in managing LTSEs. Colourful concept notes were placed on the table in the centre of the room, containing the words 'shoulder', 'body weight', 'fatigue', 'physical ability' and 'arm swelling'. These were used to remind participants that the discussion was about physical LTSEs experienced, rather than about the acute side effects experienced during MCT.

Participants were invited to share their experiences. The researcher guided the discussion using the discussion guide. An open, neutral attitude and body language was maintained by the researcher [117]. Pauses and probes were used when discussion flagged. Pauses ensured the exhaustion of a topic prior to moving on to the next, while probes ("Tell me more" or "Can you explain why you think this?"), encouraged the discussion to continue [117]. The researcher, at certain stages, summarised the information and asked if this was what participants meant to express [117]. At the end of each FGD, the researcher summarised and closed the discussion, thanked participants for their participation, informed them that a summary of the discussion would be sent to them for their comment, and invited them to have more refreshments.

2.4.7 Statistical and data analysis

2.4.7.1 Statistical analysis

Descriptive statistics were used to analyse demographic, socio-economic and cancer treatment data of participants. Data were summarised using frequencies, mean and standard deviation for normally distributed data, and median and interquartile range for non-normally distributed data.

2.4.7.2 Rigour and Trustworthiness

In qualitative research, trustworthiness is explained by key concepts such as credibility: the true value of the results; transferability: the applicability of the results; dependability: the participants' evaluation of the findings, and confirmability: the degree to which findings are confirmed by other researchers [126]. In Table 1, endeavours to promote trustworthiness are described.

Table 1: Endeavours to promote trustworthiness.

Credibility: Validity of conclusions drawn from data [127].	• Careful selection of participants that fit the inclusion criteria for the study [127]. • Verbatim transcription of audio recordings and verification of transcription. The researcher did not note conflicting non-verbal cues or guarded behaviour [128]. • Appropriate sample size. Note that larger sample sizes do not necessarily result in richer data [129]. • Member checking: The researcher summarised every discussion and sent a summary to each participant for comment to verify that what was discussed has been captured accurately [130]. • Prolonged engagement and familiarisation with the data and with the topic of interest: reading and re-reading transcripts, studying the data [131].
Transferability: Applicability of the findings in other settings [126].	• Assuring data collection continued until saturation was reached, where no new data, codes, subthemes, or themes arose [130]. • A detailed account was provided of the study setting, sample, sample size, socio-demographic characteristics, eligibility criteria, topics of discussion [127].
Dependability: Consistency of results over time [126].	• Checking for coding consistency at two points in time supported quality assurance. Data were coded initially, and then re-coded several months later to evaluate and adapt the coding frame [128]. • Member-checking to ensure that data accurately reflect participants' interpretation of the discussions [127].
Confirmability: Objectivity of the research [126].	• Efforts towards reflexivity were made by describing the researcher's credentials, training, and therapeutic alliance with participants [127]. • The researcher was aware of her own stance regarding the research topic and the subjectivity of her interpretation [128].
Triangulation of results: collation of evidence sourced by different methods of data collection.	• Coding and emerging themes were cross-checked by two experienced qualitative researchers (TB and PM): investigator triangulation [128]. • Qualitative findings were compared to findings sourced from questions forming part of the socio-demographic questionnaire, such as prevalence of shoulder morbidity, fatigue, lymphedema, and exercise participation: data triangulation [127].
Concept-driven validity: comparing the results to what is already known about the topic, by experts.	• The final coding and emerging themes and subthemes were discussed with an experienced qualitative researcher and co-supervisor of this project, TB [128].

2.4.7.3 Data analysis

Data collection and initial analysis occurred concurrently [132]. Thematic analysis, the process of identifying patterns and themes within qualitative data, was conducted to analyse data [133]. These themes were then used to interpret and make sense of the data, addressing the research question [133].

Although useful in cases where researchers expect certain responses from participants, deductive methods hold a risk of bias [132]. The predetermined and inflexible framework of deductive analysis were considered compelling reasons to avoid this approach. In contrast, inductive reasoning allows the data to drive the analysis [132], therefore this approach to data analysis was used in this study. The analysis process was conducted in the following phases:

Preparatory phase

Audio-recordings of FGDs were transcribed verbatim by an independent, professional transcription company. Once transcribed, the data were read and re-read several times by the researcher and validated against the audio recordings. Afrikaans statements made by participants were forward- and back translated to English by the researcher, who is equally fluent in both languages. Transcripts were then reviewed by the study supervisor DS, who listened to the digital recordings and compared them with the translated transcripts. The researcher summarised each FGD. Member checking was done to verify this summarised information, and to confirm the accuracy of data representation [130]. Participants who did not have access to email received the summary and a stamped, addressed envelope, in which they could place their corrections and post them back to the researcher.

Organising phase

Open coding of transcripts was performed, meaning that codes were not pre-set, but developed through the coding process. Coding is the process of assigning each segment of data that is relevant and exemplifies the same meaning, with a defining name [134]. Subthemes are a collection of codes that relate to the same theme [135]. Data were organised into codes, subthemes, and themes by the researcher, using Microsoft Excel spreadsheets [134]. A qualitative researcher PM, reviewed this initial data analysis after reviewing the transcripts [129]. The coding and organising process was repeated several months later, and this analysis was compared to the initial findings [127]. The final thematic analysis was cross-checked across transcripts by the researcher and validated by the study co-supervisor TB.

Reporting phase

In the final phase of analysis, the data are reported [135]. The subthemes and themes were reported in the results. Key pieces of text were selected to illustrate the subthemes and themes, and to assist in addressing the research question [135].

2.4.8 Research ethics

Ethical considerations are described below according to the principles of biomedical ethics [136].

2.4.8.1 Nonmaleficence and justice

This study adhered to the principles of the Declaration of Helsinki [137]. Participation involved no physical risk of harm. There was a risk that participants may experience emotional or psychological distress. To reduce this risk, participants were reminded that they may end their participation at any time. A participant who seemed distressed would have been given the option of immediate and appropriate referral to a psychologist or social worker, who were available on site. Data were kept confidential and individual privacy was protected: no identifying data were captured. Personal information was given a code and stored on a master list, to which only the researcher and study supervisors had access. All identifying data were removed from the transcripts before analysis. There was no burden on the oncology staff with recruitment or any other study procedure. Only participants and the researcher were present during a FGD (except for the first (pilot) FGD, which was attended through digital media by DS), held in a private boardroom at a public hospital in the Western Cape, SA. Hard copies of the master list and audio-recordings were securely stored in a locked cupboard in the researcher's office. Electronic data were password-protected. Data will be stored until published. Unpublished data will be stored for six years.

2.4.8.2 Autonomy

Potential participants were invited to a FGD on a day and time that was convenient for them. The informed consent form, signed by participants, stated that they understood the nature and purpose of the study. It included permission to allow the researcher access to medical records to confirm medical cancer treatment details, and permission that the FGD may be audio-recorded. The researcher kept one copy of the informed consent form and gave another copy to the participant. Potential participants were not in a dependent relationship with the researchers. Participation in this study did not influence the medical care of participants, as the researcher was not employed at the hospital where the study was conducted.

2.4.8.3 Beneficence

This study had a favourable risk: benefit ratio. Each participant received a pamphlet with the current international exercise guidelines for BC survivors, after their FGD (Appendix J). Participants were given 50 South African Rand in cash, which was a reasonable amount to reimburse their travel expenses to and from the hospital. Refreshments and snacks were served at each FGD. Furthermore, after their FGD, participants were invited to participate in a future intervention study for the management of LTSE, should an intervention be developed. Those participants who indicated interest, were invited to participate in the intervention study (Chapter 5).

2.5 Results

2.5.1 Participant recruitment and FGD attendance

Participant recruitment commenced in August 2019. Data were collected from October 2019 until January 2020. Data saturation was reached after five FGDs. A total sample of 23 participants was included in the study. Figure 3 summarises the recruitment and FGD attendance of participants. Focus group discussions lasted 60 to 90 minutes, as planned.

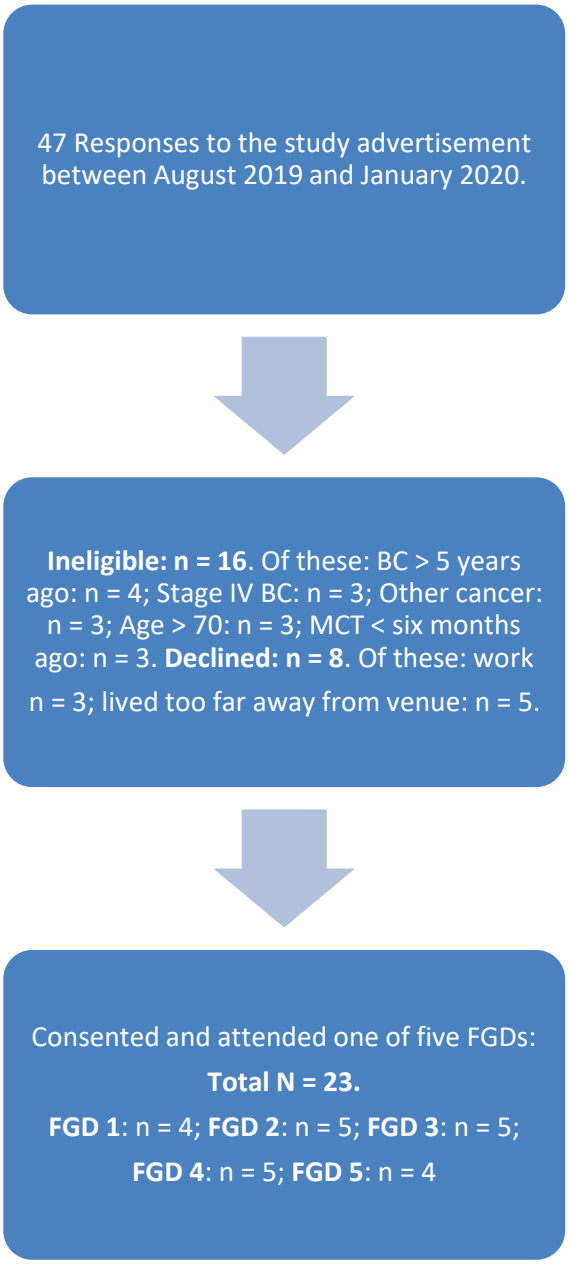


Figure 3: Recruitment of participants and focus group attendance.

2.5.2 Socio-demographic characteristics

Table 2 summarises the socio-demographic characteristics of this sample. The mean age of participants was 55.5 years (standard deviation = 8.6, range: 39 - 68 years). Participants were a median of 36.0 months (three years) since completing their MCT (interquartile range = 33.0). Ten participants were unemployed (43.5%), and 16 participants reported receiving an income of less than R 5000 per month (69.6%). Twelve participants (52.2%) had completed high school.

Table 2: Socio-demographic characteristics of participants (N = 23).

		Number of participants(%)
Education	Primary school	10(43.5)
	High school[3]	11(47.8)
	Tertiary qualification	1(4.3)
Employment	Unemployed	10(43.5)
	Employed	7(30.4)
	Pensioner	6(26.1)
Monthly income	Less than R 5000 per month	16(69.6)
	R 5 000 to R 10 000 per month	4(17.4)
	Did not disclose	3(13.0)
Home language	Afrikaans	19(82.6)
	English	3(13.0)
	IsiXhosa	1(4.3)

2.5.3 Medical cancer treatment

Table 3 summarises the medical cancer treatment details of participants. Eleven participants (47.8%) reported stage III BC, and 17 participants reported having undergone a mastectomy (73.9%). Fourteen women in this study reported taking endocrine therapy (60.9%).

[3] Grade 12 school-leaving qualification also known as National Senior Certificate, typically undertaken at age 18 years. Reference: National Senior Certificate. Retrieved 4 October 2023 from www.southafricaeducation.info/Tests/Higher-Education-Tests.

Table 3: Medical cancer treatment details of participants (N = 23).

		Number of participants(%)
Stage diagnosed	I	7(30.4)
	II	5(21.7)
	III	11(47.8)
Treatments received	Mastectomy	17(73.9)
	Lumpectomy	6(26.1)
	Surgery only	1(4.3)
	Surgery and chemotherapy	6(26.1)
	Surgery and radiotherapy	2(8.7)
	Surgery, chemotherapy, radiotherapy	14 (60.9)
Endocrine therapy	Yes	14 (60.9)
	No	9 (39.1)

2.5.4 Symptom burden and exercise participation

Table 4 summarises the reported symptoms experienced and exercise participation of this sample. Thirteen participants reported participating in regular exercise (56.5%). Upper limb problems were reported by 14 participants (60.9%). Thirteen participants reported suffering from fatigue (56.5%). Eleven participants reported suffering from lymphoedema (47.8%).

Table 4: Reported symptom burden and exercise participation of participants (N = 23).

		Number of participants(%)
Shoulder problems	Yes	14(60.9)
	No	9(39.1)
Cancer-related fatigue	Yes	13(56.5)
	No	10(43.5)
Lymphoedema	Yes	11(47.8)
	No	12(52.2)
Exercising regularly	Yes	13(56.5)
	No	10(43.5)

2.5.5 Chronic medication

Table 5 summarises the reported chronic medication of participants. Twelve participants (52.2%) reported taking medicine for high blood pressure, while three participants (13.0%) reported taking medicine for diabetes mellitus type II.

Table 5: Reported chronic medication of participants (N = 23).

	Number of participants(%)
Antihypertensives	12(52.2)
Metformin	3(13.0)
Antidepressants	2(8.7)
Lipid lowering medication	2(8.7)
Aspirin	2(8.7)
Gout medication	1(4.3)
Anti-asthmatics	1(4.3)

2.5.6 Qualitative analysis findings

Qualitative analysis constructed three main themes arising from the FGDs. Themes and subthemes are outlined in Table 6. Since participants did not assume pseudonyms, quotations are referred to as, for example, F1P1 where F indicates the focus group number and P the participant number. Participant quotes are presented in italics, and context is explained in parenthesis.

2.5.6.1 Summary of themes and subthemes.

Table 6: Themes and subthemes constructed during qualitative analysis.

Themes	**Subthemes**
Long-term side effects are unaddressed and impair quality of life	Persistent upper limb problems Fatigue is overwhelming and relentless Weight gain: an unexpected LTSE Physical function has deteriorated
Lack of information and access to support	Unequipped for LTSE and survivorship concerns, despite motivation to self-manage Disconnected from cancer support organisations Knowledge about breast cancer is power How intervention could be presented
Perception that exercise is generally good; but need specific guidance	Exercise perceptions and preferences Facilitators for an active lifestyle Barriers to regular activity

2.5.6.2 Theme: Long-term side-effects are unaddressed and impair quality of life.

2.5.6.2.1 Subtheme: Persistent upper limb problems.

Given that over 60% of participants reported experiencing shoulder problems, this was a prevalent topic in the discussions. Although participants reported experiencing pain to their healthcare providers, they did not receive guidance for addressing their shoulder pain. This suggests that upper limb problems were not taken seriously by healthcare providers.

Participant F1P4 described it as follows: *"I still have this pain that's been here all along, the doctor always said it's probably from the radiation or from the chemo. It pains terribly when I am cold. I just get a sudden stabbing pain."*

Many women need the ability to do physical work, to earn an income. Upper limb problems directly affected their ability to provide for their families.

Participant F3P1 described how shoulder pain affected her ability to work: "*I do cleaning work at a shop. It's the mop. You can work, but that kind of work you cannot do."*

Shoulder pain also affected the sleep of participants, which suggests that quality of life was impaired. F5P3 noted: "*I can't lie on it for a long time. I sleep mostly on the one side."*

Apart from pain, many women experienced muscle weakness and stiffness of the affected arm, interfering with their everyday lives. Simple daily activities were impaired by weakness and stiffness.

Participants F4P1 and F4P2 described their experience: "*This arm gets extremely tired. When I have made my bed, I must sit down. It's a tiredness that comes out of here* (upper arm)."

And: "*I can't do the washing anymore. When I hang up the washing, then this arm is stiff, I can't really use it. I also can't knead bread dough anymore. It makes my arm tired."*

2.5.6.2.2 Subtheme: Physical function has deteriorated.

Participants reported a marked decline in their overall physical function. A gap existed between what they were able to do before, compared to after their cancer. Women described how a decline in physical function markedly affected every area of their lives including work, leisure, and sport.

Participant F2P4 commented: "*Before the cancer, I could do a lot of things in one day. Now it feels like I can't go through half the work I did then."*

Participant F2P1 elaborated: "*I used to be a policewoman, always fit, always on the go, I'm not that person anymore. In my mind I think I can do all those things, but the moment I want to start my body says no."*

Participant F4P3: "*Before my cancer, I worked hard, but after the operation my system fell a bit. I do light work. I also played netball before, but now I take it slow."*

And participant F4P2: *"I'm not the way I used to be at all. Before* (the cancer) *I could do a lot of gardening, but after… many things have changed."*

Many survivors experienced a deterioration in their walking ability, and the ability to climb stairs. This necessitated one woman to move to a different house.

As participant F5P3 described: "*I could walk for longer then,* (before BC) *than I can walk now. I just walk a small distance then I must stand still, then it feels like something is pressing my chest*."

Participant F4P2: "*We moved out of a house with stairs. I couldn't anymore. It's too much."*

Several participants in this study experienced a loss of balance since their mastectomies.

Participant F1P3 described: "*When something falls down, I can't just bend, then it feels like I'm going to fall forwards."*

In this study, women denied having received rehabilitation or education to improve their physical function (apart from the exercises and advice received to improve their upper limb function, in hospital following their breast surgery).

2.5.6.2.3 Subtheme: Fatigue is overwhelming and relentless.

Participant F1P1 described that her cancer-related fatigue was relentless: "*I am very tired. I thought it's just work but even if I go to sleep at six o'clock in the evening and I get up at six, I am still tired."*

Participants in this study did not seem aware that fatigue and reduced physical capacity were commonly experienced side effects after BC treatment.

For example, F4P2 noted how she tried to hide her symptoms at work, feeling guilty about her LTSEs: "*Look it's a lot of walking, lots of moving with your arms and so on. It makes me severely tired. Then I must go and sit down, or I tell someone, you quickly do this... I look around that nobody sees me sitting down."*

Indeed, women in this study who were affected by cancer-related fatigue, emphasised the distinction between this, and normal tiredness. They expressed that cancer-related fatigue was severe and debilitating, and nothing seemed to relieve it.

As participant F2P1 described: "*It's not a tiredness where you can sleep, and you get up. Some days I'm tired for three days and I'm not a depressed person, but the tiredness is so much that I would not want to answer my phone, I don't want to entertain people. And I know it's going to take about two to three days for me to overcome this feeling. It's like you're totally knocked out."*

Participant F5P2 felt guilty for needing extra rest: "*Most of the time, I must go to sleep for a little while in the afternoon, then I feel like a bad housewife."*

It seems that cancer-related fatigue was not identified or addressed, by healthcare providers, which suggests a knowledge gap regarding this debilitating long-term side effect of cancer treatment. This led participants to feel despondent about their symptoms.

According to participant F1P1: "*It wasn't like that before* (before BC). *And they have tested me for diabetes, for high blood pressure. There's nothing."*

2.5.6.2.4 Subtheme: Weight gain is an unexpected long-term side effect.

Women in this study were shocked about their weight gain since completing MCT. Patients were not warned by their healthcare providers, about this commonly occurring complication.

Participant F3P2 stated: "*I thought I would lose weight, but he* (the doctor) *never said you could gain weight."*

Participant F1P4 described that visiting the dietician had helped her to lose the weight gained after completing medical treatment: "*I put on a lot of weight, then they sent me to the dietician, and it helped. She told me what I should eat, vegetables... she discussed everything."*

2.5.6.3 Theme: Lack of information and access to support.

2.5.6.3.1 Subtheme: Unequipped for survivorship challenges, despite being motivated to self-manage.

Participants in this study reported a lack of empowerment to manage their LTSEs, and a helpless feeling of being unprepared for the challenges of long-term survivorship.

As F1P2 and F2P4 described: "*Well, I didn't know one could do something about it* (referring to LTSEs). *I just took it as it came."*

And: *"They don't tell you the nitty gritty stuff that you really need to know. Like the thing I heard now about the memory loss, your brain is slower.* (Referring to cognitive impairment). *I thought what's wrong with me… I've been doing this stuff* (tasks at work) *for twelve, fifteen years and then I can't remember. Nobody told me about it to prepare me."*

Participant F2P3: "*You don't know what to expect afterwards. You don't know, is it finished, or what do you do now?"*

Women in this study were motivated to self-manage their LTSEs, using the resources they had. They used the upper limb exercises they had been given post-surgery, months to years before, in hospital. For example, participant F1P2 stated: *"When I see, oh, my arm doesn't work anymore then I start to exercise it."*

Participant F1P3 elaborated: "*When I get negligent and lazy, I find the shoulder starts to pain. But now I have been doing the exercises* (exercises prescribed post-surgery, in hospital) *for two weeks and the arm is getting a bit better. So, I said to myself, ah man, it was negligence. Maybe you should do more exercises, that's what seems to be the problem."*

Participant F1P2 took advice from a family member: "*My sister told me that if I don't exercise my arm it will stay like this. She bought me a sleeve to get the poison out of my arm. When you are wearing the sleeve, it pushes it out for you."*

Participants were disappointed that they were not warned about lymphoedema by their health providers. Through their own experience, they learned that lymphoedema was to be identified early. Participant F2P2 noted: "*Nothing was said ... until it happened, and then I went to physio. But by then I'd already got it."*

In participant F1P3's case, the lack of timeous lymphoedema management caused a delay of her cancer treatment*: "When I got to the physio there* (in Cape Town, 430 kilometres away)*, the doctor hadn't completed the forms that I should go and see her. I had to come all the way back* (to Eden District)*. That doctor was very disappointed; the arm couldn't move it was so swollen. And then I was only able to go for radiation later…"*

A lack of education was also noted regarding the side effects of endocrine therapy, which many women must take for years after their primary medical treatment. The impression was that these LTSEs may have been discussed for the first time during the FGDs.

Participant F2P3: "*What I also noticed with this little pill that you drink for five years, I don't know if you also notice this, but I get hot flushes again."*

Women reported not having received information about general exercise from their healthcare providers. For example, participant F1P4: "*They didn't give that kind of exercise to a person."*

Participant F5P4: *"No. Only the arms."*

Participant F2P3, who had approached her healthcare provider about exercise, received a vague, cautioning reply rather than specific, evidence-based information: "*I asked the doctor, can I go to the gym, then he said yes, you can. I must just take it slow; I mustn't do hard exercises."*

Participant F4P3 received inaccurate information about exercise from her healthcare provider: "*Sometimes one's back feels sore because you have been sitting too much. I asked the doctor, the doctor said no, it's normal because those muscles feel healthy to you, but they aren't really healed yet. Those muscles still need a lot of rest."*

Furthermore, survivors in this study relied on media aimed at the public, as their main source of information about exercise.

As participant F2P6 stated: "*The media. Everybody says you've got to exercise."*

And participant F1P3: "*We listen to the radio."*

Women in this study highlighted the lack of rehabilitation services following MCT.

Participant F1P1 explained: "*We have had no rehabilitation. She* (the physiotherapist in hospital) *just told us you must do this, and this at home. You were sent home and that's it."*

Participant F1P3: "*I rehabilitated myself*".

And participant F2P4: "*After hearing everything now, I thought it was over and done with. So now I feel like, no, I'm nowhere near rehabilitated."*

Some women held a fatalistic belief that nothing could be done to improve their symptoms.

Participant F3P1 described: "*That tiredness, sometimes your arm is sore, I think there's nothing they can do. The arm will for a lifetime, be like this."*

Others believed that their LTSEs would get better as time went by.

For example, participant F3P4: "*It feels that I will come right with time."* There were also women who felt they did not need rehabilitation.

Participant F5P1: *I feel I can continue with my previous life. There are times that my arm feels a bit sore, but I think it's mostly a muscle."*

2.5.6.3.2 Subtheme: Knowledge about breast cancer is power.

Women in this study felt that their main rehabilitation need was knowledge about BC and their survivorship journey.

Participant F2P4 explained what rehabilitation should include: *All the information that we shared now… like all the stuff that I heard now that you guys went through that I still need to go through, and I thought I was done. If I had this info, I would have been prepared. Now, I hear this and I know I need to prepare myself."*

Survivors felt the need to be informed about BC recurrence. They did not receive this information from their healthcare providers, even when they specifically requested it.

Participant F2P1 explained: "*I'm grateful for the second chance I have, but I still have this doubt, will the cancer come back. I asked the doctor that, I said how will you know if the cancer is back? And she said, oh well, you will see if there's something wrong and then you can come to us."*

Similarly, participant F3P3 stated: "*I would say we are cancer free but aren't there also symptoms that go with...*(cancer recurrence) *look, you should come back if you feel this way, or if you have a swollen gland in your leg."*

Participant F1P1 also highlighted the need for specific education regarding BC survivors' increased risk of other cancers: *"I had a lot of skin cancer. I never had that before I had breast cancer."*

The women's need for empowerment through knowledge is understandable, as they could not always rely on a thorough physical examination when visiting a healthcare provider.

Participant F3P1 described this as follows: "*When I get to the clinic doctor, he doesn't examine me. He gives me a little script in my file and there you go. They should at least have a little talk, how are you feeling... You can't just sign somebody's script in their file, and there they go."*

Women in this study were not always informed when or how often they should go for clinic follow-up visits.

Participant F1P3 noted: "*They must give me a date so I can go* (to the clinic) *now and then... even if it is only once a year or so... because I feel it is very important. They should check if I am all right or what's going on.*"

Women were sometimes approached for information or advice by others in their community with cancer, or their families. They felt unable to provide the support and information that was expected of them, highlighting their lack of empowerment.

Participant F4P3 explained: "*I know people who have just been diagnosed with cancer and they came to me. I told them, all I can explain to you is what I went through. I can't add anything for you... At the end of the day at least if I had some information, I could share it.*"

2.5.6.3.3 Subtheme: How interventions could be presented

The preferences of participants regarding how interventions could be delivered varied between those preferring information sessions and others preferring reading material.

Participant F3P2: "*If they could present a session to explain about all these things.*"

Participant F4P5: "*It can be bound into a booklet. It doesn't have to be a large booklet; it can be a small booklet. It's permanent, it's there forever... When I get rebellious or emotional, my kids can say remember, it did say that that could happen in the booklet. I have two daughters. So that I can tell them, read this.*"

Participant F2P4: "*It would have been nice if they told you, this is what's going to happen and this and this. Every step.*"

Participant F5P1: "*E-mail would be nice.*"

Participant F5P2: "*We did get pamphlets to read during the treatment to let you know how the treatment would make you feel and what to do. But not after the treatment; it would have helped.*"

One objective of this study was to clarify if survivors would prefer interventions to be peer-led or presented by a healthcare provider. Preferences varied.

Participant F1P4: "*I would say a health worker, because a health worker knows more than someone who is a survivor.*"

Participant F1P2: "*For me it's about whether that person has a passion for it.*"

Participant F4P4: "*I would say it needs to be a trained person and a survivor. Maybe the trained person doesn't have time today, then the survivor is there to take us further.*"

Participant F5P3: "*I wouldn't go with the professional because I don't want someone to tell me you've got to do this. I also think it needs to be someone who can give you guidelines about healthy eating.*"

2.5.6.3.4 Subtheme: Disconnected from cancer support organisations.

Participants identified support as a necessary constituent of rehabilitation, which they felt was lacking. The FGD was viewed as a welcome opportunity to connect with other survivors.

Participant F4P1 described: "*That is what one needs to add, moral support. What is going on with you today? Come, it doesn't happen to me, let's see what we can do. I think women are operated on and there they go."*

Participant F2P4: *"When you discuss it like this then you realise, you understand better and you know, ok, is there a solution, should one take vitamins or what should you do. Like, today feels very good, because here are women who went through the same as me*."

Participant F1P2: *"The spiritual side needs to be discussed in a group, so that that person can be lifted up and told, it's only a breast."*

Cancer support organisations in SA offer group-, individual- or telephone counselling services free of charge. In recent years, their policy has changed: the patient is now required to contact them first. Many participants were not aware of this change in policy. They were disappointed that no support was offered to them.

Participant F3P1 stressed: "*They* (cancer support groups) *don't know even, are you dead or alive? They must give more; it would help so many women. It's people you know care about you."*

Participant F1P1: "*Do you know what bothered me? That I never talked with anyone afterwards about my breast cancer, or my treatment... nobody came to me and talked to me. Now one lies in bed worrying."*

Participant F1P4: "*I went and read up for myself because I thought the cancer association would approach a person."*

Those who received cancer support services, were appreciative, highlighting the importance of these services.

Participant F2P6 explained: "*That team that comes to me, they help a lot. You feel good again. I would say it's because they care."*

Participant F3P3: *"They come to your house and ask how you are, what have you been through, how did you experience it and things like that."*

Participants highlighted their need to access support not only for themselves, but also for their families. They were not aware that family counselling or psychological support services were available on request.

As participant F1P2 explained: "*Let's take her as an example, who still has a relationship with her husband that is sexual, and her breast is removed. Now she feels she is no longer a complete woman, she doesn't want it anymore, but now the husband feels he is being rejected. This is where discussions should take place to give the husband counselling as well."*

Participant F2P4 elaborated: *"It's not just the person themselves, because it* (BC) *is a shock to him, it is a shock to the partner, it is a shock for the children, it is a shock for the parents sometimes."*

2.5.6.4 Theme: Perception that exercise is generally good; but need specific guidance.

2.5.6.4.1 Subtheme: Exercise perceptions and preferences.

Although they felt that exercise was generally important and beneficial, participants did not mention specific guidelines or benefits of exercise for BC patients, apart from arm exercises. Survivors described their exercise experiences.

Participant F2P2: "*I was never great at joining a gym or anything like that. Going for walks I enjoy; I like to garden. I get my exercise out of that and the work that I do. I do my own housework and stuff like that, but I don't want to become Mrs. Fit."*

Participant F1P3: *"I am a bit negligent; I think I don't do enough exercise. I think exercise is very, very important."* Study participants shared their exercise preferences, which varied considerably.

Participant F4P4: "*I am for walking."*

Participant F5P1: "*Yoga I think will be nice because it's not strenuous exercise."*

Participant F5P2: "*Dancing."*

Participant F4P3: "*Jogging."*

Participant F4P1: "*Aerobics, or exercises with a ball, that helps to improve the function of your arm."*

And participant F4P2: "*An exercise class."*

Participant F1P3 mentioned resistance exercise as an exercise preference. She planned to rely on intuition to guide the intensity of her training: "*You put music on, and you sit in your chair, and you exercise. You are sitting up straight, so you can exercise your arms and legs. Like perhaps lifting weights with the arms. I think you will know how heavy the weights should be that you lift."*

2.5.6.4.2 Subtheme: Barriers to regular activity.

Several barriers to regular exercise participation were identified. These included caring for their families.

Participant F1P2: "*It is hard for me because I have a husband who's in a wheelchair. So, it keeps me at home. And then I get a bit dispirited."*

Time constraints were reported to prevent regular exercise in this study. Participant F5P3: *"I don't have time during the day to go and really think of doing exercise. I mean, you must make time, but then it's this, and then you must go to the shops and then you must come back and then it's washing, and then it's the husband, then he wants that. Then it's time to do the food again."*

Living far away from other survivors was another barrier to regular exercise. Participant F1P2: "*She's in Hoekwil and she's in Blanco and I'm in Great Brak*[4]*. It's far apart. And for her it is difficult to get here. I drive, but she must take a taxi. So, it's very difficult to get all these things organised*."

Finally, financial constraints contributed further to regular exercise participation. Participant F5P2: "*Now I need to go to the gym. Now you must pay to do it. So, then I leave it…"*

2.5.6.4.3 Subtheme: Facilitators for adopting an active lifestyle

Despite having given up structured exercise, the necessity to walk for transport facilitated regular physical activity for many women.

For example, participant F3P4: *"Most of us still walk to work. We don't have transport or anything where we live."*

F4P2: "*I walk my child to the crèche in the mornings, and I fetch him in the afternoons. Also, I walk to the shops and so on."*

F4P3: "*I stopped my netball training completely. I don't run anymore, I don't go and train anymore, none of that. But I walk to the shops, and I walk back."*

Regular exercise was facilitated by being able to socialise in a group for many, while others felt more comfortable to exercise alone.

Participant F5P3 explained: "(I would prefer to exercise) *In a group. With breast cancer survivors. The more we come together, the better for us. When I'm alone I postpone, I can do this tomorrow. But they'll say, come, we're doing this now, let's go."*

In contrast, participant F5P4 stated: "*It's easier* (to exercise) *alone. You aren't judged. If you can't do this, then the people say, what is wrong with you?"*

Those who exercised regularly, were encouraged by the positive effects they experienced as a result.

Participant F3P3 described: "*When you have walked in the evening, you get up the next morning feeling different to the mornings when you haven't been walking. You get up happy, full of life, you feel like cleaning your house. You feel like working. When you haven't walked for two or three evenings, in the mornings you feel flat, you don't feel like anything."*

[4] Hoekwil, Blanco, and Great Brak river (Groot Brakrivier) are communities in the Eden District, Western Cape province of South Africa, situated between 27 and 49 kilometres apart. Sourced from Distance Between George and Groot Brakrivier (distancecalculator.co.za). Accessed 1 December 2023.

2.6 Discussion

The five FGDs yielded good corroboration from the participants. The following discussion will review the findings considering current literature and will highlight the implications for intervention development.

2.6.1 Socio-demographic characteristics

Women in this study were representative of the general BC survivor population in terms of age. Breast cancer affects mainly post-menopausal women between 50 and 70 years old [77]. Survivors in this study reported earning a low income. Furthermore, almost half of the women in this study did not complete high school and were unemployed. Compared to data reported by Statistics South Africa for this district [138], a higher proportion of women in this study were unemployed (43.5%) and did not complete high school (43.5%) compared to the population norm. Furthermore, the monthly income of less than 5 000 South African Rand per month[5] reported by almost 70% of participants in this study is lower than the average monthly per capita income of this province [138]. A plausible reason for the lower income, higher unemployment and lower educational levels of this sample may be because it consisted exclusively of women who utilised public health facilities. In SA, the utilisation of public health facilities is closely linked to lower socioeconomic parameters [89]. Although the majority of the South African population rely on public healthcare, people that are employed, earning a higher income and who have accessed tertiary education are more likely to use costly private healthcare services [89].

The implication for the development of an intervention for this population, is that it should be suitably matched in terms of readability, to an audience that is not highly educated. Concurrently, the intervention should address low literacy levels in terms of BC specifically and health generally. Specific dietary advice should include affordable, sustainable choices. Furthermore, it is likely that the women in this sample were caring for children or grandchildren, while many were also breadwinners. The design of a suitable intervention should take these financial and time limitations into account, avoiding frequent clinic visits as a requirement for participation.

The great majority of participants (82.6%) in this study indicated that their home language was Afrikaans. The Afrikaans predominance is reflected in the national census data for this district, however there were fewer IsiXhosa speaking participants in this study (4.3%) compared to the general population in this province (18.3%), according to provincial census data [139].

[5] 5 000 South African Rand is equal to about 270.70 United States Dollars, based on the current exchange rate. Retrieved from https://www.xe.com/currencyconverter/convert/?From=ZAR&To=USD on 6 May 2024.

This may reflect the outdatedness of the 2011 census data, isiXhosa speaking women may have migrated to larger cities such as Cape Town since then. However, there is no evidence to support this theory. A plausible explanation could be that survivors who were not able to read, understand, and respond to the advertisement leaflets, which were in English and Afrikaans, were not able to participate in this study. The implication for intervention development is that, when the intervention is implemented clinically, translation to other South African languages should be undertaken to secure access for all South African women.

2.6.2 Medical cancer treatment

Most women in this study had stage III BC (47.8%), had undergone a mastectomy (73.9%), and had received surgery, chemotherapy, and radiotherapy (60.9%). These results contrast with those of high income countries, where population-based screening programmes allow most breast cancers to be detected at a pre-clinical stage, requiring less aggressive treatment regimens [140]. However, the results concur with previous studies in SA, which have reported that South African women are mostly diagnosed late, leading to an unnecessary progression of the disease [75, 102].

Given that a previous diagnosis of BC is a risk factor for BC recurrence and for the development of new cancer [141], the implications for intervention development are that information to detect new and recurring cancer, instructions for breast self-examination and when to seek medical advice, should be provided in an easy to follow format. Most women in this study (60.9%) were taking endocrine therapy. This agrees with the literature, which confirms that the majority of breast cancers are hormone receptor positive [142]. Endocrine therapy is then usually prescribed for five to 10 years, as it reduces the risk of cancer recurrence, improving the prognosis of patients [142]. Therefore, as it contributes to the burden of physical LTSEs experienced [6], information about endocrine therapy and the management of associated side effects should be included in a newly developed intervention.

2.6.3 Symptom burden and exercise participation

Despite being a median of three years after completing MCT, most participants in this study reported suffering from shoulder problems (60.9%) and cancer-related fatigue (56.5%). Furthermore, many participants reported lymphoedema (47.8%). Compared to international studies of BC survivors after MCT, the symptom burden in this study was higher: a systematic review including 177 studies reported a prevalence of shoulder problems of 29.8% [143], while a systematic review on fatigue prevalence including over 12 000 BC survivors reported a prevalence of 26.9% [115]. Regarding lymphoedema, the incidence is estimated at 21.4% in post-treatment survivors [144]. However, it must be noted that both latter reviews report large heterogeneity of prevalence rates between studies.

The high symptom burden in this study in terms of shoulder problems, cancer-related fatigue, and lymphoedema was to be expected, since LTSEs are closely tied to the disease stage, extent of surgery and adjuvant treatments received [24, 26]. In addition, the research design of the present study may have attracted participants who experienced LTSEs and those who were more physically active, compared to the general BC population. These symptoms can be largely prevented and improved through education and exercise interventions, which have shown to be consistently effective in the management of chronic symptoms [80, 145]. Such interventions possibly address an underlying aetiology of LTSEs, while pharmacological interventions do not [80].

Implications for intervention development are that education and exercise information should be provided based on the international guidelines for cancer survivors, which include frequency, intensity, time, and type prescriptions for symptom management in BC patients [18]. Furthermore, specific upper limb exercises aimed at women who have completed MCT, should be provided and instructions should be included to inform patients when to seek professional advice for both upper limb morbidity and persistent fatigue [97, 146-149]. Regarding lymphoedema, all BC survivors should receive education on the early signs and symptoms to look out for, when to seek medical advice or physical treatment modalities, and on self-management strategies for lymphoedema prevention [150, 151]. Education on prevention, early detection, and effective management of lymphoedema are key to improve outcomes and to preserve the HRQoL of survivors, since BC survivors have a lifelong increased risk of developing this disabling condition [6, 24, 151].

Just over half of participants in this study (56.5%) reported regular exercise. International studies report that between 30 and 58% of BC survivors are sufficiently active following MCT [152, 153]. Patients often over-estimate their own exercise participation [154], and this could explain the high percentage reporting regular exercise in this study. However, the positive response to the exercise participation question could indicate that participants may be receptive to an intervention including exercise, and the qualitative findings of this study confirm this. Interventions should aim to increase exercise participation, and their effectiveness and sustainability for this purpose should be evaluated [52, 97, 155]. While the questions on shoulder problems, cancer-related fatigue, lymphoedema, and exercise participation included in the socio-demographic questionnaire in this study were not standardised measurement instruments, the implications for intervention development based on the responses, were that the intervention should address symptom severity and exercise participation.

2.6.4 Chronic medication use of participants

The use of medication for other chronic conditions such as high blood pressure and type II diabetes mellitus was prevalent in this study. This agreed with previous South African studies, highlighting that BC survivors often manage numerous lifestyle-related chronic diseases in addition to their BC [60, 156]. This causes much extra suffering and may burden the health system even more [62]. The loss of lean muscle mass and increased body weight resulting from MCT can further worsen chronic conditions [7]. Most chronic diseases can be improved through healthy lifestyle changes, such as regular exercise participation, body weight management and dietary changes [6, 7]. Therefore, the implications for intervention development are that it must include information to improve women's knowledge of, and self-management skills for common chronic diseases, while encouraging healthy lifestyle changes.

2.6.5 Qualitative analysis findings

2.6.5.1 Theme: Long-term side effects are unaddressed and affect quality of life

2.6.5.1.1Subtheme: Persistent upper limb problems

In this study, women reported having persistent upper limb problems including pain, stiffness, and weakness. Work, sleep, and daily tasks were affected. The literature indicates that, by one year following MCT, most upper limb morbidities should have been resolved [157]. However, numerous studies reported that upper limb problems may persist in long-term survivors [158-160]. These report very similar daily tasks being affected compared to what was reported in this study: overhead lifting, carrying, cleaning activities, and sleeping on the affected side. [158, 160]. Furthermore, the findings of the latter studies confirm the findings of this study regarding the influence of upper limb problems on the ability to work to earn an income, and on quality of life [161-163].

The trajectory from diagnosis to the completion of MCT spans a period of about a year [30]. Patient education at the time of BC diagnosis focuses on initial treatment and immediate adverse effects, and not on issues that may present after medical treatment [6]. It is logical that, during post-treatment survivorship, upper limb exercises and advice should be distinct from what is offered post-operatively in hospital [164]. For example, radiation fibrosis may cause further deterioration in upper limb function, even after surgical wounds have healed [7, 24]. Specific shoulder and arm exercises for survivors after MCT are safe and effective for improving upper limb mobility and function, thus women should be instructed to perform these regularly [164, 165]. Therefore, the message that some participants in this study received from healthcare providers – that symptoms should simply be tolerated, is not evidence-based.

It seems that participants in this study were not prescribed new exercise programmes to improve their upper limb function. They reported using their post-operative upper limb exercises prescribed in hospital.

2.6.5.1.2 Subtheme: Fatigue is overwhelming and relentless

Participants in this study were distressed about cancer-related fatigue. The distinction between 'normal' fatigue and what they were experiencing, was emphasised. They experienced their fatigue as overwhelming and debilitating, affecting their ability to work. Several women felt guilty about experiencing cancer-related fatigue. It seems that many were surprised about suffering from cancer-related fatigue beyond MCT. The women in this study perceived fatigue as relentless. Similarly, in a study by Levkovich and colleagues, women describe their cancer-related fatigue as "like being imprisoned in the body of an 80 year-old" [166].

The literature confirms that fatigue is an extremely frequently experienced, serious problem that severely compromises the quality of life of survivors [115, 167]. The distinction between cancer-related fatigue which is much more powerful and does not improve with rest; and normal tiredness, which does improve with rest, is echoed in the literature [120, 166, 167].

Similar to the findings of this study, a Taiwanese qualitative study reports that women felt embarrassed and tried to hide their symptoms of fatigue in public [168]. Furthermore, previous studies confirm that cancer-related fatigue can severely impair work productivity [13, 169]. Participants in this study reported that their fatigue had not been addressed, and they seemed unaware that cancer-related fatigue was treatable. Two systematic reviews confirm that cancer-related fatigue in BC survivors may be underdiagnosed and undertreated by healthcare providers [167, 170]. Yet, international survivorship guidelines state that healthcare providers should rule out other medical causes of fatigue, before diagnosing cancer-related fatigue. As a next step, survivors should be referred for evidence-based interventions to improve this condition, such as rehabilitation interventions including an exercise component [6]. There was a lack of South African data on fatigue experienced by BC patients at the time of writing, which prevented comparison to local studies.

2.6.5.1.3 Subtheme: Weight gain is an unexpected LTSE

In this study, women expected to lose weight because of their cancer. They were surprised and shocked about their weight gain, as their healthcare providers did not inform them of this possibility. These findings are corroborated by three international studies, reporting that weight gain was unexpected and disappointing for survivors [171-173].

Previous studies report that survivors were either given no information about weight gain by healthcare providers, or that they were warned about it but still believed that they would lose weight [171]. The literature also agrees with the findings of this study, regarding the need expressed to receive specific dietary advice after MCT [171, 174]. Indeed, weight gain is experienced by more than half of BC patients after MCT [175]. It is associated with a poor prognosis, increased risk of cancer recurrence [176] and lymphoedema [26, 177]. Furthermore, weight gain during and after adjuvant therapy constitutes increased fat mass and decreased muscle mass [178]. This change in body composition has shown to have significant adverse implications for survivors, including reduced physical function, muscle strength, and mobility [176]. A South African cross-sectional study of 48 early-stage BCS found that most women in that study were overweight or obese [101]. Only one participant in the present study reported having been referred to a dietician to address her weight gain.

2.6.5.1.4 Subtheme: Physical function has deteriorated

Participants in this study reported a decline in their physical function: they were able to do less than before their cancer, simple functional tasks such as climbing stairs had become difficult. Participants also reported not being able to walk as far as before. This is important, as many women depended on their ability to walk for transport. These findings are confirmed by numerous qualitative and quantitative studies, which have reported both subjective and objective reductions in physical function, muscle strength, and cardiorespiratory fitness, in BC survivors after MCT [179-182]. Physical deficits such as reduced overall functional capacity and walking ability are largely attributed to deconditioning following MCT [24, 165]. This leads patients to attenuate their activity, causing further loss of physical function [147]. The natural ageing process worsens this functional decline. Therefore, many cancer patients are not able to return to their previous functional level on their own [52, 183].

Regarding the loss of balance reported by participants who had undergone mastectomies, this has been well documented in the literature [184-186]. Interventions including systematic exercises have shown to be effective to prevent and improve post-mastectomy balance disorders [146, 187, 188]. Furthermore, exercises to restore balance can be effective even if they are not commenced immediately following surgery [146]. Restoring balance is important from a rehabilitation perspective. Combined with reduced overall physical function, strength, and the ageing process, balance disorders can lead to falls which may further impede the quality of life of survivors [187, 189]. Despite this, participants in this study were not offered interventions or education to improve their function.

2.6.5.1.5 Summary of the theme: Long-term side effects are unaddressed and affect quality of life

In line with previous literature [62, 118, 120, 121, 190], women in this study reported being burdened by LTSEs, affecting many aspects of their lives including the ability to earn an income. It has been suggested that LTSEs following BC seem to be experienced in a similar way across the world [122]. The findings of this study support this premise. Participants in this study seemed to have limited knowledge about addressing their side effects, and numerous international studies concur with this finding [118-121, 191]. Little has been written before about the experience of LTSEs in South African BC survivors, which limited comparisons to local research. However, Kramer and colleagues reported that three out of four BC survivors in Cape Town, SA experienced shoulder pain, one year after their primary MCT. [192]. Interventions using education and exercise have shown to be effective to ameliorate the LTSEs described above, in systematic reviews [68, 96, 193, 194].

Therefore, the implications for intervention development are that it should include education to manage problems such as upper limb morbidities, cancer-related fatigue, weight gain, and functional decline, and that it should encourage specific upper limb and general exercise participation.

2.6.5.2 Theme: Lack of information and access to support

2.6.5.2.1 Subtheme: Unequipped for long-term side effects and survivorship challenges

Many women in this study felt that LTSEs would continue indefinitely, or that the symptoms would improve with time. These findings agree with previous research conducted in India and in rural African-American BC patients [121, 122], but also with studies in higher-income settings [174, 191]. Furthermore, there seemed to be a gap in communication between BC patients and healthcare providers in this study. This has been reported extensively in previous literature [161, 195-197]. Thus, the results of this study confirm the seemingly universal need to be better equipped for long-term problems, post-treatment.

Research has shown that several LTSEs do not improve with time. Many have shown to worsen further if left unaddressed, such as upper limb morbidity, weight gain, loss of bone density, muscle atrophy, lymphoedema, and reduced physical function [7, 24, 26, 80, 198]. However, much can be done to ameliorate the impact of LTSEs. For example, lymphoedema can be prevented and successfully treated, if the signs and symptoms are detected early [67, 165]. International guidelines recommend that survivors be counselled on the prevention and risk reduction of lymphoedema, post-treatment [6]. If survivors remain unaware of potential complications, this may lead to a delay in treatment and ultimately, to permanent dysfunction [24].

Participants in this study were motivated to self-manage their LTSEs, such as getting advice from family members or friends, making use of the upper limb exercises they were given in hospital and responding appropriately when their symptoms worsened. Similarly, previous studies conducted in countries that do not offer structured survivorship care plans or interventions after MCT, found that women tried to self-manage their LTSEs using a variety of complementary methods including folklore [118, 122]. According to Handberg and Maribo [199], the care received by haematological cancer patients after MCT is limited to patients' own efforts and awareness. The findings of this study agree with this statement. Therefore, women should be strengthened in their efforts to self-manage by equipping them with evidence-based knowledge and skills [200, 201].

2.6.5.2.2 Subtheme: Knowledge about breast cancer is power

Participants in this study felt that they had received no rehabilitation or that they had 'rehabilitated themselves'. In contrast, the women in an American qualitative study by Williams and Jeanetta [190] emphasised that knowledge and understanding about BC formed an immense source of hope and empowerment for them, guiding their decision-making processes. However, the participants in that study had high levels of education, high income, and access to quality health care through health insurance. Research has shown that a cancer diagnosis constitutes a teachable moment: a chance to provide support and education to impact lifestyle choices, manage side effects and decrease the risk of suffering countless co-morbidities associated with cancer survivorship [202]. Participants of this study stressed that the provision of information was lacking in their rehabilitation, and this finding is confirmed by several qualitative studies of BC survivors worldwide [118, 120, 121, 203]. Survivorship information is available, but it is scattered throughout the scientific literature, and therefore not readily accessible to survivors [7]. Furthermore, it can be argued that it may be difficult for survivors to distinguish if information is intended for early- or late-stage BC, for just after BC diagnosis, during treatment, or for long-term survivorship. Because the largest part of a woman's life may be spent in survivorship, educational interventions supporting lifestyle changes should be included in the treatment plan of all BC survivors [7], and this is supported by published breast cancer survivorship care guidelines [6].

Some participants in this study were asked to teach others in their community about cancer. However, they felt that they had not been given enough information to embrace this role of cancer advocacy. Survivors perceiving themselves as role models to teach others about cancer has been observed in a previous South African study of BC survivors [62]. In many South African communities, cancer is associated with inevitable death [62].

Indeed, BC signifies the loss of womanhood and therefore the inability to have children, breastfeed, or attract men [60]. However, a South African study found that negative beliefs about BC were mitigated by access to information and confidence in health literacy [71]. Equipping survivors with evidence-based knowledge about their disease will empower them and improve cancer awareness of their families and the public, putting an end to unnecessary stigma [74].

Regarding cancer recurrence: the earlier it is identified, the better the prognosis of the patient [26]. Participants reported not getting concrete answers about the signs and symptoms of a cancer recurrence, from their healthcare providers. This resulted in uncertainty and fear. These feelings have an impact on quality of life, coping behaviour and functional status in BC survivors [62].
Uncertainty is exacerbated by a lack of knowledge of the disease, especially in settings where resource constraints may hamper effective tumour management [74]. The fear of cancer recurrence with pleas to be better informed of the symptoms to look out for, aligns with several other studies of BC survivors [118, 121, 122], including a South African study conducted in Soweto [62]. The latter study highlighted that, despite their fear of recurrence, women were not always informed about the importance of early detection of cancer. The South African health system does not offer routine screening for BC to women who access the public healthcare facilities [72]. Therefore, most women detect breast abnormalities themselves [62, 75]. The lack of knowledge about, and fear of cancer recurrence have the following clinical implications: First, rehabilitation interventions should include patient education on the detection of cancer recurrence and new cancers [62, 74, 204]. Second, patients and healthcare providers must be educated in terms of good and thorough communication with each other [60, 62]. Finally, healthcare providers should be trained in patient education to provide clear guidance to help patients detect cancer recurrence early [60, 62].

Many countries employ structured survivorship care plans, which have shown to have a positive effect on survivors [205]. These programmes include follow-up plans and education based on a multidisciplinary approach [206]. The apparent lack of organised, regular clinic follow-up visits was a source of concern for participants in this study: several women were not aware how often they should visit the clinic. This finding, to the knowledge of this author, has not been reported before, even in other countries without survivorship care plans or interventions after MCT. Despite having numerous unmet needs, survivors in previous studies seemed to be informed about scheduled follow-up visits during survivorship [122, 207]. Nonetheless, survivors in many countries are left to self-monitor their health when primary MCT ends [122].

This is not an easy task, as they face not only LTSEs, but also the possibility of cancer recurrence, developing new cancers, an increased risk of many acute and chronic diseases, altered body image, sexual dysfunction, and having to return to the workplace [7, 203]. Educating patients through structured interventions has shown to improve self-management, decrease anxiety, and increase the coping ability of cancer survivors [6, 208].

2.6.5.2.3 Subtheme: How interventions should be presented

The preferences in terms of intervention delivery varied in this study. Such variation is established in the literature, it has been identified in a review of systematic reviews of rehabilitation interventions for BC survivors [194]. The latter review concluded that several formats of intervention delivery can be effective to improve LTSEs, including those with low levels of supervision using telephone or e-mails [194]. Many women in this study preferred printed information in the form of a book, booklets, pamphlets, or e-mailed information, citing poor memory as a reason. Cancer-related cognitive dysfunction is a LTSE resulting from both cancer treatment and the malignancy itself [32]. It can cause transient memory loss, problems with concentration and multitasking, affecting survivors to various degrees [24, 209]. A Norwegian study concurred with the findings of this study: participants identified a continuous need for information on the one hand, paired with a tendency to forget information on the other hand [210]. This created a constant need to revisit information that had been previously provided.

Research shows that nine out of 10 South Africans own a mobile phone, and around 72% of people have internet access [211]. Digital technologies such as e-mail, WhatsApp, telehealth, and mobile health applications are increasingly being used by South Africans [212]. Therefore most, but not all BC survivors may have access to digital information. Printed information holds the advantage that survivors can easily revisit the content in the future. It can also be shared conveniently with family members or others in the community, which was another advantage identified by women in this study. However, disadvantages of printed information include that information is no longer available if a book or booklet gets lost or damaged, and that content cannot be readily updated.

Several women in this study preferred ‘talks’ or ‘sessions’, stating ‘they must tell us’. Workshops or seminars have been conducted with some success in high-resource settings [195, 213, 214]. These include the advantage of social support: survivors are given the opportunity to get together to form networks, share experiences and ideas [210].

However, seminars require organisational, financial, and staff resources, and patients must be able to travel to and from health centres offering these interventions. Offering workshops may therefore not be an affordable and sustainable option for South African BC survivors. Research shows that, by the time that patients have completed MCT, they have often depleted their finances and time off work [215]. This can make it difficult for them to attend survivorship interventions [32]. Therefore, a combination of print and digital options could potentially be an appropriate solution to provide information for participants in this study, considering both resource restrictions and participant preferences. Furthermore, digital media may be a practical solution to connect participants who would like this, to provide an opportunity for social support and the sharing of information [71, 212]. Thus, it may be an important source of support to survivors of BC, even if they live far away from each other [216].

Regarding if participants preferred healthcare provider or peer-led interventions, opinions were similarly divided. Previous studies confirm that survivor needs and preferences vary greatly, and that, if possible, a choice of interventions should be offered to individualise the care of survivors [96, 194, 210]. In low- and middle income countries such as SA, survivorship care including cancer rehabilitation is still an emerging concept [74]. Ideally, in the future, a range of suitable interventions will be available to allow survivors the choice between healthcare provider or peer-led, distance- or clinic based, group- or individual interventions.

2.6.5.2.4 Subtheme: Disconnected from support organisations

Survivors in this study felt that more engagement from cancer support organisations would contribute to their rehabilitation. This finding agrees with international studies on the unmet needs of BC patients [106, 121]. During survivorship, survivors are suddenly without the 'safety net' of their healthcare providers who lead them through adjuvant treatment for months, leaving them feeling vulnerable and isolated [106]. The findings of this study further revealed that survivors were misinformed about the policies and practices of cancer support organisations, leading to feelings of being neglected. Peer support offered by cancer support organisations has shown to be beneficial for BC survivors, therefore women should be informed how to connect with these organisations [217].

2.6.5.2.5 Summary of theme: Lack of information and access to support

The findings of this study revealed that participants had not received rehabilitation following the completion of their MCT, and that specific information about BC, the management of LTSEs, cancer recurrence, and staying healthy in the long-term was needed to improve their rehabilitation.

Furthermore, survivors in this study requested more input from support organisations. There was a lack of local comparative data, however the findings were compared to international studies. The implications for intervention development are that it should include comprehensive, multimodal education for post-treatment BC survivors about survivorship, aiming to optimise communication between women and healthcare providers. Interventions offered should inform survivors about cancer support services and offer to connect survivors and their families to these organisations. Furthermore, interventions should be flexible to allow for individual preferences. For example, allowing participants to choose between digital or printed information, and offering a choice to either connect with other survivors, or not.

2.6.5.3 Theme: Perception that exercise is important, but neglected

2.6.5.3.1 Subtheme: Exercise perceptions and preferences

In agreement with previous research [119], participants in this study felt that exercise was generally important. Women had learned through the media aimed at the non-cancer population, that exercise was good for the body. They were open to the idea of exercising more. A recent South African cross-sectional study of BC survivors confirmed that women are interested in and capable of participating in an exercise programme [101]. However, women in the present study did not receive specific information about exercise other than shoulder exercise from their healthcare providers, despite their requests for this. Such need for specific information about safe and effective exercise is corroborated by previous research [119]. Participants in this study seemed unaware of the specific benefits of exercise for BC survivors, such as managing side effects [18, 31, 80], decreasing the risk of cancer recurrence [218], and improving survival [80, 218]. Indeed, in current literature, exercise is regarded as an effective adjuvant therapy for BC [31]. This knowledge gap regarding specific benefits of exercise is not unique to this sample of BC patients [219, 220]. In contrast to the findings of this study, participants of a qualitative study in Korean BC survivors reported that they had been informed by healthcare professionals to exercise for weight management, to prevent lymphoedema, and to prevent cancer recurrence [120]. The latter findings also contrast strongly with the misinformation about exercise, that some survivors in this study had received from healthcare providers. However, similar to the Korean study [120], participants in this study relied on intuition regarding how much exercise to do. Intuition may be inaccurate and misleading in many cases, and should be supplemented by current, accurate, clear, factual data [120].

Increased awareness of the various positive outcomes of exercise for cancer survivors, may act as a facilitator for women to exercise more [219]. Research has shown that few survivors meet the physical activity guidelines for cancer survivors [80, 221].

Exercise guidelines for cancer survivors state that survivors should engage in at least 150 minutes of moderate intensity exercise per week, including muscle strengthening, at least twice per week [18]. Specific doses (from 90 minutes of moderate intensity per week) of moderate activity, can result in significant improvement of LTSEs such as fatigue, physical functioning, health-related quality of life, anxiety, and depression, if participation continues for at least 12 weeks [18]. These guidelines highlight the need to promote increased participation in physical activity, to effectively communicate the dosages of exercise required, and to offer assistance or advice with starting an exercise programme.

Exercise preferences varied amongst participants in this study, and this finding is confirmed in previous studies [222-224]. Therefore, interventions should be flexible to allow individual preferences regarding exercise [120]. A recent systematic review of systematic reviews on rehabilitation interventions for BC survivors, found that various exercise modes can have a positive effect on health outcomes [194]. A systematic review and meta-analysis found that, for cancer patients in general, supervised exercise showed a greater benefit for improving physical function and quality of life, compared to unsupervised exercise. However, the confidence levels for BC studies were larger than those for other cancer types, and no statistical differences were found for these outcomes in BC patients [225]. Therefore, unsupervised exercise may be of similar benefit as supervised exercise if prescribed at the correct dosages, to improve physical outcomes in BC survivors. Consistent with previous research [120, 226], some participants in this study preferred to exercise with their peers, while others did not. Rehabilitation interventions that encourage social support have shown to be more effective and acceptable to cancer survivors [84]. On the other hand, survivors should be offered choice and autonomy to make their own decisions about exercise [227]. Designers of interventions should therefore offer opportunities for survivors to exercise together, if they would like this [84].

2.6.5.3.2 Subtheme: Barriers to regular activity

Regarding barriers to exercising regularly, the findings of this study largely agreed with previous research. Like previous studies [202, 228], participants in this study struggled to juggle the roles of caring and providing for their families, with making time to exercise. Participants in the present study also felt self-conscious, which limited their exercise participation [120], or they didn't regard themselves as the 'sporty type' [228]. However, in contrast to previous studies, participants in this study did not perceive exercise to potentially cause or worsen lymphoedema [119] or cancer recurrence [120]. Therefore, the women in this study were not afraid to exercise due to misinformation.

Findings that may be unique to this study were that participants were unable to afford the costs of joining a gym, were living far away from other survivors, and reported a lack of transport to and from fitness facilities. Indeed, in SA the cost of transportation and distance to exercise or healthcare facilities is often a barrier to receiving care [62].

2.6.5.3.3 Subtheme: Facilitators for exercise participation

In this study, participants who exercised described that it improved their mood and energy levels. They further described that exercising in a group, motivated them to keep going. These findings are in line with previous studies, reporting similar exercise facilitators including the group as a powerful support system regarding exercise [119, 120]. On the other hand, some survivors mentioned that exercising alone was a facilitator for them, as this prevents the feeling of being judged by others. A Korean study by Kim and colleagues reported similar findings: Women in that study felt like outsiders when exercising with other people [120]. Women in the present study described that they needed the ability to walk to commute to work, to go shopping, to take children to school. This need to walk for transport remained even when other forms of exercise were discontinued. A German study by Schmidt and colleagues reported this in their follow-up of long-term BC survivors [229].However, the reader is reminded that, at the same time, many women reported a decline in their walking ability since their BC diagnosis. This emphasises the value and importance of preserving the physical function for women following MCT [6, 95].

2.6.5.3.4 Summary of theme: Exercise perceptions, preferences, barriers, and facilitators

The findings of this theme revealed that participants believed that exercise was generally beneficial, however they lacked specific knowledge about exercise for BC survivors. Exercise preferences varied considerably. Barriers to exercise participation included time, family commitments, feeling self-conscious, not perceiving themselves as sporty, financial and transport difficulties. Participants who exercised regularly felt energised and reported improvements in their mood. Exercising in a group or exercising alone were both seen as facilitators. The implications for intervention development are that survivors must be informed of the benefits of exercise for BC survivors specifically, as these have shown to facilitate exercise participation [219]. Challenges in terms of time, finances and transport should be considered during intervention development. A newly developed intervention should accommodate individual preferences regarding exercise.

2.7 Study strengths, limitations and recommendations for future research

This is one of the first qualitative studies addressing the experience of physical LTSEs and the rehabilitation needs of South African BC survivors using the public health system.

A strength of this study is that the COREQ checklist [113] was used for methodological rigour and transparency during the process of conducting the study and reporting the findings.

This research occurred in a single setting, which limits its generalisability. A further limitation of this study is that it included mainly middle-aged and older women, therefore the findings may limit transferability to young BC survivors. This study only investigated the experiences of women with early stage BC and may not reflect the experiences across other cancer populations. While the concept cards were useful to guide FGD towards physical LTSE experienced, it is acknowledged that this may have introduced bias. It is possible that, without these cards, FG discussions may have yielded more information about psychosocial, or other LTSE experienced following BC treatment. The group-based format of FGDs may have prevented some participants from raising issues that were sensitive or considered private. Similarly, participants may have felt pressurised to report experiences that were socially desirable, and this may have biased the results. Only survivors who are prepared to discuss their experiences in a group attend FGDs, and this limits the generalisability of the findings of this study to BC survivors in general.

Evidence-based interventions are urgently needed to equip South African BC survivors with strategies to manage LTSE and to promote healthy survivorship. Specifically, clinically transferable interventions requiring few resources, which can be accessed by BC survivors regardless of their socio-economic status or geographical location, are lacking. There is a dearth of epidemiological studies in SA to elucidate the prevalence of LTSEs in BC survivors. Such research, together with further qualitative studies to explore how these and other LTSE are experienced by South African survivors, are needed to inform future interventions. In addition, studies are needed to determine the physical activity levels of BC survivors. Intervention studies should measure the physical activity levels of BC survivors before and after the interventions, to elucidate the effectiveness of the administered intervention. Finally, participants in this study identified that healthcare providers may lack knowledge about BC survivorship, and this must be explored through future research.

2.8 Conclusion

This study facilitated an insight into the experience of survivorship challenges in South African BC survivors. It presents data for the development of rehabilitative interventions and provides healthcare providers with a new perspective to optimise the care of survivors. The findings revealed that post-treatment BC survivors accessing public health facilities in the Eden District of the Western Cape, SA, are burdened by physical LTSEs.

Furthermore, the findings highlight the critical need for education about LTSEs and how they can be managed, as well as for survivorship concerns including cancer recurrence and aftercare. Multiple challenges reflecting the South African context were identified: Women are expected to manage their health and rehabilitation, detect new or recurring cancers, and decide when to seek medical advice, without having been informed or equipped for this purpose. Transportation problems, limited access to support services and health and exercise facilities, and financial constraints further compound these challenges. Interventions to address the identified needs should be multidimensional, widely accessible, affordable, and flexible to suit individual preferences [80, 84, 120]. Interventions should include health education, physical, and emotional survivorship concerns [7, 24]. Self-management interventions including an exercise component may be effective and suitable to meet these needs [201, 208]. This possibility was explored in the next chapter of this thesis, through a systematic review.

Chapter 3. Self-management interventions including an exercise component, for breast cancer survivors: a systematic review and meta-analysis.

3.1 Introduction

In Chapter 2, breast cancer (BC) survivors provided insights regarding their rehabilitation needs. It is known that economic and time constraints affect the provision of health services to cancer survivors after medical cancer treatment (MCT) [230]. Supervised exercise interventions require many resources and are unlikely to become standard of care in many settings [230, 231]. Self-management interventions (SMIs) for cancer survivors are gaining popularity as more randomised controlled trials (RCTs) are providing evidence of their efficacy to manage long-term side effects (LTSEs) of BC treatment [149, 193, 208, 232]. They may be a tool to bridge the gap between the needs of BC survivors and the health system's ability to meet their needs [230]. A definition of self-management is "the systematic provision of education and supportive interventions to increase patients' skills and confidence in managing their health, including regular assessment of progress and problems, goal setting, and problem-solving support" [233]. In recent systematic reviews, support including assistance with adherence has been identified as an essential ingredient of SMIs, as this encourages participant engagement [234, 235]. Therefore, the emphasis in self-management is on empowering people to take control of their health [201]. Self-management interventions may be cost-effective, without placing a burden on overloaded healthcare systems [200]. Furthermore, SMIs may be cost saving to patients as they require fewer clinic visits, compared to supervised interventions [149, 230].

Apart from education and support [234], successful SMIs promote five core skills: problem solving, decision making, resource use, forming partnerships, and taking action [83]. This contrasts with the traditional health education model advocating the one-way delivery of information between healthcare providers and patients [83]. Exercise can be seen as a self-management technique: it is an independently executed, lifestyle-enhancing behaviour which includes health maintenance and the management of LTSEs [201]. Improved self-efficacy has been consistently linked to the self-management of chronic conditions [83, 236, 237]. Effective SMIs should therefore reduce the burden of commonly experienced LTSEs, and improve self-efficacy, health-related quality of life (HRQoL) and physical activity [201, 235].

There has been extensive exercise intervention research in early-stage BC (ductal carcinoma in situ, stage I, IIA, IIB and IIIA) [16, 96, 194, 238-240]. The next step is to determine whether SMIs including an exercise component, could offer an effective alternative to supervised interventions in this population. Most systematic reviews exploring the efficacy of SMIs in cancer, included participants with various types and stages of cancer [149, 193, 208, 230, 232]. However, interventions should be tailored to the needs of the population they serve [31]. Interventions for BC should therefore be distinct from those intended for other cancers. Including participants with diverse cancers has precluded several systematic reviews from performing meta-analyses, due to the heterogeneity of the participants and interventions [149, 208, 230]. Therefore, the aim of this systematic review was to evaluate the effects of self-management interventions including an exercise component and utilising minimal clinical visits, on physical LTSEs and physical activity, in early-stage post-treatment BC survivors.

3.2 Research question and PICOS framework

How effective are SMIs including an exercise component, to manage commonly occurring physical LTSEs such as pain and fatigue, and to improve HRQoL, self-efficacy and physical activity, in early-stage BC survivors following MCT? Refer to Table 7 for the PICOS (Population, Interventions, Comparison, Outcomes and Study Design) framework informing this systematic review.

3.3 Methods

The methods are presented based on the PRISMA (Preferred Reporting Guidelines for Systematic Reviews and Meta-analyses) guidelines for systematic reviews (Appendix K) [241]. The protocol has been registered on PROSPERO (https://www.crd.york.ac.uk/PROSPERO/; ID: CRD42022336947). No changes were made to any of the review methods from what was registered on PROSPERO.

Table 7: PICOS framework informing this systematic review.

Population	Studies including adult women up to 10 years after completing primary MCT (breast surgery, chemotherapy and / or radiation) for ductal carcinoma in situ, stage I, IIA, IIB or IIIA breast cancer.
Intervention	Self-management interventions including an exercise component, or education about exercise. A self-management or self-care intervention includes activities which survivors are instructed to perform independently, to support the management of their LTSEs [233]. Acceptable types of SMIs for this study included home-based, web-based, or mobile-/ telephone-administered interventions, information sessions, multimedia, booklets or handbooks and recommendations, or a combination of these. Interventions were to include education and support [234], plus at least one of the five core self-management skills (problem solving, decision making, resource use, forming partnerships, and taking action) [83]. To allow for cost-effective translation into practice in settings where transport to and from healthcare centres may be problematic, or where there are healthcare staff shortages, a maximum of three contact sessions of participants with research staff during the intervention (including outcome assessments), were considered feasible for inclusion.
Comparison	Women receiving usual care or standard care, wait list control groups or attention control groups, to elucidate the effectiveness of these interventions against not receiving them.
Outcomes	Pain, fatigue, self-efficacy, HRQoL or quality of life (QoL), anthropometry (body composition), physical activity, physical fitness (direct or indirect), and motivational readiness for physical activity, measured with validated instruments.
Study design	Randomised controlled trials.

3.3.1 Inclusion criteria

- This study included full-text RCTs only, to evaluate the best quality evidence of effectiveness.
- Women aged between 18 and 70, three months to 10 years after primary MCT (surgery, chemotherapy and / or radiotherapy), for ductal carcinoma in situ, stage I, IIA, IIB or IIIA (early) BC. Breast cancer is much more common in women compared to men, and most studies have been conducted in women [141].
- Intervention included education about or instructions for exercise and encouraging physical activity participation. General exercise (physical activity that aims to improve overall health and wellbeing [242]), muscle strengthening, shoulder exercises, yoga, Pilates, or a combination of these were eligible for inclusion. These forms of exercise have shown to have beneficial effects on LTSE of BC treatment in systematic reviews [67, 96, 194, 225, 243, 244].

- The intervention included an educational and supportive component (such as assistance with adherence to the intervention or feedback on progress during the intervention) [234]; promoting at least one of the five core self-management skills to improve health-related behaviours [83, 232].
- The study measured at least one of the following outcomes: pain, fatigue, HRQoL, self-efficacy, body weight or other anthropometric measurement (such as waist circumference or body mass index (BMI)), physical activity or physical fitness (self-report or direct measurements), using validated instruments.
- English language studies from any continent and country, to facilitate the collection of comprehensive data from various sources.

3.3.2 Exclusion criteria

- Research in cancers or conditions other than BC, metastatic cancer, and studies during or before the start of primary MCT.
- Supervised interventions. Interventions that included virtual supervision, such as tele-video (telemonitoring) supervision during exercise sessions, were excluded.
- Studies requiring wearable digital devices (apart from simple pedometers) or providing expensive applications or electronic devices as part of intervention delivery. These interventions are unlikely to be clinically transferable to low-resource settings due to the high costs of such devices.
- Studies that exclusively prescribed lymphatic drainage or breathing exercises. These, unless combined with other forms of exercise such as aerobic or muscle strengthening exercises, are unlikely to influence the outcomes of interest in this review [225].
- Studies published after February 2024.
- Studies where the methods or participants were not clearly described, making it unclear if the inclusion criteria were met.

3.3.3 Information sources and search strategy

A Medical Subject Heading (MeSH) search was conducted in PubMed to investigate search terms and assist in forming a search strategy. Electronic databases were selected for inclusion based on the likelihood of containing relevant information. The search terms and search strategy were developed in consultation with a Medical Librarian. PubMed, Cochrane Central Register of Controlled Trials, Web of Science and Scopus databases were searched from June 1992 until February 2024[6].

[6] Initially, the systematic review was conducted to include studies that were published until June 2022, to inform the subsequent development of the intervention in Chapter 4. The search was repeated in February 2024 to update the review in preparation for this thesis.

Grey literature was searched. Forward- and backward citation searching was conducted. Searches were repeated before the final analyses to identify and retrieve further studies for inclusion.

The search strategy consisted of four main categories including 1) “breast cancer”, 2) “self-management”, 3) “exercise”, 4) “after treatment” and their synonym keywords, in each category. Limits on the searches were set to include journal articles in English, “human” and “adult”, “female” and “random* control* trial”. The terms “qualitative research”; “male; “child” or “children” or “adolescent” or “neonate”; “rat” or “rodent” or “mouse”; “case study” or “case report” were excluded using the “NOT” Boolean search term. The full search strategy for each database is presented in Appendix L.

3.3.4 Screening and data extraction

All the citations identified were imported into Endnote® and duplicates were removed. The researcher AB screened all citation abstracts, according to the inclusion and exclusion criteria described above. Studies were excluded when it was clear from their title and abstract that they did not relate to the inclusion criteria. Where there was a lack of clarity from the title and abstract, the full text was retrieved to determine the suitability of the article. The full text of articles likely to fit the inclusion criteria during title and abstract screening, were also obtained. Three experienced reviewers (AB, PM and DS) independently reviewed the full text and extracted critical data from the included studies, using a modified data collection form from the Cochrane Collaboration [245] with the following headings: country of study, sample size, age of participants, intervention group characteristics and content, control group characteristics and content, and outcomes (pain, fatigue, self-efficacy, HRQoL, physical activity, fitness, anthropometry, or function).

3.3.5 Risk of bias assessment

The Cochrane Collaboration’s revised tool for assessing risk of bias in randomised trials (RoB 2) was used to evaluate the methodological quality of included studies [246]. The tool covers five domains of bias: bias arising from the randomisation process; bias due to deviations from intended interventions; bias due to missing outcome data; bias in measurement of the outcome, and bias in selection of the reported result. The domains were rated by two independent reviewers (AB and PM) as being “high”, “low” or “some concern” for each domain, as described in the Cochrane Handbook [247]. Disagreements between reviewers were resolved through discussion and consensus, and a third reviewer (DS) was available to resolve disagreements. A study was considered to have a “low” risk of bias if all domains were categorised as “low”, “some concern” if one or more domains were categorised as “some concern”, and “high” if one or more categories were labelled “high”, or if multiple domains were categorised as “some concern” [246].

The risk of bias in the meta-analysis was determined as follows: Risk of bias was considered “low” if 75% of studies included in the analysis were “low” risk, and “high” if more than 25% were labelled as “high” risk. An “unclear” risk was determined if more than 25% of studies had a “some concerns” risk of bias but less than 25% had a “high” risk of bias [246].

To determine the quality of evidence for each outcome in the meta-analysis, the GRADE (Grading of Recommendations, Assessment Development, and Evaluation) tool was used independently by two reviewers (AB and DS) [248]. This tool considers, for each outcome, the risk of bias, indirectness of evidence, unexplained heterogeneity, imprecision of results, and risk of publication bias [248]. Disagreements were resolved in a meeting, through discussion and consensus [247].

3.3.6 Statistical analysis

A biostatistician from the University of Cape Town conducted the statistical analysis. Data were analysed using R software, version 4.2.2 [249]. Heterogeneity across studies was analysed using I^2. This value represents the likelihood that differences between studies are due to heterogeneity as opposed to chance. I^2 is interpreted as a percentage of heterogeneity not caused by sampling error. Note that with a low number of studies these estimates should be interpreted with caution [247]. An I^2 value above 40% indicates significant heterogeneity or inconsistency between studies that measure the same outcomes. Outcomes with high levels of heterogeneity should be observed with caution [247].

Linear fixed effect models were fitted for all outcomes. The fixed effect model was chosen over the random effects model as the estimation of the random effects when the number of studies is less than 5 is inaccurate [250]. However, the choice of fixed effect models means that the generalisability of the findings is limited to the specific population being studied [251]. The estimated mean difference (or standardised mean difference, where there was a large range of measures between studies), was calculated to determine the size of the intervention effect on each outcome measure, as data were continuous. An effect size of 0.2 indicates a small effect, while 0.5 and 0.8 indicate medium and large effects [247]. Data were summarised, pooled for analysis, and reported systematically [247]. Sensitivity analyses were conducted for each of the different correlation values (0.2, 0.5, and 0.8). The model with a correlation of 0.5 was chosen as a moderate estimate.

3.4 Results

3.4.1 Study selection

Refer to Figure 4 for a summary of the study selection process. Electronic searches identified 997 studies. After the removal of duplicates, 739 citations were screened using the inclusion and exclusion criteria, of which 25 citations were retained. Of these, three were excluded as they were only available as conference abstracts [252-254].

Therefore, the full text of 22 studies identified through database searching, and a further 19 studies retrieved through hand-searching, were independently screened by two reviewers (AB and PM). Discrepancies were resolved through discussion with a third reviewer (DS). Upon exclusion of 15 and 16 studies respectively, 10 studies remained and were included.

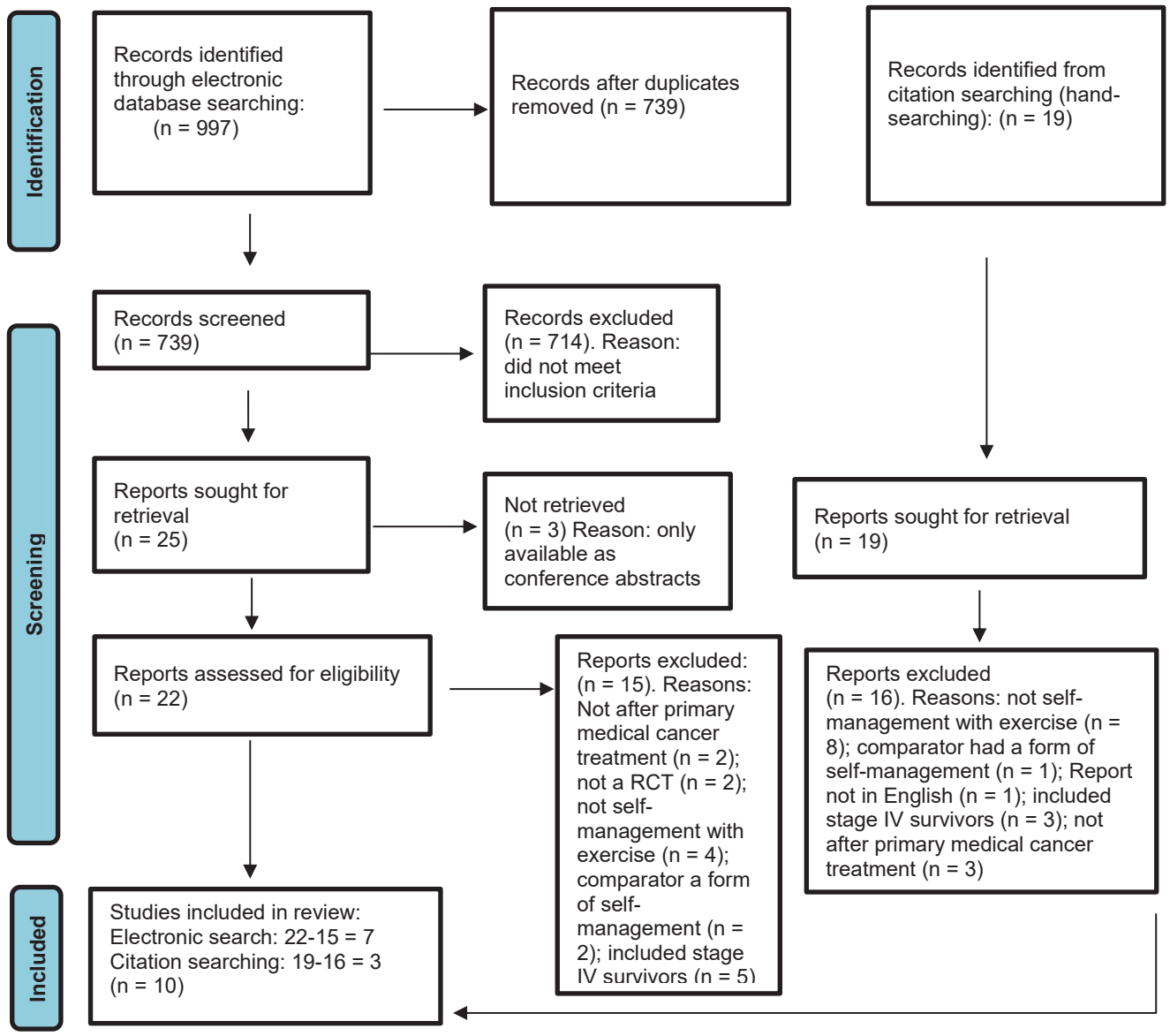


Figure 4: PRISMA flow diagram of the study selection process [241].

Several studies appeared to meet the inclusion criteria initially, but were excluded for the following reasons: studies that were conducted during MCT [150, 255-258]; included participants with metastatic disease, or did not specify the stage of disease of participants [195, 226, 259-265]; were not RCTs [266, 267]; were not SMIs including exercise, or required too many clinic visits [268-279]; the control group included a form of self-management [280-282]; or the full text was not in English [283].

3.4.2 Interventions

No adverse effects were reported in the included studies. Three studies promoted the development of all five core self-management skills in their interventions [284-286]. These were the only interventions that encouraged 'forming partnerships' (Table 8). Three studies specifically included overweight and obese BC survivors [103, 287, 288].

One study included only BC survivors who had previously undergone preventive surgical salpingo-oophorectomy [286]. All interventions included an exercise component: three studies did not specify the type of exercise prescribed; or allowed participants to choose any exercise [284, 285, 287]. Three studies used aerobic exercise only [288-291]. Three studies prescribed aerobic combined with resistance training [103, 286, 292]. All except two interventions [289, 292] were based on a structured theoretical framework. There was variability in terms of the length and format of the included interventions. The length of interventions ranged from 12 weeks to one year. Regarding the format, interventions included online [286, 290], telephone [103, 284, 285, 287-289, 291, 292] or face-to-face counselling sessions [285, 289, 291, 292], e-mails [292] and text messages [103]. These were combined with a workbook [103, 284], leaflets [285], booklet [285, 289] or tip-sheets [291]. Two interventions [285, 292] provided an exercise digital video disc (DVD), while two studies [103, 288] provided pedometers to participants. Two interventions were solely web-based [286, 290]. All interventions encouraged the adherence of participants through activity diaries or exercise logs. Control interventions included wait list [284, 292], printed brochures or newsletters [103, 285, 287-290], or contact-control groups [286, 291].

The focus of the included interventions was on improving nutrition and increasing exercise [103, 284, 286-288, 290, 292]. Several interventions also provided information about managing LTSEs such as lymphoedema [285, 289, 291] and fatigue [285]. However, no interventions in this review included comprehensive information on BC survivorship, the detection of cancer recurrence or new cancer, and shoulder problems, as requested by study participants in Chapter 2.

Table 8: Core self-management principles employed by studies in this systematic review.

	Problem solving	Decision making	Resource use	Forming partnerships	Taking action
Befort et al.	✓	✓	✓		✓
Ergun et al.		✓	✓		✓
Harrigan et al.	✓	✓	✓		✓
Kim et al.	✓	✓	✓	✓	✓
Lahart et al.	✓	✓	✓	✓	✓
Lee et al.	✓	✓	✓		✓
Pinto et al.	✓	✓	✓		✓
Reeves et al.	✓	✓	✓		✓
Sturgeon et al.	✓	✓	✓	✓	✓
Wang et al.		✓	✓		✓

3.4.3 Study characteristics

A combined sample of 823 participants was included in this review. In Table 9 following the section on outcomes, the characteristics of the 10 studies are presented including location, details of the intervention and control groups, duration of interventions, assessment, and results. All studies were RCTs, consisted of participants who self-identified as women, with ductal carcinoma in situ, stage I, IIA or III BC, after having completed primary MCT. The articles were published between 2005 and 2021. All evaluated supported SMIs including exercise and required a maximum of three face-to-face sessions with participants, including outcome assessments. Two studies consisted of three groups: a supervised exercise group, a self-management group and a control group [288, 289]. Only the self-management - and the control groups were included in this review. The remaining eight studies consisted of two groups.

3.4.4 Outcomes

A range of outcomes were evaluated. The most appropriate outcomes in each study are reported, based on their relevance to the research question. Examples of outcomes omitted as they were beyond the scope of this review, were depression and anxiety [284, 289-291], diet quality [284, 286, 288, 290], blood biomarkers such as cholesterol, glucose and insulin [103, 285, 288], and body image [103, 291].

Outcomes relevant to this review were HRQoL [103, 284, 285, 289, 290, 292]; physical activity [284-286, 288, 290-292]; fatigue [103, 284, 289-291]; anthropometry [103, 285-288, 291, 292]; fitness [286, 291, 292]; stage of motivational readiness for exercise [284, 290, 291]; muscle strength [286, 292]; self-efficacy [290, 292]; and pain [103].

Despite the differences in length and design, nine of the 10 studies demonstrated significant differences between intervention and control groups, in favour of the intervention groups [103, 284-288, 290-292]. In the following section, results are reported per outcome and the outcome measures used by each study are briefly described to provide context for the results. In outcomes where most studies reported significant between-group differences, those that failed to find significant differences are highlighted in the narrative sections below.

3.4.4.1 Health-related quality of life (HRQoL)

Of the six studies that evaluated HRQoL, five [103, 284, 285, 290, 292] showed significant improvements in HRQoL (or questionnaire subscales) in favour of the intervention groups, post-intervention (Table 9). Various questionnaires were used. The most frequent was the EORTC QLQ C30 [284, 289, 290], a 30-item cancer-specific questionnaire assessing general HRQoL [293]. Lahart and colleagues [285] used the FACT-B questionnaire. This has 36-items, with four primary domains [294]. Reeves and colleagues [103] evaluated HRQoL using the Patient-Reported Outcome Measurement Information System (PROMIS) Global Health Scale, which collects information across five domains [295]. Wang and colleagues [292] used the Functional Assessment of Cancer Therapy – Endocrine Symptoms version 4 (FACT-ES), a cancer-specific instrument including five domains [296]. Using the EORTC QLQ C30, Ergun et al. [289] (n = 40) was the only study that failed to find significant differences between intervention and control groups for HRQoL.

3.4.4.2 Physical activity (PA)

Five [285, 288, 290-292] of the seven studies assessing self-reported physical activity, demonstrated a significant improvement of their intervention groups, compared to control groups post-intervention (Table 9). Various questionnaires were used. Lahart and colleagues [285] used the IPAQ-long form, assessing the duration engaged in walking, moderate, and vigorous PA in four domains, the past seven days [297]. Lee and colleagues [290] used the seven-day exercise diaries of participants, in minutes per week of at least moderate aerobic exercise [298-300]. Pinto and colleagues [291] used the Seven-day Physical Activity Recall questionnaire (7-Day PAR), assessing hours spent in sleep and moderate, hard, and very hard activity, the past week [301].

Sturgeon and colleagues [286] and Harrigan and colleagues [288] used the Modifiable Activity Questionnaire (MAQ), which evaluates physical activity at work, during leisure time, and inactivity levels [302]. Kim and colleagues [284] (n = 45) reported no significant differences between groups, using the leisure time physical activity (LTPA) subscale of the International Physical Activity Questionnaire (IPAQ). This subscale assesses the frequency and duration of PA over the past week, during leisure time [297]. Wang and colleagues [292] (n = 60) found no significant difference between groups using the Paffenbarger Physical Activity Questionnaire (PPAQ), a 16-item measure about the time spent per day engaged in vigorous, moderate, and light physical activity [303].

Objective physical activity using accelerometry was assessed by Pinto et al. [291] (n = 86). Reeves et al. [103] (n = 159) also reported accelerometry results, in a separate publication [304]. Neither study found a significant difference in activity between groups. Harrigan et al. [288] (n = 67) and Wang et al. [292] (n = 60) assessed objective exercise participation by calculating pedometer steps per day. Neither study found significant differences between groups.

3.4.4.3 Fatigue

Three out of five studies [284, 290, 291] assessing fatigue, found a statistical difference between groups post-intervention, in favour of the intervention group (Table 9). Pinto and colleagues [291] measured fatigue using a linear analogue scale [305]. Three studies [284, 289, 290] used the Brief Fatigue Inventory (BFI): a one-page measurement tool including nine items, each rated on a 0–10 scale [306]. Ergun and colleagues [289] (n = 40) reported no significant differences between groups in their study, using the BFI. Reeves et al [103] (n = 159), used the FACIT-Fatigue questionnaire, reporting no significant differences between groups in their study. This is a 13 item tool that measures fatigue and its interference with function, in cancer patients [307].

3.4.4.4 Anthropometry

Four out of the seven studies evaluating anthropometry, demonstrated significant results post-intervention in favour of their intervention groups: Befort et al. [287] (body weight), Harrigan et al. [288] (body weight, waist- and hip circumference), Lahart et al. [285] (body weight and BMI), and Reeves et al. [103] (fat mass and waist circumference)(Table 9). Pinto et al. [291] (n = 86), Sturgeon et al. [286] (n = 35), and Wang et al. [292] (n = 60), found no significant differences between groups.

3.4.4.5 Fitness

Three out of four studies evaluating fitness levels, found significant improvements of the intervention groups, compared to controls (Table 9). Different methods were used to determine fitness levels. Pinto and colleagues [291] used the Rockport 1-mile walk test [308]. Wang and colleagues [292] assessed cardiorespiratory endurance using the number of steps performed in two minutes [309].

Lahart et al. [285] evaluated fitness using the modified Bruce protocol, in a sub-study using 40% of the study sample. Sturgeon and colleagues [286] (n = 35) evaluated cardiovascular fitness using the modified Bruce protocol [310], and this study failed to report significant differences between groups.

3.4.4.6 Stage of motivational readiness for exercise (SMR)

Three studies [284, 290, 291] assessed SMR. All three found that significantly more participants in the intervention groups progressed in SMR, compared to controls (Table 9). The SMR instrument allows participants to be classified into one of the following stages: precontemplation, contemplation, preparation, action, and maintenance, in terms of achieving the recommended public exercise guidelines [311].

3.4.4.7 Muscle strength

Wang and colleagues [292] found a significant improvement in their intervention group compared to controls, using timed biceps curls to determine upper body strength [309]. Sturgeon et al. [286] found no significant difference between groups (Table 9). The latter study determined lower body strength using a leg press machine, and upper body strength through a bench press using a flat bench and Olympic bar.

3.4.4.8 Self-efficacy

Both studies assessing self-efficacy found significant improvement between intervention and control groups (Table 9). Lee et al. [290], used a self-developed self-efficacy for exercise scale. Participants were asked: ‘‘How sure are you that you could exercise at least 30 min a day, at least 5 days a week?’’ Options for answers were: Very sure, sure, somewhat sure, unsure, and very unsure. Wang et al. [292] used the self-efficacy for physical activity scale (SEPA), a measure that asks participants to rate their self-perceived confidence to engage in exercise despite various barriers [312].

3.4.4.9 Pain

One study evaluated pain levels of participants. Reeves and colleagues [103] used the musculoskeletal pain subscale of the Breast Cancer Prevention Trial Symptom Scale [313]. They reported a significant improvement in the intervention group, compared to controls post-intervention (Table 9).

Table 9: Characteristics of included studies.

Author, year, country	Sample size, IG vs CG	IG and CG format, length	IG content and theory	Assessment	Results
Befort et al., 2016 USA	n = 172 IG = 87 CG = 85	IG: Weight loss maintenance programme for overweight / obese survivors who had lost > 5% BW in previous trial. CG: Newsletters, self-monitoring logs. 12 months	26 Bi-weekly group conference calls focused on problem solving, review of nutrition, exercise, behavioural, and survivorship topics. Weekly self-monitoring logs. The PA goal was 225 min/week. The report did not specify the type(s) of PA prescribed. Based on the social cognitive theory.	At baseline and at 12 months. Weight (re)gain: calibrated scale	Weight gain: IG regained significantly less BW vs CG (p = 0.03). Significantly more IG participants > 5% below their baseline BW, vs CG (p = 0.02).
Ergun et al., 2013 Turkey	n = 60 IG = 20 CG = 20 Supervised group (not included in this review) n = 20	IG: Home walking programme, weekly phone calls. CG: 30 min education session, booklet. 12 weeks	30-Minute on-site education about adverse effects of BC, lymphoedema prevention, booklet with lymphoedema-specific exercises. Home-based walking programme: individually prescribed pace according to heart rate. Brisk walking 3 days/week. Participants taught to measure heart rate, maximum heart rate for age. Weekly activity calendars, phone calls. Intervention theory not specified.	At baseline and at 12 weeks. QoL: EORTC QLQ C30 Fatigue : BFI	QoL: Functional score, symptom score, global health scores NSD (p > 0.05). However, functional score increased significantly in IG (p < 0.05) vs baseline. Fatigue : NSD (p = 0.827)

Author, year, country	Sample size, IG vs CG	IG and CG format, length	IG content and theory	Assessment	Results
Harrigan et al., 2016 USA	n = 100 IG = 34 CG = 33 In-person group not included in this review (n = 33)	IG: Telephone counselling to improve diet and exercise, for overweight and obese BC survivors. CG: Usual care: Nutrition and PA brochures. Six months	30 minute telephone counselling based on a workbook once per week for first month, every 2 weeks (months 2 and 3), then once per month (months 4, 5 and 6). Sessions were according to a curriculum with information on nutrition, exercise, and behavioural strategies. Encouraged to achieve PA guidelines (150 min of exercise per week) through moderate activity of choice, such as brisk walking. Based on social cognitive theory.	Baseline; six months. Anthropometry: BW, waist and hip circumference, body fat (DXA) PA: MAQ, pedometer steps	BW: Significantly > BW loss IG vs CG (p = 0.009). Waist circumference: IG > CG (p = 0.005). Hip circumference: IG > CG (p = 0.01). Body fat: NSD (p = 0.37). PA: MAQ: IG > CG (p < 0.017). Pedometer steps: NSD.
Kim et al., 2011 South Korea	n = 45 IG = 23 CG = 22	IG: Exercise and diet prescriptions through telephone counselling and a workbook. CG: Usual care. 12 Weeks	Weekly telephone counselling, workbook with exercise and diet information, individual exercise and diet prescription. Diet and exercise goals customised according to SMR. Exercise and diet diary. Participants could choose any type of moderate intensity PA, at least 30 min per day, at least 5 days per week. Based on the transtheoretical model.	Baseline; 12 weeks. SMR for exercise PA: LTPA subscale of IPAQ QoL: EORTC QLQ C-30 Fatigue : BFI	IG progressed > SMR (exercise), vs CG. (p = 0.006). PA: NSD between groups (p = 0.086). QoL: IG > CG emotional functioning (p = 0.004). Other QoL subscales NSD. Fatigue: IG > CG (p = 0.001)
Lahart et al., 2016 United Kingdom	n = 80 IG = 40 CG = 40	IG: Home-based physical activity CG: Usual care (received current physical activity guidelines) Six months	One face-to-face PA counselling consultation, 3 monthly telephone calls, 2 monthly mailed leaflets, booklet on exercise safety and exercise with lymphoedema, DVD, exercise diary with goal of 150 min exercise / week. Type of exercise recommended was not specified. Based on motivational interviewing principles.	Baseline; six months. PA: IPAQ long form Anthropometry: BW, BMI, body fat QoL: FACT-B Fitness: aerobic capacity (evaluated in 29 participants)	PA: IG > CG (p = 0.024). Anthropometry: IG significant reductions in BW (p = 0.04), BMI (p = 0.03), not body fat (p = 0.594) vs CG. QoL: IG > CG (p = 0.024). Fitness: Likely beneficial effects IG > CG (d = .44)

Author, year, country	Sample size, IG vs CG	IG and CG format, length	IG content and theory	Assessment	Results
Lee et al., 2014 South Korea	n = 59 IG = 30 CG = 29	IG: Web-based exercise and diet self-management programme CG: Educational booklet on exercise and diet 12 weeks	Web-based assessment, education (tailored information based on assessment), action planning. Exercise and diet diaries were compared to guidelines, automated tailored feedback given. Education was individualised according to SMR. Goal was to meet PA guidelines. The intervention prescribed aerobic exercise selected by participants. Based on transtheoretical model.	Baseline ; 12 weeks. PA : 7-day exercise diaries QoL: EORTC QLQ C-30 Fatigue : BFI SMR for exercise SE for exercise	PA: IG > CG meeting PA guidelines ($p < 0.0001$). QoL: physical functioning IG > CG ($p = 0.023$). Global QoL: NSD ($p = 0.369$). Fatigue: IG > CG ($p = 0.032$). SMR exercise: IG > CG ($p < 0.0001$) SE for exercise : IG > CG ($p = 0.024$)
Pinto et al., 2005 USA	n = 86 IG = 43 CG = 43	IG: Home-based PA, telephone counselling, exercise tip-sheets. CG: Weekly calls and tip sheets (contact control). 12 weeks	IG: One in-person PA instruction session, home logs, pedometers. Goal was to meet PA guidelines. Weekly activity counselling via telephone, mailed tip sheets and individual summaries of progress. The programme promoted aerobic exercise selected by participants. Based on the transtheoretical model.	Baseline; 12 weeks. PA: 7-day PAR Fitness: Rockport 1 mile walk test Objective activity: accelerometer Anthropometry: BMI, body fat SMR for exercise Fatigue : linear analogue scale	PA: IG > CG ($p = 0.001$). IG more likely to meet PA guidelines ($p = 0.001$). Fitness: IG > CG ($p = 0 .001$). Objective activity: NSD ($p = 0.36$) Anthropometry: NSD for BMI ($p = 0.244$) and body fat ($p = 0.22$). SMR for exercise: IG > CG ($p = 0.001$). Fatigue : IG > CG ($p = 0.001$).

Author, year, country	Sample size, IG vs CG	IG and CG format, length	IG content and theory	Assessment	Results
Reeves et al., 2021 Australia	n = 159 IG = 79 CG = 80	IG: Remotely delivered diet and PA intervention for overweight and obese breast cancer survivors. Aimed at weight loss through improving diet and increasing physical activity. CG: Usual care 12 months	Participants provided with workbook, scale, measuring tape, pedometer, calorie-counter book, self-monitoring diary. First 6 months: 16 motivational interviewing calls (six weekly then 10 bi-weekly), optional text messages. Second 6 months: six monthly calls, tailored text messages. Aim was weight loss through improving diet and increasing PA. The programme encouraged a goal of moderate-to-vigorous aerobic activity, 210 min/week and 2–3 resistance exercise sessions/week. Based on social cognitive theory.	Baseline; 12 months. BW: calibrated scale Anthropometry: fat mass, waist circumference. QoL: PROMIS (provides summary scores for physical and mental health) Fatigue : FACIT-fatigue Pain : Musculoskeletal subscale from BCPTSS Objective activity: Accelerometer Sitting time	BW: Significantly > BW loss IG vs CG ($p < 0.001$), at 18 months ($p = 0.007$). Anthropometry: IG > CG fat mass ($p < 0.001$); at 18 months ($p = 0.023$); waist circumference ($p = 0.007$). QoL: physical QoL IG > CG ($p = 0.007$). Mental QoL NSD ($p = 0.067$). Fatigue : NSD ($p = 0.110$). Pain : IG > CG ($p = 0.003$). Objective activity : NSD ($p = 0.075$). Reported in a separate publication [304]. Sitting time: NSD ($p = 0.966$). Reported in a separate publication [304].
Sturgeon et al., 2017 USA	n = 35 IG = 19 CG = 16	IG: Web-based commercially available lifestyle modification programme: 'Precision Nutrition' CG: Contact control: biweekly emails 12 months	Customised exercise programme, reading material, access to an online female coach as needed. A workout, habit, lesson each day. Goal was to improve cardiovascular and bone health through increasing PA and improved nutrition. The programme required 160 min/week of exercise (3 days/week progressive resistance exercise, 2 days/week interval aerobic exercise, and 1 day/week active recovery aerobic exercise). Online daily activity logs.	Baseline; 12 months. Fitness: aerobic capacity PA: MAQ Anthropometry: BMI, BW, fat mass, body fat (DXA) Muscle strength: 1RM upper- and lower body.	Fitness: NSD ($p = 0.07$). PA: IG > vs CG ($p = 0.04$). Anthropometry: NSD. IG: decreased BMI ($p = 0.007$), BW ($P = 0.007$), fat mass ($p = 0.02$), body fat ($p = 0.04$) vs baseline. Muscle strength: NSD.

			Based on the social cognitive theory.		
Author, year, country	**Sample size, IG vs CG**	**IG and CG format, length**	**IG content and theory**	**Assessment**	**Results**
Wang et al., 2021 USA	n = 60 IG = 31 CG = 29	IG: Personal trainer-led home-based PA intervention CG: Wait-list Up to 30 weeks	Personal trainer-prescribed customised home exercise programme according to exercise prescription guidelines for cancer survivors. Three sessions with the personal trainer, two email / phone contacts, feedback on progress. Exercise logs, exercise DVD. Aerobic and resistance exercise was prescribed, goal was 150 minutes of moderate to vigorous exercise per week. Based on PA guidelines for cancer survivors.	Baseline; 30 weeks. PA: PPAQ SE: SEPA scale QoL: FACT-ES Steps per day: pedometer Fitness: 2-minute step test. UBF: back scratch test. UBS: timed bicep curls. Anthropometry: BMI	PA: NSD (p = 0.80) SE: IG > CG (p = 0.047). QoL: NSD (p = 0.23). Physical wellbeing subscale IG > CG (p = 0.023). Steps per day: NSD (p = 0.46). Fitness: IG > CG (p = 0.036). UBF: NSD (p = 0.13). UBS: IG > CG (p = 0.002) Anthropometry: NSD (p = 0.54).

Table 3.3 Legend and abbreviations:

IG: Intervention Group, CG: Control Group; >: Significant difference between groups, in favour of the intervention group unless otherwise stated. Results apply to the whole duration of the study, unless otherwise specified. vs: compared to; PA: Physical activity; BCPTSS: Breast Cancer Prevention Trial Symptom Scale; BFI: Brief Fatigue Inventory; BMI: Body Mass Index; BW: Body weight in kilograms; DVD: Digital Versatile Disc; DXA: Dual-energy X-ray Absorptiometry; EORTC QLQ C30: The European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Core 30; FACIT-Fatigue: Functional Assessment of Chronic Illness Therapy-Fatigue; FACT-B: Functional Assessment of Cancer Therapy – Breast; FACT-ES: Functional Assessment of Cancer Therapy – Endocrine Symptoms; IPAQ: International Physical Activity Questionnaire; LTPA: Leisure time physical activity; MAQ: Modifiable Activity Questionnaire; Min: minute(s); NSD: No significant difference (between groups); PPAQ: Paffenbarger Physical Activity Questionnaire; PROMIS: Patient-reported Outcome Information System; QoL: Quality of life; HRQoL: Health-related quality of life; SE: Self-efficacy; SEPA: Self-efficacy and Physical Activity Scale; SMR: Stage of motivational readiness: precontemplation, contemplation, action, maintenance; UBF: Upper Body Flexibility; UBS: Upper Body Strength; USA: United States of America

3.4.5 Risk of bias within studies

The Cochrane Collaboration's revised risk of bias tool (RoB 2) for randomised trials [246] was used to assess the included studies. Table 10 provides a summary of the risk of bias assessment results. The main domain that increased the risk of bias within the studies, was the lack of blinding of participants and assessors. While participants are seldom blinded in health intervention research [314], an additional complication for risk of bias was the reliance on participant-reported outcomes.

Apart from Harrigan et al., none of the included studies used a single assessor for their outcome measurements, and intra- and interrater reliability were not reported for outcomes requiring judgment, such as waist and hip circumference, height for calculating BMI, or flexibility. The overall risk of bias within studies was therefore assessed as 'high', except for Befort et al. [287], whose overall risk of bias was rated as 'low'. Although Befort et al. did not use blinding of their outcome assessors, their only outcome of interest in this study was body weight. The measurement of body weight using a calibrated digital scale and a standardised procedure, does not require judgment by the outcome assessors. Therefore, the risk of detection bias was rated as 'low' in that study. Reeves et al. [103] was the only study that used blinding of outcome assessors. The risk of bias for body weight, fat mass, and activity (pedometer) outcomes in that study, were therefore rated as 'low'. Reeves et al. also employed several participant-reported outcomes, which were rated as 'high' due to the lack of blinding of participants.

Table 10: Risk of bias within included studies.

	Bias arising from the randomisation process	**Bias due to deviations from intended interventions**	**Bias due to missing outcome data**	**Bias in measurement of the outcome**	**Bias in selection of the reported result**	**Final evaluation**
Befort et al.	Low	Low	Low	Low	Low	**Low**
Ergun et al.	Low	Low	Low	High	Low	**High**
Harrigan et al.	Low	Low	Low	High	Low	**High**
Kim et al.	Low	Low	Low	High	Low	**High**
Lahart et al.	Low	Low	Low	High	Low	**High**
Lee et al.	Low	Low	Low	High	Low	**High**
Pinto et al.	Low	Low	Low	High	Low	**High**
Sturgeon et al.	Low	Low	Low	High	Low	**High**
Reeves et al.	Low	Low	Low	High	Low	**High**
Wang et al.	Low	Low	Low	High	Low	**High**

3.4.6 Risk of bias across studies in the meta-analysis and GRADE quality of evidence of the meta-analysis

Because the risk of bias within each study included in the meta-analysis was 'high', the overall risk of bias across all studies included in the meta-analysis was considered 'high'. However, the risk of bias for body fat, body weight, and pedometer steps were considered low, as these outcomes were not subject to an increase in bias in the measurement of the outcome. Therefore, the risk of bias for these outcomes in the meta-analysis, was deemed 'not serious' in the GRADE quality assessment. As two studies in the meta-analysis [103, 288] included exclusively overweight and obese BC survivors, one study [286] included survivors following a preventive salpingo-oophorectomy, and one further study included only sedentary BC survivors [291], several outcomes were rated down in the domain 'Indirectness'. The overall GRADE quality of evidence scores for the outcomes in the meta-analysis were deemed to be low (fatigue, HRQoL, body fat, body weight, and waist circumference), moderate (physical activity and BMI) and high (pedometer steps). Table 11 provides a summary of the GRADE quality of evidence for each outcome included in the meta-analysis.

Table 11: GRADE evidence profile of included studies.

Quality assessment							Number of participants		Effect	
Outcome	**No. of studies**	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Intervention**	**Control**	**Absolute**	**Quality**
HRQoL	2	RCTs	Serious	Not serious	Not serious	Serious	43	42	EMD: 8.91 better (SE: 3.90)	+ + - - LOW
Body fat	4	RCTs	Not serious	Serious	Serious	Serious	126	125	EMD: -0.70 better (SE: 0.50)	+ - - - LOW
BMI	3	RCTs	Serious	Not serious	Not serious	Not serious	92	92	EMD: -0.79 better (SE: 0.72)	+ + + MODERATE
Fatigue	2	RCTs	Serious	Serious	Not serious	Not serious	43	42	EMD: -1.06 better (SE: 0.45)	+ + - - LOW
PA	2	RCTs	Serious	Not serious	Not serious	Not serious	60	55	SMD: 0.64 better (SE: 0.19)	+ + + - MODERATE
Body weight	4	RCTs	Not serious	Not serious	Serious	Serious	163	152	EMD: -1.92 better (SE: 0.73)	+ + - - LOW
Waist circumference	2	RCTs	Serious	Not serious	Serious	Not serious	113	113	EMD: -3.36 better (SE: 1.17)	+ + - - LOW
Pedometer steps	2	RCTs	Not serious	Not serious	Not serious	Not serious	65	62	EMD: 3131.98 better (SE: 363.08)	+ + + + HIGH

Abbreviations: BMI: Body mass index; EMD: Estimated mean difference; HRQoL: Health-related quality of life; PA: Physical activity; RCTs: Randomised controlled trials; SE: standard error; SMD: Standardised mean difference.

3.4.7 Synthesis and analyses of results

For the meta-analysis, only studies that used identical instruments for a specific outcome were used, as the scale of the similar instruments were too different to meaningfully combine. This meant that the results for self-efficacy, stage of motivational readiness, and muscle strength were not included. The study by Lee et al. [290] was removed from the analyses, as they did not report standard deviations, standard errors, or confidence intervals for any means so there was no way to recover the standard deviations of the differences. For fatigue, BMI, and body fat, the baseline measurements were very similar between the control and intervention groups. Therefore, the difference between the post values of the two groups were used. This meant that Wang et al. [292] was removed from the analysis for BMI and body fat, as it did not report post values. For the direct measurement of cardiovascular fitness, the results of the sub-study by Lahart et al. [315] could not be combined with those of Sturgeon et al. [286] as latter study did not report standard errors, standard deviations or confidence intervals, for this outcome. Similarly, results for activity measured through accelerometry could not be combined as Pinto et al. [291] reported kilocalories and Reeves et al. [103], in a separate publication by Terranova et al. [304], reported accelerometry data in minutes per week.

Sensitivity analyses produced similar results for each of the different correlation values (0.2, 0.5, and 0.8). The significance of these results was also very similar on all three models. Given the similarity of the results, the model with a correlation of 0.5 was chosen as a moderate estimate.

3.4.7.1 Effect of self-management interventions including exercise, on HRQoL.

Apart from Lee et al. [316], two studies [284, 289] used the EORTC-QLQ C30 to evaluate the effect of their SMI including exercise, on HRQoL. The results of the global health score of the instrument were pooled for this analysis. The results for HRQoL show a significant difference between intervention and control groups in the studies, in favour of the intervention group (p=0.022). There was no evidence of heterogeneity between the two studies (Table 12 below this section). Figure 5 provides a forest plot of this information.

A note on interpreting forest plots: The squares represent the estimates from the individual studies. The bars represent the 95% confidence intervals. The size of the square indicates the contribution of that study to the pooled estimate (determined by the amount of variability in the estimate). The centre of the diamond is the pooled estimate (across the studies). The length of the diamond gives the width of the 95% confidence interval [317].

Figure 5: Forest plot of HRQoL model results.

3.4.7.2 Effect of self-management interventions including exercise, on self-reported physical activity.

The LTPA subscale results of the IPAQ, used by Kim et al. [284] and Lahart et al. [285] were pooled for analysis. The results for self-reported physical activity show a significant difference between intervention and control groups in the studies, in favour of the intervention group ($p = 0.001$). There was no evidence of heterogeneity between the two studies (Table 12). Figure 6 provides a forest plot of this information.

Figure 6: Forest plot of self-reported physical activity model results.

3.4.7.3 Effect of self- management interventions including exercise, on cancer-related fatigue.

Apart from Lee et al. [290], two studies used the BFI to assess cancer-related fatigue [284, 289]. The results show a significant difference in fatigue between groups in the studies ($p = 0.018$), in favour of the intervention group. However, the I^2 statistic indicated moderate heterogeneity (Table 12). Figure 7 provides a forest plot of this information.

Figure 7: Forest plot of fatigue model results.

3.4.7.4 Effect of self- management interventions including exercise, on body weight.

For body weight, Reeves et al. [103], Lahart et al. [285], and Harrigan et al. [288] reported the mean differences between pre- and post-measurements with 95% confidence intervals. These differences were used, and the standard deviations of the differences were recovered. Sturgeon et al. [286] reported means and standard deviations. Befort et al. [287] was removed from the analysis, because the latter study only reported weight change (not absolute values). The results for body weight show no significant difference between intervention and control groups (p = 0.093). Heterogeneity between the studies was low (Table 12). Figure 8 provides a forest plot of this information.

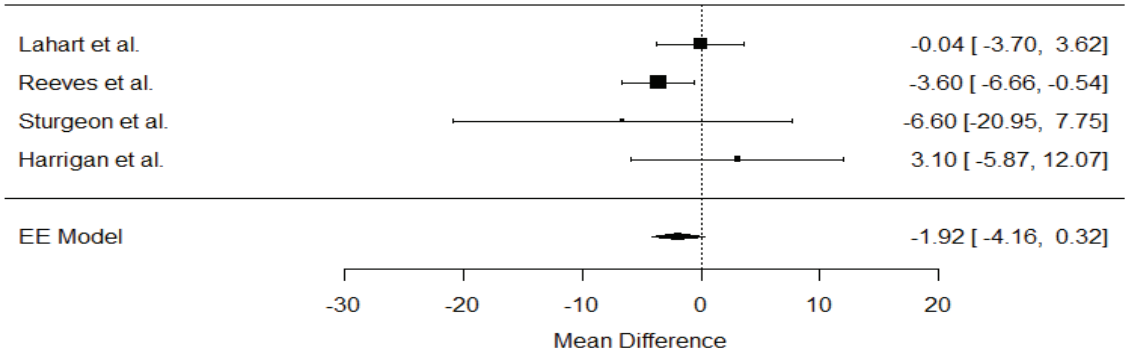


Figure 8: Forest plot of body weight model results.

3.4.7.5 Effect of self- management interventions including exercise, on BMI:

Apart from Wang et al. [292], three studies assessed the effect of their SMI on BMI [285, 286, 291]. The results for BMI show no significant difference between the intervention and control groups in the three studies (p = 0.277). The test for heterogeneity showed no evidence of heterogeneity (Table 12). Figure 9 provides a forest plot of this information.

Figure 9: Forest plot of BMI model results.

3.4.7.6 Effect of self- management interventions including exercise, on body fat:

Apart from Wang et al. [292], four studies evaluated the effect of their SMI including exercise, on body fat [285, 286, 288, 291]. The results show no significant difference in body fat between the intervention and control groups of the three studies (p = 0.162). The I^2 statistic indicates possible high heterogeneity (Table 12). Figure 10 provides a forest plot of this information.

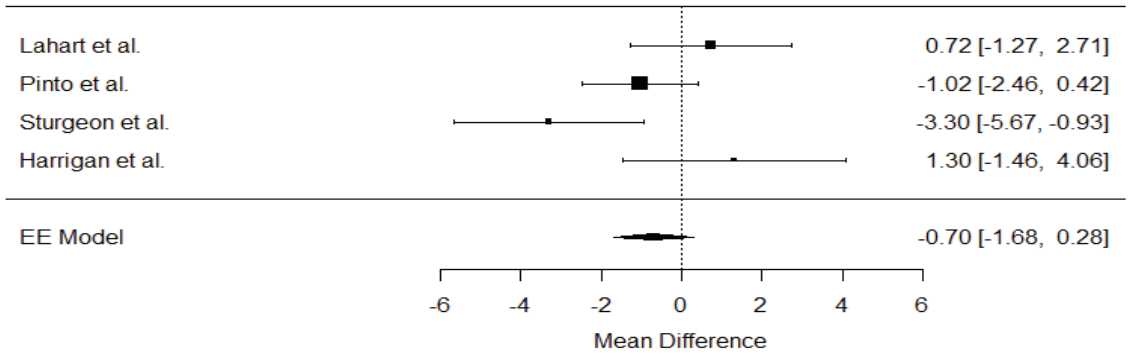


Figure 10: Forest plot of body fat model results.

3.4.7.7 Effect of self- management interventions including exercise, on waist circumference

Two studies [103, 288] evaluated the effect of their SMI including exercise, on waist circumference. The results show a significant improvement of waist circumference, in favour of the intervention groups (p = 0.004). The I^2 statistic indicates no evidence of heterogeneity (Table 12). Figure 11 provides a forest plot of this information.

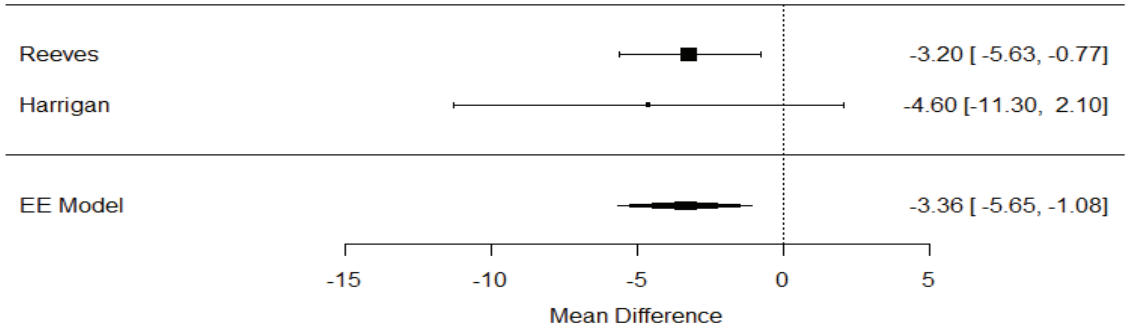


Figure 11: Forest plot of waist circumference model results.

3.4.7.8 Effect of self- management interventions including exercise, on pedometer steps

Two studies [288, 292] evaluated the effect of their SMI on pedometer steps per day. The results show a significant difference between intervention and control groups, in favour of the intervention groups (p = 0.0001). The I^2 statistic indicates no evidence of heterogeneity (Table 12). Figure 12 provides a forest plot of this information.

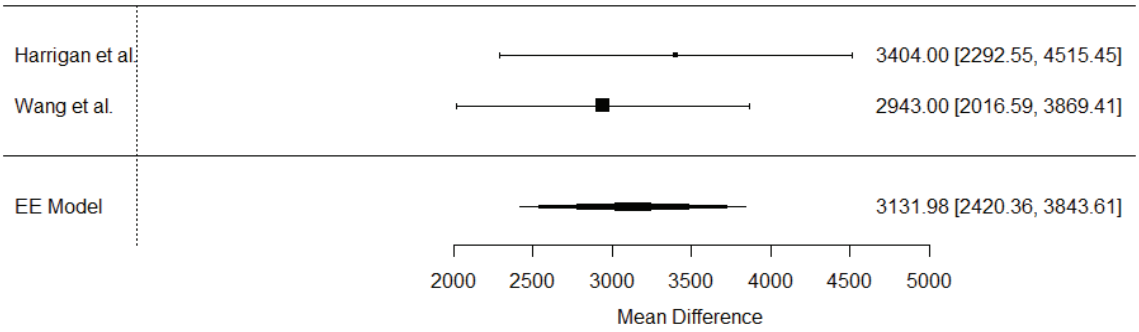


Figure 12: Forest plot of objective physical activity (pedometer steps) model results.

Table 12: Summary of meta-analysis model results.

	Estimate	Standard error	p-value	95% CI	I^2 value
HRQoL	8.91	3.90	0.022*	1.26, 16.56	0.00%
Physical activity	0.64	0.19	0.001*	0.27, 1.02	0.00%
Fatigue	-1.06	0.45	0.018*	-1.95, -0.18	55.94%
Body weight	-1.92	0.73	0.093	-4.16, -0.32	20.70%
BMI	-0.79	0.72	0.277	-2.20, 0.63	0.00%
Body fat	-0.70	0.50	0.162	-1.68, 0.28	65.83%
Waist circumference	-3.36	1.17	0.004*	-5.65, -1.08	0.00%
Pedometer steps	3131.98	363.08	0.0001*	2420.36, 3843.61	0.00%

Legend and abbreviations: * Indicates a significant difference between intervention and control groups, in favour of the intervention group. BMI: Body mass index; CI: Confidence interval; HRQoL: Health-related quality of life. HRQoL and physical activity: model with ρ = 0.5.

3.5 Discussion

3.5.1 General interpretation of results in context of other evidence

This systematic review and meta-analysis presented evidence for the effectiveness of SMIs including an exercise component, and using minimal face-to-face clinical visits, to improve LTSEs of treatment, HRQoL, and physical activity, in post-treatment BC survivors. Specifically, evidence is presented regarding HRQoL, fatigue, self-reported and objective physical activity, and waist circumference. The findings also underscore the diversity in effective designs of SMIs including an exercise component, in the published literature.

Exercise is a well-established component of chronic disease management programmes [83, 233, 318]. Numerous systematic reviews have shown that exercise can improve the LTSEs of BC treatment [67, 68, 96, 319]. Moreover, exercise participation has been consistently linked with improved survival, reduced rates of cancer recurrence, LTSEs and other co-morbid conditions, in BC survivors [31, 218, 320, 321]. This review combined the results of 10 SMIs that included an exercise component. It has shown that SMIs, even with minimal supervision, can result in significant increases in physical activity, compared to women who do not receive these interventions. Breast cancer survivors experience decreased quality of life, which can continue for many years after MCT [322-324]. This decrease is frequently interrelated with fatigue, weight gain, and with low levels of exercise [325-329].

This review provides evidence that women who participate in SMIs including an exercise component, have improved HRQoL, reduced fatigue, and a lower waist circumference compared to survivors without access to such interventions.

The findings of this review corroborate and update those of previous systematic reviews. In mixed cancer survivors, Boland and colleagues [230] reported that SMIs lead to improvements in fatigue, physical function, distress, and self-efficacy. Similarly, SMIs were found to significantly improve HRQoL and fatigue in a review by Kim and colleagues [232]. The latter review failed to find significant effects for improvement of self-efficacy. Howell and colleagues [149] performed a systematic review to investigate health outcomes in response to SMIs, in mixed cancer survivors. Heterogeneity of interventions and studies prevented a meta-analysis, in that study. However, narrative qualitative synthesis suggested that SMIs improve symptoms such as pain, fatigue, depression, anxiety, emotional distress, and quality of life. Specific to BC, Boogaard and colleagues [200] identified in 2016, that effective SMIs in BC may be structured programmes that include an exercise component. The latter systematic review investigating the effectiveness of SMIs with and without exercise components and including all stages of BC survivors during and after MCT, found significant improvements in HRQoL, coping ability, and fatigue, in their meta-analysis.

Another systematic review by Van Dijck and colleagues, also published in 2016, evaluated SMIs including exercise, in BC survivors during and after MCT [201]. Most of the studies included in the review by Van Dijck et al. demonstrated a positive effect on quality of life, fatigue, and physical function. After primary cancer treatment, survivors require unique self-management skills related to their medical care, exercise programmes and role management [208]. Thus, interventions offered during the post-treatment cancer trajectory should be unique to this cohort of patients. The diversity of participants and interventions included in the latter review, and the small number of available studies by its publication date, prevented a meta-analysis.

The finding of this review that SMIs including an exercise component may significantly improve both self-reported and objectively measured physical activity, agrees with a recent systematic review including 16 pre/post studies and RCTs by Dorri and colleagues [235], which found that interventions delivered electronically can improve physical activity in BC patients and survivors. Notably, anthropometric outcomes apart from waist circumference were not found to improve significantly in intervention compared to control groups, in the meta-analysis of the present review. This might be because significant reductions in anthropometric measures such as BMI, body fat, and body weight typically take around 12 months to achieve [330].

Thus, several interventions used in studies included in this review may not have been long enough to achieve significant improvements in body composition. In addition, with their focus on increasing physical activity and managing LTSEs, not all studies in this review emphasised nutritional counselling. Nonetheless, waist circumference, an important health indicator as it provides a measure of central adiposity, is strongly associated with all-cause and cardiovascular mortality [331]. Therefore, the results pertaining to this outcome in the current review are encouraging.

3.5.2 Limitations of evidence included in this review

The considerable diversity in the characteristics of the interventions in the studies included in terms of format and content, prevented definite conclusions regarding the effective components of SMI. Further, the methodological quality of the evidence pertaining to SMIs, needs further improvement. Specific to this review, nine of the 10 included studies had a 'high' risk of bias. This, in combination with relatively low sample sizes and the small number of studies, resulting in wide confidence intervals in the meta-analysis, heeds caution in the interpretation of the results. In the meta-analysis, the GRADE evidence profile of outcomes that showed significant results in favour of the intervention group, were low (HRQoL, fatigue, body fat, body weight, and waist circumference), moderate (physical activity, BMI), and high (pedometer steps) quality. The results should be interpreted with this in mind. However, HRQoL and fatigue are subjective, self-reported outcomes. These will always have a 'high' risk of bias, due to inherent bias in their measurement.

The scientific rigour of the interventions in this review was not optimal. Of the 10 studies, only three [103, 286, 292] explicitly prescribed a combination of aerobic and resistance exercise as per the published exercise guidelines for cancer survivors [18]. The lack of alignment with exercise guidelines across the seven other studies, is likely to have diminished their intervention effects. Indeed, combining aerobic and resistance training has shown to be safe and optimal to improve long-term symptoms of BC, in systematic reviews [332-334]. Similarly, nutrition is considered an important element of self-management in cancer patients. Research shows that interventions should be multimodal, including nutrition, exercise, and psychological support [335]. Survivors need to be empowered to self-manage their diet to prevent excessive weight gain, co-morbidities, and cancer recurrence [335]. Despite this, four out of the 10 included studies provided no dietary education as part of their intervention [285, 289, 291, 292].

An RCT that lacked scientific rigour is the study by Ergun and colleagues [289], which failed to demonstrate between-group differences in terms of their patient-reported outcomes fatigue and HRQoL. The latter study did not provide a sample size calculation.

Apart from the small sample size (n = 40) which may have compromised the internal validity of that study, the intervention prescribed walking only, to the home exercise group. The dosage prescribed was low compared to the exercise guidelines for cancer survivors [18], and no strength training was prescribed. In addition, there was no mention that the intervention included nutritional guidance, which could further explain the lack of significant effects observed in that study.

It is interesting to note the possible reasons for insignificant findings observed by the other studies in this review. Like the study by Ergun and colleagues [289], the studies by Kim and colleagues [284] and Wang and colleagues [292] were also exploratory, pilot studies with small sample sizes. This was cited as the reason why these studies failed to find significant differences between groups, for physical activity. Compounding this was that the control group in the study by Wang and colleagues reported higher physical activity levels at baseline, compared to the intervention group. The study by Wang and colleagues used three face-to-face personal training sessions, two of which were held on the same day as their baseline or endpoint outcome measurement sessions. Sessions were one month apart, and participants were prescribed a home exercise programme for the time between these appointments. In that study, the attrition rate was 20%, many participants stated being too busy to attend the three on-site sessions. Reasons cited for other outcomes that failed to show significant between-group differences, such as fatigue in the study by Reeves and colleagues [103], and anthropometric outcomes in studies by Pinto and colleagues [291], and Sturgeon and colleagues [286], were that these outcomes were secondary, and the respective studies had not been sufficiently powered for the outcomes in question. Furthermore, participants in the study by Pinto and colleagues [291] reported technical difficulties with the use of their accelerometers, which may have prevented significant increases in objectively measured physical activity in that study.

Eight of the 10 interventions in this review were theory-based (Table 9), an encouraging finding. Previous systematic reviews of SMIs for mixed cancers [234, 336] have suggested that interventions be grounded in theory. Of those studies in this review that were based on theory, four studies utilised the social cognitive theory [103, 286-288]. The nature of theoretical framework employed by the other four studies varied. Various decision support tools have been developed to inform the selection of an appropriate theoretical framework for new interventions [337]. When designing SMI, researchers should address all five core self-management skills [83, 232]. Only three out of the 10 included studies achieved this [284-286]. The self-management skill most frequently neglected by interventions was forming partnerships. This is unsurprising, considering that interventions used minimal face to face contact with participants. Forming partnerships enables the integration of SMI into cancer care, and this should therefore still be actively encouraged between patients, providers, and family [84].

As mentioned in the results section, the intervention format varied between studies in this review. This finding is confirmed by previous systematic reviews evaluating SMIs in BC patients [200, 201]. The results of the present review indicate that different methods, or likely a combination of modalities (as employed by most studies in this review) can be effective in the rehabilitation of BC survivors after treatment. A pragmatic approach, where resources allow, could be to offer survivors a choice (web-based, telephone calls, workbooks, booklets, individual consultations), to suit their individual preferences. This is in line with a recent review of systematic reviews on rehabilitation interventions in BC, which found that different types of interventions that include an exercise component, can have a positive effect on symptoms [194].

Three included studies [103, 287, 289] did not evaluate whether their intervention resulted in an improvement in physical activity. It is important to assess whether an intervention can influence behavioural change, especially since the prescribed exercise was unsupervised across the included studies. Of the seven studies that measured physical activity, five [285, 286, 288, 290, 291] reported significant improvements in self-reported physical activity, in the intervention group compared to controls. Control group participants in studies promoting exercise often increase their activity levels as well [201]. This can reduce the difference between groups and bias the results. Furthermore, only three studies [288, 291, 292] used direct measures of physical activity, such as an accelerometer or a pedometer. Three out of the 10 studies [286, 291, 292] used an objective measurement of fitness to evaluate the efficacy of their intervention, and only two studies evaluated the muscle strength of their participants [286, 292]. The credibility of the results of the studies in this review would have been enhanced if more had evaluated their SMIs through direct, objective tests.

Only one of the included studies evaluated the pain levels of participants [103]. Pain could not be included in the meta-analysis of this review, therefore conclusions regarding the efficacy of SMIs including exercise for pain in post-treatment BC patients cannot be drawn. While supervised exercise has shown to significantly improve pain levels in BC patients [68, 338], it would have been useful to determine if SMIs including an exercise component, could achieve similar results.

Only two studies in this review measured the long-term effects of their SMI [103, 288]. Although both studies reported significant sustained effects of their anthropometric measures, it was not possible to suggest the long-term effectiveness of SMIs including an exercise component, based on these studies alone. Since a previous systematic review in mixed cancer populations suggested a lack of SMI sustainability [230], this must be explored further in the future.

Finally, although the search was updated in 2024, the most recent studies in this review were from 2021. This may be because, considering the growing evidence base for SMIs, recent interventions have provided control groups with forms of self-management, instead of usual care. For example, the RCT by Kim and colleagues reported in 2022 [339]. Another plausible explanation for the lack of recent studies that met the inclusion criteria for this review, is that the development of recent interventions may have occurred during the coronavirus pandemic. This possibly yielded interventions providing materials to participants without a supportive component. For example, the RCT reported by Puklin et al. in 2023 [340], evaluating a completely self-guided intervention.

3.5.4 Implications of results for practice, policy, and future research

The current evidence shows that SMIs including an exercise component should be offered to early-stage BC survivors after MCT who are not receiving supervised rehabilitation interventions, and who are without contra-indications to unsupervised exercise. The studies in this review used intervention durations that ranged from 12 weeks to 12 months. Previous systematic reviews of SMIs in cancer survivors have suggested that interventions of longer duration seem more effective than shorter interventions [200, 230]. This was not confirmed in the current review: shorter [284, 288, 290, 291], medium [285, 292], and longer length interventions [103, 286, 287], demonstrated significant between-group differences post-intervention. It seems, from the studies included in this review, that 12 weeks may be adequate to improve HRQoL, fatigue, and physical activity, post-intervention. The systematic review by Cheng and colleagues [341] evaluating the effect of SMIs on HRQoL in BC survivors, found that most studies used this intervention duration. On the other hand, future studies are needed to investigate SMIs with longer durations, specifically targeting anthropometric outcomes such as body weight, BMI, and body fat reduction, in BC survivors [103, 287, 330].

A consideration for practice is that only female BC survivors who had completed MCT for early BC, were included in this review. Survivors during medical treatment, or patients with metastatic disease may have different intervention needs. Therefore, the authors of this review heed caution in applying the results of this study to other cancers, to other BC populations, or to men. Regarding implications for policy, the results of this review indicate that important health-related outcomes can safely be improved through SMIs requiring minimal clinic visits. The implications for research are that more studies of greater methodological quality and lower risk of bias are needed to further expand the findings of this review.

Overall, the rigour of research methods appears to have improved in recent years, with a greater number of RCTs evaluating SMIs including an exercise component in BC survivors, than previous systematic reviews have observed [200, 201].

Most interventions of studies in this review were adequately described, included at least three essential self-management skills, were aimed at improving the lifestyle of participants, were grounded in evidence-based theoretical frameworks, and were guided, at least in terms of aerobic exercise prescribed, by the published exercise guidelines for cancer survivors. Because blinding of participants is rarely achieved in behavioural studies, strategies such as concealed allocation of participants and blinding of assessors should be employed in future research, where resources allow. This improves the credibility of results. Future studies can consider including participants who have high levels of fatigue; low exercise levels or HRQoL scores. This would prevent the 'ceiling effect', where studies show non-significant results because participants did not suffer from the outcome in question.

The outcomes of several studies in this review could not be included in the meta-analysis, due to inadequate reporting of results. Authors of future studies are urged to ensure that standard deviations, standard errors, or confidence intervals are reported for all means, and that results can be replicated. This will allow future reviews to include more studies in their meta-analyses. Direct measuring of outcomes such as fitness, strength and activity should be used wherever feasible.

The rehabilitation of cancer survivors is often neglected in resource-constrained settings [122, 159, 342]. Self-management interventions could potentially be useful in low-resource settings, where the need for information and intervention is most pertinent [102, 235]. Yet, no studies in this review were conducted in low- and middle income countries. Furthermore, none of the interventions in this review met the comprehensive informational needs identified by participants in Chapter 2 of this thesis. The reason for this may be that BC survivors in many high-income countries have access to survivorship care plans [343]. These, although not comprehensively addressing LTSEs, do meet some needs such as education about the type of cancer and its treatment, and instructions for follow-up visits to the breast clinic [343]. In addition, in two included studies, information had already been provided to survivors as part of standard care, separate from the study intervention [285, 288].

Therefore, interventions in this review either included information on healthy lifestyle (such as exercise and nutrition), without specific information on BC and its related LTSEs, or they included information regarding LTSEs (such as lymphedema), without BC-specific health literacy or information on healthy lifestyle. Specific instructions for upper limb exercises (apart from exercises for lymphoedema) and broader survivorship concerns such as information on cancer recurrence, were not addressed in the included studies.

Thus, the combination of needs including general- and upper limb exercise, with information on healthy lifestyle, health literacy, survivorship concerns, and support described by participants in the qualitative study in Chapter 2, was lacking across the included studies. Research is needed to develop and evaluate innovative SMIs that meet the needs of survivors in low- and middle income countries, such as SA.

3.5.3 Limitations of review processes used

To the knowledge of this author, this may be the first systematic review of SMIs including an exercise component and requiring minimal face-to-face visits, in early-stage, post-treatment BC survivors. The reviewed studies are all RCTs. Four databases were searched, and hand searching was used to retrieve as many eligible studies as possible. Furthermore, the PRISMA guidelines were used to guide this systematic review. The following limitations should be considered when interpreting the findings of this review. It is acknowledged that using studies published in English only, may have caused selection bias. Only one researcher screened the titles and abstracts, which may have led to eligible studies being missed. Several studies in this review [284, 286, 288] had low sample sizes, which could have limited their internal validity and the ability to achieve significant results. The selection of studies could have been biased, due to the lack of a universal definition of self-management. An *a priori* decision was taken to include studies that utilised a maximum of three face-to-face sessions with participants, to allow for data collection at baseline, endpoint and follow-up. This was to aid the distinction of SMIs from supervised interventions, and to ensure that clinically transferable studies to low- and middle income settings, were included. The result was the exclusion of SMIs with more contact sessions.

A further limitation is that this review did not include psychological outcomes such as anxiety or depression. While psychosocial issues were beyond the scope of this review, the importance of addressing the emotional impact of cancer post-treatment is acknowledged. Self-management interventions including an exercise component may be beneficial for improving psychosocial symptoms in cancer patients [149]. This should be explored further in the future. Finally, the importance of many other BC-related complications and LTSEs are recognised, which could not be addressed in this review.

3.6 Conclusion

The current evidence demonstrates that SMIs including an exercise component, utilising minimal face-to-face contact sessions, can significantly improve both self-reported and objectively measured physical activity, HRQoL, fatigue, and waist circumference post-intervention, in women who have completed primary MCT for early-stage BC.

It seems that various methods of administering SMIs including an exercise component, can lead to beneficial effects on health-related outcomes in BC survivors. Researchers should take care to base future interventions on scientific evidence pertaining to cancer rehabilitation and self-management. Further high quality studies are warranted, to expand our understanding of the effects of SMIs in post-treatment survivors of BC. Specifically, SMIs are needed to match the needs of BC survivors in low- to middle income countries such as SA. The content of the interventions in this review did not match the needs identified by participants in Chapter 2 of this thesis. However, this review directly informed the structure and theory of a new intervention that was likely to be successful (refer to Chapter 4, 4.2.4 Reviewing published evidence). The development of this new intervention was described in the next chapter of this thesis.

Chapter 4. Development and acceptability evaluation of a self-management intervention for breast cancer survivors.

4.1 Introduction

The systematic review in Chapter 3 of this thesis provided evidence that self-management interventions (SMIs) are effective to promote positive behaviour change and self-management of long-term side effects (LTSEs), in breast cancer (BC) survivors. These interventions can reach many patients, and require relatively few resources to implement [230]. To allow effective translation into clinical practice, an SMI must be designed within the context of the specific population it serves. Content must be informed by behaviour change theory and the specific needs of patients; and described systematically [84, 208]. Furthermore, the acceptability of the intervention should be established. The author intended to adhere to the above standards. Therefore, the aim of this chapter is to describe the development of an evidence-based, theory-driven, structured SMI to support the self-management of LTSEs of BC treatment, and to address unmet information needs about long-term survivorship identified in Chapter 2. The transparent, logical description of steps taken, processes followed, and content included will assist the adaptation of the intervention in the future. In addition, it may accelerate the development of similar future interventions, thereby reducing research waste [344].

4.2 Methods

Development of the intervention 'Survive and Thrive' was guided by the Medical Research Council (MRC) guidelines for intervention development, which have recently been updated and adapted [85, 345]. These guidelines were originally proposed by Campbell and colleagues in 2000 [346]. Since then, they have been applied widely [345]. Actions to consider include understanding the problem and its context; planning the process; involving stakeholders; bringing together a team; reviewing published evidence; drawing on existing theories; articulating programme theory; designing and refining; primary data collection; and attending to future implementation. These are not necessarily intended to be addressed in sequence, but dynamically, iteratively, and creatively [85]. Actions taken to develop the intervention 'Survive and Thrive', inspired by the MRC guidelines, are detailed below. An overview of their application is provided in Table 13.

Table 13: List of actions to consider, and summary of actions taken during the development of the intervention 'Survive and Thrive'.

Actions to consider [85, 345]	**Actions taken to develop the intervention: 'Survive and Thrive'**
Understanding the problem and its context	• The problem was identified and discussed amongst the research team. • The context was explored through initial review of the literature. Local research confirms the need for intervention in BC survivors of this country who have completed medical cancer treatment (MCT) [60, 62, 75, 101, 192, 347].
Planning the process	• Identified MRC guidelines to provide a checklist of steps to consider during intervention development. • Identified the budget for this project. • Discussed possible interventions that may be feasible for South African BC survivors, considering resource restrictions. The intervention was to be evidence-based, and potentially transferable into clinical practice in low- and middle income countries.
Involving stakeholders	• A qualitative study consisting of focus group discussions with BC survivors informed the nature and content of the intervention: Chapter 2 (Table 14).
Reviewing published evidence	• A systematic review and meta-analysis was conducted to evaluate the effectiveness of SMIs for improving LTSEs and physical activity, in BC survivors: Chapter 3.
Drawing on existing theories	• The intervention was designed using the model of patient-centred care [82], incorporating self-management principles [83] and the social cognitive theory [37]. These principles have been used successfully in interventions for other chronic disease populations in South Africa (SA) [81, 348, 349].
Articulating intervention theory	• Above theories were applied throughout the design of the intervention handbook (Table 15).
Bringing together a team, and establishing a decision-making process	• The research team: the Ph.D. candidate and three experienced researchers in the field of rehabilitation and BC, established a process where all decisions taken during intervention development, were discussed amongst the team. • External review: Five South African clinical BC experts from various disciplines, individually reviewed the intervention handbook. Feedback was discussed amongst the research team, and the handbook was adapted according to their comments and suggestions (Table 16). The resultant handbook is included in Appendix M.
Designing and refining	• Initial design: The Ph.D. candidate designed a prototype handbook, using the MRC checklist of actions [85]. • Internal review: The three researchers (supervisors of this project) reviewed the prototype handbook. • Refinement: The handbook was refined according to the feedback given by the researchers. • External review: Five local clinical experts independently reviewed the handbook (see above, bringing together a team). • Refinement: The handbook was adapted according to the feedback given by the clinical experts. • Acceptability evaluation: see below, undertaking primary data collection. Intervention was refined accordingly. • Feasibility, safety, and preliminary outcomes of the intervention were evaluated: Chapter 5.
Undertaking primary data collection	• Acceptability evaluation: Small qualitative study conducted to establish the acceptability of the intervention 'Survive and Thrive'. The results were used to adapt the intervention, before continuing recruitment for the intervention study, Chapter 5.

Actions to consider [85, 345]	**Actions taken to develop the intervention: 'Survive and Thrive'**
Attending to future implementation	• Readability of the intervention handbook was set at the appropriate level. • Content of intervention handbook was informed directly by stakeholders: BC survivors and local expert clinicians. • Theory and content of intervention is described systematically, to support the implementation and modification of the intervention in the future (Table 14). • Chapter 5: feasibility, safety and preliminary outcomes were explored in South African BC survivors.

4.2.1 Understanding the problem and its context

International guidelines recommend that BC survivors should receive interventions to support the management of LTSEs and to promote a healthy lifestyle, following the completion of their MCT [6, 350]. This is because there are good data supporting the safety and efficacy of rehabilitation interventions, for this population of cancer survivors [165, 194]. However, to date, most rehabilitation interventions have been developed in high income countries, and have been resource intensive to implement [351]. For this reason, and also due to the limited knowledge about cancer rehabilitation on the parts of survivors and healthcare providers, interventions have not been widely implemented [352].

Self-management interventions have emerged as potentially effective, feasible alternatives to supervised rehabilitation interventions, for cancer survivors [149, 208]. Systematic reviews have indicated that these interventions are likely to be most effective if they contain an exercise component [200, 201]. Recently, countries such as the United Kingdom and Australia, have adopted self-management as a means to provide survivorship care to BC survivors following MCT [84]. The systematic review in Chapter 3 of this thesis, provided evidence that SMIs including an exercise component and requiring few on-site clinical visits, may be effective to improve several health outcomes. However, the included studies did not meet the specific information needs requested by the participants in the qualitative study, Chapter 2. Therefore, an intervention similar in terms of the structure and components of the interventions included in the systematic review was deemed appropriate; tailored to the specific identified informational requirements of local BC survivors. The new intervention was to be evidence-based, widely accessible, affordable, and implementable without placing a strain on the overburdened and under-staffed South African public health system. Indeed, interventions must be designed based on the context, needs and preferences of survivors [84, 353].

At the public tertiary hospital in the Western Cape, Eden District where the qualitative study in Chapter 2 was conducted and, to the knowledge of this author, also at other South African hospitals, standard care is to provide two information leaflets to BC patients in hospital following their breast surgery. One leaflet contains post-operative mobility exercises for the hand, elbow, and shoulder, advice on positioning of the arm, and wound care. These instructions are specific to the acute phase of healing in the first week after breast surgery [354]. The second leaflet contains information about lymphoedema prevention, also specific to the acute post-operative period. Apart from these two leaflets, local BC survivors currently do not receive survivorship information about the LTSEs of MCT, as part of standard care.

Once BC survivors have completed their primary MCT several months after their breast surgery, the rehabilitative exercises prescribed should be updated with the emphasis shifting towards improving scapular mobility, stretching, and introducing upper limb strengthening exercises [90, 148, 164, 354]. Additionally, the focus during survivorship should extend towards re-building general exercise capacity, according to current BC survivorship guidelines [6, 354]. Completing primary MCT is experienced as a milestone for many BC survivors, and it constitutes a teachable moment: an opportunity to introduce healthy lifestyle changes [7]. Although not specifically regarding LTSEs, South African BC survivors have expressed the need for information and support for managing issues affecting them in the long-term [60, 62], and have indicated their interest in receiving information about BC-specific exercise [101]. Furthermore, studies in SA report that survivors have very low knowledge of the signs and symptoms of BC [62, 75]. This problem is exacerbated by the context in low-resourced areas: stunted general health education, low income, poor access to health services and communication barriers with healthcare providers [62, 75, 102]. South Africa does not offer population-based screening services for BC in the public health system [72]. Indeed, participants in Chapter 2 identified that the burden of detecting cancer recurrence or new cancers, rested largely on their own shoulders. Therefore, an intervention considering the above factors, was needed.

4.2.2 Planning the process

The research team opted to use published guidance for the intervention development. These include points to consider during the process of developing an intervention, that other developers have found useful [85]. The MRC guidelines for the development of complex interventions were chosen because of their pragmatic, flexible, and comprehensive checklist of actions [85, 345]. The research team had initial ideas, since there have been several successful interventions developed for other chronic disease populations in SA [81, 348, 349, 355]. A recent study of arm and shoulder pain in BC survivors conducted in four sub-Saharan countries, recommended that affordable self-management strategies should be emphasised in this region, to optimise access to survivorship care [59]. Similarly, a systematic review reported that receiving easy to understand and accurate information about the management of LTSEs, cancer recurrence, healthy lifestyle, and self-management skills, were amongst the top survivorship care needs of BC survivors [356].

The findings of the qualitative study, Chapter 2, suggested that an intervention requiring clinical visits may not be transferable or sustainable in this country: Participants identified a lack of transport to medical facilities as an obstacle to receiving care, and this finding has been reported in other South African studies as well [62, 75].

South African BC survivors often live far away from each other and from healthcare facilities [62, 357]. Additionally, the high number of visits to medical facilities for MCT over many months, cause financial strain as women are faced with countless out-of-pocket expenses associated with their disease, and often have to forfeit paid work to accommodate their cancer treatment [215]. Furthermore, this intervention was developed as the coronavirus pandemic unfolded in 2020 and 2021. These factors prompted the research team to explore self-management as a potentially suitable intervention type.

The Ph.D. candidate had secured funding for direct research expenses, through a research training grant. However, the project remained largely unfunded. It was anticipated that a resource-efficient intervention would increase the chances of transferability into clinical practice, in the public health sector of SA [84]. Therefore, costs were kept to a minimum throughout the intervention development. Adapting an existing South African intervention developed for other chronic diseases [348, 358, 359], was not considered appropriate for the following reasons: These interventions were only six weeks in duration, required weekly attendance of participants at a healthcare facility, and they included general exercise only. Breast cancer survivors require information not only about BC, but also about caring for their affected upper limb, and about the prevention and early detection of lymphoedema. An upper limb exercise routine specific to the survivorship phase of BC was required. Furthermore, the intervention needed to include comprehensive information on BC recurrence, new cancer, survivorship concerns unique to BC, and breast self-examination.

4.2.3 Involving stakeholders to develop the intervention.

Five focus group discussions (FGDs) with BC survivors were conducted in Chapter 2 (*N* = 23). The purpose of that study was to explore the lived experience of physical LTSEs of BC treatment and to investigate their rehabilitation needs, since there was a lack of research regarding this. This work was preliminary, investigations at population level are needed. However, the findings facilitated a deeper understanding of the challenges that South African women face during survivorship; assisted in identifying their needs and priorities; and generated ideas for the new intervention [84, 85]. Refer to Chapter 2 for a detailed description of the research process and results. Briefly, three main themes were identified. First, participants were burdened by LTSEs affecting their quality of life, such as persistent upper limb pain and stiffness, cancer-related fatigue, weight gain, and reduced physical function. Second, participants expressed the need for information about LTSEs and BC survivorship and requested improved access to support organisations. Third, participants felt that exercise was generally good, however they lacked specific guidance regarding the benefits of exercise for BC survivors. Preferences, facilitators, and barriers for regular exercise were identified.

Involving BC survivors early during the development process, placed the focus of the intervention on their specific needs. Further, the information generated steered the intervention away from a supervised intervention, towards an SMI which did not require on-site clinical visits but provided support and opportunities for social engagement. Self-management interventions can be individually tailored and are flexible [84]. For example, as a response to a variety of preferences identified by participants, the intervention handbook was delivered via email or WhatsApp, and as printed copies. In Table 14, the topics, content, and motivation for inclusion of content of the intervention handbook are detailed, referencing the influence of Chapter 2 themes, and current BC rehabilitation research.

Table 14: Handbook 'Survivorship information for breast cancer': topics, content, and motivation for inclusion.

Topic	Content	Motivation for inclusion of content
Week 1: Breast cancer: how to manage common long-term effects.	The management of common long-term effects of BC treatment [24, 80] [6, 7]. *Tasks of the week: scheduling my annual visit to the breast clinic. Long-term effects of cancer treatment affecting me; my plan to manage them.*	Survivors in Chapter 2 expressed the need for this information. Recent research identified a need for providing information to BC survivors to improve cancer care [60, 62, 342]. *Chapter 2 themes: LTSEs are unaddressed and impair quality of life; Lack of information and access to support.*
Week 2: How to manage common long-term effects of BC (continued).	The management of common long-term effects of BC (continued) [7, 24, 26, 360]. *Tasks of the week: Easy exercise action plan.* *Long-term effects of cancer treatment affecting me; my plan to manage them* [83].	As above.
Week 3: How to become an excellent self-manager and how to plan an exercise programme	Steps to self-management: Action planning, problem solving [83]. Benefits of exercise for BC survivors [18]. Pre-exercise screening [3]. Exercise precautions for BC survivors [6] Types of general exercise [3] *Tasks for the week: Types of exercise I would enjoy. Action plan to overcome excuses that are preventing my regular exercise.*	In Chapter 2, BC survivors identified the need for empowerment to manage their health. Self-management interventions have shown effect in various chronic disease populations [208]. Participants in Chapter 2 reported not having received information about general exercise for BC survivors. The positive effect of exercise on LTSEs of medical cancer treatment is well established [31, 67, 96, 97, 145]. *Chapter 2 themes: Perception that exercise is generally good but need specific guidance; Lack of information and access to support.*
Week 4: How to start your exercise programme	How to get started. How to do strength and flexibility exercises. How to ensure that you do enough of each type of exercise [3]. Exercise intensity [18]. Exercise progression [3]. A general exercise routine example [354, 358]. How to check if your fitness has improved over time [234]. *Tasks for the week: Exercise action plan. Exercise diary [234].*	Exercise guidelines for cancer survivors have been published [18, 350]. Furthermore, survivorship care guidelines for BC survivors state that women should be encouraged and instructed to exercise [6]. Participants in Chapter 2 requested specific information about exercise. *Chapter 2 themes: LTSEs are unaddressed and impair quality of life; Lack of information and access to support; Perception that exercise is generally good but need specific guidance.*
Week 5: How to manage your affected shoulder and arm	Effects of medical cancer treatment on your affected side [24, 164]. How to manage upper limb problems [147, 164]. An upper limb exercise routine example [148, 361]. How to find out if your affected side is improving [362]. *Tasks for the week: Arm and shoulder problems affecting me, my plan to manage them* [83].	Shoulder and arm morbidity are very common in BC survivors [57]. Participants in Chapter 2 experienced upper limb problems, which affected their daily lives and ability to earn an income. Information about upper limb problems, with the correct exercises, are effective to prevent and reduce pain and disability [164, 363]. Survivors in SA reported a high prevalence of upper limb problems after MCT [192]. *Chapter 2 themes: LTSEs are unaddressed and impair quality of life; Perception that exercise is generally good but need specific guidance.*

Topic	Content	Motivation for inclusion of content
Week 6: Lymphoedema	How to detect lymphoedema early [364]. How to prevent or improve lymphoedema [364]. How to exercise with lymphoedema [67] How to self-manage your affected side [151] Action plan for the shoulder and arm [83] *Task for the week: Action plan for my shoulder. Signs of lymphoedema affecting me, my plan to manage them* [83].	Lymphoedema is a common and debilitating complication in BC [364]. It can start at any time during survivorship [24]. Early detection, correct self-management and appropriate exercises can significantly reduce the morbidity and disability associated with this condition[67, 364]. Several women in Chapter 2 had not received information about lymphoedema, following MCT. Participants reported experiencing delays in the diagnosis and treatment of this condition. *Chapter 2 themes: LTSEs are unaddressed and impair quality of life; Perception that exercise is generally good but need specific guidance.*
Week 7: How to manage your body weight	The effects of being overweight [7]. How to work out if you are overweight [7]. How to self-manage if you are overweight [6]. How to choose the right foods [365, 366]. Food safety [367] How to eat well if your body weight is normal [365]. *Tasks for the week: Calculating my BMI* [7]; *Shopping list with healthy food items* [368, 369].	Weight gain after completing MCT is commonly experienced [24]. Obesity is associated with a higher risk of cancer recurrence, LTSEs and chronic diseases [7]. Participants in Chapter 2 were not warned about weight gain following MCT. They requested information on weight management and living healthy lives after BC. *Chapter 2 themes: LTSEs are unaddressed and impair quality of life; Lack of information and access to support.*
Week 8: How to manage stress and pain.	How to manage your stress, anxiety, poor sleep, depression [370, 371]. How to manage your pain [158]. *Tasks for the week: Problems with stress, anxiety, depression, pain affecting me. My plan to manage them.*	Information about pain and stress management, and sleep problems are major supportive care needs of BC survivors [356]. Pain, anxiety and depression, and insomnia are commonly experienced LTSEs [95]. Current clinical oncology guidelines recommend that all cancer survivors should receive education regarding anxiety and depression [370]. Chapter 2 participants reported being burdened by these problems. *Chapter 2 themes: LTSEs are unaddressed and impair quality of life; Lack of information and access to support.*
Week 9: How to detect a cancer recurrence early	Signs and symptoms of BC: local / distant [7]. How to do a breast self-examination [372]. What to do if you find a lump in your breast [372]. *Tasks for the week: Signs and symptoms of cancer affecting me, my plan to address them.*	Women in Chapter 2 were concerned about suffering a BC recurrence. Indeed, fear of recurrence is one of the highest ranked supportive care needs of BC survivors [356]. In SA, cancer is often diagnosed late, treatment delays are common [75]. Therefore, BC survivors must be educated on early detection and when to seek medical care [62, 75]. *Chapter 2 theme: Lack of information and access to support.*

Topic	Content	Motivation for inclusion of content
Week 10: How to identify skin cancer and blood clots early; and talking to your healthcare provider	Signs and symptoms of skin cancer [373, 374] Signs and symptoms of a blood clot [375] How to prevent a blood clot [375] Talking to your healthcare provider [7, 376] *Tasks of the week: Action plan for breast self-examination* [37]. *Skin cancer and blood clot checklist* [374, 375].	Breast cancer survivors have increased risk of skin cancer and blood clots, compared to the general population [7]. South Africa has a high incidence of skin cancer [374]. Successful interaction with healthcare providers is an important element of self-management, particularly for South African BC survivors [62, 75]. Chapter 2 participants highlighted the communication gap between them and healthcare providers. *Chapter 2 theme: Lack of information and access to support.*
Week 11: How to continue as a successful self-manager	How to be a successful self-manager [208, 377]. *Tasks of the week: Review of action plans made, and actions taken* [83].	In interventions based on cognitive behavioural principles, patients increase their knowledge and learn to apply this knowledge through goal setting [208, 378]. Chapter 2 participants expressed a need for empowerment to manage their health after BC. A recent systematic review of supportive care needs identified that effective self-management of survivorship concerns is an important skill for women after BC [356]. *Chapter 2 theme: LTSEs are unaddressed and impair quality of life; Lack of information and access to support.*
Week 12: How to continue as a successful self-manager, useful contacts, and further reading	How to continue as a successful self-manager [377]. Re-calculate BMI [7]. List of contacts: support organisations. Reading list. *Tasks for the week: Review of healthy habits: exercise, diet, self-examinations, communicating with HCP, action plans* [18, 377, 379].	Chapter 2 participants wished to connect with cancer support organisations. They asked for sources of information about BC. Support organisations are a valuable source of social support for BC survivors [6] *Chapter 2 theme: Lack of information and access to support*.

4.2.4 Reviewing published research evidence.

A systematic review to synthesise the evidence for SMI including an exercise component and requiring minimal face-to-face clinical visits, in BC survivors who have completed their MCT, was conducted. The results are detailed in Chapter 3. Briefly, nine of the 10 included RCTs in the review, found significant benefits of SMI to improve outcomes such as self-reported and objectively measured physical activity, HRQoL, cancer-related fatigue, various measures of anthropometry, self-efficacy, and pain. None of the studies reported serious adverse events related to the interventions. Self-management interventions including exercise therefore appear safe for early-stage BC, after the completion of MCT. The included studies required a maximum of three clinical visits, including outcome assessments.

A meta-analysis revealed that SMIs are effective to improve HRQoL, self-reported and objectively measured physical activity, fatigue, and waist circumference. Four interventions lasted for 12 weeks, three were six months, and three were 12 months long. Eight of the 10 studies were theory-based, the most frequently used theory was the social cognitive theory (four studies). The format of intervention delivery varied across the included studies, including online, telephone, on-site counselling, email, and text messages. These were combined with printed material such as a workbook, leaflets, booklets, or tip-sheets, by seven of the 10 interventions. Notably, all interventions encouraged the adherence of participants through activity diaries or exercise logs. These findings directly impacted this intervention design as follows:

- A supported SMI without face-to-face clinic visits was designed. The evidence gained from the systematic review suggested that interventions requiring no, or minimal clinical visits may be an effective alternative to supervised, on-site interventions. Eliminating face to face visits meant that the intervention would be accessible to BC survivors throughout SA and thereby optimised its potential reach.
- The intervention duration was set at 12 weeks, as this was the most frequently used intervention duration of the included studies in the systematic review.
- The intervention was based on the social cognitive theory [37] and on self-management principles [83]. The social cognitive theory was chosen as it was the most frequently used by studies in the systematic review, and because interventions for other conditions in SA have used this theory with success [348, 358, 359].

- As seven of the 10 studies included in the systematic review used printed material in combination with email, text messages, or online activities, a handbook combined with emails, WhatsApp, or text messages was chosen as the basis for the intervention (Appendix M). WhatsApp was chosen as it is an extremely popular instant messaging service in SA [380].
- The intervention recommended exercise, correct nutrition, and healthy lifestyle changes, like the interventions of studies included in the systematic review, and according to current evidence and published guidelines for cancer survivors. Information included was relevant to the South African context using local recommendations where available, such as from the Cancer Association of South Africa. Further local relevance was achieved through the process of establishing content validity.
- The intervention was flexible to allow participants to choose the type of exercise they preferred [234]. Of the 10 studies included in the systematic review, seven used this approach.
- The intervention handbook included an exercise diary to encourage exercise adherence. Exercise diaries or activity logs were used by all the interventions of studies included in the systematic review.

4.2.5 Drawing on existing theories.

Supporting behaviour change through established mechanisms is fundamental to self-management [208]. The intervention 'Survive and Thrive' was based on a modified conceptual framework for person-centred care [82], integrating the essential components of self-management [377] and cognitive behavioural principles [37]. The social cognitive theory (SCT) was considered a useful framework for informing this intervention because it has shown to be effective in behaviour change interventions in cancer [155, 381]; and useful for understanding the exercise patterns of cancer survivors [382, 383]. For example, self-efficacy, a key construct of the SCT, has shown to correlate with physical activity in BC survivors [384, 385]. Furthermore, the SCT offers predictors and principles on how to inform, enable, guide, and motivate patients to adopt health-enhancing habits [37]. Self-management interventions provide education and support, promoting core practical skills [83, 232]. These can be effectively combined with evidence-based social cognitive constructs: setting health goals, overcoming barriers to behaviour change, self-efficacy, self-regulation, and outcome expectations [37, 83, 208]. In SA, interventions that combined SCT and self-management principles have demonstrated effectiveness in other chronic disease populations [81, 348, 349].

4.2.6 Articulating programme theory.

The key SCT constructs [37] and self-management components [83] are presented in Table 15, with examples of how they were applied in this intervention.

4.2.7 Bringing together a team and establishing a decision-making process.

The value of a team became apparent early during the intervention development. For example, as the need for information was emphasised by participants in Chapter 2, a set of brochures was designed by the Ph.D. candidate. However, when the brochures were discussed within the research team, their shortcomings became evident. Brochures were unable to accommodate the comprehensive informational needs described by participants in Chapter 2. The research team discussed the abovementioned successes of participative, workbook-based interventions that have shown promise in other chronic disease populations in SA [81, 348, 349]. This encouraged the engagement with previous local research in chronic conditions. Throughout the development process, decisions were taken through discussion and consensus amongst the research team. As a next step, the Ph.D. candidate designed a structured, theory-informed prototype intervention handbook, independently reviewed by the three researchers supervising the project ('internal review') and adapted according to their feedback. The prototype handbook was then presented to five South African clinical experts in the field of BC.

Table 15: The application of social cognitive theory and self-management principles in the design of the intervention 'Survive and Thrive'.

Social cognitive theory construct [35, 37]	**Core self-management components [83, 233]**	**'Survive and Thrive' intervention examples**
Self-efficacy: confidence to engage in health-enhancing behaviour (such as exercise, healthy eating, breast self-examination); confidence to overcome barriers to health-enhancing behaviour.	-Action planning - Goal setting - Decision making - Problem solving	- Action planning and goal-setting activity each week relating to the weekly theme: what, when, how much. -Specific instructions: *how to* start an exercise programme, avoid unhealthy food, etc. - Barriers to behaviour change are presented with possible solutions. - Steps to take to solve problems are discussed with practical, relevant examples. - Specific information: how often to visit the breast clinic for follow-up visits.
Environment: external factors that influence the behaviour of an individual.	- Forming partnerships - Problem solving -Resource use	-Encouraging participants to think of a person / people in their immediate circle they could share their action plan with (promotes encouragement and opportunities for practical help). - Acknowledging barriers, encouraging participants to consider solutions to overcome them. - Provision of contact details for local cancer and breast cancer support groups. - Providing participants with the opportunity to join a WhatsApp group with other survivors.
Behavioural capability: knowledge of what to do and provision of the skills to perform specific activities.	- Resource use - Taking action - Forming partnerships with health providers	- Specific guidelines (e.g., exercise, healthy eating) stated and discussed in every chapter, with 'how-to' instructions. How to calculate BMI, what to do if you are overweight. - Illustrations, written descriptions, and videos on how to perform general and upper limb exercises; relaxation exercises; shopping list with healthy food items to tick off. - Practical tips for effective communication with healthcare providers.
Outcome expectations: expected effects of behaviour change.	- Education - Decision making - Taking action	- Overview of scientific evidence for the benefits of health-enhancing behaviours. Evidence was described in terms of reducing commonly experienced LTSEs such as fatigue, shoulder problems, and weight gain. - Instructions on how to measure improvement in arm function / BMI / fitness.
Self-control: Personal regulation of goal-directed behaviour, includes activities such as goal setting, self-monitoring, problem solving and self-reward.	- Decision making - Goal setting - Action planning	- Exercise diary - Shopping list - Action plans - Symptom checklists - Reminders to complete exercise diary, shopping list, self-examinations, action plans.
Social (observational) learning: A form of learning that occurs through observing others.	- Effective use of resources - Taking action	- Option of WhatsApp group with other BC survivors for support, to exchange ideas and experiences. - Quotations from BC survivors were included in the handbook. - Opportunities to ask questions and raise concerns during intervention. -List of useful organisations with their contact details were provided in the handbook.

The experts included an oncologist at a breast clinic situated in a public general hospital, a medical doctor who is also a BC survivor and working in a public general hospital, a physiotherapist with a special interest in BC, a dietician specialising in nutrition for South African BC survivors, and a psychologist specialised in psycho-oncology. The clinical experts were invited to comment on the content of the handbook, and to suggest any improvements regarding their respective fields of expertise, or overall ('external review'). In this step, practical areas of potential improvement were identified, and subsequently addressed. Table 16 presents a summary of the comments and recommendations provided by the multidisciplinary clinical experts. The handbook was adapted according to their comments and suggestions. This process of external review provided content validity, established clinical relevance and transferability into practice.

Table 16: Summary of the comments and recommendations provided by a multidisciplinary team of clinical experts, to improve the content of the intervention handbook.

Clinical expert	Comments and recommendations
Oncologist	The handbook is well written, will be very useful clinically. Particularly the sections on exercise and self-management are important for local BC survivors.
Medical doctor, also a BC survivor	Avoid using the term Tamoxifen, rather refer to hormone blocking agents or endocrine therapy, throughout.
Dietician	Avoid advice that is too restrictive, making good eating habits unachievable and impractical. Example: Limiting sugar intake vs. eliminating sugar intake.
Physiotherapist	Recommended using an identical series of headings in each chapter. Recommended restructuring headings into a practical 'How to…' format.
Psychologist	Recommended that more emphasis be placed on anxiety, as it occurs more frequently than depression in post-treatment BC survivors. An additional recommendation was that basic, practical relaxation exercises be included in the handbook.

4.2.8 Design and refine the intervention.

The aims of the intervention 'Survive and Thrive' were to:

- Provide education and increase confidence (self-efficacy) of survivors, to manage common LTSEs, such as pain and cancer-related fatigue.
- Encourage the development of health-enhancing behaviour, such as exercise, correct nutrition, and stress management.
- Educate women about BC, the signs and symptoms of cancer recurrence, new cancer and other potential health problems that may affect them during survivorship.

- Promote effective communication with healthcare providers, provide the opportunity to connect with cancer support organisations and, if they wish, with other survivors.

The intervention 'Survive and Thrive' included working through a section of the handbook each week and completing tasks in it (Appendix M), remote access to a facilitator (the Ph.D. candidate) for support, questions, or concerns, and joining an optional WhatsApp group with other participants. Twelve chapters were designed to be read consecutively each week, to encourage survivors to work through content at regular intervals. Every week focused on a specific topic (Table 14). To encourage adherence to and engagement with the intervention, a preview highlighting the key concepts for the next two weeks was sent to them at the beginning of each fortnight. Every week, participants received a reminder to work through the weekly content, to complete the tasks for the week, and to contact the facilitator in case they had any questions. Participants were required to respond to these weekly messages via WhatsApp, email, or text message. Exercise diaries and shopping lists with healthy food items were provided, and participants were encouraged at regular intervals to use these. Participants were invited, but not required, to send their completed action plan forms and exercise diaries to the facilitator (PhD candidate). This was a further endeavour to encourage adherence to the intervention, whilst maintaining programme flexibility [386, 387].

The exercise guidelines for cancer survivors informed the design of the general exercise routine example in the handbook, including aerobic, strengthening, and stretching exercises [18, 350]. Exercises were selected considering the safety needs of BC survivors and limited availability of equipment [81, 349]. An example upper limb exercise routine was also included, guided by the specific needs of BC survivors after completion of MCT [148, 361]. The routine contains strengthening and stretching for the upper body, and scapular mobilisation exercises to improve and maintain upper limb function. For each example routine, a link to a video developed by the PhD candidate demonstrating these exercises, was provided. The duration of the example routines was set at 25 and 15 minutes respectively. However, survivors were advised to start with whatever duration they could manage [18].

The intensity recommended for the general exercise routine was according to the Borg scale level 'somewhat hard', which has been found to reflect a 60% effort of maximum heart rate [18, 388]. Appropriate descriptions were used in the handbook to explain what was meant by this intensity. The chapter on exercise included information on exercise safety, including when not to exercise due to illness [3].

Once participants were able to complete the general- and the shoulder specific exercise routines three times per week; or once they were completing either routine every day, they met the minimum exercise guidelines required to improve cancer-related health outcomes (90 minutes of moderate exercise per week) [18]. Detailed guidance was provided for participants to gradually progress their exercise towards 150 minutes of moderate intensity exercise per week, as per the guidelines for cancer survivors [18].

Dietary information for the chapter on nutrition was based on the American Cancer Society nutritional guidelines for BCS [350], recommendations from the World Cancer Research Fund [389] and from the Cancer Association of South Africa (CANSA) [369]. Clear instructions were provided for participants to adhere to their usual medical treatment or specific advice given by their healthcare provider [81]. Participants who wished to connect with other survivors, were entered into an optional WhatsApp group, which they were permitted to leave at any time during or after the study. This was to enable women to network with other BC survivors if they wished, a source of context-specific group support [390]. The Ph.D. candidate acted as the group administrator. Only participants of the intervention study were included in the group.

4.2.9 Primary data collection: Acceptability evaluation.

Acceptability describes how well an intervention is received by its target population, and the extent to which the intervention meets their needs [391]. Qualitative methods using interviews are appropriate for assessing the acceptability of new interventions [392]. Therefore, the acceptability of the proposed intervention was evaluated qualitatively in a small study using a descriptive design, among the first three BC survivors who participated in the intervention. This study was nested within the intervention study described in Chapter 5. The aim of the acceptability evaluation was to refine the intervention before evaluating further feasibility domains and preliminary outcomes in a larger sample of BC survivors (Chapter 5). Three participants comprised 10% of the projected sample size, which is sufficient to evaluate acceptability [393]. Recruitment and eligibility criteria, data management and ethical considerations of the acceptability evaluation were as for Chapter 5. In addition to completing all patient-reported outcome measures described in Chapter 5, participants completed a semi-structured interview after their 12-week intervention. The interview included open-ended questions regarding the acceptability of the intervention (Appendix N). The intervention was subsequently adapted according to this evaluation.

Ethical approval for this study was obtained from the University of Cape Town Faculty of Health Sciences Human Research Ethics Committee (HREC ref: 227/2022)(Appendix O). Purposive sampling was used. Only participants who met the eligibility criteria for the intervention study in Chapter 5, were purposefully selected to ensure alignment with the study objectives. Participants were recruited by inviting participants from the qualitative study in Chapter 2, per e-mail and WhatsApp or SMS, who had indicated that they would be willing to take part in BC research in the future. The first three BC survivors who responded to the invitation and provided informed consent, were enrolled if they met the eligibility criteria outlined in Chapter 5. The three participants provided informed consent for the acceptability evaluation through an additional clause within the informed consent form of Chapter 5 (Appendix P). There were no women contacted, who refused to participate.

The Ph.D. candidate had met the participants before, as they had participated in the qualitative study (Chapter 2). The ages of the participants were 61, 62 and 53 years. All were early-stage BC survivors accessing the public health system, who had completed their MCT at least six months previously. Following their 12-week intervention, the Ph.D. candidate conducted telephonic, semi-structured, individual interviews with each participant at a time convenient for them, using open-ended questions from the interview guide (Appendix N). The duration of each interview was approximately 30 minutes. Interviews were recorded using a Philips DVT6010 digital audio-recorder, with the participants' permission. The Ph.D. candidate received training in conducting interviews for qualitative research, by an experienced qualitative researcher (NN). The Ph.D. candidate was not involved in the clinical care of participants. The participants were aware of the reasons for conducting this study. The Ph.D. candidate may have been biased due to her endeavour to develop a successful intervention for BC survivors. However, this bias was managed using the interview guide, through the implementation of member checking, and through the validation of the data analysis and findings by a co-supervisor of this study (TB). Efforts to promote trustworthiness were undertaken as outlined in Chapter 2, Table 1. These efforts included reflexivity: by describing the researcher's credentials, training, and therapeutic alliance with participants [127]. The interview guide consisted of evidence-based questions for intervention evaluation. The interview guide was self-developed by the research team, however it was based on the acceptability evaluations of previous interventions for chronic conditions [348, 394].

The three audio-taped telephonic interviews were transcribed verbatim, then forward- and back-translated from Afrikaans to English by the Ph.D. candidate, fluent in both languages. A summary of the interview was sent to each participant for comment. This is known as member checking [130], used to verify the information. Text was coded using open coding and an inductive approach [134]. Codes were organised into categories, using a word processing package.

Content analysis was used to analyse data, as content to be explored was well defined and interview data could be arranged accordingly [395]. Qualitative data showed responses to the interview questions, and quantitative information highlighted the frequency of the codes counted [396]. In content analysis, categories may be influenced by the frequency of codes in the text [396]. The analysis was validated by a researcher who co-supervised this project (TB). Results were discussed amongst the research team, before adjusting the intervention accordingly [129]. Results of the acceptability evaluation are presented in Tables 17, 18, 19, 20, and 21.

'Survive and Thrive' was well received by the three BC survivors. Participants enjoyed working through the content, appreciating the printed copy of the handbook as they were able to share it with family members (participants 1 and 3). Participant 1 reported having become more aware of the possibility of cancer recurrence, because of the intervention. The women in this study found the chapters on exercise and nutrition, useful. These findings indicate that the content of the intervention handbook was successful in terms of raising awareness of BC recurrence, and to provide specific health education regarding exercise and nutrition. The implication for the refinement of intervention delivery, was that printed copies of the intervention handbooks should be provided at the start of the intervention.

Table 17: What did you like about the intervention?

Count	Category	Participant	Example of responses
2	Exercises	3	"*The walking exercises I liked, and the arm exercises I liked a lot*."
2	Advice about healthy eating	3	"*I got a bit thinner with the eating habits, I also liked that."*
1	Going through the survivorship information	1	*"I enjoyed going through everything like that."*
1	Receiving the hard copy of the handbook	1	"*I can pass it* (the handbook) *on to my daughter as well, so that she can also realise what she must do, because she is turning 40 next year."*
1	Liked everything about the intervention	3	*"I liked everything that was in the handbook. It was passionate for me, the three months."*
1	Intervention was interesting, refreshing, insightful	2	*"It was very interesting and refreshing. It gave a person a lot of insight to be able to do things."*
1	Information was comprehensive	2	*"I think you covered just about everything."*

Table 18: What didn't you like about the intervention?

Count	Category	Participant	Example of responses
2	Nothing that she didn't like	3	*"No, there's really nothing that I didn't like."*
2	Would have wanted to receive the hard copy earlier on during the intervention.	1	"*When I got the* (hard copy) *handbook, I went through it from the beginning again, and paged through it at my leisure. It was quite nice."*
		3	*"My phone is like this: you can't see everything in the handbook on my phone. I must make it bigger, and then I can't see everything that is written there. The handbook is better, I can page through it and see everything."*

Table 19: How do you feel about exercise, now that you have completed the intervention?

Count	Category	Participant	Example of responses
1	Exercises have helped to improve arm mobility, which she needs for work.	3	*"I still do the exercises every day, I feel alright now. The work that I do is more exercise for my arms, that I must stretch out like this. I feel passionate about my daily exercises, the arm that I stretch out and then relax it again, like that."*
2	No change, was already exercising before the intervention.	2	*"I did the exercises and went for nice walks with my dogs. So not much has changed as far as that's concerned."*

Table 20: How do you feel about your ability to manage LTSE, now that you have completed the intervention?

Count	Category	Participant	Example of responses
1	Intervention has increased awareness of BC and possibility of recurrence	1	"*I am quite a lot more aware of it* (cancer recurrence) *now."*
1	Intervention has encouraged self-management of LTSE.	2	"*I have my compression garment again because I can see my arm grew a bit, but the sock* (compression garment) *pressed it nicely better again. And today we have put it on again, so it's going well."*
1	Feels better overall	3	*"I feel different now, it doesn't even feel like I am sick anymore."*
1	Intervention has encouraged her to obtain a breast prosthesis for the first time.	2	*"I feel very different now… I always used to walk around without a prosthesis. Now, I have bought two more bras, and that pink breast* (prosthesis*) from CANSA."*

Table 21: Would you have preferred to receive the intervention in another language?

Count	Category	Participant	Example of response
3	No further language preferences	1	"*No. Afrikaans is my language*."

Participant 2 reported that the intervention had encouraged her to address her lymphoedema management, and to obtain a breast prosthesis for the first time. These findings indicate that the intervention, apart from providing information and exercises, empowered this participant to self-manage her long-term BC-related health challenges. The improved upper limb mobility reported by participant 3, demonstrates the potential of this intervention to contribute to physical function.

A shortcoming of the intervention delivery identified by participant 3 was that she was not always able to open and view intervention content on her mobile phone. She had received the printed copy of her handbook a few weeks after the start of the intervention. Therefore, upon discussion with the research supervisors, the student researcher undertook to send off the printed copies to participants as early as possible.

No further changes to the intervention were identified. Recruitment for the study further exploring feasibility, safety, and preliminary outcomes (Chapter 5) could continue. As no changes were made to the intervention itself, quantitative patient-reported outcomes collected from participants who completed the acceptability evaluation were pooled and reported with the remainder of the sample in Chapter 5. Women who participated in the acceptability evaluation completed the study in Afrikaans. They did not express further language requirements for the intervention.

4.2.10 Attending to future implementation.

'Survive and Thrive' was designed with the intention of maintaining applicability and transferability to clinical practice, in low- and middle income countries such as SA. For example, only one participant in the qualitative study, Chapter 2, had received tertiary education. The handbook therefore uses simple language. The Flesch-Kincaid Grade level of the handbook 'Survivorship Information for breast cancer' is 6.7. [19]. A grade level of 6.7 means that a child aged 12 should be able to read and understand the text. As described above, an acceptability evaluation of the intervention was conducted. Further domains of feasibility, safety, and preliminary outcomes including pain, cancer-related fatigue, quality of life, self-efficacy, and exercise participation were assessed in Chapter 5.

The structure of the intervention 'Survive and Thrive' was directly informed by the systematic review in Chapter 3: the review informed the intervention type (supported SMI requiring no clinical visits), duration (12 weeks), format (printed handbook combined with email, text messages, and / or WhatsApp), underlying theory (social cognitive theory), activities prescribed (exercise diary, type of exercise chosen by BC survivor) and the content (information and self-management skills regarding exercise, nutrition, and healthy lifestyle). It should be noted that several interventions included in the systematic review used telephone- or video calls (mostly combined with other modalities), to deliver their interventions. Attending to future implementation in low-resource clinical settings meant that calls to deliver the intervention were not deemed appropriate for the South African context: they would require greater resources in terms of qualified staff, compared to providing support to participants as needed. In addition, there were no participants in the qualitative study, Chapter 2, who mentioned calls as an intervention preference. Therefore, 'Survive and Thrive' was designed without the need for telephone-, conference- or video calls to deliver the intervention.

Larger studies to confirm the utility of this intervention must be conducted in the future. Once the feasibility and effectiveness of the intervention have been established, further actions to consider for future implementation will include a cost-effectiveness analysis, translation into other official South African languages, and appointing and training facilitators to administer the intervention. The intervention must also be updated regularly according to the latest scientific research, and in response to local developments: If a specific region offers new exercise classes for patients with chronic diseases, this local information should be included in the intervention handbook. It may also be helpful in the future, to conduct studies to determine the optimal balance between effectiveness and feasibility, considering the cost-effectiveness of intervention delivery. For example, providing two to three face-to-face group sessions with participants may be more effective, but perhaps less feasible and transferable clinically, compared to the current remotely delivered format. Such further refinement would expand and optimise the implementation of 'Survive and Thrive' into clinical settings.

Once 'Survive and Thrive' has progressed to the implementation phase, its utility should be re-evaluated through updated literature review(s), qualitative studies, re-design or further refinement and (re)-evaluation of the modified or new intervention. Therefore, ideally the cycle of refinement should continue to strive to meet the needs of BC survivors, and to be updated according to current best evidence.

4.3 Final thoughts on the development of 'Survive and Thrive'

A variety of SMIs including exercise and requiring minimal face-to-face clinic visits have been developed for early-stage, post-treatment BC survivors, albeit in high-income countries [103, 284, 285, 288, 290]. Characteristics of 'Survive and Thrive' that differentiate it from other interventions, are its target population; its content: providing comprehensive survivorship information with practical, evidence-based behaviour change techniques; that it required relatively few resources to implement; and its reach: no clinical visits were required to complete the intervention. The novel intervention tailored to the needs identified by the BC survivors in Chapter 2 was developed, drawing on the experience and guidelines in other chronic conditions [81, 348, 349, 397], and on the results of the systematic review, Chapter 3. Further work is needed to establish the utility of this intervention, such as further domains of feasibility, safety, and outcomes [344]. A potential limitation of this development process may be that time lost due to the coronavirus pandemic, and budgetary constraints did not allow for multiple iterations of steps taken to further refine 'Survive and Thrive'. Budgetary constraints meant that the PhD candidate, who had administered the intervention, also conducted the interviews for the acceptability evaluation. This may have impacted the responses of participants, leading to bias of the results. Future, larger studies should use an independent researcher to administer the acceptability evaluation. A further limitation is the small number of BC survivors used to design and refine the intervention. However, given the researcher, BC survivor and clinician involvement to inform the intervention, and the feedback from women who completed the acceptability evaluation, this was probably adequate work prior to further evaluation.

It was not possible to accommodate all the preferences identified in Chapter 2, in terms of the intervention mode. In the future, a variety of interventions should be developed which meet the needs of survivors and accommodate their individual preferences. Another limitation was that the intervention was provided in two languages (the language needs identified by participants), and that all participants who participated in the qualitative study in Chapter 2 and in the acceptability evaluation, came from the Western Cape, Eden District, SA. Therefore, further translation and cultural adaptation must be considered for larger South African studies in the future. Given the patient-centred nature of 'Survive and Thrive', and the universality of LTSE experienced by BC survivors post-treatment [24], hopefully much of this intervention will be translatable across languages and cultures.

There are many published guidelines for behaviour change intervention development. One set of guidelines has not shown to be superior to others [85].

Examples of alternatives to the MRC guidelines for the development of complex interventions, include Intervention Mapping [398], the 6SQuID approach to quality intervention development [399], the knowledge to action cycle [400], the ORBIT model [401], and many more. Each has their own unique focus and approach. However, they all use a core set of key steps including: an analysis of the problem and developing intervention objectives, causal modelling, defining intervention characteristics, a logic model of change, materials and interface, and empirical optimisation. These steps are followed by process and outcome evaluation, and implementation [344]. Systematic development of new interventions is important to ensure they stand a good chance of being effective [85]. A 'checklist' of actions to consider during development makes logical sense, as it is not always possible to correct a step in the process once the project has progressed beyond the development phase.

4.4 Conclusion

In this chapter, the development of an evidence- and theory-based SMI for early-stage, post-treatment BC survivors, was systematically described. This process consisted of using evidence gained from a systematic review, theories, BC survivor, and healthcare provider involvement. The development process also facilitated the exploration of the feasibility domains intervention content and delivery, and acceptability, through a small qualitative study. The feedback from BC survivors who participated in the acceptability evaluation was positive, indicating that the intervention was well received. Participants enjoyed working through the content, and intervention delivery seemed feasible. An amendment to the timing of the delivery of printed copies was required following this study. The resultant intervention may be a first step to provide valuable patient information and self-management skills for the LTSEs of BC and survivorship concerns, to South African BC survivors after completing primary MCT. Interventions are complex to develop, consisting of many different components [344]. When the intervention is adapted in the future, these components and actions taken can be revisited and updated, using the information in this chapter. New interventions should demonstrate their benefit, while causing no harm [344, 345]. Therefore, 'Survive and Thrive' warrants evaluation of further feasibility domains, safety, and outcomes. This was undertaken in the next chapter of this thesis.

Chapter 5. A single-group, pre-test post-test study to evaluate a supported self-management intervention for breast cancer survivors.

5.1 Introduction

Breast cancer is the most common form of cancer worldwide [402], and in South Africa (SA) [46, 72]. The number of breast cancer (BC) survivors is increasing: most women with early-stage disease will become long-term survivors [43, 47, 403]. Physical long-term side effects (LTSEs) following primary medical cancer treatment (MCT) including surgery, chemotherapy, and radiation, can occur for 10 years or more, and may cause significant disability if left unaddressed [6]. International guidelines state that women require comprehensive information regarding BC and other health challenges associated with long-term cancer survivorship [6, 53, 350]. Furthermore, previous studies suggest that rehabilitation and information requirements of South African BC survivors are not being met by the current standard of care [60, 62, 102].

In Chapter 2 of this thesis, BC survivors were engaged through a qualitative study to investigate their experience of LTSEs, and to gain an understanding of their perceived rehabilitation needs. The implication of these findings is that pragmatic, evidence-based management strategies are required to address the needs of women with early-stage BC following the completion of primary MCT. Informed by the qualitative study, the systematic review in Chapter 3, and published guidelines, a resource-efficient self-management intervention (SMI) was developed and described in Chapter 4. The intervention advocated a patient-centred approach for women with early-stage BC in SA, following MCT. As a next step, aspects of feasibility not yet addressed in Chapter 4, safety, and potential utility to improve commonly occurring LTSEs, health-related quality of life (HRQoL), self-efficacy, and physical activity, were explored.

5.2 Aim and objectives

The aim of this study was to evaluate if the newly developed intervention was feasible and safe to deliver, and if it was associated with improvements in commonly occurring physical LTSEs, physical activity, HRQoL, and self-efficacy.

5.2.1 Objectives

- To describe the sample of BC survivors in terms of their socio-demographic characteristics, MCT details, and reported chronic medication use.
- To determine the feasibility of the intervention, based on the pragmatic evidence-based feasibility domains recruitment, data collection, retention, adherence, outcomes, intervention delivery, and participation costs. (The domains acceptability, intervention content and initial delivery, were addressed in Chapter 4).
- To determine the safety of the intervention, based on the number of adverse events related to participation in the study.
- To determine if there was a significant difference in the following patient-reported outcome measures after participating in the intervention, compared to baseline:
  - Pain prevalence, severity, and interference with function using the Brief Pain Inventory (BPI).
  - Self-efficacy using the Self-efficacy for Managing Chronic Disease 6-item Scale (SE-6).
  - Health Related Quality of Life (HRQoL) index- and EQ-VAS scores using the EQ-5D-3L questionnaire.
  - Physical activity levels using the IPAQ-SF (International Physical Activity Questionnaire Short Form).
  - The number of participants who met the minimum exercise guidelines for the management of cancer-related health outcomes (at least 90 minutes of moderate activity per week [18]), using data from the IPAQ-SF.
  - The hours spent sitting on weekdays, using the sitting question from the IPAQ-SF.
  - Fatigue prevalence, severity, and interference with function, using the Brief Fatigue Inventory (BFI).

5.3 Methodology

An aim of health research is to increase knowledge, thereby providing scientific evidence on which the quality of patient care can be based, and ultimately influencing decisions for change and policymaking [404]. Feasibility evaluation is used to determine if an intervention is suitable for further testing in the future [405]. This addresses predetermined domains relating to evaluation design and to the intervention itself [345]. According to recent guidelines for feasibility studies, pragmatic feasibility domains of delivering and evaluating interventions can be explored within the bounds of available resources [406]. With the exploration of feasibility and safety, another objective of this study was to evaluate preliminary outcomes to gain an indication of the potential utility of the intervention.

Quantitative research was deemed useful for this purpose, as it tends to be objective and focuses on narrow, measurable aspects of health and human behaviour [404]. The emphasis in quantitative research is on a few concepts in a concise and controlled manner to test relationships and describe interactions between variables [404].

5.3.1 Research design

Feasibility criteria relevant to this study that had not yet been addressed in Chapter 4, were explored, to inform the practicality of delivering and evaluating the intervention. The safety of the intervention was reported, based on the number and nature of adverse events related to participation. In line with the Medical Research Council (MRC) Guidelines for the Development of Complex Interventions [345], a quasi-experimental, single-group, pre-test post-test study was conducted to evaluate for preliminary evidence of change following the intervention. The purpose of quasi-experimental studies is to identify or explore causal relationships [404], allowing associations to be made between the intervention and outcomes [407]. Quasi-experimental research allows an intervention to be tested for possible implementation into practice, yet study participants are not randomly assigned to groups either receiving the intervention or not [407]. The benefit of this study design was that all BC survivors who wished to participate and who met the inclusion criteria for this study, had access to the intervention, which included evidence-informed information based on their needs. Therefore, with feasibility and safety, this study design was suitable to explore initial relationships between participating in the intervention, and outcomes.

It should be noted that quasi-experimental designs are frequently used when it is not logistically feasible, practical or ethical to conduct a randomised controlled trial (RCT) [408]. Several considerations prevented the implementation of an RCT in this study. Contextual needs were identified by participants in Chapter 2, such as the need for information regarding the management of LTSEs, detecting cancer recurrence and other cancers, and how often to visit the breast clinic for follow-ups. A control group receiving usual care would have entailed withholding such information from control group participants. To the knowledge of this author, usual care in South Africa (SA) currently does not offer interventions or structured information about survivorship issues to BC survivors, following the completion of their primary MCT. Therefore, offering the intervention to control group participants after 12 weeks (such as a delayed intervention RCT) was not considered. Providing information to a control group without the exercise component was another option deemed unsuitable, based on the well-established benefits of exercise for improving both cancer-related and general health outcomes, in this population [18].

Moreover, to the knowledge of this author and based on the systematic review (Chapter 3), no appropriate alternative intervention existed that could have been used as a control in this study. These are legitimate arguments in favour of a quasi-experimental design [409]. Therefore, outcomes relating to LTSEs, self-management, HRQoL, and exercise participation were selected in the hope of detecting within-group differences post-intervention, compared to pre-intervention.

External factors also influenced the nature of the intervention and study design. Uncertainty regarding the coronavirus pandemic, specifically the slow vaccine roll-out in SA during the proposal and intervention development of this study, led to concerns regarding the safety of participants. On the one hand, MCT may cause chronically compromised immune function in cancer survivors [410]. On the other hand, exercise and adopting a healthy lifestyle can contribute to an improved immune function in cancer survivors [411]. Participants in Chapter 2 identified that they experienced transportation problems to and from the breast clinic. Therefore, the intervention and testing procedure were designed to not require face-to-face clinic visits. Furthermore, this study was unfunded and therefore the placing of research assistants at various clinical sites was unaffordable. A lack of funding also necessitated that, in this study, the same researcher who facilitated the intervention, also administered the (standardised) patient-reported outcome measures.

An advantage of the remotely delivered intervention and study design was an increased reach: Survivors from the entire country could participate, transportation problems to and from healthcare centres were eliminated, and women who worked or looked after children and grandchildren, were able to participate. Indeed, remotely delivered interventions may be feasible, practical, and cost saving to participants whilst requiring relatively few resources to implement [103, 412, 413]. Furthermore, the systematic review and meta-analysis in this thesis (Chapter 3) provided evidence that SMIs using minimal clinic visits, may be effective to improve health outcomes, HRQoL, and physical activity participation in post-treatment BC survivors.

5.3.2 Participants

Participants were recruited from three sources: the sample of women who participated in the qualitative study in Chapter 2; women who responded to the qualitative study recruitment advert and were eligible, but unable to participate in that study; and through cancer support organisations. Adult women who had received a diagnosis of early-stage BC, and who had completed MCT six months up to 10 years previously, were eligible for participation.

5.3.3 Inclusion criteria

The following criteria were used to determine if prospective participants were eligible for inclusion:

- Women aged between 18 and 70 years. Breast cancer affects primarily post-menopausal women, but younger women may be more heavily burdened by LTSEs [414].
- Ductal carcinoma in situ, stage I, II or III A BC following medical cancer treatment. Surgery, chemotherapy, and radiation are risk factors for developing LTSE [24, 415]. Stage IV (metastatic) BC treatment and rehabilitation is distinct from early stage BC [8].
- Primary medical cancer treatment completed within the last 10 years. The qualitative study (Chapter 2) included survivors up to 5 years following the completion of their primary MCT. However, since then, new studies have reported that physical treatment-related side effects may persist for 10 years or more [57, 416, 417].
- Completed MCT at least six months prior to their enrolment into the study. This was to allow for acute side effects from MCT to attenuate [418].
- Breast cancer survivors who lived in SA, as the intervention was developed for the South African context.
- Fluent and able to speak, read and write in an official South African language. Participants needed to be able to read the handbook, complete patient-reported outcome measures, and to express questions or concerns during the intervention. While language needs were explored as part of the acceptability evaluation (Chapter 4), further language needs beyond English and Afrikaans would have been accommodated for this study, if necessary.
- Access to a mobile phone. Baseline and end-point questionnaires were administered telephonically, to allow participation in the study even if participants did not have smartphones or were not computer literate. Mobile phones were required as participants were asked to respond to weekly messages sent to them, through either short message service (SMS), email, or WhatsApp (an extremely popular mobile application in SA) [380].

5.3.4 Exclusion criteria

Women were excluded if they:

- Had other malignancies or metastatic disease, to ensure that outcomes reported were related to early-stage BC or its medical treatment.
- Had communication difficulties due to cognitive impairments.
- Were unfit to participate in exercise, according to the American College of Sports Medicine (ACSM) preparticipation screening, as the intervention encouraged exercise (Appendix X).

- Had taken part in other clinical trials in the past six months, to avoid cross-contamination of results from different research activities.
- Had suffered musculoskeletal injuries in the past six months, or injuries receiving medical treatment or rehabilitation. This was to ensure that participants could exercise, and to prevent contamination of results.
- Were pregnant. Pregnancy may alter the experience of LTSEs, for example fatigue [419]. Furthermore, pregnant BC survivors require close medical surveillance [420].
- Reported participating in more than 16 hours of moderate or vigorous exercise per week. Measurement instruments and the intervention were intended for the general population. Unreasonably high amounts of exercise were regarded as outliers and would have been excluded from data analysis [297].
- Were receiving active treatment for lymphoedema, such as complex decongestive therapy. This was to prevent contamination of results from the two interventions received [421].

5.3.5 Sample size calculation

The sample size for this study was to be appropriate both for informing feasibility and for presenting outcome data. Studies usually include approximately 30 participants to allow informed decisions regarding the feasibility of delivering and evaluating an intervention [406]. To inform the assessment of patient-reported outcomes, the sample size was also calculated for paired t-tests according to a sample size calculator developed by Chow and colleagues [422]. Pain was selected as the primary outcome measure to calculate the sample size because it is the most commonly reported LTSE in BC survivors [24]. Change in pain severity scores of the Brief Pain Inventory (BPI) after the intervention was therefore used to determine the sample size. Using data from a previous intervention study for pain in a similar population [423] with statistical significance set at $p < 0.05$ and a power level of 80%, 30 participants provided 95% probability of achieving an effect size of 0.85 ± 1.72 in pain. Therefore, to allow for drop-out, 33 individuals were the target sample size for this study to inform both feasibility and the preliminary impact of the intervention.

5.3.6 Sampling and recruitment

Voluntary sampling using the snowballing approach was used. Therefore, participants were asked to notify other BC survivors by sharing the leaflet advertising the study, and by word of mouth. Preference was given to the participants of the qualitative study (Chapter 2), where participants had indicated verbally to the researcher that they would like to participate in future research.

Therefore, the researcher sent the leaflet advertising the present study to the participants of the qualitative study first, by WhatsApp, e-mail, or MMS (Multimedia Messaging Service)(Appendix Q). The first three women who responded, who met the inclusion criteria and signed informed consent, participated in the acceptability evaluation (Chapter 4). Recruitment paused until the intervention had been adapted according to the results of this evaluation.

Respondents to the qualitative study advert who had not been able to attend a focus group discussion (FGD), but who verbally indicated interest in future BC research, were invited. The leaflet advertising the present study was then distributed by the Cancer Association of South Africa (CANSA) and the Reach for Recovery breast cancer support organisation (R4R) via their regional offices to community-based volunteers and posted on their social media platforms. Survivors who responded and who met the inclusion criteria were sent an informed consent form (ICF) (Appendix P). Recruitment was continuous, allowing women to start participating as soon as they returned the signed ICF. Record was kept of their starting date using a master list (Appendix R).

5.3.7 Instrumentation

5.3.7.1 Socio-demographic questionnaire

This self-developed questionnaire was administered to collect basic information of participants, such as age, cancer stage and treatment, and employment status (Appendix S). The questionnaire was closely based on socio-demographic questionnaires used in previous BC rehabilitation studies [118, 119], and on the socio-demographic questionnaire used in Chapter 2 (Appendix C). The latter questionnaire, available in the languages English and Afrikaans, had been piloted and subsequently adapted to establish its validity, during the first focus group discussion in that study. The question regarding household income was omitted in this study, to protect the privacy of participants as data were collected telephonically [424]. The screening questions regarding shoulder problems, fatigue, and exercise participation from the socio-demographic questionnaire in Chapter 2 were omitted in this study, as these outcomes were addressed through standardised patient-reported outcome measures.

5.3.7.2 Feasibility

The Medical Research Council (MRC) guidance for the evaluation of complex intervention criteria were used to evaluate aspects of feasibility that were pragmatic and relevant to this study [345]. These criteria are based on the Consolidated Standards of Reporting Trials (CONSORT) statement extension to randomised pilot and feasibility trials [425].

Adherence refers to the extent to which participant behaviour coincided with advice given in the intervention [426]. Although there is no consensus on the optimal method of measuring adherence in SMIs, the most widely used method in previous studies, is through the recording of exercise in home diaries [427]. However, while most South Africans have access to mobile phones - even in rural areas [428, 429], it could not be assumed when designing this study that all participants would have access to smartphones, or to other mobile devices with cameras. Therefore, there was uncertainty if all participants would be able to share their completed exercise diaries and weekly tasks. Making this a requirement for participation, could potentially have resulted in the exclusion of participants without access to these digital technologies. Another widely used method for determining adherence in SMIs, is through a single-item questionnaire [427]. Therefore, a modest indicator of adherence was obtained through the response rate of participants to weekly reminders to work through intervention content. A single reminder message was sent at the start of each week. A characteristic of SMIs is their flexibility, allowing participants to work through content in their own time [208]. Therefore, participants were given one week to respond to each weekly message, before recording whether they had responded or not. A summary of the feasibility domains addressed in this study is presented in Table 22.

Table 22: Summary of the feasibility domains that were addressed.

	Feasibility criteria addressed to evaluate 'Survive and Thrive'
Criteria relating to evaluation design	The rate and ease of **recruitment** of participants was described.
	Data collection process was described.
	Retention was calculated. Acceptable retention was set at 80% [33].
	Sensitive, appropriate and validated patient-reported **outcome measures** were used. These aspects are discussed in the Instrumentation section below.
Criteria relating to intervention	**Content and initial delivery** of the intervention were assessed through a small qualitative study, in Chapter 4. Changes were made to improve the intervention delivery following the latter study. Aspects of intervention delivery were reflected on again in this study, as the sample size of participants receiving the intervention, was larger.
	Acceptability was evaluated through the abovementioned qualitative study, Chapter 4. The intervention was highly acceptable based on the feedback given by participants of the latter study.
	Adherence was encouraged during the intervention through weekly emails / WhatsApp messages with the content for every week, and through biweekly previews. Participants were required to respond to the weekly messages, indicating that they had received the content and were participating in the intervention. An indication of adherence was obtained by keeping record of these responses [427].
	Cost effectiveness was estimated based on the costs of the intervention per participant.

5.3.7.3 Safety

In line with the recent guidance on recording harms of behaviour change interventions [430], participants were encouraged to report any adverse event or an increase in symptoms related to their participation, to the researcher. This was communicated verbally after the baseline data collection of patient-reported outcomes. It was also encouraged in writing, on the ICF (Appendix P). Furthermore, participants were reminded to report this at the start of Week 7 of their intervention, when they received the preview for Weeks 7 and 8, through their preferred communication channel. Following the data collection of end-point patient-reported outcomes, the researcher verbally enquired again if participants had experienced any increase in symptoms in response to their participation in the intervention. In this study, an adverse event was defined as any significant increase in symptoms (such as an increase of three or more out of 10 for pain or fatigue severity according to the BPI or BFI respectively) [431, 432], reduced ability to move the affected arm freely, or an increase in arm or chest swelling [6], in response to activities advocated by the intervention. Adverse events were documented on an adverse events form (Appendix T).

5.3.7.4 Brief Pain Inventory (BPI)

Pain and fatigue are the two most common and debilitating LTSEs experienced by BC patients, often for many years [24]. The BPI [433] was used to generate scores for pain prevalence (number of 'yes' responses to the pain prevalence question), severity (pain severity score) and pain interference with function (pain interference score) as described by the authors of the instrument [431]. The BPI was developed for use by cancer patients and is widely used in BC [434, 435]. Furthermore, the BPI has shown to be sensitive and able to detect clinical changes in pain, in BC survivors [436]. This questionnaire has demonstrated reliability and content, criterion, and construct validity when interviewer administered [431].

The BPI has been validated in SA for use in several South African languages including South African English and Afrikaans [433]. It and has been used in various chronic conditions in this country [81, 355, 437, 438]. The questionnaire started by clarifying that although it is normal to experience some kind of pain regularly, the questionnaire explores whether the respondent has experienced more pain than they would normally expect ('yes' or 'no'). The pain prevalence rate of the study sample was obtained from the 'yes' responses to this question. The pain severity and pain interference scores allowed for the evaluation of the impact of pain on function through scores out of 10, which was useful to quantify pain severity and interference with function in this study.

Furthermore, the BPI allowed for the classification of pain severity as either being mild (a score of two or less), moderate (a score of two to six) or severe (a score of more than six) [439]. This classification was not used in statistical analyses however it facilitated an estimate of the clinical relevance of change in pain (Appendix U).

5.3.7.5 The Brief Fatigue Inventory (BFI)

The BFI [432] was used to describe the prevalence, severity, and interference with function of cancer-related fatigue participants were experiencing. Cancer-related fatigue is distressing and the symptom that interferes most with the daily life of cancer survivors [167]. The BFI was developed for cancer patients based on the BPI for pain. The BFI is available in over 45 languages, including South African English, Afrikaans, and three further indigenous South African languages [306]. The BFI uses simple wording which makes it easy to understand for survivors of various educational backgrounds. Fatigue prevalence was established through the number of 'yes' responses to the first question: "Have you felt unusually tired or fatigued in the last week?" [306]. The BFI also measured the fatigue severity (fatigue severity score) and interference with function (fatigue interference score), using scores between zero and 10 [306]. The questionnaire allowed fatigue to be categorised as mild (1-4), moderate (5-6) or severe (7-10), based on fatigue-related interference with function. This classification was not used in statistical analyses in this study however it allowed an estimate of the clinical relevance of change in fatigue. The BFI has been found a reliable, valid, and sensitive measure of cancer-related fatigue in various parts of the world, including Africa [306, 440, 441]. It has been widely used in BC, to evaluate rehabilitation interventions [442-444] (Appendix U).

5.3.7.6 EQ-5D-3L Questionnaire

This instrument was used to describe the HRQoL of participants. This standardised generic instrument was developed by the EuroQol Group [445] to measure the health of an individual. The EQ-5D-3L was used to generate a general health status score (EQ-VAS) and a weighted health index score. The health profile consists of five descriptive domains of function: mobility, self-care, usual activities (work, study, housework, family, leisure); pain and discomfort; and anxiety and depression. These five domains are frequently affected by the LTSEs of BC treatment [24, 446]. The telephonic EQ-5D-3L includes respondents imagining a scale marked 100 at the top ('best imaginable health'), and 0 at the bottom ('worst imaginable state of health'). Respondents are asked to tell the administrator the point on the scale where they would put their state of health today. This score forms the general health status (EQ VAS) score [445].

The EQ-5D-3L has been culturally and linguistically adapted for 172 language versions, including Afrikaans and isiXhosa [447]. As no validated South African tariff set for the EQ-5D-3L weighted health index [447] existed, this was calculated using the York A1 tariff derived from a population survey conducted in the United Kingdom [448]. Scores derived using the York A1 tariff set range from 1.0 indicating 'perfect health': no problems in any of the five dimensions of descriptive domains, 0 being 'equal to death', while up to -0.149 indicates severe problems in all five dimensions, or a state 'worse than death' [448]. The instrument has good reliability, construct, and concurrent validity [449-451]. The EQ-5D-3L has been validated in different settings in SA [438, 452]. Furthermore, the EQ-5D was found sensitive, responsive, and appropriate for evaluating health interventions in BC after treatment [446, 453, 454] (Appendix U). Health index scores below 0.500 for this outcome are associated with low HRQoL [447]. Therefore, participants who reported scores lower than this value, were offered referral to their healthcare provider.

5.3.7.7 The Self-efficacy for Managing Chronic Disease 6-item Scale (SE-6)

The SE-6 was used to describe levels of self-efficacy of the participants. It has been consistently reported that people with high levels of self-efficacy have lower reported levels of disability than people with lower self-efficacy [455-457]. An exploration of self-efficacy was also deemed relevant for this study based on the relationship between self-efficacy and self-management [83, 208, 233]. The SE-6 was developed specifically to test the efficacy of chronic disease education programmes, by Lorig and colleagues [458], in English. It covers the dimensions symptom control, role function, emotional functioning, and communication with healthcare professionals [458]. It has a simple structure asking respondents to indicate how confident they are on a numeric rating scale from zero ("not at all confident") to 10 ("totally confident") that they can perform certain activities. Furthermore, self-efficacy levels can be classified as low (score of < 5), moderate (score between 5 and 7) or high (score > 7) [459]. The SE-6 has been found valid and reliable for measuring self-efficacy in chronic conditions, also in SA [81, 349, 355, 460]. It has been used extensively in cancer, including BC, and its psychometric properties support sensitivity to detect change in self-efficacy [458, 461-463]. The SE-6 is suitable to be interviewer administered [458], and validated Afrikaans [464] and isiXhosa [358] versions are available. A single score was generated from the SE-6 using the formula described by the authors (Appendix U) [458].

5.3.7.8 International Physical Activity Questionnaire - Short Form (IPAQ-SF)

Because of the favourable impact of exercise on LTSEs of cancer treatment, effective interventions should achieve an increase in exercise participation [68, 96, 319]. The IPAQ-SF [465] was used to describe the physical activity levels of participants. The IPAQ-SF has been found a reliable and valid measure of physical activity [297, 466]. It is a brief, commonly used measure of physical activity in SA and elsewhere in Africa [467-469]. The IPAQ-SF has been found valid and locally sensitive for use in SA while generating meaningful and internationally comparable data [297]. Furthermore, it has been widely used and shown sensitive to assess change in physical activity, in BC survivors [266, 470-472]. Although objective measures through wearable technology may offer a more precise estimate of physical activity volume, self-report measures represent a pragmatic, cost-effective method of obtaining physical activity data [468]. In addition, objective measures obtained through wearable devices may not accurately capture upper limb training [473]. Upper limb exercises are important in the rehabilitation of BC survivors [147, 363, 474]; hence these were emphasised in this intervention.

In the IPAQ-SF, participants report the frequency (days per week), and duration (minutes per day) of vigorous (intense home or gardening activity, intense aerobic exercise), moderate (moderate home or gardening activities, carrying light loads, or cycling at a steady pace), walking, and average sitting time in hours per day. The IPAQ SF allowed for the conversion of data in metabolic equivalent minutes per week (MET-min / week), where each activity is associated with the metabolic equivalent of the task (MET): MET = 8 for vigorous, MET = 4 for moderate, MET = 3.3 for walking [475].

Using the total weekly physical activity reported by participants, it was possible to estimate if they were meeting the minimum exercise guidelines for improving cancer-related health outcomes. These guidelines recommend at least 90 minutes of moderate activity per week, which has been shown to improve outcomes such as fatigue, HRQoL, and physical function in cancer survivors [18]. Therefore, if participants reported 90 minutes or more of moderate or vigorous physical activity per week, the response was classified as ‘yes’ (meeting guidelines for the management of cancer-related health outcomes). If they reported less than 90 minutes of moderate physical activity per week, the response was classified as ‘no’ for this question. To improve health and HRQoL, interventions should aim to reduce sitting time [476], which is another outcome measured by the IPAQ-SF. Therefore, data reported regarding sitting time on weekdays, were extracted from this questionnaire (Appendix U).

5.3.8 Intervention

The 12-week supported SMI 'Survive and Thrive', based on the social cognitive theory [37] and self-management principles [83], described in Chapter 4, was used in this study to determine the preliminary outcomes of participating in the intervention. The handbook 'Survivorship information for breast cancer', formed the basis of this intervention (Appendix M). The intervention included working through information in the handbook completing one section every week; action plans and tasks relating to the weekly theme; access to the researcher who facilitated the intervention for support; and joining an optional WhatsApp group with other participants. Women were able to participate in the intervention from home.

The purpose of the WhatsApp group was to offer women an opportunity for forming partnerships even if they lived far apart [83]. It served as a platform for women to share their experiences, feelings, and ideas with other BC survivors as a form of social support, a need identified by participants in Chapter 2. The researcher, who facilitated the intervention, acted as the group administrator without active engagement. Forming partnerships as a form of social support, is important to many BC survivors [120, 121, 190]. Therefore, SMIs should offer this element of self-management support [477]. However, not all women have the desire to connect with others [478]. Therefore, to achieve intervention flexibility and to accommodate individual preferences - both regarded as further elements of successful SMIs [84], joining the WhatsApp group was not a requirement for participation.

Each week of the intervention focused on a specific topic, such as information and self-management skills regarding BC and its long-term sequelae, other health problems related to BC, general and upper limb exercise, nutrition, breast self-examination, stress management, and effective communication with healthcare practitioners. At the beginning of each week, the researcher sent the handbook content of that week to participants via WhatsApp or email, with a reminder to work through the information. Adherence was encouraged through an exercise diary and through the weekly activities recorded in the handbook. Women were encouraged, but not required, to send a photo of these handbook pages, to the researcher each week. Participants were informed that they may contact the researcher during their participation, with questions or concerns. Every fortnight, a short preview for the themes of the next two weeks was sent to participants. This preview was sent with the weekly reminder to work through intervention content. Participants were requested to indicate receipt of the reminder each week, via their preferred communication channel.

A printed copy of the intervention handbook was sent to participants at the start of their participation. Women who did not have smartphones, received the handbook with the previews as printed copies.

Reminders were then sent via SMS. Participants underwent testing of patient-reported outcome measures at 0 and 12 weeks. An outline of the intervention content is provided in Table 23.

Table 23: Outline of intervention topics and weekly content of the intervention 'Survive and Thrive'.

Week, intervention topic	Summary of content and weekly tasks
Week 1: How to manage common long-term effects of BC treatment.	The management of common LTSEs of BC treatment. Long-term effects of cancer treatment affecting me; my plan to manage them.
Week 2: How to manage common long-term effects of BC treatment (continued).	The management of common LTSEs of BC treatment (continued). Long-term effects of cancer treatment affecting me; my plan to manage them.
Week 3: How to become an excellent self-manager and how to plan an exercise programme.	Steps to self-management. Action planning, problem solving. The benefits of exercise for BC survivors. Pre-exercise screening; exercise precautions for BC survivors. Types of general exercise.
Week 4: How to start your exercise programme.	How to start an exercise routine. How to exercise at the right intensity. How to progress your exercise. An exercise routine example. How to check if your fitness has improved. Exercise action plan; exercise diary.
Week 5: How to manage your affected arm and shoulder.	Effects of medical cancer treatment on your arm and shoulder. How to manage upper limb problems. An upper limb exercise routine example. How to tell if your affected side is improving. Arm and shoulder problems affecting me; my plan to manage them.
Week 6: How to prevent and manage lymphoedema.	How to detect lymphoedema early. How to prevent or improve lymphoedema. How to exercise with lymphoedema. How to self-manage your affected side. Action plan for the shoulder and arm. Signs of lymphoedema affecting me, my plan to manage them.
Week 7: How to manage your body weight.	The effects of being overweight. How to work out if you are overweight. How to self-manage your weight. How to choose the right foods. Food safety. How to eat well if your body weight is normal. Calculating my BMI; shopping list with healthy food items.
Week 8: How to manage stress and pain.	How to manage stress, anxiety, poor sleep, depression, and pain. Problems with stress and pain affecting me; my plan to manage them.
Week 9: How to detect a cancer recurrence early.	Signs and symptoms of BC: local / distant. How to do a breast self-examination. What to do when you find a lump. Signs and symptoms of cancer affecting me; my plan to manage them.
Week 10: How to detect skin cancer and blood clots early; and talking to your healthcare provider.	Signs and symptoms of skin cancer. Signs and symptoms of blood clots. Talking to your healthcare provider. Skin cancer and blood clot checklist. Action plan.
Week 11: How to continue as a successful self-manager.	How to be a successful self-manager. Review of action plans made, and actions taken.
Week 12: How to continue as a successful self-manager, useful contacts, and further reading.	How to continue as a successful self-manager. Re-calculate BMI; review of healthy habits: exercise, nutrition, breast self-examinations, communicating with healthcare providers, action plans. List of contacts, support organisations, and reading list.

5.3.9 Procedure

Ethical approval was obtained from the University of Cape Town Faculty of Health Sciences Human Research Ethics Committee (HREC ref: 227/2022) (Appendix O). The advertisement leaflet and ICF were translated into Afrikaans upon ethical approval, as Chapter 2 participants (who predominantly preferred this language) were invited to participate first. For this study, translation into further South African languages was not necessary. Permission was obtained to distribute leaflets via CANSA and R4R (Appendix V). The research process is described in the following section.

The study advert was e-mailed, sent per WhatsApp, or per MMS to participants, then to respondents of the qualitative study in Chapter 2, who had indicated their interest verbally to participate in future BC research. Thereafter, the leaflet was distributed by CANSA and R4R via online platforms and to their community-based volunteers. Interested women who met the inclusion criteria responded to the advert by contacting the researcher via e-mail, WhatsApp, or SMS.

The researcher confirmed eligibility of participants, using the inclusion and exclusion criteria. An ICF explaining the study in detail was sent per WhatsApp, e-mailed, or mailed. The prospective participant signed the ICF and returned it by WhatsApp, e-mail, or mail. Mailed hard copies of the ICF would have included a stamped, self-addressed envelope to allow the prospective participant to return the ICF. However, this was not required: all participants were able to return their signed ICF either via email or WhatsApp. The ICF included permission that the researcher may contact women telephonically and captured their preferred communication channels. The researcher phoned the participant when convenient to answer any questions from the prospective participant about their participation, and to complete the ACSM preparticipation screening questionnaire (Appendix W). This was to ensure that it was safe to participate in unsupervised exercise. Prospective participants who failed this screening, were excluded from the study, and were offered referral to their healthcare provider.

If deemed safe to participate in unsupervised exercise according to the ACSM preparticipation screening, the participant completed the baseline patient-reported outcome measures (socio-demographic questionnaire, BPI, BFI, EQ-5D-3L, SE-6, IPAQ-SF), during the same call. Questions of the patient-reported outcome measures were read to participants exactly as they appeared on the respective questionnaires, by the researcher. Participants received the weekly handbook content via WhatsApp and / or e-mail, with a reminder to work through the content and that they may contact the researcher if they had any questions or concerns.

A printed copy of the full handbook was sent to participants via courier. Participants confirmed receipt of their handbook, before starting their intervention.

Participants were advised to continue with their usual medical care during their participation. Participants who had indicated interest through the ICF, joined a WhatsApp group with other participants. Every two weeks during the intervention, a one-page preview and reminder to work through weekly curriculum, was sent to participants via their preferred communication channel. Previews are included following on after the intervention handbook (Appendix M). Participants were asked to respond to the weekly messages with intervention content for that week, indicating that they had received the content and were participating in the intervention. Twelve weeks after receiving the handbook, participants completed end-point patient-reported outcome measures (BPI, BFI, EQ-5D-3L, SE-6, IPAQ-SF). For this purpose, each participant was contacted telephonically when convenient for them, by the researcher. Following the intervention and data collection, participants were discharged from the study and encouraged to continue with positive lifestyle changes made.

5.3.10 Data analysis and management

The Transparent Reporting of Evaluations with Nonrandomised Designs (TREND) guidelines, aligned with the CONSORT guidelines, were used to inform the design, analysis, and presentation of data [479] (Appendix X). A data management plan was established to describe how data were collected, stored, analysed, and curated (Appendix Y). Data were analysed using IBM-SPSS statistical package, version 28.0.1.1 (SPSS Inc., Chicago, Illinois, USA). Descriptive statistics were calculated for socio-demographic data using summary statistics [means ± SD] and frequency distributions where appropriate.

Baseline scores were calculated for pain and fatigue prevalence, severity, and interference with function, HRQoL index and EQ-VAS, self-efficacy, physical activity participation, and sitting time. Pre-test post-test outcomes were used to evaluate for preliminary evidence of change following the intervention. The pain severity score from the BPI was the primary outcome variable. Paired t-tests were used to evaluate pre- to post-intervention score changes for parametric interval data. Wilcoxon's signed rank tests were used for non-parametric interval data. The McNemar's test was used to analyse for change in prevalence of pain and fatigue and for change in meeting the exercise guidelines for cancer-related health outcomes (either meeting the guidelines, or not meeting them), as these were paired nominal data [480]. The null hypothesis of the latter test is that the intervention had no effect on the proportion of 'yes' or 'no' responses. The McNemar's test follows a chi-square distribution, testing for consistency between dichotomous variables. Therefore, these results were presented as chi-squared statistics [480].

As this was a feasibility study with a relatively small sample size, only the data of participants who completed the study were used for evaluating pre-test post-test outcomes [406, 481]. Data were presented as mean ± standard deviation, or as median and interquartile range. Statistical significance was accepted as $p < 0.05$. Quantitative outcomes of the three participants who completed the acceptability evaluation (Chapter 4) were analysed and reported with those of this study, as changes made following the qualitative analysis were minor and did not impact the nature of the intervention.

Previous studies have suggested that inverse relationships may exist between variables such as pain and socio-economic status [482] and HRQoL [347]; pain and age [160, 347]; physical activity and fatigue [239]; age and physical activity [483]; months since MCT and fatigue [484]; and socio-economic status and sitting time [485]. Furthermore, studies have suggested that linear relationships may exist between employment status and physical activity [483]; physical activity and HRQoL [483]; and self-efficacy and exercise [385]. Therefore, with the assistance of a biostatistician, regression analyses were conducted to determine if possible relationships between improvements in physical activity, weekly sitting time, self-efficacy, months since MCT, public or private health system use (as an indicator of socio-economic status), education level, and age; and an improvement in pain and fatigue prevalence, pain and fatigue severity scores, pain and fatigue interference scores, EQ-5D-3L EQ-VAS and index scores, and exercise; existed in this study, following participation in the intervention. The pre- and post- measurements were subtracted from each other for continuous variables, so that a positive value indicated a positive change or improvement [486].

Binary variables were each categorised as observing an improvement or no improvement. Simple linear regression models were fitted for continuous variables. For binary variables, logistic regression models were fitted. There was an attempt to fit the models in a multivariate setting to account for multiple testing and possible correlation between responses. However, these models would not converge, the sample size was too small to allow this. Therefore, multivariate analyses were not performed. Retention (percentage of participants recruited who complete the study) was calculated as one of the feasibility criteria of the intervention. Acceptable retention was set at 80% [33].

5.3.11 Ethical considerations

This study conformed to the principles of the Declaration of Helsinki [137]. Ethical considerations were described according to the bioethical principles: autonomy, beneficence, non-maleficence, risk, and justice [136].

5.3.11.1 Autonomy and privacy

Participants were informed that participation was voluntary and that it would not affect their medical care (for example, visits to the breast clinic) in any way. Participants were not in a dependent relationship with the researcher or study supervisors; and the researcher and study supervisors were not employed at breast or primary health clinics. Participants were informed that they could withdraw from the study at any time, without penalty. The informed consent form containing detailed information about the study, was sent to participants. Through this form, participants were informed what information was to be collected from them telephonically. Participants were able to schedule the calls for data collection when convenient for them, at their discretion. No information regarding their household income was collected, to protect participants' privacy [424].

An opportunity to clarify questions was provided prior to obtaining signed, written informed consent from participants. Data were kept confidential and individual privacy was protected, for all aspects of research. Electronic data were password-protected. Electronic data were also protected by up-to-date anti-hacking software. Data were stored for five years. Questionnaires were kept as hard copies in a secure, locked cabinet, marked with only the participant numbers. WhatsApp calls were used instead of regular phone calls where possible, as this application uses end-to-end encryption to protect user information [487]. The master list containing the names of participants was stored on an external hard drive with password protection. A hard copy of the document was kept in a secure, locked cabinet. If a participant's name was to be released to refer them for further assessment or treatment, the participant's consent was sought.

5.3.11.2 Beneficence

Participants were remunerated according to their preference, for data or airtime costs incurred during the study. Three hundred South African Rand was either paid electronically into their bank account following participation; or they received a data top-up of the same value according to their preference, after baseline testing. There were several further benefits from the study: participants completed questionnaires which though not diagnostic, could have indicated a need for intervention. For example, participants reporting a baseline intensity of six out of 10 or more, classified as 'severe' pain; or seven or more out of 10 for fatigue ('severe fatigue') [306, 439] in the BPI or BFI, were offered referral to their healthcare provider. Participants potentially benefited from learning about their condition through evidence-based information which had been reviewed by the three supervisors of this project, local multidisciplinary clinical experts, and BC survivors, before being evaluated in this study.

Information on cancer support organisations and additional reading was included in the intervention handbook. In addition, participants were given the opportunity to connect with other BC survivors, through the WhatsApp group. Participants could keep the intervention handbook for future reference, a further benefit. There were no restrictions on the dissemination of the handbook after the study. The decision was taken to allow all participants in this study to receive the intervention, without a control group not receiving it or only receiving parts of the intervention. For their potential benefit, eligible participants of Chapter 2 were invited to participate in this study, since they had generously donated their experiences, and insights to inform the intervention.

5.3.11.3 Non-maleficence

The researcher held a master's degree in physiotherapy and was certified in good clinical research practice (Appendix Z). All efforts were made to ensure that the content of the intervention was safe to implement - best current evidence was used to inform the intervention, and it was subjected to stringent review before being evaluated in this study. This study had a favourable risk: benefit ratio. Participation involved a very small physical risk of harm. The risk of participation in exercise was minimised by screening participants, before admitting them into the study. Prospective participants, found unfit to participate in exercise according to the ACSM preparticipation screening, were offered referral to their healthcare provider. Clear guidelines on exercise safety were included in the handbook. Participants were encouraged to contact the researcher if they had questions or concerns and they were contacted weekly by the researcher, during the intervention. In the interest of transparency, it is noted that the researcher relocated from South Africa to another country during the protocol development phase of this study. However, this did not affect the implementation of this study. The researcher was available at all hours to the participants, through their preferred communication channels. The availability of the researcher for support, questions, or concerns, was communicated to participants verbally and in writing through the ICF, at the start of the intervention. Furthermore, participants were reminded that they may contact the researcher at any time, through the reminders accompanying their weekly electronic handbook content.

In this study, adverse events were approached on an individual basis, in consultation with the supervisory team consisting of three experienced researchers who are also qualified physiotherapists. The principal investigator of this study was a specialised BC researcher. Adverse events reported during the intervention were recorded with information on referral for assessment or treatment (Appendix T). Once a participant contacted the researcher or study supervisor, the principal investigator acted within 24 hours to assist the participant and to refer her appropriately.

As previous SMI studies in post-treatment BC survivors did not report serious adverse events, a safety committee was not deemed necessary and stopping rules were not applied.

5.3.11.4 Justice

The methods for data analysis used standardised approaches and involved rigorous assessment of the findings. The proposed social value of this study was to evaluate an evidence-based intervention, and to support the self-management of women during BC survivorship. Women are often primary breadwinners, while being responsible for their families and carrying the additional burden of their cancer recovery [60]. This research may form a basis for future studies in SA. It is hoped that the findings may help improve the level of support offered by healthcare facilities. Findings were disseminated to participants via e-mail or mail, to BC survivors through cancer support organisations, to the Western Cape Department of Health, SA through a research report, and through the publication of articles of interest to those working in oncology and rehabilitation.

5.4 Results

5.4.1 Description of the sample

The study sample arising from the recruitment process is summarised in Figure 13. Of the Chapter 2 participants, five were not contacted as their age at the time of recruitment was more than 70 years. One Chapter 2 participant had passed away due to cancer recurrence, and one had suffered a stroke. Ten participants of Chapter 2 were not contactable. Six eligible Chapter 2 participants were contacted, and all six consented to participate in this study. The first three of these six participants also completed the acceptability evaluation (Chapter 4), following their intervention. Eight respondents to the Chapter 2 recruitment advert were contacted. Of these, one woman had received MCT more than 10 years before, and seven agreed to participate.

The study advert yielded 38 responses. Of these, 14 women were ineligible based on the ACSM preparticipation screening or exclusion criteria. Four respondents to the study advert refused participation. Twenty respondents to the study advert provided informed consent and participated in the study. In summary, six participants from the qualitative study in Chapter 2, seven respondents to that study, and 20 participants recruited through the study advert, formed the total sample of 33 participants. Of this sample, 31 participants completed the intervention. Two participants withdrew during the study due to unrelated medical reasons: One participant had a motor vehicle accident during the intervention and required surgery to repair a leaking breast prosthesis. Another participant had a scheduled hysterectomy during participation.

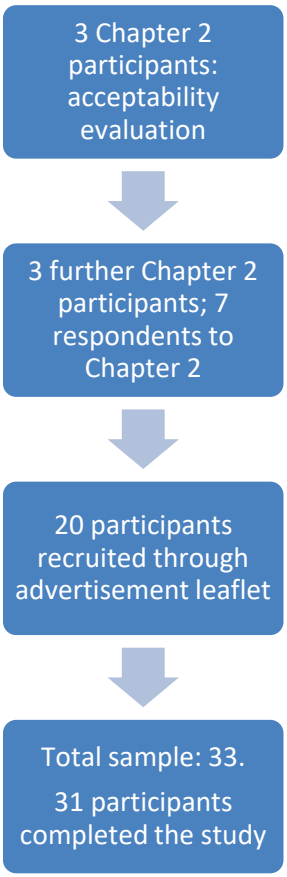


Figure 13: Flow diagram summarising the study sample.

5.4.2 Socio-demographic characteristics

Table 24 summarises the socio-demographic information of participants in this study. The mean age of participants (n = 33) was 54.4 years (SD = 9.0). Of this sample, 57.6% resided in the Western Cape and 54.6% used public health facilities. Twenty participants were employed (60.6%). Nineteen participants (57.6%) had obtained no higher qualification, following high school.

Table 24: Socio-demographic information of study participants (N = 33).

Variable	Category	n(%)
Health system	**Public**	18(54.6)
	Private	15(45.5)
Province	**Western Cape**	19(57.6)
	Gauteng	10(30.3)
	Eastern Cape	1(3.0)
	Northern Cape	1(3.0)
	North West	1(3.0)
	KwaZulu Natal	1(3.0)
Employment	**Employed**	20(60.6)
	Unemployed	5(15.2)
	Retired	8(24.2)
Highest level of education	**No school**	0(0.0)
	Primary school	0(0.0)
	High school	19(57.6)
	Higher qualification	14(42.4)

5.4.3 Medical cancer treatment information

Table 25 summarises the medical cancer treatment information reported by participants. Fifteen participants (45.5%) reported stage III BC. Twenty three (69.7%) participants reported having undergone chemotherapy, and 24 participants (72.7%) had received radiotherapy. Twenty one participants (63.6%) had had a mastectomy, while 22 (66.7%) participants reported surgery to the left breast.

Table 25: Medical cancer treatment information of study participants (N = 33).

Variable	Category	n(%)
Breast cancer stage	**I**	6(18.2)
	II	12(36.4)
	III	15(45.5)
Chemotherapy	**Yes**	23(69.7)
	No	10(30.3)
Radiotherapy	**Yes**	24(72.7)
	No	9(27.3)
Surgery type	**Mastectomy**	21(63.6)
	Lumpectomy	12(36.4)
Surgery side	**Left**	22(66.7)
	Right	7(21.2)
	Bilateral	4(12.1)
Endocrine therapy	**Yes**	17(51.5)
	No	16(48.5)
Months since cancer treatment	**Mean (SD)**	46.8(28.9)

5.4.4 Chronic medication

Table 26 summarises the reported chronic medication of participants in this study. Thirteen participants (39.4%) reported taking antihypertensives, while five participants (15.2%) reported taking medication for diabetes and hypothyroidism, respectively.

Table 26: Reported chronic medication of study participants (N = 33).

Medication	n(%)
Antihypertensives	13(39.4)
Metformin / Insulin	5(15.2)
Thyroid medication (thyroxin)	5(15.2)
Antidepressants	3(9.1)
Antiepileptics	2(6.1)
Anti-gout agents	1(3.0)
Aspirin	2(6.1)

5.4.5 Feasibility and safety of the intervention

5.4.5.1 Recruitment

Ten participants of the qualitative study (Chapter 2) were no longer contactable. All six participants and the seven of the eight respondents to the qualitative study who were eligible and contactable, were also willing to participate in this study. The response to the advert distributed by the cancer support organisations was good, and this seemed an efficient recruitment strategy. Of the 38 women who responded to the advert through support organisations, four declined participate. Of these, two women stated that they did not have time, one felt that she did not need an intervention, and one was advised by her family not to become a 'guinea pig' for research. Although the inclusion criteria were stipulated clearly on the advert, several respondents who wished to participate had had either metastatic BC or were more than 10 years after completing their MCT. Therefore, most respondents to the recruitment advert who fitted the inclusion criteria, were willing to participate. It was not possible to estimate the recruitment rate in terms of the eligible participants enrolled at baseline, compared to the invited population [406], as the number of women exposed to the study advertisement was unknown. However, following the acceptability evaluation of the intervention (Chapter 4), 30 participants for this study were recruited within seven months (November 2022 until May 2023). Therefore, four to five participants per calendar month were recruited.

5.4.5.2 Data collection

The process of collecting patient-reported outcome data serves to demonstrate the feasibility of data collection methods [406]. Data collection for this study was planned to be conducted telephonically. As all the participants in this study had access to this application, WhatsApp calls were used to complete the telephonic pre- and post-test patient-reported outcome measures. This ensured that there was no charge for telephone calls, apart from standard data charges, for which participants were reimbursed. In addition, WhatsApp calls use end-to-end encryption, ensuring that calls remained private and could not be accessed by a third party [487]. Participants were able to schedule their baseline and end point calls at their convenience. Patient-reported outcome data were collected within one week after completing the 12-week intervention.

5.4.5.3 Retention

Of the 33 women enrolled, 31 (94.0%) completed the study. One participant had a vehicle accident during the intervention, which caused a leak in her breast prosthesis and required surgery. The second participant underwent an elective hysterectomy during her intervention. The recovery period of this procedure prevented exercise participation, for several weeks.

Both participants kept their intervention handbooks and planned to complete their interventions upon medical clearance by their respective doctors.

5.4.5.4 Adherence

Of the 31 participants who completed the intervention, responses were recorded for 340 of the 372 messages sent, a response rate of 91.4%. However, note that this is merely an indication and cannot be considered a robust measure of adherence to the intervention.

5.4.5.5 Outcomes

The patient-reported outcome measures used in this study have been validated for use in BC survivors, and in the South African context. This information was provided under the heading Instrumentation. In this study, the combination of outcomes did not seem too long to deliver.

5.4.5.6 Intervention delivery

The initial process of intervention delivery had been piloted through the acceptability evaluation (Chapter 4). No further challenges in terms of intervention delivery were identified, however the following is noted regarding intervention delivery in this study. A local courier company was used to deliver hard copies of the intervention handbook to participants. This company delivered to the nearest Pep stores anywhere in the country, for a set fee of 60 South African Rand (about 3.33 US Dollar[7]). This is a chain of department stores with a very dense network of branches, including rural areas, throughout SA [488]. All participants in this study had a Pep store branch close to their home or workplace. Participants were therefore able to fetch the handbooks at their convenience. In addition to the hard copies, participants also received electronic content every week (week 1; week 2; week 3 and so on, of the handbook). The electronic content for each week was sent separately, with a reminder to work through the relevant weekly material. Several participants did not have access to email. However, as all participants in this intervention could access WhatsApp, this was an effective method to deliver electronic weekly handbook content.

[7] Calculated according to the following United States Dollar (USD) to South African Rand (R) exchange rate: 1 USD = R 18.02. https://www.xe.com/currencyconverter/convert/?From=ZAR&To=USD. Retrieved 20 June 2024.

Twenty two participants (66.7%) opted to make use of the WhatsApp group with other participants. The researcher acted as the group administrator. Through this group, women exchanged information on topics such as breast reconstruction, cancer support groups, public cancer awareness activities such as World Cancer Day, public exercise opportunities including Parkrun or fun runs, exercise videos, meditation and relaxation applications, and milestones reached in terms of beating BC. Many women stayed in the group after their intervention ended, and the WhatsApp group was still active at the time of writing. Two participants (9.1%) left the group during their 12-week intervention.

5.4.5.7 Intervention costs

By dividing the cost of the intervention with the number of participants, costs per participant were calculated. For this intervention, the total cost per participant amounted to 560 South African Rand (R), about 31 United States (US) Dollar[8]. Renumerating participants for airtime or data use was the main expense (R 300). This enabled participants to complete their pre- and post-test outcomes via WhatsApp calls, to contact the facilitator (researcher) for questions, and to contact fellow survivors through the optional WhatsApp group. Further costs (included in the total amount) included printing of the intervention handbooks (R 200), and a courier fee to deliver the handbooks (R 60).

5.4.5.8 Safety of the intervention

No adverse events were reported by participants in this study.

5.4.5.9 Summary of the feasibility results

Table 27 provides a summary of the feasibility results of this study. Note that acceptability and intervention content were addressed in Chapter 4.

Table 27: Summary of the feasibility results of this study.

Feasibility domain	Result
Recruitment	Feasible
Data collection	Feasible
Retention	Feasible
Adherence	A reliable measure of adherence to the intervention could not be obtained in this study
Outcomes	Feasible
Intervention delivery	Feasible
Intervention costs	Seem feasible considering QALY gain (refer to the discussion section). Future investigation of cost-utility in a future study is warranted

[8] Calculated according to the following United States Dollar (USD) to South African Rand (R) exchange rate: 1 USD = R 18.05. https://www.xe.com/currencyconverter/convert/?From=ZAR&To=USD. Retrieved 18 June 2024.

5.4.6 Comparison of outcomes post-intervention to pre-intervention

5.4.6.1 Brief pain inventory: pain prevalence

There was a significant decrease in pain prevalence after the intervention, χ 2 (1) = 13.07, p <0.001. Therefore, the number of participants who responded 'yes' to the question in the BPI: 'Throughout our lives, most of us have had pain from time to time (such as minor headaches, sprains, and toothaches). Have you had pain other than these everyday kinds of pain today?', decreased significantly from 22 (71.0%) pre-intervention to 7 (22.6%) post-intervention. This amounts to a decrease of 48.4% in pain prevalence, following the intervention (Figure 14).

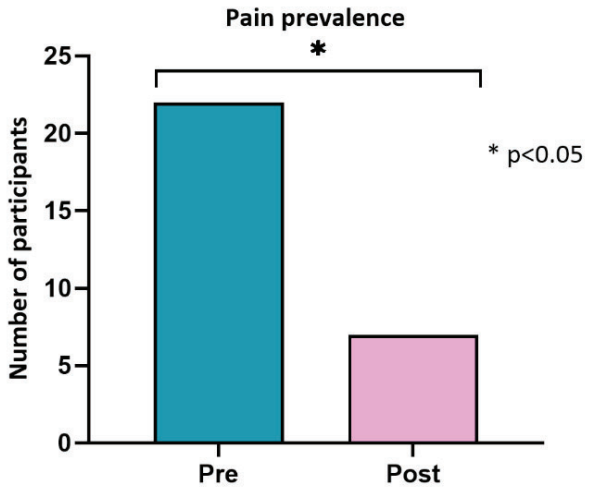


Figure 14: Brief Pain Inventory: Comparison of the number of participants who reported pain (indicated by 'Yes'), before, and after the intervention (n = 31).

5.4.6.2 Brief pain inventory: pain severity and interference scores

There were significant improvements in the pain severity scores after the intervention (median = 0.00, IQR = 0.00 - 0.00), compared to before the intervention (median = 3.30, IQR = 0.00 - 4.80), z = -3.80, p < 0.001, with a large effect size, r = 0.68. (Figure 15).

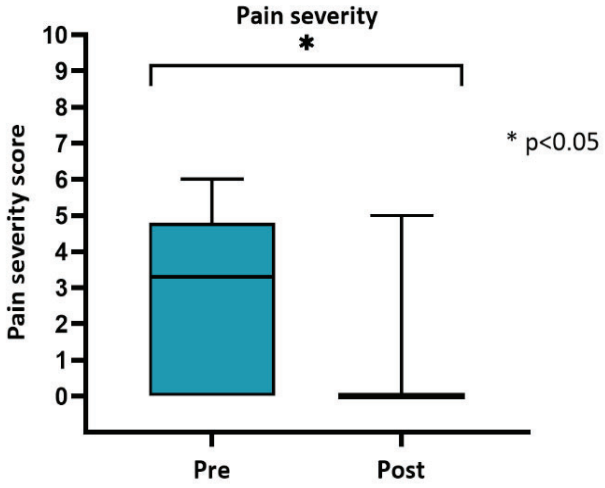


Figure 15: Brief Pain Inventory: Comparison of pain severity scores before, and after the intervention (n = 31). Median; Box: 25%-75%; Whisker: range. Higher scores indicate increased pain severity.

There were significant improvements in the median pain interference scores after the intervention (median = 0.00, IQR = 0.00 – 0.00) compared to before the intervention (median = 3.00, IQR = 0.00 – 5.30), z = -3.91, p <0.001, with a large effect size, r = 0.70. (Figure 16).

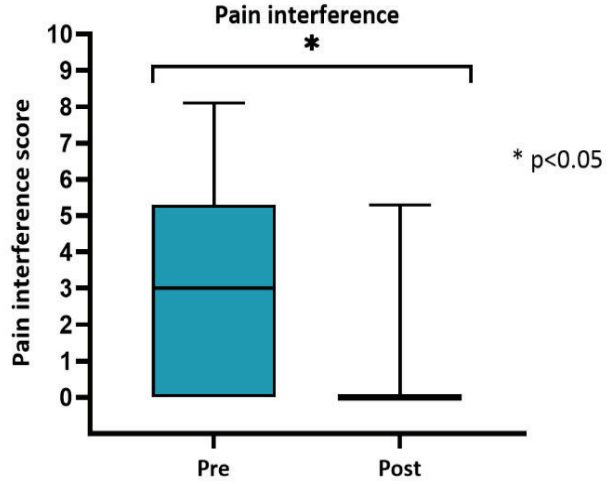


Figure 16: Brief Pain Inventory: Comparison of pain interference scores before, and after the intervention (n = 31). Median; Box: 25%-75%; Whisker: range. Higher scores indicate increased pain interference with function.

5.4.6.3 Brief fatigue inventory: fatigue prevalence

There was a significant decrease in fatigue prevalence after the intervention, $\chi 2\ (1) = 13.07$, $p < 0.001$. Therefore, the number of participants who responded, 'yes' to the question: 'Throughout our lives, most of us have times when we feel very tired or fatigued. Have you felt unusually tired or fatigued in the last week?' decreased significantly from 24 (77.4%) to 9 (29.0%). This amounts to a decrease in fatigue prevalence of 48.4% (Figure 17).

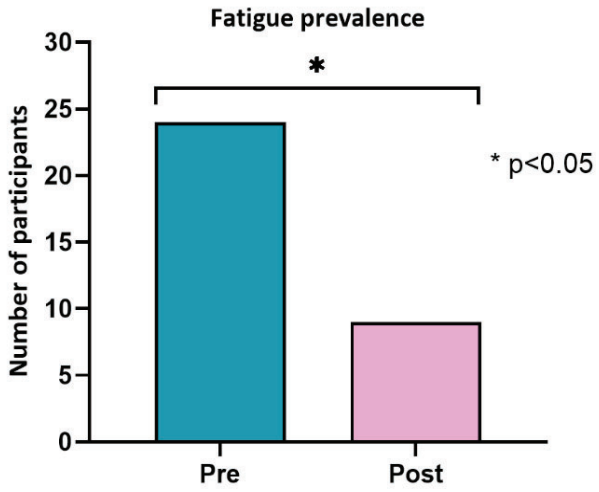


Figure 17: Brief Fatigue Inventory: Comparison of the number of participants who reported fatigue (indicated by 'Yes'), before, and after the intervention (n = 31).

5.4.6.4 Brief fatigue inventory: fatigue severity and interference scores

There were significant improvements in the fatigue severity scores after the intervention (median = 0.00, IQR = 0.00 - 3.30), compared to before the intervention (median = 6.00, IQR = 2.00 - 7.30), z = -3.91, p < 0.001, with a large effect size, r = 0.70 (Figure 18).

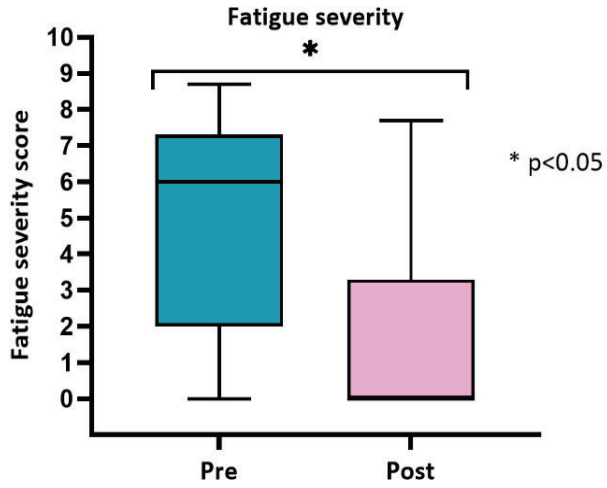


Figure 18: Brief Fatigue Inventory: Comparison of fatigue severity scores before, and after the intervention (n = 31). Median; Box: 25%-75%; Whisker: range. Higher scores indicate increased fatigue severity.

There were significant improvements in the median fatigue interference scores after the intervention (median = 0.00, IQR = 0.00 – 0.50), compared to before the intervention (median = 4.30, IQR = 0.00 – 5.80), z = -4.06, p < 0.001, with a large effect size, r = 0.73 (Figure 19).

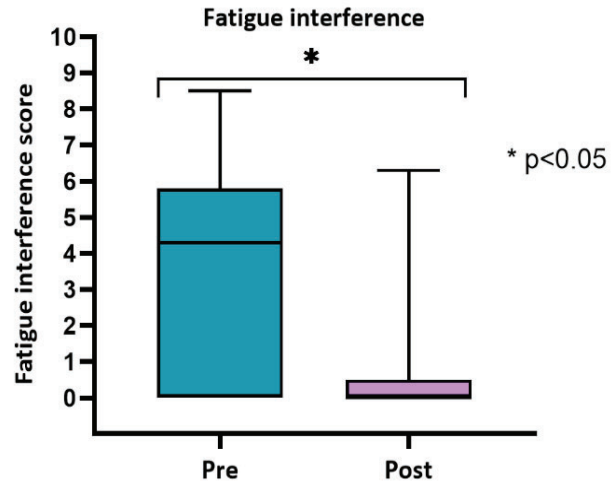


Figure 19: Brief Fatigue Inventory: Comparison of fatigue interference scores before, and after the intervention (n = 31). Median; Box: 25%-75%; Whisker: range. Higher scores indicate increased fatigue interference with function.

5.4.6.5 EQ-5D-3L: Health index and general health scores

There were significant improvements in the median EQ-5D-3L health index scores after the intervention (median = 1.000, IQR = 0.725 – 1.000), compared to before the intervention (median = 0.725, IQR = 0.620 – 0.796), z = -3.82, p < 0.001, with a large effect size, r = 0.69 (Figure 20).

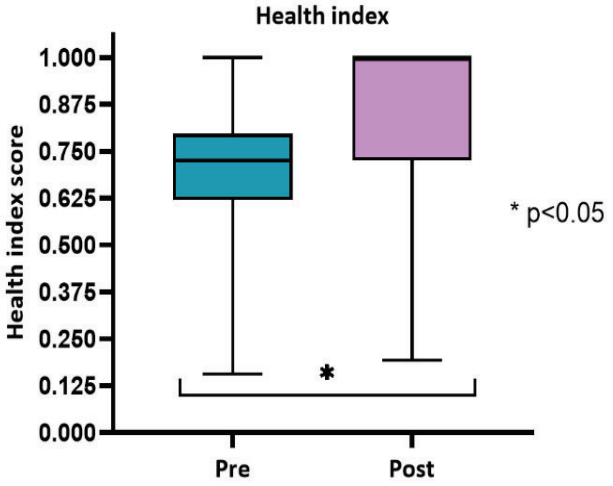


Figure 20: EQ-5D-3L: Comparison of health index scores before, and after the intervention (n = 31). Median; Box: 25%-75%; Whisker: range. Higher scores indicate increased HRQoL.

There were significant improvements in the median EQ-5D-3L EQ-VAS scores after the intervention (median = 90.00, IQR = 80.00 – 96.00), compared to before the intervention (median = 75.00, IQR = 60.00 – 80.00), z = -3.35, p < 0.001, with a large effect size, r = 0.60 (Figure 21).

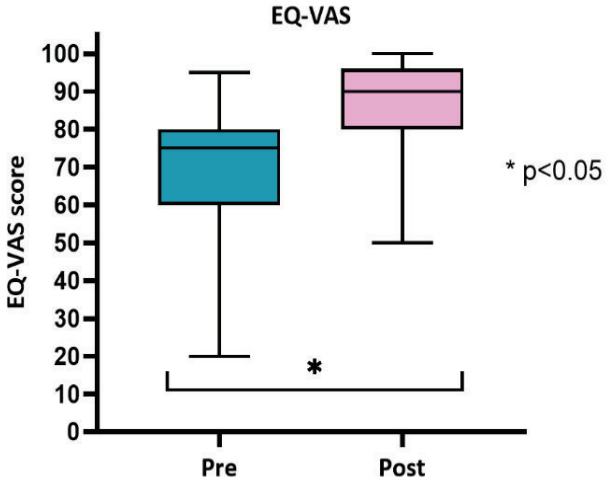


Figure 21: EQ-5D-3L: Comparison of EQ-VAS scores before, and after the intervention (n = 31). Median; Box: 25%-75%; Whisker: range. Higher scores indicate increased HRQoL.

5.4.6.6 Self-efficacy for Managing Chronic Disease 6-item Scale (SE-6): self-efficacy scores

There were significant improvements in the median SE-6 scores after the intervention (median = 9.50, IQR = 8.00 – 10.00), compared to before the intervention (median = 7.80, IQR = 6.20 – 8.80), z = -4.06, p < 0.001, with a large effect size, r = 0.73 (Figure 22).

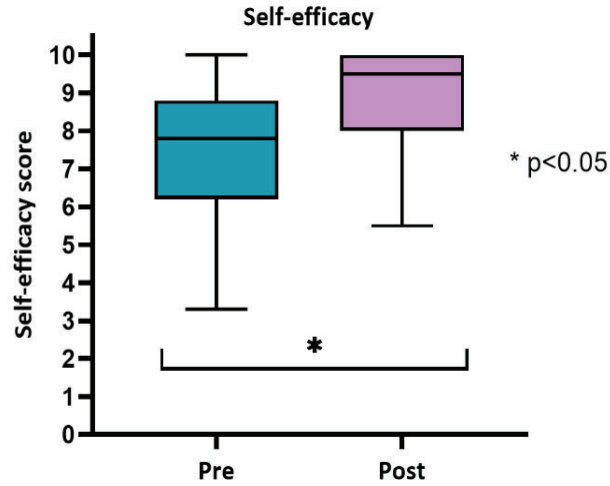


Figure 22: SE-6: Comparison of self-efficacy scores before, and after the intervention (n = 31). Median; Box: 25%-75%; Whisker: range. Higher scores indicate increased self-efficacy.

5.4.6.7 IPAQ-SF: Physical activity participation

There were significant improvements in the median MET-minutes per week of physical activity participation after the intervention (median = 767.00, IQR = 297.00 - 1426.00), compared to before the intervention (median = 396.00, IQR = 0.00 - 813.00), z = -2.99, p = 0.003, with a large effect size, r = 0.54 (Figure 23).

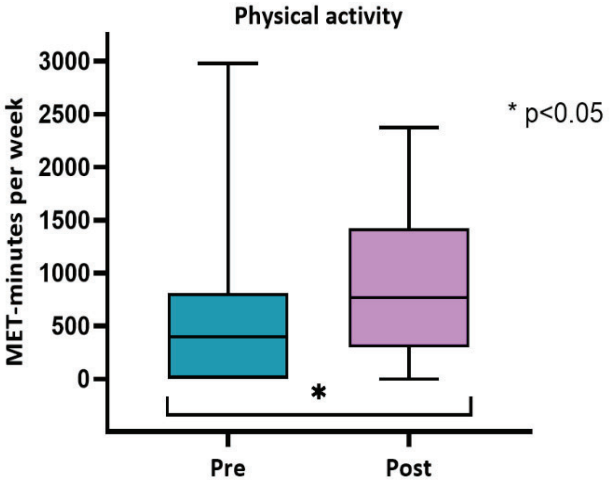


Figure 23: IPAQ-SF: Comparison of physical activity participation (MET minutes per week) before, and after the intervention (n = 31). Median; Box: 25%-75%; Whisker: range. Higher scores indicate increased weekly physical activity participation.

5.4.6.8 IPAQ-SF: Sitting time on weekdays

There were significant reductions in the median hours per week of sitting time after the intervention (median = 20.00, IQR = 15.00 - 30.00), compared to before the intervention (median = 30.00, IQR = 15.00 - 40.00), z = -2.67, p = 0.008, with a moderate effect size, r = 0.48 (Figure 24).

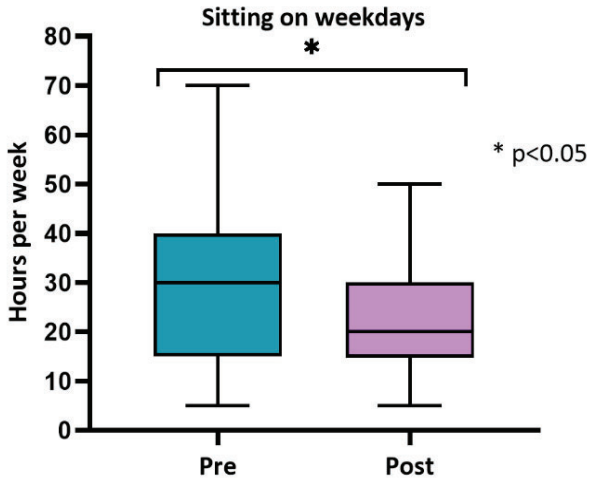


Figure 24: IPAQ-SF: Comparison of time spent sitting on weekdays before, and after the intervention (n = 31). Median; Box: 25%-75%; Whisker: range. Higher scores indicate increased hours spent sitting on weekdays.

5.4.6.9 Meeting exercise guidelines for the management of cancer-related health outcomes

There was a non-significant increase in participants who met the exercise guidelines for the management of cancer-related health outcomes (90 minutes of moderate exercise per week or more), post-intervention (χ 2 (1) = 3.27, p = 0.065. Therefore, the number of participants who met these guidelines, increased from 17 (54.8%), to 24 (77.4%), post-intervention. This amounts to an increase of 22.6% (Figure 25).

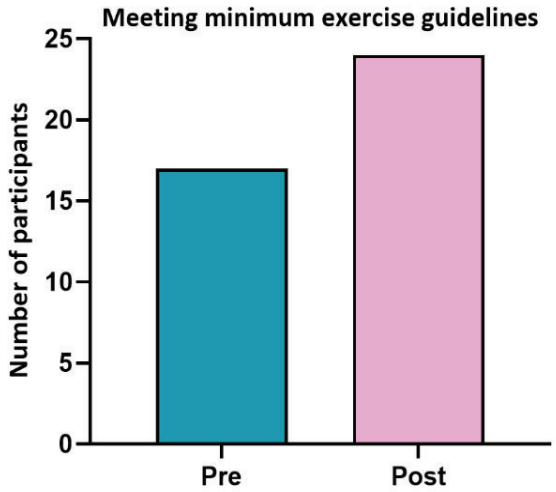


Figure 25: IPAQ-SF: Comparison of the number of participants who met the minimum exercise guidelines for the management of cancer-related health outcomes (indicated by 'Yes'), before, and after the intervention (n = 31).

5.4.7 Regression analyses

Table 28 summarises the regression analyses results indicating possibly significant relationships between variables; and relationships approaching significance, in this study. Results of regression analyses revealed that, in this study, significant relationships may exist between improvements in self-efficacy scores, and improvements in pain severity scores, fatigue severity scores, and EQ-5D-3L index scores. Furthermore, the odds of improvement in pain severity scores were higher in participants who had only completed high school, compared to those who had received a higher (tertiary) education.

Relationships which approached significance were those between improvement in self-efficacy and improvement in pain prevalence. This can be interpreted as a 67% increase in odds of an improvement in pain prevalence, for every unit of improvement in self-efficacy scores. The relationship between improvement in self-efficacy and improvement in fatigue interference, approached significance. Finally, the relationship between an increase in exercise participation and an improvement in EQ-5D-3L EQ-VAS scores, approached significance. Note that the p-values of the regression results were not adjusted for multiple testing, and that adding this may have led to a reduction in the number of significant findings.

Table 28: Summary of regression analyses which indicated possibly significant relationships between variables, and relationships which approached significance.

Per unit of improvement of self-efficacy:	**Estimated effect size**	**P-value**
Pain severity score	0.609	0.025*
Fatigue severity score	0.992	0.013*
EQ-5D-3L index score	0.085	0.003*
Pain prevalence	0.667	0.054
Fatigue interference score	0.648	0.066
Per unit of improvement of exercise participation : EQ-5D-3L EQ-VAS	0.012	0.067
High school only versus higher education. Odds of improvement of: Pain severity score	2.61	0.044*

Note: *indicates $p < 0.05$

5.4.8 Summary of results

This study evaluated pragmatic aspects of feasibility, safety, and outcomes of delivering 'Survive and Thrive', a SMI to support BC survivors after MCT. Of the 33 BC survivors recruited, 31 women completed the study. Delivering and evaluating this intervention were feasible and seemed cost-effective. The intervention was safe to implement in this study. Baseline scores showed that symptoms were a burden for participants. Participation in this study was associated with significant improvements in pain prevalence ($p < 0.001$), pain severity ($p < 0.001$), pain interference ($p < 0.001$), fatigue prevalence ($p < 0.001$), fatigue severity ($p < 0.001$), fatigue interference ($p < 0.001$), HRQoL index ($p < 0.001$), EQ-VAS ($p < 0.001$), self-efficacy ($p < 0.001$), physical activity participation ($p = 0.003$), and sitting time ($p = 0.008$). Minimally important clinical difference represents the amount of change necessary in a variable, to provide a noticeable change in outcome [489]. Improvements observed for pain severity and interference; and for fatigue severity and interference, were greater than the minimum clinically important differences for the BPI [490, 491] and BFI [492], respectively.

Post-intervention, more participants reported meeting the minimum exercise guidelines for BC survivors for the management of cancer-related health outcomes, compared to baseline. This improvement approached significance ($p = 0.065$). Linear regression analyses revealed possibly significant relationships between improvement in self-efficacy and improvements in pain and fatigue severity and HRQoL index scores, following the intervention. Logistic regression analyses yielded a possibly significant relationship between lower education levels and an improvement in pain severity, following the intervention.

5.5 Discussion

The results of this study, despite its limitations, support the hypothesis that a pragmatic, remotely delivered, supported SMI may be feasible, safe to implement, and potentially effective to improve various health outcomes in South African BC survivors. Within the context of the available evidence, the socio-demographic and medical treatment information of participants will be discussed first, followed by pragmatic aspects of feasibility and safety. Thereafter, the pre-test post-test comparisons of outcomes will be discussed. The section will conclude with the strengths and limitations of the study, and recommendations for future research.

5.5.1 Socio-demographic characteristics of participants

The mean age of participants in this study (54.4 years) reflects the mean age of women at BC diagnosis in SA, according to a recent population-based registry study [47]. It is therefore reasonable to suggest that this sample was representative of the South African BC survivor population, in terms of age: BC predominantly affects post-menopausal women [24, 324].

The participants in this study were well into their survivorship journey: a mean of three years and 10 months. This is partly because qualitative study participants and respondents were invited to participate in this study, which was conducted three years later. Long-term adverse effects of treatment may reach a peak during the first year following MCT [24, 493]. However, LTSE may persist for 10 years or more, continuing to negatively affect BC survivors [56, 57, 324].

Participants in this study predominantly utilised public health facilities (54.5%). However, according to a recent General Household Survey in SA, the proportion of South Africans who make use of public health facilities is approximately 84% [91]. Therefore, this sample does not accurately reflect the overall population of BC survivors in terms of health system use. Most participants in this study had obtained no tertiary education following high school, however all the women had completed high school. In the general population, the high school completion rate is reported to be between 68% and 72% [91]. The education levels of this sample were thus slightly higher, compared to those of the general South African population. Recent South African studies have reported significant negative relationships between education levels and vulnerability to poverty [494, 495].

The predominant use of public health facilities and low tertiary education levels in this sample, suggest that the women in this study were mostly of a low socio-economic status. In SA, people who use the public health system face greater challenges in accessing quality healthcare, compared to those who can afford private facilities [496, 497]. A South African study found that lower levels of education were associated with higher stages of BC, and therefore with poorer health outcomes [102]. Given the established links between low income and disability, the women in this study may be vulnerable to disability, which can further exacerbate their experience of poverty [498].

Most BC research concerning health outcomes in post-treatment survivors to date, studied women from high-income countries with adequate access to healthcare and rehabilitation facilities [49, 50]. In this sample, 60.6% of participants were breadwinners. It is encouraging that this study was able to recruit and retain women who were working to earn an income. Previous South African studies of rehabilitation interventions for other chronic diseases have reported difficulties to recruit breadwinners, as these participants were frequently unable to attend clinical visits required by those interventions [81, 499]. This suggests that a remotely delivered intervention such as ‘Survive and Thrive’ might be appropriate for women who balance earning an income with taking care of their families.

5.5.2 Cancer treatment details and medication

Regarding medical cancer treatment, this sample consisted of mostly stage III survivors, most had undergone mastectomies (rather than breast conserving surgery) and most had received the full combination of surgery, chemotherapy, and radiation to treat their cancer. These findings agree with previous South African studies in BC, which have reported that patients in this country are typically diagnosed later, requiring more aggressive treatment regimens [75, 102, 156, 500]. In BC, long-term health challenges are proportional to the type and extent of treatment received [24]. Therefore, women in this study may be more exposed to LTSEs compared to women in high-income countries, where early detection, breast conserving surgery and advanced treatment options have become standard of care [142, 501].

More than half of participants were taking endocrine therapy, which is usually prescribed for five to 10 years [6]. These hormone blocking agents typically add to the burden of LTSEs experienced [7, 24]. In addition, many women were taking medication for chronic diseases of lifestyle, such as hypertension, hyperlipidaemia, and diabetes mellitus. Indeed, the co-morbid suffering of South African BC survivors has been described in previous studies [60, 62]. The combination of the natural ageing process, chronic diseases of lifestyle, and long-term health challenges related to their BC can result in great webs of suffering for survivors [60].

5.5.3 Feasibility and safety of the intervention

5.5.3.1 Recruitment

There is a lack of local BC intervention research to draw comparisons in terms of recruitment, between this and previous studies. However, a South African intervention study by Barnes and colleagues [359] including women with other chronic diseases such as hypertension and diabetes mellitus type II, was not able to recruit enough participants to reach the required sample size. A plausible reason may be the type of intervention: women in the latter study had to commit to attending weekly group sessions at a health facility, while participants of the present study were able to complete the study from home. Another reason for the relative ease of recruitment observed in this study compared to intervention studies in the non-cancer population, could be the teachable moment associated with a cancer diagnosis. This is a pivotal moment in the life of a cancer survivor, after which individuals have shown to be more receptive to interventions advocating behaviour change to improve their health [502, 503]. Chronic diseases such as hypertension, diabetes mellitus type II and obesity typically develop gradually over many years, without such a distinct ‘wake-up call’ [504].

Using cancer support organisations was efficient to recruit post-treatment BC survivors for this study, despite this method yielding several participants who accessed private healthcare.

However, this sample still seemed comparable to the qualitative study sample (which consisted of participants accessing public health facilities only), in terms of age, cancer stage and treatment, and chronic medication use. Like their counterparts using public healthcare, women who access private health facilities in SA do not receive structured education or rehabilitation interventions, following the completion of their MCT. Regression analyses in this study did not reveal that either public or private participants were more likely to benefit from a positive change in health outcomes following this intervention. Therefore, recruiting participants from the combination of public health facilities and cancer support organisations is feasible and acceptable for future intervention studies, provided that a representative sample of both public and private health facility users is sought [505].

Recruiting through cancer support organisations yielded several responders who had metastatic BC, or who were still receiving MCT – despite the inclusion criteria being stated on the recruitment advert. This may indicate that there is a demand for SMIs for this group of BC survivors in SA. Indeed, successful SMIs have been developed for patients with metastatic BC [506, 507] and for early stage BC survivors during MCT [254, 257, 508], elsewhere in the world.

5.5.3.2 Data collection

The feasibility question "Can participants comply with data collection protocols?" [481], can be answered with 'yes', in this study. Data collection was pragmatic and convenient using WhatsApp calls, an application to which all participants in this study had access. WhatsApp is a free messaging application for mobile devices with over two billion users worldwide [487]. It enables voice calls and the sharing of messages, images, and videos. WhatsApp calls operate differently from traditional telephone calls. They use a voice over internet protocol to transmit voice data packets, which is similar to email or web pages. These calls therefore do not incur telephone call charges [487]. Participants in this study were able to complete their baseline- and end-point questionnaires without having to arrange and pay for transport to and from a health facility. This may have influenced the high retention rate of this study. An ethical consideration during this study was to protect the participants' privacy during data collection. Participants were informed of the nature of data that were to be collected from them, and they could schedule their data collection sessions for when they were able to converse privately. Several previous BC intervention studies have successfully used telephonic data collection [509-511], and this study serves to confirm its feasibility in the South African context.

5.5.3.3 Retention

The high retention rate observed in this study suggests that the intervention was well received by participants and indicates that the evaluation design was feasible. It could be argued that the retention rate may be associated with the R 300 [9] renumeration received for participating. The amount was intended to cover the costs of data and airtime use for 12 weeks, to allow participants to communicate with the facilitator (researcher), and with each other. This may have been perceived as a reward by some participants. However, those participants who chose to receive data or airtime top-ups before their participation (as opposed to the same amount in cash at the end of the study), were retained despite having received their reimbursement before participating.

5.5.3.4 Adherence

It has been suggested that remotely delivered interventions may yield improved adherence to intervention activities compared to on-site interventions, as they may be more accessible to participants [95, 512]. On the other hand, it is difficult to pragmatically measure the adherence of participants to unsupervised interventions, without the use of expensive technology [513]. Previous SMIs using few or no clinical visits have either not reported intervention adherence [285, 289, 290, 340], have used a single-item measure similar to this study [284], have used response rates to telephone calls [103, 287, 291], web-based technology, or wearable devices as a measure of intervention engagement [286, 292]. However, wearable devices have shown to be unfeasible in a previous South African intervention study in women with chronic diseases, as they were either lost, broken or re-set [359]. The high response rate to reminder messages sent to participants in this study cannot be viewed as a robust measure of adherence to inform the fidelity of the intervention [406]. However, the insights gained from this study can be used to advise determinants of adherence in future studies.

[9] Three hundred South African Rand is equal to approximately 16.75 United States Dollar. Calculated according to the following United States Dollar (USD) to South African Rand (R) exchange rate: 1 USD = R 17.91. https://www.xe.com/currencyconverter/convert/?From=ZAR&To=USD. Retrieved 21 June 2024.

5.5.3.5 Outcomes

The intervention was associated with significant improvements in all the patient-reported outcomes in this sample. This confirms their feasibility and their previously reported validity for use in SA, and in BC survivors. However, one participant reported fatigue severity scores classified as 'severe', post-intervention [306]. This participant was offered referral to her healthcare provider. She declined this offer, ascribing the increased fatigue to her recent night duty shifts as a nurse. Another participant reported low EQ-5D-3L health index scores, post-intervention. This participant reported that she had moved heavy rocks in her garden two days prior to her end-point assessment of patient-reported outcomes. This resulted in back pain, which she described as not severe but nagging, and influencing her post-intervention HRQoL scores. The participant communicated to the researcher that she was to seek treatment if the pain and discomfort persisted.

The above 'non-responders' to the intervention highlight that several factors unrelated to participation in an intervention, may influence the experience of symptoms and perceived HRQoL. In addition, cancer-related fatigue may be exacerbated by medical conditions such as anaemia, thyroid- and cardiac dysfunction [6]. Similarly, pain in BC survivors may be attributed to rotator cuff injury, adhesive capsulitis of the shoulder, or axillary web syndrome [6]. These conditions require individual medical assessment and appropriate referral. Therefore, patients with 'severe' baseline or end-point scores in the BPI and BFI, or 'low' HRQoL scores, were offered referral to their healthcare providers in this study. Screening for high scores and 'non-responders' is also recommended when the intervention is implemented clinically in the future (refer to Chapter 6, Clinical recommendations), to ensure that medical conditions and injuries are not overlooked, and that survivors receive appropriate diagnosis and treatment.

5.5.3.6 Intervention delivery

Women were able to complete the intervention content in their own time. This may have reduced attrition due to work and family commitments or due to transport problems, in this study. The acceptability evaluation in Chapter 4 provided an initial indication of the feasibility of delivering 'Survive and Thrive'. The response rates to reminders which were accompanied by electronic content for each week, indicate that participants received the content and were engaging with (but not necessarily adhering to) the intervention. The engagement of participants with the WhatsApp group is a further indication of the feasibility of the intervention in this study. The finding that not all women wanted to join this group, substantiates current research recommending that SMIs should be flexible and adaptable to suit individual preferences [84, 234].

This intervention delivery including provision of electronic content supplemented by printed copies of the handbook, the opportunity to connect with other BC survivors, and remote access to a facilitator, can be further explored through qualitative studies including both BC survivors and facilitators, in the future.

5.5.3.7 Costs

Prior to large scale implementation of the intervention, the costs incurred by an intervention should be assessed against the costs to the health system if participants do not receive the intervention [514]. Providing survivors with reimbursement for participating may well be cost-effective compared to the expenses associated with receiving treatment for symptoms or impairments affecting quality of life, which are amenable by participating in an intervention [515, 516]. The costs should be considered in light of the substantial increase in the quality-adjusted life years of participants in this study. (Refer to 5.5.4.3 Health-related quality of life for this calculation).

To date, few previous SMIs have reported the costs of their interventions. A SMI delivered in the USA, reported costs of 280 US dollars per participant [287], while an Australian unsupported intervention providing intervention materials only, reported a cost per participant of only 6.04 US dollars [340]. In contrast, a supervised, on-site intervention reported costs of 487.64 US dollars, per participant [517]. Considering the above, the costs for the intervention evaluated in this study seem low, however further contextual investigation is warranted. Unfortunately, previous South African studies investigating interventions using self-management principles for other chronic conditions [348, 358, 359], albeit using group-based, on-site formats, did not report the costs of their interventions. It can be argued that the provision of research assistants or facilitators, equipment, refreshments, and weekly reimbursement for transport for each participant, were likely to incur higher costs compared to the intervention evaluated in this study, but this hypothesis is untested.

5.5.3.8 Safety

The intervention 'Survive and Thrive' seems safe to implement in BC patients who are free of contra-indications to unsupervised exercise. Similarly, the RCTs included in the systematic review (Chapter 3) and previous systematic reviews of SMIs in BC survivors both during and after MCT, did not report adverse events related to the interventions [200, 201], which emphasises the safety of supported SMIs for early-stage BC survivors. However, participants were screened using the ACSM preparticipation guidelines, to ensure that it was safe to engage in unsupervised exercise. No participants reported an increase in swelling of the chest or upper limb, during their intervention.

This finding agrees with numerous systematic reviews and a review of systematic reviews, which have reported that interventions including an exercise component, can improve BC-related lymphoedema [66, 67, 474, 518].

5.5.4 Comparison of outcomes post-intervention, to pre-intervention

Patient-reported outcomes evaluate patients' perceived state of health, without external interpretation [519]. Patient perspectives of their health help to define their needs beyond primary cancer treatment, informing integrated, holistic cancer care. Self-reported health outcomes determine the extent to which cancer has affected patients' lives, to explicitly inform interventions [519]. They are the gold standard of measurement for outcomes that are subjective by nature, such as pain, fatigue, HRQoL, and self-efficacy [520]. In BC survivors who live their lives with long-term health challenges, patient-reported outcomes should be measured and compared across institutions and countries [521]. This provides opportunities to improve health services [521]. Little is known about the health status of long-term BC survivors, in SA. To the knowledge of the author, this study was the first to evaluate outcomes such as cancer-related fatigue, HRQoL and self-efficacy in South African post-treatment survivors. Therefore, baseline findings will be discussed in relation to previous research before interpreting the pre-test post-test comparisons.

5.5.4.1 Pain prevalence, severity, and interference with function: BPI

The prevalence of pain reported by participants at baseline in this study was 71%. A systematic review including 187 studies reported a pooled pain prevalence of 35% [143]. In contrast, but in keeping with the findings of this study, a South African cross-sectional study of BC survivors one year after MCT, reported a shoulder pain prevalence of 75% [192]. Regarding the severity and interference scores for pain in this study, median baseline scores can be classified as 'moderate' (scores between two and six) [431]. A previous study reported their baseline pain severity and interference scores, to be 'mild' (between zero and two) [522]. The baseline findings regarding pain in this study are not surprising, given the previously mentioned research reporting late diagnosis, aggressive treatment regimens and low health literacy in the South African BC population [75, 102, 357]. Compounding this is the lack of BC education and rehabilitation interventions after cancer treatment [60, 62, 74].

The significant improvements in all three pain-related outcomes in this study suggest that participation in the intervention may have contributed to the effective self-management of pain. Persistent pain is a commonly occurring, debilitating symptom in BC survivors after MCT [6]. It includes but is not limited to upper limb morbidity and chest wall pain: endocrine therapy has been known to cause chronic joint pain in BC patients [338]. A systematic review has reported the benefits of exercise interventions on persistent pain in BC survivors [68].

However, despite the substantial challenge that pain poses for BC survivors, pain has been relatively under-studied in the literature of post-treatment survivors compared to fatigue, HRQoL and physical function. Systematic reviews investigating the effect of self-management interventions in mixed cancers have suggested a positive effect on pain, although these studies were not able to conduct meta-analyses [149, 230]. The systematic review in Chapter 3 of this thesis yielded only one study investigating the effect of a SMI including exercise, on pain. That study by Reeves and colleagues [103] found a significant between-group difference in pain, in favour of the intervention group. Their intervention consisted of progressively tapered telephone calls, mailed material and text messages to promote exercise participation, over 12 months. The latter study utilised a longer intervention period, different exercise dosages, and a different mode of intervention delivery, compared to the current study. Perhaps these findings suggest that various theory- and evidence-based SMI promoting exercise could result in significant short-term improvements in pain. Thus far, the long-term benefits of exercise interventions on pain have not been established. Few studies have reported long-term pain-related outcomes of their interventions. Of those who have measured and reported long-term results, both a supervised [523] and an unsupervised [103] intervention failed to show long-term benefits over usual care.

There are no comparative data from other South African intervention studies in BC survivors. However, South African interventions for women with other chronic conditions such as osteoarthritis [348], human immunodeficiency virus (HIV) [349], and chronic diseases of lifestyle [81] utilising self-management strategies based on social cognitive principles, have found significant improvements in pain post-intervention, measured by the BPI. These findings suggest that theory-based, specific SMI including exercise and education may be effective to improve pain in South African women with chronic conditions. One mechanism by which these interventions may influence pain, could be due to the patient-centred, self-management empowering framework employed, such as by 'Survive and Thrive'. This evidence-based model of care is aimed at enhancing knowledge, self-management skills and self-efficacy [37, 83, 377].

5.5.4.2 Cancer-related fatigue prevalence, severity, and interference with function: BFI

The prevalence of fatigue reported by participants in this study was 77.4%. This is high compared to a systematic review on fatigue including 129 studies, which reported a prevalence of 49% in BC survivors [524]. Regarding the severity and interference scores for fatigue in this study, the median baseline scores can be classified as 'moderate' (scores between two and seven) according to the authors of the BFI [306]. Previous studies conducted in high-income countries, found fatigue severity and interference scores to be 'low' or 'mild' in post-treatment survivors [525-527].

Interventions promoting exercise have shown to be effective to reduce fatigue and pain for decades [65, 68, 525]. The baseline findings of this study therefore highlight the need for such interventions to support South African survivors to manage fatigue, and to encourage exercise participation.

The significant reductions in fatigue prevalence, severity, and interference with function in this study suggest that a 12-week SMI including exercise may contribute to improve fatigue in post-treatment BC survivors. International exercise guidelines recommend at least 90 minutes of moderate aerobic exercise, or a combination of aerobic and resistance exercise per week, for at least 12 weeks, to reduce cancer-related fatigue in BC survivors [18]. Numerous systematic reviews have documented the positive effects of exercise interventions on fatigue [97, 239, 528]. Systematic reviews have indicated that SMIs may also be effective to reduce fatigue in cancer survivors, although, to date, most have used narrative synthesis [149, 230, 236]. The findings of the present study add to this growing body of evidence. These findings also concur with the systematic review in Chapter 3, which found a significant improvement in fatigue, in favour of the intervention groups of two pooled studies [284, 290], and one further study not included in the meta-analysis [291].

Like the intervention used in the present study, these studies were 12 weeks in duration and included either web-based education or telephone calls, paired with a workbook. However, two studies in the systematic review: Reeves and colleagues [103] and Ergun and colleagues [289] found no significant difference in terms of fatigue, in their intervention groups compared to controls. It must be noted that the intervention by Ergun and colleagues prescribed a low dosage of exercise, which may not have been sufficient to achieve significant results. The intervention by Reeves and colleagues was 12 months in duration, and it tapered off after the first 16 weeks. Therefore, the effects of the intervention may have attenuated by the end of the 12-month period.

5.5.4.3 Health-related quality of life (HRQoL)

At baseline, the median EQ-5D-3L index value for this study was 0.725. A systematic review including nine studies of stage I-III BC survivors, reported values ranging from 0.740-0.880 [529], while a cross-sectional multicentre study including 2626 early-stage BC patients reported a mean value of 0.887 [530]. A multinational study of post-treatment BC survivors in several high-income countries, found that their mean EQ-5D-3L index scores were comparable to normative scores of the general population [531]. Normative EQ-5D-3L index values for the general population were not available for SA, at the time of writing. However, scores in the United Kingdom and in Zimbabwe were found to be 0.856 and 0.842, respectively [532].

Therefore, baseline HRQoL measured by the health index score of participants in this study was low compared to BC survivors in other countries, and possibly lower compared to the general South African population.

Regarding the EQ-VAS scores (indicating general health) in this study, the median score at baseline was 75.0. This score is similar to other studies in BC, reporting 75.6 [530], 74.4 [531], and 69.0 [533]. In contrast, an Egyptian cross-sectional study including survivors of mostly low socio-economic status, found a mean EQ-VAS score of only 50.0 in their sample of 125 BC survivors [534]. EQ-VAS population norms for South Africa and other African countries were not available at the time of writing. However, the EQ-VAS population norm for the United Kingdom was reported to be 83.0 in an analysis of population-based surveys. Between 20 countries, the mean EQ-VAS scores varied between 70.4 and 83.3 [532].

Patient-reported HRQoL contextualises the impact of disease and treatment: several studies in BC have shown an association between symptoms such as pain, fatigue, and HRQoL, with symptoms impacting HRQoL throughout the survivorship trajectory [535]. Conversely, improved HRQoL has been correlated with a healthy lifestyle, favourable prognosis, and lower mortality in BC survivors [533]. Therefore, considering the high prevalence and moderate levels of pain and fatigue in this study, the relatively low HRQoL index scores were an expected finding, highlighting that an intervention was required in this sample.

It appears that the intervention 'Survive and Thrive' contributed to an improvement in participants' HRQoL. The improvement of median index scores from 0.725 to 1, an improvement of 0.275, is clinically significant as the index score represents one quality adjusted life year (QALY) [447]. This improvement implies that participants in this study gained almost a third of a year of healthy life, provided that the intervention effects are sustained for one year [447]. The National Institute of Excellence and Health Care of the United Kingdom (NICE), which uses the EQ-5D-3L index score to calculate the cost utility of various interventions, estimates that £20,000-£30,000 is a reasonable amount to pay per QALY [536]. To contextualise this information: the gain of the intervention group would justify the expenditure of approximately £6,000 or R144 000 (7 600 United States Dollar) at current exchange rates. Although the threshold cost of a QALY gain in a high income country such as the United Kingdom would be higher than in SA, this serves to highlight that the improvement in HRQOL associated with participation in this intervention was considerable.

In support of the index scores, the EQ-VAS scores also improved significantly. A review of systematic reviews on non-pharmacological interventions revealed that exercise is effective in the short- and in the long-term to improve HRQoL in cancer survivors [96]. Regarding BC specifically, a systematic review found that regular moderate or high intensity aerobic or resistance exercise benefited HRQoL [334]. These findings are supported by the meta-analysis of RCTs in Chapter 3, where the pooled results of two SMI studies including exercise, demonstrated a significant improvement in HRQoL compared to controls [284, 289]. Four further studies included in the systematic review but not in the meta-analysis, reported significant improvements in HRQoL compared to usual care in their physical HRQoL subscales [103, 285, 290, 292]. At the time of writing, there were no comparative data from other South African BC survivors in terms of HRQoL. However, person-centred, South African studies of theory-based interventions utilising self-management principles have demonstrated improvements in HRQoL, in women with other chronic conditions [81, 348]. Together, these findings emphasise that women with chronic conditions engaging in education and exercise interventions based on self-management principles, can improve their HRQoL significantly.

5.5.4.4 Self-efficacy (SE-6)

The median self-efficacy score reported by participants in this study (7.8) can be categorised as 'high' [459]. This agrees with previous studies in BC survivors, which have reported mean scores of 7.1 [461] and 6.3 [463]. In previous studies, an increased symptom burden has been associated with reduced self-efficacy [537, 538]. This was not observed in the present study: participants reported moderate pain and fatigue and low health index scores, while reporting high self-efficacy levels. A plausible explanation for this could be selection bias: participants were recruited through study advertisements. Survivors who responded to the adverts were likely to be motivated to address their health problems, hence their confidence levels to manage their health may already have been high. Another explanation for the high self-efficacy levels reported in this study could be that, in the absence of structured survivorship care programmes or other health interventions following MCT, BC survivors in SA might be accustomed to having to take care of their own health. Given the link between self-efficacy and self-management [377], South African BC survivors may be especially receptive to SMI providing skills and information for effective health management, owing to their high levels of self-efficacy. More studies are needed to further explore the self-efficacy levels of BC survivors in developing countries such as SA.

The self-efficacy scores of participants in this study improved significantly post-intervention, compared to baseline. There is substantial evidence that people with chronic disease have lower self-efficacy scores compared to those without chronic disease, and that self-management interventions should include a focus on self-efficacy to achieve behaviour change [312, 377, 379]. Moreover, a systematic review in BC survivors found that self-efficacy influences physical and mental health, quality of life, pain management, communication with health providers and medical health-seeking behaviour [539]. The findings of this study concur with those of Lee and colleagues [290] and Wang and colleagues [292]. These were the studies in the systematic review (Chapter 3) that included self-efficacy in their outcomes, using the self-efficacy for exercise and the self-efficacy for physical activity scales, respectively. Both were SMIs including exercise, utilising a maximum of three face-to-face clinical visits.

There were no comparative data regarding self-efficacy in South African BC survivors, while South African studies in other chronic diseases have reported mixed successes to improve self-efficacy using education and exercise interventions. Hendricks et al. [348], Saw et al. [540], and Parker et al. [349] found that theory-based interventions using self-management principles resulted in significant improvements in self-efficacy, while Barnes et al. [81] did not. The authors of the latter study concluded that its small sample size was a fundamental limitation.

The results of this study demonstrate that a remotely delivered SMI including exercise is associated with improvements in self-efficacy for the management of chronic disease, in a South African sample of BC survivors. Given the concurrent improvement in symptom burden (pain and fatigue), HRQoL, and physical activity participation, the findings of this study substantiate that self-efficacy is an important component in the self-management of LTSE for patients with BC.

5.5.4.5 Physical activity participation and sitting time on weekdays (IPAQ-SF)

The median reported MET-minutes per week at baseline in this study were 396.0, which means that many participants in this study did not meet the minimum exercise guidelines recommended for cancer survivors [18]. As a reference: 150 Minutes of moderate intensity exercise per week (the general exercise guideline to promote overall health and wellbeing, for cancer survivors)[18] amount to approximately 600 MET-minutes per week. These low physical activity levels are concerning, given the established benefits for cancer survivors - not only for the management of LTSEs, but also for improving overall survival, cardiovascular health, prevention of other chronic diseases, cancer recurrence, and other cancers [18, 68, 541].

The median baseline MET minutes per week of physical activity in this study were low compared to previous research, reporting 1354.7 [285], 1711.8 [284] and 1189.5 [470] MET minutes per week. This could be because the other studies were conducted in high income countries, where the standard of care after MCT is to provide specific information about exercise [253, 285, 523]. It is therefore likely that participants in those interventions were already well informed about the benefits of general exercise in BC, resulting in higher baseline weekly energy expenditure.

It can be argued that the knowledge levels about general exercise in this sample was likely to be low, and this argument is reflected in the low baseline energy expenditure of this sample. Indeed, one study including only Latina BC survivors in Puerto Rico and the United States of America: a group of survivors who did not receive any education about exercise after MCT, reported levels as low as 76.5 MET minutes per week [542]. However, it must be noted that the latter study by Ortiz and colleagues purposefully recruited sedentary BC survivors, which contrasts with the present study.

At baseline, 54.84% of the women in this study reported meeting the minimum exercise guidelines for the management of cancer-related health outcomes. These guidelines: at least 90 minutes of moderate exercise per week, are less than the general guidelines for cancer survivors to improve overall health and survival, which recommend at least 150 minutes per week [18]. Considering that self-reported physical activity levels are likely to be subject to an over-estimation bias [229], the results of this study reflect low levels of exercise participation at baseline in this sample, revealing a pressing need for intervention to encourage exercise and physical activity in South African BC survivors. In BC survivors, there is convincing evidence that meeting the minimum exercise guidelines for symptom management, results in improvement of health-related outcomes [18]. Thus, much of the symptom burden reported at baseline by this sample: chronic pain, cancer-related fatigue and low HRQoL, was likely to be amenable.

This study found a significant improvement in the median MET-minutes per week of physical activity participation after the intervention, compared to baseline. Moreover, the median MET-minutes per week of reported exercise participation in this study progressed from ‘low’ – not meeting the minimum international exercise guidelines for cancer survivors, to ‘moderate’ levels of exercise – meeting the minimum exercise guidelines for cancer survivors. This increase is unlikely to be related to seasonal increases in physical activity: the study was conducted from summer, through autumn until the end of the South African winter. Therefore, there was seasonal variation during the study with a relatively even participation in the study through the seasons.

The results are encouraging, considering the well-established benefits of meeting these guidelines, including improved survival and a reduced risk of cancer recurrence [350].

Six RCTs in the systematic review (Chapter 3) assessed exercise or physical activity participation, of which four found significant improvements of their intervention groups, compared to the control groups. The meta-analysis found significant improvements of intervention groups compared to controls. The results of the present study therefore align with those of the systematic review and meta-analysis. Possible explanations for these similarities in findings between this study and the studies in the systematic review in Chapter 3, could be that all these studies encouraged adherence to the intervention through aids such as exercise diaries, goal setting, and through regular reminders sent to participants. In the systematic review (Chapter 3), two interventions failed to achieve significant results for exercise participation. These studies by Wang and colleagues [292] and Kim and colleagues [284] had both recruited participants with exercise levels that were already high. These may be plausible reasons why their interventions failed to demonstrate significant differences between groups, for exercise participation.

The results of this study are encouraging given the unsupervised, resource preserving nature of this intervention. To date, comparative data in terms of general exercise from South African BC survivors is lacking. A recent systematic review of behavioural interventions promoting exercise for other chronic diseases in Africa [543], which included two South African studies, found that these interventions improved exercise participation both in the short- and long-term. The latter review recommended that interventions should include behaviour-change techniques, aim to improve knowledge of the chronic disease in question, and address barriers to regular exercise participation.

5.5.4.6 Sitting time on weekdays (IPAQ-SF)

The median baseline hours of weekday sitting time reported by women in this study was 30.0, amounting to six hours per weekday. In the literature, most studies utilising the IPAQ-SF did not report sitting time, even though the questionnaire collects this information. This is unfortunate, since significant positive correlations have been reported between sitting time measured by self-report, and accelerometer measurements, in BC survivors [544]. Time spent in sedentary behaviour may be an independent risk factor for chronic disease [545]. Therefore, interventions must aim to reduce sitting time while promoting exercise participation [18, 546]. Studies that did investigate sitting time in post-treatment survivors of BC, reported 38.75 [544], 30 [382] and 43.3 [263] hours per week. Therefore, the baseline findings for sitting time on weekdays in this study concur with the high levels of those of international studies.

A recent study using data from six low- and middle income countries, found that sitting for more than two hours per day was associated with an increased risk of obesity independent of exercise expenditure [547]. This means that interventions should set a target of achieving no more than 10 weekday sitting hours per week, to achieve a risk reduction for obesity. Combined with low levels of exercise, increased sedentary time is associated with all-cause and cardiovascular mortality [548].

Unfortunately, South Africa has not collected surveillance data in the last 10 years, on time spent sitting in the general population [549], therefore comparisons cannot be drawn between this sample of BC survivors and the general South African population. Similarly, no previous studies were available at the time of writing, regarding the sitting time of South African BC survivors.

Participation in this intervention was associated with significant decreases in sitting time on weekdays. In contrast to the present findings, neither a 12-week telephone-delivered intervention by Pinto and colleagues [544], nor a 12-month SMI by Reeves and colleagues [103], reported by Terranova and colleagues [304], resulted in significant between-group changes, in terms of sedentary behaviour. The results of the current study also differed to those of Short and colleagues (2015) [263], who found no significant difference between groups in terms of sitting time. The authors argued that the instrument used to assess sitting time may not have been adequately sensitive. Furthermore, wearing a device that measures sitting time may not accurately reflect sedentary time when not wearing the device [550]. Another reason could be the nature of the intervention: Short and colleagues provided printed reading material without support, as an intervention. Therefore, their intervention may not have been multifactorial enough to affect behaviour change.

A mobile health intervention by Allicock and colleagues [259] resulted in reductions in sedentary time that approached significance. In that study, the authors concluded that the small sample size may have prevented significant findings. The present study may be one of the first to examine this outcome after a SMI including an exercise component, in BC survivors. At the time of writing, no South African studies examining the effect of interventions on sedentary time in BC survivors, or in other chronic diseases, were identified.

5.5.5 Regression analyses

This study had a relatively small sample size, which caused wide confidence intervals in the regression results. However, possibly significant relationships were identified between improvements in self-efficacy scores and improvements in pain severity, fatigue severity and HRQoL. In addition, there were trends of relationships between an improvement in self-efficacy scores and improvements in pain prevalence, and fatigue interference which approached significance.

These findings align with numerous international studies in cancer survivors, observing that interventions which improve self-efficacy, are likely to also achieve success in improving pain, cancer-related fatigue and HRQoL [230, 237, 551-553]. Furthermore, the findings of this study strengthen the established relationship between self-efficacy and the effective self-management of chronic conditions, which has been identified in the literature [377, 554].

The apparent relationship between improved self-efficacy and reduced symptom burden after participating in this study, suggest that the intervention 'Survive and Thrive' was effective to empower participants to improve their health, through fostering self-efficacy. Another possible finding of the regression analyses in this study, was that a lower level of education (as opposed to tertiary education obtained after high school), may have been related to an increased improvement in pain severity following participation in this intervention. This suggests that the intervention content was pitched at the correct level for participants without a higher education, which may have enabled it to successfully influence the pain severity of these survivors.

Given that the majority of BC survivors in this study did not receive a higher education, and that these women may be most in need of health education interventions [62, 75], this finding substantiates the applicability of the intervention for BC survivors with low education levels. This finding further confirms that survivors with low education levels must be included in future interventions as they may benefit the most, in terms of pain reduction.

Interestingly, regression analyses in this study did not reveal that participants using either public or private health facilities were associated with a greater improvement in health outcomes. This suggests that women accessing both types of healthcare in SA can benefit from self-management interventions. The same can be argued for employed, unemployed and retired participants in this study. Regression analyses did not reveal that either of these groups seemed to benefit more than another, in terms of an improvement in the patient-reported outcomes measured in this study.

5.5.6 Strengths of this study

The main strength was that the study design matched its purpose: The single-group pre-test post-test design was ideal to explore initial, pragmatic aspects of feasibility, safety, and utility of this intervention. It served as a platform for future intervention studies, as various formats of this and new interventions can now be compared, in South African BC survivors. The sample size was sufficient to evaluate both feasibility and change in outcomes associated with intervention participation.

This study was able to efficiently recruit and retain BC survivors, of whom many were working to earn an income, and who mostly used the public health facilities in SA. The results of this study therefore positioned the intervention for evaluation of effectiveness through a future RCT. This study showed that the intervention duration was sufficient: short enough to maintain participant retention, and long enough to be associated with significant improvements in patient-reported outcomes. Validated outcome measures were used which were appropriate for BC survivors, and for use in SA.

The present study allowed the calculation of costs per participant, and no adverse events were reported by participants. This study provided insights into the significant baseline symptom burden of LTSEs experienced, which emphasise the need for interventions for this group of survivors. Finally, this study complied with the TREND reporting guidelines [479].

5.5.7 Study limitations

The main flaw of this study was that a robust measure of adherence to activities and behaviour advocated by the intervention could not be obtained. Therefore, improvements in patient-reported outcomes cannot with certainty, be associated with participating in the intervention. Direct questions such as 'Have you completed your task of the week?', or 'Did you reach your (set exercise goals) this week?', may have been more indicative of adherence compared to the response rate to weekly reminder messages used in this study [427]. The high usage of WhatsApp observed in this study means that this can be remedied in the future: participants can be requested to share their weekly tasks and exercise diaries through this or a similar application, which will provide a far more accurate assessment of adherence.

The intervention was informed by the qualitative study (Chapter 2), the systematic review (Chapter 3), and refined through the acceptability evaluation (Chapter 4), before being evaluated in this study. The qualitative studies described in Chapter 2 and 4 were conducted in a single, semi-urban setting in SA. The findings of these studies may therefore not be generalisable to the entire South African BC survivor population.

Participants who responded to advertisements were recruited for this study. These participants were likely to be highly motivated to improve their health, and many were in contact with a cancer support organisation. Therefore, these participants may not accurately reflect the general BC population in SA. In addition, participants and respondents of the qualitative study in Chapter 2 were provided with the opportunity to participate in this study, for their potential benefit.

Although only six qualitative study participants (18.2% of the sample) participated in this study, this may have caused bias due to the potentially favourable views of these women regarding an intervention that had been developed for them. It is also possible that participants provided favourable outcomes post-intervention due to social desirability bias. While pragmatic, including women who were six months to 10 years following the completion of primary medical cancer treatment may have biased the results of this study: the nature and severity of LTSE experienced may vary somewhat during the survivorship trajectory.

The pre- post study design meant that participants completed the same outcome measures before and after the intervention. Therefore, a learning effect may have biased the results. Although questionnaires were rigorously administered according to the official instructions for each instrument, a lack of funding meant that the same researcher facilitated the intervention and conducted the assessments. Therefore, there was a lack of blinding, which may have created further room for bias.

A patient-reported questionnaire was used to assess physical activity participation, which possibly resulted in inaccurate data due to self-reporting bias. An objective measure of physical activity could not be obtained in this study, which limits the credibility of the findings regarding physical activity and sedentary time.

5.6 Recommendations and conclusion

5.6.1 Recommendations for future research

As a next step, an RCT should be undertaken to determine the effectiveness, against a control group receiving a variation of the developed intervention. This will be useful to exclude the possible influence of time or other confounding factors on the patient-reported outcomes. Adding a qualitative component would strengthen and expand the findings, providing insights into the perceived benefits and limitations of participating in the intervention. Furthermore, it is recommended that a cost-effectiveness analysis should be undertaken. In this study, the costs for staff time to deliver and administer the intervention were not included in the estimation of the intervention costs. As each participant worked through the intervention independently, time needed to deliver the intervention was estimated to be low. However, in future studies this should be included to provide a more accurate reflection of the total intervention costs.

Future studies should attempt to achieve a representative sample of women who use public and private health facilities. The proportion of women who utilised public health facilities in this study was 54%, while the proportion of South Africans using public health facilities has been reported to be approximately 84% [91].

Younger survivors may have different intervention needs and respond differently to intervention delivery, compared to older BC survivors. This should be explored in future studies, as intervention content may need to be tailored to specific age groups. Similarly, South African BC survivors who are six months following the completion of their MCT may have intervention needs that are distinct from those of long-term survivors, and this requires exploration in future studies.

Overweight and obesity are highly prevalent in BC survivors and are linked to poor health-related outcomes [555]. However, improvements in BMI and body weight are known to take longer to achieve [335]. Therefore, future studies should explore the delivery of this intervention and interventions of longer duration including long-term follow-up, in relation to BMI or body weight.

In this study, limited funding and the diverse geographical location of participants prevented the assessment of lymphoedema, physical function and fitness. Therefore, this study was unable to determine a positive association between participation in the intervention, and these outcomes. Future studies should consider the addition of such assessments, performed by blinded assessors.

The findings of the regression analyses conducted in this study, with those observations approaching significance, indicate that future larger trials should investigate the relationships between self-efficacy and education levels, and cancer-related health outcomes, in South African BC survivors.

Although the sample size in this study was not sufficient to detect significant predictive relationships between variables, trends were observed particularly in the relationships between improved self-efficacy and improvement in outcomes related to pain, cancer-related fatigue, and HRQoL. Larger sample sizes would increase the chances of finding significant relationships between variables, in regression analyses. Such investigation may be valuable to inform future interventions.

5.6.2 Conclusion

The main aim of this study was to implement and evaluate an evidence-based SMI advocating a patient-centred approach for women with early-stage BC following MCT, in South Africa. The study found that a 12-week remotely delivered SMI facilitated by a physiotherapist, appears feasible, safe to implement clinically, and potentially effective, in women able participate in unsupervised exercise. The intervention was associated with a significant improvement in the primary outcome: pain severity, and related secondary outcomes namely: pain prevalence and interference, fatigue prevalence, severity, and interference, HRQoL index and EQ-VAS scores, self-efficacy, and physical activity. The findings of this study therefore demonstrate the potential benefit of a SMI for South African women with early-stage BC, after MCT.

Chapter 6: Discussion, summary, and conclusion

6.1 Long-term side effects of breast cancer can be addressed

Breast cancer (BC) results in long-term health challenges which contribute to the burden of disability globally and locally [46, 60, 192, 556]. Considering the scant literature regarding rehabilitation needs, and the lack of interventions suitable for the South African context, the modified model of person-centred care was used as the underpinning theoretical framework for this thesis [82]. It is based on the biopsychosocial model, which is multidimensional to incorporate biological, individual, and social aspects of health and environmental factors together, which can all affect health outcomes [557]. Using this framework of person-centred care, an understanding of the constant interactions between the context, process, and outcomes was developed. This facilitated a holistic understanding of the long-term health challenges experienced and of the rehabilitation needs of women with BC. It also informed the development and evaluation of an appropriate, feasible, potentially effective intervention. A discussion was presented in each of the research chapters of this thesis. In the following sections, further aspects relating to the main findings will be discussed within the context of the available evidence, using the framework of patient-centred care.

6.2 Discussion

6.2.1 Context

Approximately 19.4 million South African women are at risk of developing BC [558]. Recently, the South African public healthcare system has experienced substantial budget reductions, affecting patient care and healthcare providers: In 2023/24, the budget allocation of the National Department of Health was reduced by 4.4 billion South African Rand [559]. Concurrently, healthcare providers have a responsibility to ensure that BC survivors have access to long-term symptom management [6]. This highlights the benefit of developing and evaluating resource conserving interventions for the South African context, which can improve the health-related quality of life (HRQoL) of cancer survivors, while potentially reducing the burden of continuing care on health systems [95, 234].

Exploration of the lived experience of long-term side effects (LTSEs) in this thesis, supports the adoption of the biopsychosocial model in BC survivors. This model proposes that health challenges are caused and influenced by multiple interactions between several variables [557]. These variables may originate from biological, psychological, and social mechanisms. Long-term side effects may include biological contributors [418].

However, biological contributors may interact with diverse psychosocial factors, such as low levels of education and the perception of symptoms being overlooked, neglected or unaddressed by healthcare providers. These aspects can influence the severity and functional impact of LTSEs such as pain and fatigue [418, 557]. Considering these multifactorial causes of LTSEs, it makes sense that complex interventions addressing biological and psychosocial mechanisms, such as 'Survive and Thrive', are likely to be effective to mitigate these long-term health challenges.

This thesis contributed to the existing body of knowledge by providing insights into the physical, psychosocial, and logistical challenges experienced by South African BC survivors. A key finding of Chapter 2 was that the main rehabilitation needs perceived by participants in that study, were access to comprehensive information and support. As discussed in Chapter 2, the needs for information and support are not unique to this cohort of BC survivors. These have been found to be some of the most frequently expressed supportive care needs of BC survivors in a systematic review including 40 studies [356]. However, the extent of the information requested by participants, with the finding that many women did not know that anything could be done to improve LTSEs, were unique to that study. In part, an explanation for these findings could be that South Africans do not have access to a Survivorship Care Plan following their MCT, which would have addressed some of their most basic information needs [560]. Compounding this, was that women reported receiving vague or inaccurate responses when they asked their healthcare providers about issues such as cancer recurrence and exercise. This suggests that healthcare providers do not always have the time or the knowledge to address the information and supportive care needs of BC survivors, which has been observed in previous South African studies in BC survivors [60, 62]. These findings regarding the rehabilitation needs of BC survivors within the South African context, highlighted the need for a supportive intervention which does not place further strain on an already overburdened health system [62, 89].

No other qualitative studies were identified specifically investigating the rehabilitation needs of BC survivors in other sub-Saharan African countries. Regarding other low- and middle income countries (LMICs), researchers in India have recently explored the burden of LTSEs such as fatigue and functional decline, in BC survivors [122, 561]. Authors have concluded that interventions are needed to mitigate these problems. Similarly, the burden of LTSEs has been explored in Iranian BC survivors [207]. In that country, researchers have developed a supervised rehabilitation intervention initially [562], followed by a mobile-based application to improve the self-management of lymphoedema [563].

An unexpected, but encouraging finding of the qualitative study in Chapter 2, was that participants did not seem to believe that exercise was harmful, in terms of causing cancer recurrence or worsening lymphoedema, which previous studies in other countries have reported [120, 219]. Additionally, although not specifically investigated in this study, participants did not mention that they felt the need to keep a level of secrecy regarding their disease, as reported by previous South African [60, 74] and Indian [122] studies of BC survivors. Considering the diversity of cultures within South Africa (SA), secrecy and stigma surrounding BC survivorship, and possible misinformation regarding exercise or physical activity, should be investigated in future studies.

Breast cancer survivors have an increased risk of overweight and obesity [6]. There is an established link between overweight and obesity, and adverse long-term health outcomes [564]. In some African countries including South Africa, there is a misperception surrounding overweight and obesity. Skinny persons are perceived by society as being affected by poverty or ill health, while overweight or obese persons represent health, wealth, and happiness [565]. These perceptions were not observed in the qualitative study in this thesis. Participants noted with disbelief that they had put on weight following their medical cancer treatment (MCT), when they had expected to lose weight because of their cancer. However, the context of existing cultural perceptions in SA underscores the importance of providing women with education and self-management skills regarding excessive weight gain following their MCT. For example, the intervention 'Survive and Thrive' provided detailed information about overweight and obesity, with instructions to measure and re-measure BMI, and how to proceed if body weight and BMI are not within the healthy normal ranges [7, 350, 369].

Another main finding relating to the local context, was that many participants of the qualitative study reported walking as a necessary form of commuting. Other forms of transport were perceived to be too expensive. This highlights the need to regain physical function following MCT: many women in the qualitative study noted a remarkable decline in their overall physical function. This presents a major opportunity for education of BC survivors: functional decline should not be viewed as an irreversible consequence of BC [24]. Rather, as in the intervention 'Survive and Thrive', women should be provided with step-by-step instructions on how to regain their physical fitness, and they should receive information on when to seek help from a healthcare or rehabilitation professional [95, 234]. In addition, women can be advised that physical activity as a means of transport, such as walking to work, or physical activity during work or gardening, is beneficial and that it contributes to the accumulation of weekly physical activity recommended by the exercise guidelines for cancer survivors [18].

The finding that women in the qualitative study, Chapter 2, were motivated to self-manage their LTSEs by using the resources they had, was encouraging. Using their social network including family and friends, their intuition and their acute post-surgical upper limb exercises to manage LTSEs, indicated that BC survivors may be receptive to interventions providing them with self-management knowledge and skills. As previous studies have suggested the benefit of self-management interventions (SMIs) including an exercise component, for BC patients and survivors [200, 201], this possibility was explored further in this thesis.

6.2.2 Process

The prospect that rehabilitation needs identified by local BC survivors could potentially be addressed using a resource-efficient intervention, led to the conduction of a systematic review in Chapter 3 to investigate the evidence for this. The systematic review revealed new findings regarding the benefits of SMIs including an exercise component and requiring minimal clinical visits to complete, for several health outcomes in early-stage BC survivors who have completed their primary MCT. These findings have the potential to influence both research and practice. Future similar reviews will likely be able to include more studies to allow more definite conclusions. The findings of the systematic review in this thesis may therefore contribute to driving the development and delivery of SMIs in diverse settings, including those facing resource restrictions. This may facilitate the provision of rehabilitation interventions to BC survivors following MCT, to include LMICs in the future.

In this thesis, an intervention was developed and delivered utilising a combination of printed material and digital technology, addressing the rehabilitation needs identified in Chapter 2. In the literature, an array of SMIs are described that use printed material only [263, 270, 566], digital / web-based or mobile technology only [259, 280, 290, 567], or a combination [103, 568]. Seven of the 10 interventions of studies included in the systematic review in Chapter 3, used printed material in the form of books, workbooks or tip sheets, which were combined with emails, text messages, digital video discs (DVDs), or phone- or conference calls. In recent years, there seems to be a global trend towards using more mobile-based and digital technologies for new interventions developed for cancer survivors [235, 569]. As the digital literacy of BC survivors in SA evolve, it is expected that, in the future, new interventions may become more reliant on technology and perhaps include less printed material. However, the acceptability evaluation in this thesis revealed that women particularly appreciated their printed handbook copies. This is substantiated by the results of a study conducted in the United Kingdom (UK), which evaluated an intervention using a combination of digital and print-media for mixed cancer survivors [568].

The authors of the latter study concluded that the intervention's printed aspects may have been more effective compared to the electronic tools, and that the women who participated in that intervention, preferred to use the printed material.

The benefits of rehabilitation interventions for BC survivors have been established [52, 194]. However, factors including a lack of patient and healthcare provider education about cancer rehabilitation, costs involved, and staff shortages, have prevented their widespread implementation [352]. Thus, on-site rehabilitation interventions have not been widely accessible to BC survivors even in many high-income countries [95]. The growing evidence base for SMIs, with their resource-saving characteristics, has led to some countries (such as the United Kingdom and Australia) adopting supported SMIs as a key focus for survivorship care in recent years [84]. In African countries, national survivorship objectives and strategies rarely extend beyond palliative care [560]. This is unfortunate, as it means that millions of cancer survivors have not had access to rehabilitative interventions following their MCT, despite the evidence base for these [95, 194, 560]. This thesis has shown that interventions need not be resource-intensive to meet the needs of BC survivors and to achieve clinically significant improvements in health outcomes.

Structured rehabilitation interventions are not, to the knowledge of this author and supervisors, being offered to BC survivors following MCT in either the public or the private health system, in SA. However, rehabilitation facilities including professionals such as Physiotherapists, Occupational Therapists and Dieticians, are available and may be consulted if patients have a doctor's referral (in the public health system), or with or without a doctor's referral (in the private health system) [570]. 'Survive and Thrive' intended to support these existing facilities such as out-patient physiotherapy services, by empowering BC survivors through the provision of education, self-management skills, and support [83]. For example, by informing women when it is necessary to seek advice from a healthcare or rehabilitation professional [83, 149]. This is particularly relevant and important in the South African context. Public hospitals with rehabilitation facilities are typically located at tertiary hospitals, which are often a considerable distance from the patients they serve. Far fewer are situated in semi-urban and rural areas, compared to urban areas [570]. As it can be difficult for many BC survivors to access rehabilitation facilities, it is even more important that they are informed when it is necessary to seek professional advice [570].

Fostering the development of self-efficacy and encouraging effective self-management in BC survivors, may lead to more efficient healthcare utilisation, thereby contributing to reduce the overall patient load of healthcare facilities [234].

When ‘Survive and Thrive’ is adapted in the future in other countries, or when new, similar interventions are developed, the existing health facilities in that country should be considered and the intervention content adapted accordingly. For example, some LMICs might be even more restricted in terms of healthcare facilities and resources, compared to SA and this will likely influence the intervention content.

South Africa is known for its diversity in terms of ethnicity, cultures, languages, and geography [571]. Therefore, within SA, the adaptation of the intervention developed in this thesis to various cultures, should be considered in the future. Although the exercise example routines provided in ‘Survive and Thrive’ were appreciated by the women who participated in the acceptability evaluation, Chapter 4, this may not be the case when acceptability is evaluated in other regions in SA. For example, in an intervention developed for women with osteoarthritis in the Free State province [359], participants requested more dancing to be added to the exercise routine. In contrast, exercises that were similar to the general exercise routine example in ‘Survive and Thrive’, were well received in studies that included women with human immunodeficiency virus (HIV) [358] and osteoarthritis [348], in the Western Cape province, SA. Similarly, regional variations are likely to affect the nutritional recommendations, once ‘Survive and Thrive’ is adapted to specific regions within SA. In arid and semi-arid regions of this country, it is challenging to grow vegetables and fruit due to limited water supply and high temperatures [572]. Therefore, the regional availability and affordability of certain foods must be considered when adapting these recommendations in the future. ‘Survive and Thrive’ was available in two languages, however, there are nine further official languages in SA [86]. Once the effectiveness of the intervention has been established, translation into further languages should be undertaken along with cultural adaptation.

6.2.3 Outcomes

This thesis provided both qualitative and quantitative evidence of the extent of LTSEs affecting South African BC survivors, after their MCT. The baseline findings of the intervention study revealed relatively high levels and prevalence of pain and fatigue, relatively low HRQoL index scores, and low levels of physical activity of participants. These poor patient-reported outcomes were somewhat unexpected since most participants in that study were several years following the completion of their MCT, and baseline scores from previous international studies reported a lower symptom burden in long-term survivors [143, 470, 522, 530].

However, the high retention rate and the significant improvements in patient-reported outcomes observed in the intervention study were encouraging, given the exploratory nature of the intervention. This thesis has shown that the symptom burden experienced by BC survivors, and their need for information and support, can feasibly be addressed through a remotely delivered intervention. The resource-preserving nature of the intervention make it potentially applicable for use in primary health care settings. The findings of this thesis support the preposition that outcomes such as pain, fatigue, and HRQoL, are biopsychosocial in nature. Therefore, they can be expected to improve in response to complex interventions addressing biological, and psychosocial components through education and a participative, evidence-based approach.

Participation in the intervention seemed to address biological (through exercise and education) and psychosocial factors (through education, self-management, self-efficacy, and exercise). In complex interventions such as 'Survive and Thrive', the multicomponent nature of these interventions mean that it is usually not possible to tell which intervention ingredients, have led to the positive outcomes observed [84, 85]. In the intervention 'Survive and Thrive', it is likely that the provision of specific information, with practical step-by-step instructions regarding exercise and other healthy lifestyle habits, and the provision of social support, led to an increase in self-efficacy and HRQoL. Biological mechanisms related to improved physical activity and reduced sedentary time, are likely to have contributed as well, particularly to the improved symptom burden post-intervention [194]. Indeed, it has been suggested in recent studies, that the success of an intervention depends on the extent to which it meets the needs of a target population [194, 234, 345].

Previous South African interventions using self-management principles developed for women with other, more prevalent chronic conditions, have used an on-site, group-based format [348, 358, 359]. Therefore, potential participants who lived far away from the clinic sites, and women who worked or looked after children during office hours, were unable to participate. These studies did not provide exact cost analyses; however, they were likely to have incurred costs to reimburse participants for travelling to attend weekly clinic sessions. Interestingly, in the study by Barnes et al. [359], the physical activity levels of participants did not increase significantly in the intervention group compared to the control group, and the minimum exercise guidelines for adults were not met, post-intervention. The authors concluded that the 60 minutes of supervised clinic exercise each week, were insufficient to result in measurable health benefits in their sample of women with chronic diseases.

It can be argued that providing supervised exercise sessions three to five times per week (aiming to meet the published exercise guidelines) would be unfeasible in most low- to middle income settings. Therefore, methods should be explored to foster independent, self-guided exercise focusing on self-management education and self-efficacy [201, 230].

In the study by Parker and colleagues evaluating a group-based SMI for women with HIV [358], there were significant improvements in almost all health-related outcomes post-intervention, in both the intervention group which attended in-person sessions, and in the control group which relied on a workbook including self-management and social cognitive principles. Post-intervention, there were no significant differences between the intervention and control groups in that study. The findings of the latter two studies suggest that on-site clinic visits are likely unnecessary to improve physical activity and other health-related outcomes such as pain and HRQoL, in South African women with chronic conditions. On the other hand, the participants of the abovementioned two studies may have benefitted from the weekly face-to-face social interaction with each other, which the intervention in this thesis did not provide. Indeed, the potential added benefit and sustainability of studies requiring on-site attendance should be explored against well designed, remotely delivered SMI, considering the added costs incurred to provide staff, facilities and transport.

Recently, peer-driven interventions have shown promise in the rehabilitation of BC survivors [217, 573]. Delivering 'Survive and Thrive' through fellow survivors who are trained and supported by a physiotherapist, may be a cost-and resource-saving opportunity to expand the clinical application of this intervention in the future. Women who have completed 'Survive and Thrive' may be interested in acting as peer facilitators of the intervention. After receiving training, they could offer mentoring support to future participants completing the intervention. The outcomes of this peer-driven intervention delivery may be evaluated against the mode of delivery described in this thesis (physiotherapist-facilitated), using mixed methods. This may shed light on the added benefits that peer-driven rehabilitation might offer, while investigating the outcomes of 'Survive and Thrive'. Empowering women with BC to act as role models for others, may or may not encourage them to continue with positive changes they have made to their own health, and this presents a further research opportunity.

This thesis contributes to the growing body of evidence supporting remotely delivered, accessible interventions that include rehabilitation and physical activity [95]. Baseline levels of pain and fatigue, HRQoL, self-efficacy and physical activity levels, were revealed in a sample of South African BC survivors.

The feasibility, safety, and potential benefit of the developed intervention were demonstrated in this thesis. This work represents a first step towards providing quality survivorship care to South African BC survivors. It aimed to address commonly experienced physical LTSE and to improve the HRQoL of women, providing a platform for future improvements in the quality of survivorship care.

The clinical and research recommendations arising from this thesis are highlighted in the following section.

6.2 Recommendations

6.2.1 Clinical

Clinical recommendations arising from the studies in this thesis are as follows:

- Ideally, baseline patient-reported outcome measures of pain, cancer-related fatigue, and physical activity should be taken of all early-stage BC survivors who have completed their primary MCT. An intervention such as the one presented in this thesis, should be offered, and assessment should be repeated at follow-up to determine the effectiveness of the intervention. If baseline measurements are categorised as 'severe' according to the authors of an administered instrument, that BC survivor should be offered referral for further evaluation to establish the cause of her severe symptoms, before commencing with the intervention.
- Time and staff restrictions may prevent the blanket administration of baseline patient-reported outcome measures, as recommended above. At a minimum, the use of an early warning system for upper limb morbidity is recommended. This system, developed by Shamley and Robb [574], uses the pain questions from the Shoulder Pain and Disability Index (SPADI) [362] with the early symptoms of lymphoedema, to identify women who are at high risk for upper limb morbidity and therefore require early rehabilitation intervention. However, this system does not identify women with high levels of cancer-related fatigue, which also requires medical investigation [6]. Therefore, measuring cancer-related fatigue is recommended in addition to the early warning system for upper limb morbidity.
- Physiotherapists employed at healthcare facilities that include breast clinics, should be trained to screen if BC survivors may safely engage with unsupervised exercise and provide each woman with a 'Survivorship information for breast cancer' handbook. The physiotherapist should offer to connect interested survivors of BC with each other, through a WhatsApp group, or through a similar application.

The physiotherapist should be familiar with the handbook content, facilitate the intervention for 12 weeks, and be prepared to offer remote support through email, SMS, WhatsApp, or through a similar communication channel.

- Healthcare providers should actively encourage not only upper limb-, but also regular general exercise [350]. They should provide BC survivors with evidence-based, accurate, and specific exercise guidelines for cancer survivors [18], thereby supporting and reinforcing rehabilitation interventions. Such clear guidance from healthcare providers may significantly impact physical activity in BC survivors [575, 576].

6.2.2 Research

The studies presented in this thesis indicate a need for further research. The following research recommendations should be considered:

- Qualitative studies are required to further explore the experience of LTSEs, and the rehabilitation needs of women from other sociocultural backgrounds in SA. This would inform the generalisability of the qualitative study findings and facilitate further tailoring of the intervention, as required. Understanding the needs of BC survivors would assist healthcare providers in specific regions to plan, prioritise, and improve the survivorship care that they offer.
- Large-scale epidemiological studies are needed to determine the prevalence of important health indicators such as pain, cancer-related fatigue, overweight and obesity, lymphoedema, physical activity levels, and psychological outcomes including anxiety and depression, in South African BC survivors. In cancer research, such scarcity of reliable data is common in low- and middle income countries, owing to a lack of funding and resources in these regions [577].
- Now that an intervention has been developed, the next step in evaluating 'Survive and Thrive', should be through a well-funded RCT, including long-term follow-up. This will allow comparison of different versions of the intervention to explore its effectiveness, without necessitating a control group not receiving the intervention. A mixed-methods approach is recommended, to allow further refinement and adaptation of the intervention in response to the study results.

6.2.3 Social integration and community participation

- Participation in 'Survive and Thrive' was associated with significant improvements in pain, cancer-related fatigue, HRQoL, self-efficacy, and physical activity.

To help maintain the positive health changes made during their participation, women should be referred by their breast clinics to free local community health initiatives promoting a healthy lifestyle. One example, which has been selected as most of the participants in the intervention study were from this province, is Western Cape on Wellness (WOW). Social integration through participating in this or similar programmes may motivate women to continue with their adopted healthy lifestyle, and this may lead to further improvements in their health.

- Participants in the qualitative study, chapter 2, reported that they would appreciate an improved connection to cancer support organisations. Therefore, it is recommended that BC survivors are encouraged by healthcare providers, to contact and engage with cancer support organisations, if they would like this [558, 578]. These organisations offer valuable peer support, and they provide long-term survivors, with the opportunity of supporting newly diagnosed BC patients. This may lead to further empowerment, successful social integration, and community participation [356, 558, 578].

6.3 Limitations

- Although it is an advantage that the intervention was informed by the qualitative study findings (Chapter 2), the latter study was conducted in a single setting, using BC survivors from one South African province. As mentioned above, further work is needed to establish the generalisability of these findings.
- The systematic review in Chapter 3 included 10 studies, of which several were pilot studies with small sample sizes, and with a 'high' risk of bias. Several of the included studies could not be pooled for the meta-analysis due to insufficient reporting. The quality of evidence in the meta-analysis was high only for objectively measured physical activity.
- The acceptability evaluation of the intervention (Chapter 4) had a small sample size. Therefore, the views of participants in that study did not necessarily represent those of the entire BC survivor population.
- In the intervention study, Chapter 5, it was not possible to determine the adherence of participants to activities advocated by the intervention. Finally, psychological outcomes such as anxiety and depression, were not evaluated in the intervention study.

6.4 Summary

The main aim of this thesis was to explore the rehabilitation needs, then to develop, implement and evaluate a new rehabilitation model of care with a wide reach, advocating a person-centred approach for South African early-stage BC survivors following the completion of primary MCT, who are living with the long-term effects of their disease. The chapter-specific aims of this thesis were addressed as outlined below:

1. *To explore the lived experience of physical LTSEs, and to investigate the rehabilitation needs of BC survivors in a semi-urban setting in SA.*

To address this aim, a study was conducted using a qualitative descriptive design, through focus group discussions. This study recruited a sample of 23 women using a South African public health facility. Participants were predominantly unemployed with a low household income, and low levels of education. In this study, most participants had stage III BC and had needed mastectomies plus a combination of both chemo- and radiotherapy.

Using inductive analysis, three main themes emerged from the data: 1. Long-term side effects of BC treatment are unaddressed and impair quality of life: Participants described how problems such as shoulder and chest wall pain, upper limb stiffness, cancer-related fatigue, weight gain, reduced overall physical function, and lymphoedema, were affecting their daily lives and their ability to earn an income. 2. Lack of information and access to support: Following the completion of MCT, they had received no form of education or intervention to support their rehabilitation. Thus, upon completion of their MCT, participants in this study relied on the upper limb exercises they had been given post-surgery, in hospital; on advice from family or friends; or on intuition, to self-manage their LTSEs. Participants stated that they needed information on every aspect of BC survivorship, including the management of LTSEs, how often to go for follow-up visits at the clinic, how to detect cancer recurrence or new cancer, how to stay healthy, and how to manage anxiety and stress. Many women in this study had never been in contact with cancer support organisations, and they felt that emotional support would benefit their recovery. 3. Perception that exercise is generally good but specific guidance is needed: Participants in this study felt positively about exercise in general. However, they reported that they had not received specific information about general exercise for BC survivors. Women who had asked their healthcare providers about exercise, received vague, cautioning responses instead of evidence-based information. Preferences regarding the mode of exercise and intervention delivery varied, and common barriers and facilitators for exercise were identified.

One barrier was the lack of transport to and from healthcare facilities, since transport was perceived to be expensive. These findings indicated that an intervention was required to support women as they manage survivorship. An intervention was to be multifactorial to include all commonly experienced BC survivorship concerns. It was to provide tailored information about and instructions for both upper limb and general exercise. The intervention was to offer to connect women with support organisations, and with other BC survivors. Furthermore, the intervention was to be accessible to BC survivors within SA, regardless of their income, employment status, or geographic location.

To the knowledge of this author, this study was one of the first to investigate the experience of LTSEs and rehabilitation needs, in South African BC survivors. The study uncovered unnecessary suffering and important health-related needs of this group of cancer survivors. The findings of this study echoed a lack of BC specific health literacy which had been reported by previous South African studies [75, 102]. It also highlighted the inability of health services to cope with the burden of long-term problems resulting from BC. Reviews of systematic reviews have shown that supervised interventions using exercise can ameliorate LTSEs of BC [52, 96, 239], and international exercise guidelines for cancer survivors exist [18]. However, the findings of this study suggested that an on-site intervention may not be sustainable, clinically transferable, and widely accessible in SA, considering the massive resource restrictions characterising the public health system [89, 497]. Providing information and exercise with self-management skills, using evidence-based behaviour-change strategies, and facilitative support, were essential components based on the findings of this study. However, as an alternative to supervised interventions, the effectiveness of SMIs including an exercise component, was unknown [200, 201]. Therefore, a systematic review was needed to investigate this.

2. *To evaluate the effects of supported self-management interventions including an exercise component and utilising minimal clinical visits, on physical LTSEs and physical activity, in early-stage post-treatment BC survivors.*

To address this aim, a systematic review and meta-analysis was conducted to determine if SMIs requiring a maximum of three clinical visits (to allow for outcome assessments), and without supervision of participants, expensive equipment or digital wearable devices (for example, smartwatches), are effective at improving outcomes such as pain, fatigue, HRQoL, and physical activity. This review was registered on PROSPERO and was informed by the PRISMA [241] reporting guidelines.

A systematic search of four databases was undertaken with the assistance of a Health Science Librarian. Studies retrieved through database- and hand searching were independently screened by two reviewers. Ten RCTs met the inclusion criteria, including a total of 823 participants. Data extraction was conducted by two researchers independently, discrepancies were discussed with a third reviewer until consensus was reached. The included studies were from South Korea [284, 290], Australia [103], the USA [286-288, 291, 292], Turkey [289], and the UK [285]. Interventions varied regarding their mode of delivery (online, web-based, printed workbooks, DVDs, text messaging, telephone, face-to-face counselling), length (12 weeks to 12 months), and underlying theory (social cognitive theory, transtheoretical model, motivational interviewing). Of the 10 interventions, nine reported significant improvements in health-related outcomes compared to control groups, post-intervention.

Five of the six studies assessing HRQoL; five of seven studies assessing self-reported physical activity; three of five studies assessing fatigue; four of seven studies assessing anthropometry; three of four studies assessing physical fitness; three of three studies assessing motivational readiness for exercise; one of two studies assessing muscle strength; two of two studies assessing self-efficacy; and one of one study assessing pain; found significant improvements in their intervention groups compared to controls. Using the Cochrane collaboration's revised risk of bias tool (RoB 2) [246], the overall risk of bias within the 10 studies was rated as 'high'. The results of the meta-analysis revealed significant improvements in HRQoL, fatigue, self-reported and objectively measured physical activity, and waist circumference of the intervention groups, compared to control groups. The application of the GRADE quality assessment tool yielded low (HRQoL, fatigue, body fat, body weight, and waist circumference), moderate (self-reported physical activity, BMI), and high (objective physical activity) quality of evidence. No adverse events relating to participation in the interventions were reported in the studies.

This systematic review and meta-analysis provided evidence that SMIs including an exercise component, and requiring minimal clinical visits, can improve health-related outcomes in early-stage post-treatment BC survivors. More studies are needed using larger sample sizes, improved methodological rigour, and long-term follow-up, to draw definite conclusions. However, this systematic review revealed that SMIs should be recommended to survivors of early-stage BC after MCT, if they do not have access to supervised interventions, and if they can safely participate in unsupervised exercise. The content of interventions included in this review did not match the comprehensive informational requirements identified by participants in the qualitative study, Chapter 2. Moreover, there were no studies that used interventions developed for low- and middle income countries.

Apart from providing evidence that SMIs may be effective, the following evidence gleaned from this systematic review, informed the structure of the intervention to be developed:

Most of the included studies utilised an intervention duration of 12 weeks and used the social cognitive theory as a basis. To encourage exercise adherence, the interventions included in this review used exercise diaries or activity logs. Seven out of 10 included studies used printed material such as a booklet, workbook or tip-sheets. Most interventions combined different modalities, for example, printed material with emails or text messages. Finally, most of the included interventions allowed participants to choose the mode of exercise that they preferred. Therefore, the new intervention was informed by the above evidence, and by the rehabilitation needs identified in Chapter 2. As a next step, the intervention development was described systematically using published guidelines.

3. *To develop an intervention using published guidelines, based on the data from the preceding chapters, and to evaluate its content validity and acceptability.*

Development of the intervention 'Survive and Thrive' was guided by the Medical Research Council (MRC) guidelines for intervention development, which have recently been updated and adapted [269, 270]. Actions recommended by the guidelines include understanding the problem and its context; planning the process; involving stakeholders; bringing together a team to design the intervention; reviewing published evidence; drawing on existing theories; articulating programme theory; primary data collection; designing and refining; and attending to future implementation. These actions were taken during the development of the intervention and were described in detail.

The intervention included studying a section of the intervention handbook each week for 12 weeks, and completing tasks in it, remote access to a facilitator (PhD candidate) for support, questions, or concerns, and joining an optional WhatsApp group with other participants. Twelve chapters were designed to be completed consecutively. Every week focused on a specific topic. The handbook was designed using published local and international evidence, based on the social cognitive theory [37] and self-management principles [83]. The results of the qualitative study in Chapter 2 and the systematic review in Chapter 3, directly influenced the content of the intervention. The content was validated by the three researcher-supervisors of this project, and by a multidisciplinary team of five local clinical experts in the field of Oncology and Rehabilitation. The intervention was refined according to this feedback, before being evaluated for acceptability through a small qualitative study including three BC survivors. Informed by the results of this study, the intervention was refined further.

Characteristics of 'Survive and Thrive' that differentiate it from other interventions, are that it was designed to be pragmatic, resource-efficient, delivered comprehensive information about BC and related health challenges using simple language, and promoted specific upper limb and general exercise through step-by-step example routines that could be completed from home, needing minimal equipment. Furthermore, the intervention was developed specifically for South African BC survivors after MCT, offered to connect BC survivors with each other as a source of group support, and had a wide reach: no clinical visits were required to complete the intervention. The newly developed intervention warranted exploration of further feasibility domains, safety, and preliminary outcomes. This was undertaken in the next chapter of this thesis.

> *4. To evaluate if the newly developed intervention was feasible and safe to deliver, and if it was associated with improvements in commonly occurring physical LTSEs, physical activity, HRQoL, and self-efficacy.*

The 12-week SMI was evaluated using a single-group, pre-test post-test study design. Breast cancer survivors from six South African provinces were efficiently recruited and retained (retention rate 94%). Intervention delivery was feasible in this study. Previously validated outcomes were used to evaluate the utility of the intervention. Participant response rates to weekly reminder messages to work through content and to complete activities advocated by the intervention, were high.

Costs per participant to deliver the intervention seemed low compared to on-site interventions and considering the substantial gain in QALYs calculated. No adverse events related to participation were reported. Baseline patient-reported outcome measures revealed that women in this study experienced a relatively high prevalence of pain and cancer-related fatigue. Furthermore, pain and fatigue severity and interference scores were moderate. Health-related quality of life index scores and physical activity levels were low compared to BC survivors in previous studies, conducted in high-income countries. The patient-reported outcomes assessed this study indicated that women who participated had significantly reduced pain and fatigue prevalence, and significant improvements in pain severity and interference, fatigue severity and interference, HRQoL, self-efficacy and physical activity participation, following the intervention. Furthermore, improvements observed for pain, fatigue, and HRQoL, were found to be clinically significant. Therefore, this study provided preliminary evidence that the 12-week, remotely delivered SMI is feasible, safe, and potentially effective.

6.5 Conclusion

This thesis has shown that LTSEs are a significant burden for South African BC survivors from a low socio-economic background. These women, who are often breadwinners and caretakers of their families, continue to experience side effects affecting their HRQoL, for many years following MCT. Furthermore, South African BC survivors revealed their rehabilitation needs and preferences to address LTSEs. Although SMIs may be effective to improve health outcomes, there was a lack of contextually relevant interventions for South African BC survivors. In this thesis, the process of developing and evaluating a novel SMI was described in detail, using published intervention development guidelines.

The thesis demonstrated that a remotely delivered SMI is feasible, safe, and potentially successful to address pain, cancer-related fatigue, HRQoL, physical activity and self-efficacy, in South African BC survivors. The evidence gained from this thesis shows that SMIs should be offered to BC survivors who are not receiving supervised interventions, and who can safely participate in unsupervised exercise. This thesis provides a platform for BC rehabilitation research in low- and middle income countries, by exploring the development, implementation, delivery, and utility of a pragmatic intervention with a wide reach, using evidence-based strategies.

Appendices

Appendix A: Consolidated criteria for reporting qualitative studies (COREQ) checklist.

Developed from:

Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

YOU MUST PROVIDE A RESPONSE FOR ALL ITEMS. ENTER N/A IF NOT APPLICABLE

No. Item	Guide questions/description	Reported on Page #
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Inter viewer/facilitator	Which author/s conducted the interview or focus group?	35
2. Credentials	What were the researcher's credentials? E.g., PhD, MD	35
3. Occupation	What was their occupation at the time of the study?	35
4. Gender	Was the researcher male or female?	35
5. Experience and training	What experience or training did the researcher have?	35
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	35
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g., personal goals, reasons for doing the research	37
8. Interviewer characteristics	What characteristics were reported about the inter viewer/facilitator? e.g., Bias, assumptions, reasons and interests in the research topic	35
Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	33
Participant selection		
10. Sampling	How were participants selected? e.g., purposive, convenience, consecutive, snowball	34
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	35
12. Sample size	How many participants were in the study?	42
13. Non-participation	How many people refused to participate or dropped out? Reasons?	42
Setting		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	33

15. Presence of non-participants	Was anyone else present besides the participants and researchers?	37
16. Description of sample	What are the important characteristics of the sample? e.g., demographic data, date	43
Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Appendix D
18. Repeat interviews	Were repeat inter views carried out? If yes, how many?	35
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	35
20. Field notes	Were field notes made during and/or after the interview or focus group?	N/A
21. Duration	What was the duration of the inter views or focus group?	42
22. Data saturation	Was data saturation discussed?	34
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	N/A
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	How many data coders coded the data?	40
25. Description of the coding tree	Did authors provide a description of the coding tree?	N/A
26. Derivation of themes	Were themes identified in advance or derived from the data?	40
27. Software	What software, if applicable, was used to manage the data?	40
28. Participant checking	Did participants provide feedback on the findings?	40
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g., participant number	40
30. Data and findings consistent	Was there consistency between the data presented and the findings?	45
31. Clarity of major themes	Were major themes clearly presented in the findings?	45
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	45

Appendix B: Recruitment poster for Chapter 2

Appendix C : Socio-demographic questionnaire for Chapter 2

Initial socio-demographic questionnaire for first (pilot) focus group discussion:

Study number: _____

Characteristic	Value
Age:	
Employment Status (please tick or mark with an X):	
Employed	
Unemployed	
Pensioner	
Household Income per month	
R 5 000 or less	
R 5 000 – R 10 000	
R 10 000 – R 20 000	
More than R 20 000	
Education (please tick):	
Primary school	
High school	
Higher qualification / degree: please specify	
Do you exercise regularly, or do you regularly walk / cycle for transport? Yes / No	
Do you have problems with your shoulder? Yes / No	
Do you often experience extreme tiredness that does not get better with rest? Yes / No	

Adjuvant therapy (please tick or mark with an X):	
Chemotherapy	
Radiotherapy	
Months since completing treatment:	
Cancer stage: I, II or III	
Surgical treatment:	
Lumpectomy: Left / Right / Both sides?	
Mastectomy: Left / Right / Both sides?	
Do you have arm or chest swelling? If yes, where?	
Do you take hormone therapy? Yes / No	
Other chronic medicine? Please specify	

Amended socio-demographic questionnaire, following first (pilot) focus group discussion:

Study number: _____

Characteristic	Value
Age:	
Employment Status (please tick or mark with an X):	
Employed	
Unemployed	
Pensioner	
Household Income per month	
R 5 000 or less	
R 5 000 – R 10 000	
R 10 000 – R 20 000	
More than R 20 000	
Education (please tick):	
Primary school	
High school	
Higher qualification / degree: please specify	
Do you exercise regularly, or do you walk or cycle for transport? Yes / No	
Do you have problems with your shoulder? Yes / No	
Do you often experience extreme tiredness that does not get better with rest? Yes / No	

Adjuvant therapy (please tick or mark with an X):	
Chemotherapy	
Radiotherapy	
Months since completing treatment:	
Cancer stage: I, II or III	
Surgical treatment:	
Lumpectomy: Left / Right / Both sides?	
Mastectomy: Left / Right / Both sides?	
Do you have arm or chest swelling? If yes, where?	
Do you take hormone blocking medicine for example, tamoxifen? Yes / No	
Other chronic medicine? Please specify	

Appendix D: Semi-structured discussion guide for Chapter 2 focus group discussions

An investigation of the rehabilitation needs for long-term physical treatment-related side effects in breast cancer survivors.

a) Experience of body changes, fatigue, and quality of life questions

You may experience the following long-term physical side effects for many years after the end of your treatment: **shoulder pain and shoulder problems, fatigue (extreme tiredness that does not get better with rest), weight changes, lymphoedema (arm swelling) and changes in your overall physical function**.

This section aims to explore how these side effects have impacted your lives.

1. Describe the physical changes in your body that you or others have noticed since you completed your cancer treatment.
2. How have you been feeling (physically/psychologically/emotionally/cognitively) since you completed cancer treatment?
3. How have your energy levels been as a cancer survivor?
4. Are there any activities you are no longer able to participate in since your diagnosis?
5. Have the long-term side effects of breast cancer treatment affected your employment prospects or status?
6. Have you tried anything to improve these symptoms in the past few months?
7. Did a healthcare provider warn you that these long-term side-effects may occur before you started your breast cancer treatment?

b) Perceptions of exercise as a cancer survivor

By exercise, we mean exercise apart from the shoulder exercises you received after your breast surgery.

1. Tell me about your exercise levels now and before your diagnosis.
2. How do you feel about exercise as a cancer survivor?
3. During your breast cancer journey so far, has a healthcare provider recommended that you should exercise?
4. Where did you get information about exercise?

c) Information needs and preferences.

1. Would it have been helpful if you had received more information about living with early-stage breast cancer?
2. How (in what format) would you have liked to receive this information? (hard copy, e-mail, WhatsApp, website, app)
3. What type of information do you think is important to be included in this? (more info on physical / psychological / emotional aspects of living with breast cancer)
4. When would you have preferred to receive this information? (at diagnosis, pre-op, post-op, at end of treatment)

d) Willingness to participate in an intervention including exercise, and rehabilitation needs.

1. Describe any regular exercise you were doing before your breast cancer diagnosis.
2. What makes it easy for you to exercise?
3. What makes it hard for you to exercise?
4. What type of exercise can you imagine yourself participating in?
5. Would you prefer training sessions to be led by a qualified rehabilitation professional or a trained fellow breast cancer survivor from your community?
6. Is there a place near your home or work where it is safe to exercise, do you have a specific place in mind?
7. Since completing your medical cancer treatment, have you received sufficient rehabilitation to allow a return to your previous level of function?
8. If not, what do you think would have been helpful?

Sections a (1-7), b (1-4) and d (1-4): Sander AP, Wilson J, Izzo N, et al. Factors that affect Decisions about Physical Activity and Exercise in Survivors of Breast Cancer: A Qualitative Study. *Phys Ther* 2012; 92(4):525-36.

c (1-4), d (5-8): These questions are specific to the context of this study.

Appendix E: Ethical approval letter for Chapter 2

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room E53-46 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6626
Email: shuretta.thomas@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

29 July 2019

HREC REF: 506/2019

A/Prof Delva Shamley
Clinical Research Centre

Dear A/Prof Shamley

PROJECT TITLE: AN INVESTIGATION OF THE REHABILITATION NEEDS FOR THE LONG-TERM PHYSICAL SIDE EFFECTS OF TREATMENT IN BREAST CANCER SURVIVORS. (PHD CANDIDATE: MS A BEUTEL)

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year until the 30 July 2020.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

Please quote the HREC REF in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necessary, before the research may occur.

The HREC acknowledge that the student, Anita Beutel will also be involved in this study.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE
Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938
This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical

Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH 2006), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI), and Declaration of Helsinki (2013) guidelines.
The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

Appendix F: Letters to and from stakeholders. Western Cape Department of Health, facility managers of breast and community health clinics, for Chapter 2.

Letter to the Western Cape Department of Health

Western Cape Health Research Committee

To whom it may concern

RE: Requesting permission to conduct a research study

I, Anita Beutel, am currently doing my PhD in Physiotherapy at the Department of Health and Rehabilitation Sciences at the University of Cape Town. I would like to inform you about the research study I wish to conduct in breast cancer survivors in the Southern Cape, accessing George Regional Hospital.

Background:

Breast cancer is the most common malignancy in South African women, and its survival rate is high. Apart from acute side effects experienced during medical treatment, survivors face a plethora of long-term side effects following the completion of surgery, chemotherapy, and radiation. These side effects are commonly experienced, affect their daily function, quality of life and their ability to return to work. Long-term problems include shoulder morbidity, cancer-related fatigue, reduced physical function, weight gain, lymphoedema, and others. Most of these can be ameliorated through targeted education and exercise interventions, which are recommended by international survivorship guidelines. At present, survivors in our country do not have access to structured interventions following the completion of their primary cancer treatment. Yet, many women in this country are expected to be breadwinners, while at the same time providing care for their families. In South African women, long-term physical problems after breast cancer treatment are not well researched, and it is unknown what type of intervention would be suitable to address their needs.

Thus, the title of my study is:

"AN INVESTIGATION OF THE REHABILITATION NEEDS FOR LONG-TERM PHYSICAL SIDE EFFECTS OF TREATMENT IN BREAST CANCER SURVIVORS."

The intention of this study is to explore the rehabilitation needs of breast cancer survivors, particularly in a relatively under-resourced area such as the Southern Cape, through a qualitative study using focus group discussions. Using this information, a suitable rehabilitation intervention can then be developed. Care will be taken to develop an intervention in the next phase of research that does not place a strain on the health system, and that will be widely accessible to women.

The specific objectives of the study are:

- To explore the lived experience of long-term physical side effects of breast cancer.
- To describe survivors' perspectives of exercise participation.
- To describe women's rehabilitation preferences, regarding content, delivery, modes of exercise or activity, venue, frequency, health care provider or peer led.

Ethical Considerations

The study will conform to the principles of the Declaration of Helsinki (2008). Ethical approval has been obtained from the Faculty of Health Sciences, University of Cape Town (Reference number: 506/2019). All information obtained from participants will be kept confidential. Their identity will be anonymous and will only be used for data analysis and writing of results. All stakeholders will be acknowledged with all publications and conference proceedings. The findings of the study will be disseminated to you and respective departments.

I would like to request permission to access the breast clinic and primary health care clinics to place flyers advertising the study in waiting areas, from approximately July 2019 to February 2020, or until we have reached data saturation. Sealed boxes will be provided for interested breast cancer survivors to place their contact details in, should they be interested in participating in this study. I will empty these collection boxes regularly. There will be no strain placed on the staff at any of these facilities. I also request permission to use a boardroom at George Regional Hospital, for focus group discussions with breast cancer survivors. There will be a maximum of six breast cancer survivors in each discussion. These sessions will take no more than two hours. We will require exclusive use of the venue when it is not otherwise in use. I will liaise with the contact person at the hospital to book the venue. Lastly, I would like to request permission to access the hospital files of the participants in this study, to confirm their medical cancer treatment details. We estimate that the sample size for this study should be no more than 30 women.

I have attached a copy of my research proposal if you require any additional information regarding my study.

I look forward to hearing from you and your assistance is greatly appreciated.

Sincerely

Anita Beutel (PhD student)

BTLANI@myuct.ac.za

Supervisors:

A/Prof Delva Shamley delva.shamley@uct.ac.za

A/Prof Theresa Burgess theresa.burgess@uct.ac.za

A/Prof Niri Naidoo niri.naidoo@uct.ac.za

Prof. M Blockman (Human Research Ethics Committee, Faculty of Health Sciences,) marc.blockman@uct.ac.za

Tel: 021-406-6626

Letter to Facility Manager (Breast clinic, primary health clinics)

To whom it may concern:

RE: Requesting permission to conduct a research study

I, Anita Beutel, am currently doing my postgraduate studies in Physiotherapy (PhD) at the Department of Health and Rehabilitation Sciences at the University of Cape Town. I would like to inform you about the research study that I wish to conduct in breast cancer survivors attending the breast clinic or community health clinics in George. Specifically, I would like to learn more about their experience of long-term side effects of breast cancer treatment, and their rehabilitation needs. This information is needed to inform the development of a rehabilitation intervention that would meet their needs and help to reduce the functional and socioeconomic impact of long-term side effects on women and on state resources.

A non-pharmacological management approach, comprising of exercise and education using a cognitive behavioural approach, may be a suitable method to ameliorate the impact of long-term side effects such as shoulder morbidity, cancer-related fatigue, weight gain, lymphoedema, and reduced physical function, on function and quality of life. However, there seems to be a dearth of sustainable, evidence-based, and feasible interventions for women after breast cancer treatment, in South Africa.

Thus, the topic of my study is: "AN INVESTIGATION OF THE REHABILITATION NEEDS FOR LONG-TERM PHYSICAL SIDE EFFECTS OF TREATMENT IN BREAST CANCER SURVIVORS."

The intention of this study is to explore the rehabilitation needs of breast cancer survivors, particularly in a relatively under-resourced area such as the Southern Cape, through a qualitative study using focus group discussions. Using this information, a suitable rehabilitation intervention can then be developed. Care will be taken to develop an intervention in the next phase of research that does not place a strain on the health system, and that will be widely accessible to women.

The specific objectives of the study are:

- To explore the lived experience of the long-term physical side effects of breast cancer.
- To describe survivors' perspectives of exercise participation.
- To describe women's rehabilitation preferences regarding content, delivery, modes of exercise or activity, venue, frequency, health care provider or peer led.

Ethical Considerations

The study will conform to the principles of the Declaration of Helsinki (2008). Ethical approval has been obtained from the Faculty of Health Sciences, University of Cape Town (Reference number: 506/2019). All information obtained from participants will be kept confidential. Their identity will be anonymous and will only be used for data analysis and writing of results.

Stakeholders will be acknowledged with all publications and conference proceedings. The findings of the study will be disseminated to you and respective departments.

I would like to request permission to access the breast clinic and primary health care clinics to place flyers advertising the study in waiting areas, from approximately July 2019 to February 2020, or until we have reached data saturation. Sealed boxes will be provided for interested breast cancer survivors to place their contact details in, should they be interested in participating in this study. I will empty these collection boxes regularly. There will be no strain placed on the staff at any of these facilities. I will take full responsibility for the placement and collection of flyers and boxes, and I ensure you that service delivery at your facility will not be affected in any way. I cannot give an exact date by when the study will be completed but I will alert you on the progress of the study. I also would like to request permission to obtain medical information from the folders of the participants involved in the study.

I have attached a copy of my research proposal if you require any additional information regarding my study.

I look forward to hearing from you and your assistance is greatly appreciated.

Sincerely

Anita Beutel (PhD student)

BTLANI@myuct.ac.za

Supervisors:

A/Prof Delva Shamley delva.shamley@uct.ac.za

A/Prof Theresa Burgess theresa.burgess@uct.ac.za

A/Prof Niri Naidoo niri.naidoo@uct.ac.za

Prof. M Blockman (Human Research Ethics Committee, Faculty of Health Sciences,) marc.blockman@uct.ac.za

Tel: 021-406-6626

Permission letter for Chapter 2, from the provincial Department of Health

Western Cape Government
Health

STRATEGY & HEALTH SUPPORT
Health.Research@westerncape.gov.za
tel: +27 21 483 6857: fax: +27 21 483 9895
5th Floor, Norton Rose House,, 8 Riebeek Street, Cape Town, 8001
www.capegateway.gov.za

REFERENCE: WC_201908_002
ENQUIRIES: Dr S Petros

Room E53-46 Old Main Building
Groote Schuur Hospital
Observatory 7925

For attention: **Dr Delva Shamley**

Re: An investigation of the rehabilitation needs for long-term physical side effects of treatment in breast cancer survivors

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research. Please contact the following people to assist you with any further enquiries in accessing the following sites:

Garden Route District	**Dr Terence Marshall**	**044-803 2752**

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. Researchers, in accessing provincial health facilities, are expressing consent to provide the department with an electronic copy of the final feedback (annexure 9) within six months of completion of research. This can be submitted to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).
3. In the event where the research project goes beyond the estimated completion date which was submitted, researchers are expected to complete and submit a progress date (**Annexure 8**) to the provincial Research Co-ordinator.
4. The reference number above should be quoted in all future correspondence.

Yours sincerely

Dr Melvin Moodley
Director: Health Impact Assessment
10 SEP 2019

DR M Moodley
DIRECTOR: HEALTH IMPACT ASSESSMENT
DATE:
CC **DIRECTOR:**

Appendix G: Informed consent form Chapter 2

DHRS
Department of Health and Rehabilitation Sciences
FACULTY OF HEALTH SCIENCES

University of Cape Town • iYunivesithi yaseKapa • Universiteit van Kaapstad

Divisions of • Communication Sciences & Disorders • Disability Studies • Nursing & Midwifery • Occupational Therapy • Physiotherapy

F45 Old Main Building, Groote Schuur Hospital
Observatory, Cape Town, South Africa, 7925
Telephone: +27 (0) 21 406 6401
Website: www.dhrs.uct.ac.za

An investigation of the rehabilitation needs for long-term physical side effects of treatment in breast cancer survivors.

Dear breast cancer survivor,

My name is Anita Beutel. I am a doctoral student at the University of Cape Town, Division of Physiotherapy. We are doing a study about how long-term physical side effects are experienced after breast cancer treatment. Also, I would like to know how you would feel about exercise rehabilitation. This study has been approved by the Human Research Ethics Committee, Faculty of Health Sciences, University of Cape Town (reference number 506/2019).

Why is this study being done?

Some side effects of breast cancer treatment (like hair loss and nausea) go away after your treatment. There are also long-term side effects. Long-term side effects like weight changes, shoulder problems, arm swelling, and extreme tiredness, can continue for years after surgery, chemotherapy, and radiation. Exercise rehabilitation may be helpful to improve these. We do not know what type of intervention would help South African women yet. This is what we are trying to find out.

Why am I being asked to take part?

You have shown interest by giving us your contact details, or by contacting us. You may take part because you are a woman breast cancer survivor. It has been six months to five years since you completed chemotherapy and / or radiation. Taking part in this study is voluntary.

You may decide to stop at any time, without penalty. You do not have to give us a reason if you decide you no longer want to take part.
We as researchers do not work at the hospital, so taking part will not affect your medical care or visits to the breast clinic. We want to understand how you have experienced the long-term physical side effects of cancer treatment, and how you would feel about exercise rehabilitation.

How many people will take part in the study?
There will be two to six other women who are breast cancer survivors, in the discussion with you.

What will I be asked to do?
I will ask you to come to the boardroom at George Hospital at a time and day that suits you. I will explain what we are going to do and then you may ask any questions. After you have read and signed this form, you will be given a confidentiality agreement to sign. This means you promise not to talk to others about any private things that are discussed. Next, you will be given a short questionnaire. This includes questions such as your cancer, the type of treatment you were given and your age. Your study number (not your name) will be written on this form. If you are unsure about some of the medical questions, I could check this in your hospital file, if you agree.

We ask you to take part in a conversation of about one hour with other women, also breast cancer survivors. I will ask questions about how your experience as a breast cancer survivor has been so far, and how you feel about exercise. Here you may share your experiences and enjoy snacks and drinks afterwards. If you agree, the session will be recorded, and we will take notes. Information will stay confidential and anonymous. At the end of each part of the discussion, I will check your responses by summarizing them. Here you may correct me in case I did not understand something you said in the right way. After the conversation we will send you a summary. This is so that you can check that what we discussed is in the summary. If you have any comments, you can email or mail them back to us.

Recordings and notes will be stored on a password-protected computer. Hard copies will be stored in a locked cupboard in my office until we have completed the data analysis. All raw data will be returned to the university. Recordings and notes will be stored for up to two years, or until data are published. Unpublished data will be stored for six years after the study.

How long will the research take?

We ask you to sign this form and the confidentiality agreement, fill in a short questionnaire and to participate in a single discussion. It will take about an hour and a half in total.

What are the risks of taking part in this study?

There are no physical risks. It could be that thinking and talking about your experiences may cause you to become emotional. You do not need to answer any question with which you are uncomfortable. You are allowed to stop taking part in the study at any time. If you become upset, we can refer you, if you agree, to a psychologist or social worker who will help you. We will ask everyone to not speak to others about private things we talked about in the group. We will ask everyone to only use their first names, or a name that they have made up. We cannot guarantee that other women will keep the discussions private. Filling in of questionnaires and the conversation will be held in a private boardroom at George Hospital.

What are the benefits of taking part in this study?

There are no direct benefits to you. It is an opportunity to share your experiences with others who may have gone through similar things. There will be drinks and snacks available after the discussion and you will be paid R 50 in cash to cover your transport to and from the hospital. You will also get an information leaflet about exercise for breast cancer survivors.

Will the results of the research be shared with me?

After the research we can send you the results by email. We will also host a study feedback session at George hospital, we will invite you.

Who will see the information that is collected about me in the study?

Only the researchers will see the information collected. Your individual identity will not be used in any report or publication. Your personal information will be given a code. Only the researchers will be able to link your name to the study code.

Who do I contact for any questions about the study?

Please feel free to contact me, Anita Beutel 071 539 4920 beutelphysio@gmail.com or any of my study supervisors:

Supervisor: A/Prof Delva Shamley 074 377 5287 delva.shamley@uct.ac.za

Co-supervisor: A/Prof Theresa Burgess 021 406 6171 theresa.burgess@uct.ac.za

Co-supervisor: A/Prof Niri Naidoo 021 406 6171 niri.naidoo@uct.ac.za

If you have any ethical concerns or questions about your rights or welfare as a participant of this research study, the chairperson of the Human Research Ethics Committee, University of Cape Town can be contacted: Professor Marc Blockman 021 406 6338 marc.blockman@uct.ac.za

Consent statement:

By signing this form, you confirm that you have had an opportunity to have your questions about the study answered and that you understand the potential risks. You confirm that you understand what the study is about. You are allowed to stop taking part at any time without giving a reason. You agree that I may confirm medical information relating to your cancer treatment, from your hospital file.

Full name of participant: _____

Signature of participant: _____

Date: _____

E-mail address: _____

OR Postal address: _____

_____

_____

Appendix H: Confidentiality agreement Chapter 2

DHRS
Department of Health and Rehabilitation Sciences
FACULTY OF HEALTH SCIENCES

University of Cape Town • iYunivesithi yaseKapa • Universiteit van Kaapstad

Divisions of • Communication Sciences & Disorders • Disability Studies • Nursing & Midwifery • Occupational Therapy • Physiotherapy

F45 Old Main Building, Groote Schuur Hospital
Observatory, Cape Town, South Africa, 7925
Telephone: +27 (0) 21 406 6401
Website: www.dhrs.uct.ac.za

Dear Participant, dear research assistant and dear translator,

Thank you for supporting breast cancer research. During our focus group discussion, you may hear information that is confidential. We would like to protect the individual privacy of all our study participants, therefore please read and sign the agreement below:

Confidentiality agreement:

As a study participant / translator, I agree not to talk about private matters I may hear during the discussion session, to any outside party. I agree to only use people's first names.

Full name: _____

Signature: _____

Date: _____

Whom do I contact for any questions about the study?

Please contact me, Anita Beutel 071 539 4920 beutelphysio@gmail.com or any study supervisors:

Supervisor: A/Prof. Delva Shamley 074 377 5287 delva.shamley@uct.ac.za

Co-supervisor: A/Prof. Theresa Burgess 021 406 6171 theresa.burgess@uct.ac.za

Co-supervisor: A/Prof. Niri Naidoo 021 406 6171 niri.naidoo@uct.ac.za

In case you have any ethical concerns or questions about your rights or welfare as a participant of this research study, the chairperson of the Human Research Ethics Committee, University of Cape Town can be contacted: Professor Marc Blockman 021 406 6338 marc.blockman@uct.ac.za

Appendix I : Master List Chapter 2

Participant name	Date of birth	Hospital file number	Study number

Appendix J: Chapter 2 breast cancer and exercise information pamphlet for participants

6 Reasons Why Breast Cancer Survivors Should Exercise

1. **REDUCES FATIGUE**
   Start slowly and increase gradually to at least 150 minutes of moderate exercise per week. Moderate means that you are able to talk but not sing while you exercise. Walk whenever you can, always take the stairs and not the lift.

2. **LESS SHOULDER PAIN**
   Continue with the shoulder exercises you were given in hospital after your surgery, to maintain your shoulder motion. They may feel slightly uncomfortable, but should never be painful.

3. **LOWERS YOUR RISK OF ARM SWELLING**
   If you were given an arm sleeve or bandages, wear these while you exercise. STOP exercising and see your health provider if your arm suddenly feels swollen or heavy.

4. **PREVENTS WEIGHT GAIN**
   Include a warm-up, cool-down and stretching phase in your workouts. Get clearance from your doctor before you start a new exercise programme. STOP exercising and see your health provider if you suddenly become weak, lose your balance or have pain that gets worse.

5. **IMPROVES MUSCLE TONE**
   Weight training and household tasks will help to make your body strong. Aim to do strengthening exercises 2-3 times per week. Ask your physiotherapist if you are unsure which exercises are suitable for you.

6. **INCREASES YOUR HEART HEALTH**
   Cancer treatments increase your risk of heart disease. Exercise such as walking, jogging, swimming dancing and netball helps to make your heart strong and healthy again. Choose a type of exercise that you enjoy.

TIP: Training with a friend or in a group is more fun!

Appendix K: PRISMA checklist for systematic review

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Page 70
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	N/A
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Page 71
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Page 71
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Page 72
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	Page 73
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Appendix L
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	Page 74
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	Page 74
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	Page 72
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	Page 74
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	Page 74
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	Page 75
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	Page 75
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	Page 90

Section and Topic	Item #	Checklist item	Location where item is reported
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Page 90
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	Page 75
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	N/A
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	Page 90
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	N/A
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	Page 88
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	Page 76
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	Page 76
Study characteristics	17	Cite each included study and present its characteristics.	Page 82
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	Page 87
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	Page 82
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	Page 95
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	Page 90
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	Page 90
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	Page 89
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	Page 95
	23b	Discuss any limitations of the evidence included in the review.	Page 97

Section and Topic	Item #	Checklist item	Location where item is reported
	23c	Discuss any limitations of the review processes used.	Page 102
	23d	Discuss implications of the results for practice, policy, and future research.	Page 100
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	Page 71
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	Page 71
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	N/A
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	N/A
Competing interests	26	Declare any competing interests of review authors.	N/A
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	Page 74

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

Appendix L: Systematic review search strategy

1) "Breast cancer" OR "breast neoplasm*" OR "breast carcinoma"

2) "self-management" OR "self management" OR "self-care" OR "self care" OR “self-help” OR "self-education" OR "education" OR "training program*" OR "course*" OR self-administ*” OR “self-guided” OR “self-directed”

3)"Exercise*" OR "physical activity" OR "physical training" OR "yoga" OR "Pilates"

4) “post-treatment” OR “post treatment” OR “after treatment” OR “follow-up care” OR “survivor*”

5) 1 AND 2 AND 3 AND 4

Boolean search strategies in different databases:

Pubmed	(“breast neoplasms”[MeSH] OR “breast neoplasms”[All Fields] OR “breast cancer”[All Fields] OR “breast carcinoma”[All Fields]) AND (“self-care”[MeSH} OR “self-care”[All Fields] OR “self-management”[All Fields] OR “self-education”[All Fields] OR “self-help” [All Fields] OR “self-guided” [All Fields] OR “self-directed” [All Fields] OR “self-administered” [All Fields] OR “education”[Subheading]) AND (“exercise” [MeSH] OR “exercise”[All Fields] OR “physical activity”[All Fields] OR “physical training”[All Fields] OR “yoga”[All Fields] OR “Pilates”[All Fields]) AND (“aftercare” [MeSH] OR “after care” [All Fields] OR “post-treatment” [All Fields] OR “post treatment” [All Fields] OR “after treatment” [All Fields] OR “follow-up care” [All Fields] OR “survivorship” [All Fields])
Web of Science	TS=breast neoplasms OR breast cancer AND TS=self-care OR self-management OR self-education OR training programs OR courses OR self-help OR self-guided OR self-administered OR self-directed AND TS=Exercise OR Exercises OR physical activity OR physical training OR yoga OR Pilates AND TS=after care OR after treatment OR post treatment OR post-treatment OR follow-up care OR survivorship
Scopus	TITLE-ABS-KEY breast cancer OR breast neoplasm* OR “breast carcinoma” AND TITLE-ABS-KEY self-management OR self-care OR “self-education” OR “self-directed” OR “self-administered” OR education OR self-help OR self-guided OR course* AND TITLE-ABS-KEY exercise OR physical activity OR physical training OR training program* OR yoga OR Pilates AND TITLE-ABS-KEY “after care” OR after treatment OR “post treatment” OR “follow-up care” OR survivors*
Cochrane Library for clinical trials	breast neoplasms OR breast cancer AND self-care OR self-management OR self-education OR patient education OR self-help OR self-guided OR self-directed AND exercise OR exercises OR physical activity OR physical training OR yoga OR pilates AND after care OR post-treatment OR post treatment OR after treatment OR follow-up care OR survivorship

Filters: Female Humans, English language, publication date 1992-2024, RCTs

Survivorship Information

A handbook for breast cancer survivors

Image: Clipart Library

Name: _____ Date: _____

Survivorship information: a handbook for breast cancer

Welcome to this practical information handbook for breast cancer survivors. You have survived breast cancer, this is wonderful. Well done on winning your battle with cancer. Medical cancer treatments have probably saved your life. The long-term effects of cancer and its treatment can affect you for many years [95]. Long-term challenges like pain, problems with your arm, shoulder and chest, fatigue, weight gain and muscle weakness can lead to disability if they are not addressed [7, 24].

The aims of this handbook are [6, 37, 83, 234]

- To inform breast cancer survivors about commonly occurring long-term side effects of breast cancer and its medical treatment.
- To teach you what you, the survivor can do to prevent and manage the long-term side effects of breast cancer.
- To inform you when to seek professional help, whom to ask for help, and how best to communicate with your healthcare providers.
- To encourage you to develop healthy lifestyle habits, such as eating healthy food and exercising regularly. A healthy lifestyle not only minimises your long-term side effects, but also helps to prevent a cancer recurrence and other chronic diseases from making you ill.

We would like to help women like you, with breast cancer (ductal carcinoma in situ, stage I, stage IIA, IIB or stage IIIA), to be healthy and strong after cancer treatment. After breast cancer treatment, your condition becomes like a chronic disease. Chronic diseases need to be carefully managed, together with your healthcare team. We hope that using this book may help you to learn more about breast cancer survivorship, discover your own potential as a self-manager and to bridge the gap between just surviving, and thriving.

To design this book, we have used information from current research in breast cancer care, breast cancer survivors just like you, researchers, and clinical experts in the field of breast cancer. The clinical experts included a medical doctor who is also a breast cancer survivor, an oncologist, a physiotherapist, a dietician, and a psychologist.

What will I need to do? [37, 83, 208]

To get the most out of this handbook, you will set yourself goals and work to achieve them. You will need to undertake activities, rather than just reading. During your chemo- and radiotherapy, your main goal was to get through it, to survive. But now, as a cancer survivor, you must put that behind you.

Now is the time for a mind shift, where you become motivated to learn how to thrive. The handbook is intended as general information, NOT as a substitute for your medical care. If your healthcare provider has given you different advice to that in this book, follow their guidance as they know your individual situation.

How does this programme work?

In the next 12 weeks, we will discuss different sections of information especially for breast cancer survivors like yourself. You will have 1 week to work through every section. This is to allow you to go through everything carefully and to participate in the activities in every section.

Week 1: Breast cancer: How to manage common long-term effects

Week 2: How to manage common long-term effects of breast cancer (continued)

Week 3: How to become an excellent self-manager and how to plan an exercise programme

Week 4: How to start your exercise programme

Week 5: How to manage your affected shoulder and arm

Week 6: How to detect and manage lymphoedema (arm or chest swelling)

Week 7: How to manage your body weight

Week 8: How to manage pain and stress

Week 9: How to detect a cancer recurrence

Week 10: How to detect skin cancer, blood clots and how to communicate with health providers

Week 11: How to continue as a successful self-manager

Week 12: How to continue as a successful self-manager, useful contacts, and further reading

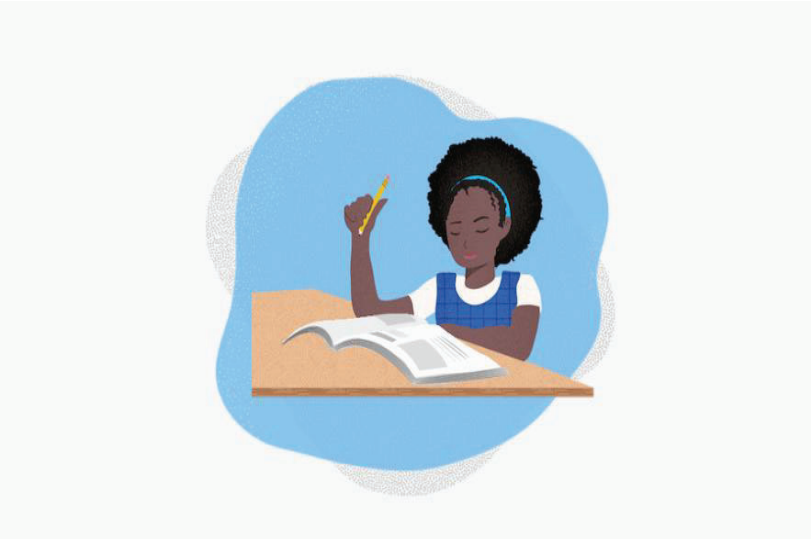


Image: Clipart Key

Who can benefit from this book?

This handbook is specifically for women who have finished their medical cancer treatment. With medical cancer treatment we mean breast surgery to remove the cancer, chemotherapy, and radiation [558]. **You can work through this book once you have finished chemotherapy and / or radiation. If your treatment included breast surgery only, without chemotherapy or radiation, use it from three months after your breast surgery** [6].

Real breast cancer survivors like you, said this about their lives after breast cancer treatment:

'You don't know what to expect afterwards. You don't know, is it finished or what do you do now?' 'I'm just saying that if I had this information, I was going to be prepared… you need to focus on this now and you need to focus on this now. So now, I must change my way forward. I must change the way I think.'

'For me, I didn't know that all these things are going to happen to me. So now I hear this stuff and I know I need to prepare myself.'

'I know people who have just been diagnosed with cancer and they came to me. Then I told them, all I can explain to you is what I went through. I can't add anything for you.'

'If it can be bound into a booklet. It doesn't have to be a large booklet. It can be a small booklet. It's permanent; it's there for ever... A person forgets so quickly. When I get rebellious or emotional, my kids can say remember, it did say that that could happen in the booklet.'

'We did get pamphlets to read during the treatment to let you know how the treatment would make you feel and what to do. But not after the treatment. It would have helped.'

You will find more quotes of real breast cancer survivors further on in this handbook.

Before you start [83, 208]

- Tell a friend or a family member that you are taking part in this intervention. Talk to them regularly about how it is going.
- Use this book regularly and complete the activities in it. Then, after working through it, keep up the changes you have made.
- Get ready to go through the content with an open mind regarding how you can become healthy and strong. The goal is to thrive, rather than just to survive!

Week 1: Breast cancer: How to manage common long-term effects

Concepts Explained:

Breast cancer is when *cells* (the smallest living parts of your body) start to grow faster than they should. Breast cancer is when cells start to grow out of control in the breast [77, 558].

A tumour is when the breast cancer cells together form a lump. A lump that contains cells that can spread to other parts of the body is a *malignant* tumour. Many lumps are not cancer, meaning they do not contain cells that can spread to other parts of the body. These are *benign* tumours [77].

Types of breast cancers: Breast cancer can start in the tubes that carry milk to the nipple (*ductal* cancer) or in the glands that make breast milk (*lobular* cancer). There are also other, less common types. If the cancer has spread within the breast or to an area near the breast, it is *invasive* breast cancer. If the cancer has spread to distant body parts, this is called *metastatic* breast cancer [77].

Hormone receptive breast cancers respond to hormones, which means they respond to hormone blocking medicine such as Tamoxifen [6].

Breast cancer spreads when the cancer cells get into the blood or lymph system. This way they get taken to other parts of your body where they can grow out of control [77].

Your cancer stage depends how big the tumour is and if it has spread or not. If you had stage I, II or III breast cancers, this means that your cancer did not spread to other parts of your body, or that it spread to lymph nodes close to your breast (*local* lymph nodes). If found early and treated with surgery, chemo- and radiotherapy and sometimes with hormone-blocking medication, you have a good chance of survival. Stage IV (4) means that the cancer has spread to parts far away from your breast like the bones, lungs, or liver. This is advanced breast cancer [77].

Anaemia can occur when there are not enough oxygen carrying cells in your blood. Anaemia can have many different causes. One of the causes is not having enough iron in your body (*iron deficiency*) [6, 7].

Thyroid dysfunction is when the thyroid gland is not working as it should. Your thyroid is a gland that makes little messengers called *hormones*. These help your body to function as it should. If your thyroid does not make enough hormones, this will cause you to feel tired and weak [6].

Cardiac dysfunction is when the heart is not working or pumping blood properly. This can be because of narrowed tubes (*arteries*) in your heart or from high blood pressure. Ask your clinic sister to check your blood pressure when you visit the clinic [6].

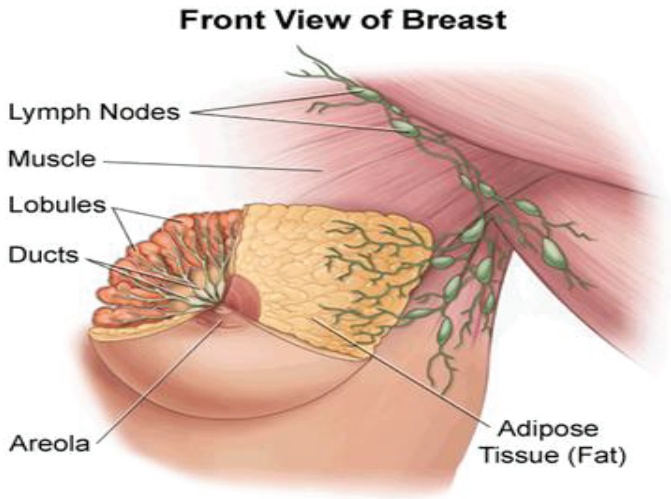


Image: Johns Hopkins Medicine

Background [6, 7]

Breast cancer usually occurs in women, but rarely men can get it too. Most types of breast cancer are hormone receptive, which means they respond to hormone blocking medicine.

Depending on your cancer stage and if your cancer is *hormone receptive*, your doctor may have decided to use only surgery or a combination of surgery, chemo- and radiotherapy with or without hormone blocking medication (also called adjuvant therapy). Therefore, if you speak to other breast cancer survivors, they may have had different treatment to yours. Treatments like surgery, chemotherapy, radiotherapy and Tamoxifen or other hormone blocking medicine, can take away and stop the growth of cancer if it is found early enough. For this reason, **you should keep taking hormone blocking medicine, if it has been prescribed for you**. It can be hard to keep going but it will be worth it.

If you don't know your cancer stage, ask your health provider when you visit the clinic. Knowing your cancer stage helps you to understand your chance of survival. It also helps you when you read about breast cancer. The information in websites, books or pamphlets may be intended either for *early stage* (stages I, II or III), or *advanced* breast cancer (stage IV) survivors. This handbook is designed for women with early stage breast cancer.

Write down your cancer stage here: _____

If you have early stage breast cancer (ductal carcinoma in situ, stage I, II, or III, **you must visit your breast clinic at least once per year for follow-up. Be sure to schedule and attend this visit**, even if you are feeling well. During this visit, the healthcare provider will monitor for any breast cancer recurrence and spread of the cancer to other tissues. This is a chance to tell your healthcare provider about the long-term side affects you are experiencing. This way, problems can be identified and managed before they become severe. **Ask** your healthcare provider if these annual visits are sufficient, or if you are required to visit more regularly, as every breast cancer survivor is unique.

Image: IMGBIN

Image: Clipart Library

The effects of cancer treatment on your body

Short-term (acute) effects of breast cancer treatment [77, 558]

While you were getting chemo- and radiotherapy, you might have felt the following side-effects. These usually go away when your treatment is finished, or soon thereafter.

- Nausea
- Loss of appetite
- Changes in smell and taste
- Hair falling out
- Feeling very tired

Cancer treatments also have *long-term* side effects, which can affect you for many years. These problems can also come from the cancer itself. There are many long-term side effects. Usually, one person does not get all of them. How severe you get them varies from person to person. It is important that you learn about the long-term side effects. This way you can manage them correctly from the start and prevent them from getting worse [24, 95].

Common long-term side effects of breast cancer treatment [6, 24]

- Stiffness and weakness of the shoulder and arm
- Arm or chest swelling (lymphoedema)
- Reduced fitness and function (difficult to do activities you used to do before the cancer)
- Weight gain and loss of muscle strength (your body stores more fat, and less muscle)
- Cancer-related fatigue: extreme tiredness that does not get better with rest
- More chance of getting chronic illnesses such as diabetes, heart disease and *osteoporosis* (low bone mass)
- Feeling depressed or low mood
- Being more forgetful than before your cancer (problems with memory, also called *cognitive dysfunction*)
- Problems with your body image as a breast cancer survivor
- Side effects associated with hormone blocking medicine such as Tamoxifen: hot flushes, mood swings, depression, less interest in sex, and vaginal dryness. These usually go away once you stop using this medication.

Image: Clipart Key

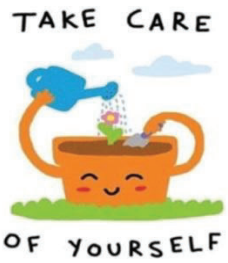


Image: Teen Talk

'It's a different tiredness. And I know it's going to take about two to three days for me to overcome this feeling. It's not like before cancer when you are tired, you're just sort of breathless, and you can drink some water and you feel fine. This tiredness is different. It's like you're totally knocked out.'

'When I have cleaned my house for example, I mean you sweep and you wash the floors, then I must go and lie down. Then I'm very tired.'

'The memory loss, it is very bad for me, and nobody told me about it to prepare me.' **– Breast cancer survivors.**

How to manage common long-term effects of breast cancer treatment

[6, 18, 24, 95]

Shoulder and arm problems; arm and chest swelling: The surgery and radiation may have caused your shoulder to feel stiff, painful, and tight. Without correct regular shoulder exercises, this can get worse. Shoulder and arm problems are discussed in detail in **week 5 and 6** of this handbook, with an example shoulder exercise routine for breast cancer survivors.

Reduced fitness and function: You may find that you cannot walk as far as before your cancer. Maybe you get tired when you have done household tasks that used to be easy. Some survivors assume this will improve with time. People might tell you cancer is a serious illness. They might say you should not complain, rest and be grateful to be alive. This is not good advice. Your muscles can only get strong again with exercise. During cancer treatment feeling nauseous, poor appetite and being inactive, means you lose muscle mass.

If your activity level stays low after treatment because you are feeling tired and weak, your body does not have a chance to get stronger. With time your body gets weak if you do not make good changes. Use all the exercise tips and information provided in **week 3 and 4**. There is also an easy example exercise routine. Ask a family member or a friend to support you as you embark on getting strong again.

Weight gain: Starting your exercise routine and eating well help to get your weight back to normal and to get strong and healthy. You will find information on weight management and eating well for breast cancer survivors in **week 7 and 8** of this handbook.

Image: PNGTree

Image: Clipart Library

Cancer-related fatigue: extreme tiredness that does not get better with rest: Not all women are affected. Those who have cancer-related fatigue will tell you that this type of tiredness is unlike any tiredness they had before. Rest does not help cancer-related fatigue, so it can be very frustrating. Cancer-related fatigue is caused by chemotherapy, radiation and by the cancer itself.

Fatigue can continue for years after the end of your cancer treatment. Sometimes it comes and goes in episodes, or it may be a constant feeling of being exhausted. Ask your health provider to check if your fatigue is caused by anaemia, thyroid dysfunction, or cardiac dysfunction, which can be treated with medicine. If they are not causing your exhaustion, it is most likely cancer-related fatigue. Research shows that regular exercise can make cancer-related fatigue better. It helps your body to get fitter and stronger (see **week 3 and 4** in this book). Importantly, exercise causes the release of hormones that make you feel good. Eating a healthy diet containing the nutrients your body needs can also help to improve fatigue (**week 7 and 8**).

Good news:

Not long ago, getting a cancer diagnosis meant one was likely to die from it. Not anymore! Medical breast cancer treatment has become very effective so many women these days live long lives [95].

Task for the week [37, 83]

You have now completed the content for week 1. Next week, we will discuss the management of more long-term side effects of breast cancer. Now you are ready to complete your homework: the question and table below. If you are unsure of a plan to manage your long-term side effect, go back and check the instructions on how to manage that problem. As you work through the content of this book over the next weeks, you can track your progress as a self-manager.

Important question: Have you scheduled and attended your annual follow-up visit to the breast clinic? _____ If not, do this as soon as possible!

	Long-term side effect affecting me (please tick)	My plan to manage this long-term side effect
Arm or shoulder problems		
Lymphoedema		
Reduced fitness and function		
Weight gain		
Fatigue		
Other		

Please feel free to contact me, Anita Beutel, in case you have questions, concerns or uncertainties about anything in this handbook. I can be contacted at beutelphysio@gmail.com or BTLANI001@myuct.ac.za.

Week 2: How to manage common long-term effects of breast cancer (continued)

Concepts explained [6, 7, 24]

Diabetes is a condition that causes the blood sugar levels to become too high. It increases your risk of getting serious problems with your eyes, heart, and nerves.

Osteoporosis is low bone mass and strength.

Heart disease is when the heart is unable to pump blood effectively, over time.

Anxiety is when you feel worried and afraid most of the time, such that your daily life is affected by it.

Depression happens over weeks and is a general feeling of low mood. It also includes physical problems. Depression is caused by a chemical imbalance in the brain. Depression is an illness. It is not the scared, lonely, stressed feelings from the shock of your cancer. These feelings were a normal reaction to your disease.

Cognitive dysfunction is problems with your memory. This can be a long-term side effect of chemotherapy.

Body image concerns: It may be that you don't feel good about how your after-cancer body looks. Maybe you feel less interested in sex than before the cancer. The loss of a breast can be very difficult to accept because we associate it so strongly with our femininity.

Breast reconstruction This is when, in an operation, your breast is re-shaped with tissue from your own body, or an artificial implant. The aim of a reconstruction is for your new breast to look and feel like your other breast.

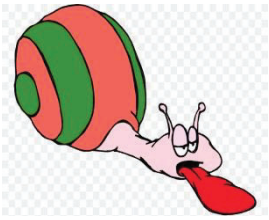


Image: FAVPNG

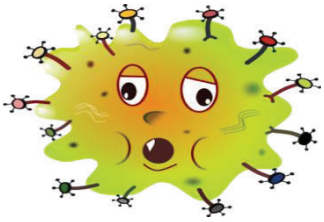


Image: PNGTree

How to manage common long-term effects of breast cancer (continued) [6, 7, 24, 350, 558]

Increased chance of getting chronic health problems such as diabetes, heart disease and osteoporosis: Cancer and its treatment make it more likely that you will develop these illnesses. But you can lower your chances of getting them, or make them better if you:

- Don't smoke. Ask others in your household to smoke outside. If you need help to stop smoking, you can ask at your clinic.
- Exercise regularly (**week 4**).
- Eat nutritious food, keep a healthy body weight, and manage your stress (**week 7 and 8**).
- Do not drink alcohol or have no more than one alcoholic drink per day.

Feeling anxious, depressed, or low mood. Breast cancer survivors sometimes become anxious or depressed as they struggle to cope with their new normal. You may feel anxious or depressed because you are scared your cancer might come back.

- Read and learn as much as you can about breast cancer (for example this book and further reading, **week 12**).
- Learn how to recognise a cancer recurrence (**week 9**).
- Exercise regularly: at least 30 minutes, 3 times per week and add muscle strengthening exercises (**week 4**).
- Follow a healthy diet (**week 7**), and do not smoke or drink alcohol.
- Learn to manage stress and to relax (**week 8**).
- Try to develop a good relationship with your clinic sister and doctor, by communicating effectively (**week 10**).
- **Get emotional support before feelings of depression take over**. Breast cancer is life-changing and a huge shock for any person. Sometimes breast cancer survivors feel that other people can't fully understand their situation, or what they have been through. Therefore, it can be very helpful to connect with **cancer support services**. Non-profit organisations such as CANSA offer many types of emotional support to breast cancer survivors, and it's free of charge [558].
  You can decide if you would like individual, group, online or tele-counselling. They also offer support via WhatsApp. Phone their toll-free number provided at the end of this book or look on their website to see which of their services would suit your needs. Or get involved as a volunteer to help other breast cancer survivors.

  You may be wondering why you weren't visited by a representative from a support organisation in hospital or afterwards. This is because the policy has changed. The responsibility now lies with the survivor themselves to contact a support organisation. You can contact them at any time, even if it has been years since you finished your treatment. **Contact details for cancer support organisations are listed at the end of this handbook.**

  See the anxiety and depression checklist below. If you have many of these symptoms, tell your healthcare provider. Depression is treated with medicine and psychological support.

Image: Clipart Key

Image: Novocom Top

Depression and anxiety checklist [370]:

- Do you feel down, worried, or afraid most of the time?
- Do you no longer enjoy fun things like music or dancing?
- Do you try to find peace by eating too much?
- Or do you lack appetite and have lost weight?
- Do you sleep badly at night?
- Do you struggle getting up in the morning?
- Do you get angry and irritated very easily?
- Do you feel very passive?
- Do you lack energy every day?
- Do you have trouble concentrating?
- Is it difficult to decide about simple things?
- Do you feel guilty?
- Do you often feel worthless?
- Do you think of death a lot?
- Do you think of killing yourself?

If you answer **yes to many of the above questions**, you may have anxiety or depression. Speak to your health provider about how you are feeling. If you are thinking of hurting yourself or someone else, get help immediately.

If you answer **yes to a few of the above questions**, you may have anxiety or a depressed mood. You can self-manage this with some of the skills in the section on stress management in this handbook **(week 8**). Talking to someone who understands, a counsellor from a support organisation or to a health professional can be very helpful. **Tips on how to self-manage anxiety or a depressed mood:** [6, 83, 370]

- ✓ **Reduce alcohol or do not drink at all**, even if it makes you feel better in the short-term. Alcohol affects the way your brain works to make depression worse.
- ✓ **Stay active.** Keep doing 30 minutes of exercise, 3 times per week, plus shoulder exercises (**week 4**). Get dressed and go out every day, even if you don't feel like doing things.
- ✓ **Make action plans** for the future – this week, next week, and next year. Start to believe that things will get better and try to make them better.
- ✓ **Stay in touch** with your family and friends, showing interest in their lives. Be honest to them about how you are feeling, without complaining all the time.

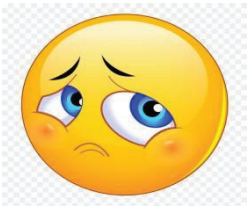


Image: Clipart Library

Image: Clipart Library

Cognitive dysfunction: The first step to manage this is to tell your family members that you have difficulty remembering and that you need their help and support. They can help by reminding you when you forget things you should have remembered.

Consider telling your colleagues at work that you are having problems with memory, and that it's a normal side effect of your breast cancer treatment. Cognitive dysfunction takes time to improve. You can play games that help memory and concentration (like Memory, Scrabble, crossword puzzles, Sudoku). Getting enough exercise (**week 4**), sleep (**week 8**), and eating a healthy diet (**week 7)** are also important to restore brain function.

Body image concerns: Talk to other breast cancer survivors, or to a counsellor from a support organisation, about how losing a breast affected them. **Speak to** your partner about your feelings and body image; get his or her input on the situation. If you feel you need more help to improve your body image, a doctor can refer you to psychology for counselling. The important thing is for you to **acknowledge** your own feelings, and then to **find** the support that works for you.

Visit your CANSA office or other support organisation to find out about the breast prostheses and special bras they have. A breast prosthesis looks and feels like a real breast. It is inserted into a special bra with pockets for the prosthesis to fit. Some prostheses are available to survivors free of charge. An even look and feel under your clothes may help you to feel good about your body.

Image: After Breast Cancer

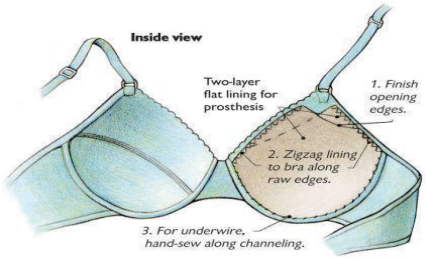


Image: Threads Magazine

For some women, a *breast reconstruction* may be an option. Reconstructions are not routinely offered to survivors in the state system. **Discuss** reconstruction with your doctor once you have read about its benefits, risks, and side effects, if you feel that it is an option. Reading material about breast reconstruction can be found on the websites listed at the end of this book.

Side effects of Tamoxifen or other hormone blocking medicine. If you get severe hot flushes, **tell** your doctor. He / she can prescribe medicine that can help. Apply a water-based lubricant (KY jelly) if you suffer from a dry vagina. It is available off the shelf at pharmacies, or at your clinic. A good diet (week 7 and 8), enough regular exercise (week 3 and 4) and maintenance of a normal body weight (week 7 and 8) can help to improve the side effects of hormone blocking medicine.

Good news

Many long-term side effects can be prevented or improved with the correct self-management [18, 201]. **Keep your doctor informed of any side effects that are too hard to manage on your own** [6].

Task for the week [83]

Make an exercise action plan for this week that you can easily manage.

This week I will:

_____ (what)

_____ (how much)

_____ (when)

_____ (how many)

(For example: this week I will walk for 20 minutes in the evening on four days)

Are you confident that you can complete this action plan? Yes / No. If you answered no, make the plan easier so you are confident that you can do it!

Please complete the table below, ticking off the long-term side effects that affect you. If you are unsure how to manage it, go back to that section and check the suggested way to self-manage your problem.

	Long-term side effect that affects me (please tick)	How I plan to manage this long-term side effect
Diabetes		
Heart disease		
Osteoporosis		
Anxiety or depression		
Body image concerns		
Hot flushes		
Dry vagina		
Other		

Week 3: How to become an excellent self-manager and how to plan an exercise programme

Concepts explained

Self-management means that you take responsibility for your health. This does not mean that you must do everything yourself. It means you work in a team with health providers to look after yourself. It also means you can use the knowledge you gain from this book, to make good decisions [83, 208].

Background [37, 83, 201, 234]

To be a good self-manager you need to understand your body. You need to understand your breast cancer, how it was treated and what will help you in the future. You also need to think how your breast cancer still affects you and what you can do to improve the situation.

A good self-manager decides what she would like to be able to do, how she is going to do it, then learns and practices the skills she needs. Some skills you will learn when using this workbook are exercising, eating healthy food, and managing the long-term effects of your cancer.

You may not know much about the topics in this handbook, or you may know a lot. Go through all the information over the 12 weeks to make sure you didn't miss anything. Share the information in this book with your closest family members. This way they understand what you are experiencing, and they can learn how to support you. If you are in contact with other breast cancer survivors, make sure that they get access to this information.

Let's look at the **steps to self-management** in more detail:

Step 1:

Decide *what* it is that you would like to be able to do. For example, you may want to be able to walk to the shop, play ball with your children or grandchildren, or return to work.

Write down three things you would like to be able to do:

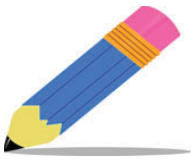


Image: Clipart Library

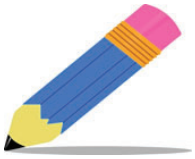
1. _____
2. _____
3. _____

Step 2:

Deciding that you want to walk to the shop or play ball doesn't mean that it will happen. You need to make it happen. A self-manager decides *how* she is going to do it.

Consider every option. Do not think that what you want to be able to do is impossible. For example: if you want to be able to play ball, you could throw and catch a ball with a friend for 10 minutes, three days per week. If you want to be able to hang up the washing, you could arrange for the washing line to be dropped lower, until you are able to reach its original height.

Write down three ways you could try to do, or practice something that you would like to be able to do:



2. _____
3. _____
4. _____

Now make an ***action plan.*** This must be realistic if you want to succeed. How to do this?

- Decide what you are going to do *this week.*
- Make a *specific* plan:
- *What* are you going to do? Example, throw and catch a ball.
- *How much* are you going to do? Example, 10 minutes.
- *When?* Example, Monday, Wednesday, and Friday after work.
- *Is it a good plan?* If you are confident that you can achieve your action plan, then it is a good plan. If you are not, think why you aren't confident that you can achieve your plan.

What are the problems? Can you solve the problems or change the plan so that you can achieve it?

Step 3

Write down your action plan and put it somewhere you will see it every day. Use the **action plan** at the end of this section and use the other 5 at the end of every week. Draw more of these for future plans.

A good action plan…

- Is *specific*
- Is something you *want* to do
- Is something you *know* you can do
- Answers questions such as *what, when* and *why*

Tell a family member or a friend about your plan. Report back to them how your plan is going. This will encourage you to start and keep going. It helps to discuss problems or ways to overcome them.

Step 4

Now do what you have planned. How do you feel now that you have started or practiced what you planned to do? Congratulate yourself for the effort you have made.

Image: Clipart Library

Image: Clipart Library

But what if my plan doesn't work?

There are 7 steps you can follow to help solve a problem:

1. Decide *what* is the problem?
2. List ideas to solve the problem.

3. Select an idea that could solve the problem.
4. Was it successful?
5. If it didn't work, try another idea.
6. If your ideas don't work, ask somebody else or a health professional to help solve the problem.
7. If the above steps don't work, you may have to accept that you can't solve the problem now.

A good self-manager

- Makes action plans
- Writes down ways to achieve the action plans
- Takes action
- Regularly checks her progress
- Can change her plans if a problem arises
- Rewards herself for taking action

Exercise

Concepts explained [3, 354]

Endurance or aerobic exercise: This type of exercise makes breathing and heart rate faster. Endurance exercise is often repetitive and rhythmic, like walking, running, or swimming. Most team sport is aerobic, for example playing netball, basketball, hockey, or soccer. Dancing or Zumba counts as aerobic exercise.

Strengthening exercise. To strengthen your muscles, you exercise against a resistance until you become tired. If you are not used to strengthening exercises yet, be careful of placing excessive strain on your affected arm, such as where most of your body weight is on your hands. Exercises on your hands and knees are safe for breast cancer survivors.

Stretching exercises help to keep our joints and muscles flexible. The challenge with exercise is to keep doing it again and again. Only *regular* exercise benefits our health in the long-term. When you stop exercising, the good effects on your body also stop. Do not fall into the trap of making excuses not to exercise.

Image: IMGBIN

Image: Clipart Library

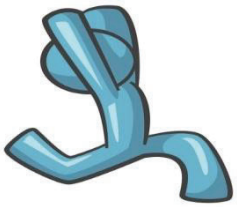


Image: Clipart Library

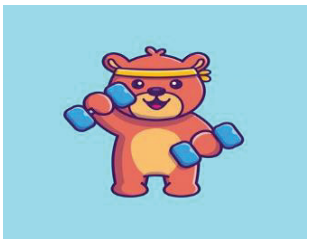


Image: Freepik

Background [3, 18]

Exercise is important for health. It trains the muscles of the heart to pump strongly. It helps the body to absorb nutrients from food. It keeps your muscles strong and joints flexible. Research shows that regular exercise makes people happy. It boosts concentration, memory and improves sleep.

Before, people who had cancer were advised to rest as much as possible. Maybe your family members tell you to rest, and that exercise is a bad idea. You can reassure them. There have been many years of research on exercise for breast cancer survivors. These research studies have shown that exercise acts like medicine for the long-term side effects of breast cancer. Breast cancer now has international exercise guidelines. These state that we should aim to **exercise moderately (quite hard or somewhat hard) for a total of 2 and a half hours every week. We should include strengthening and flexibility (stretching) exercises in our training at least twice per week.**

The minimum amount of exercise needed to improve most long-term side effects of cancer treatment is 30 minutes, at least 3 times per week, for a period of at least 8 to 12 weeks. For most of the side effects, more exercise gives a greater benefit if you increase your exercise gradually. Therefore, working towards a goal of 2 and a half hours per week, split up as you prefer, is ideal.

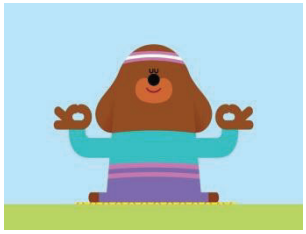


Image: PNG Key

Image: Cliparting

The effects of exercise in breast cancer [350, 354]

- Strengthens the heart muscle, which may be weakened from chemotherapy treatment
- Improves your fitness, often reduced from the cancer treatment
- Makes your bones and muscles strong, often weakened after cancer treatment
- Improves cancer-related fatigue (extreme tiredness which does not get better with rest)
- Reduces body fat
- Helps your arm and shoulder to get strong and mobile again
- Reduces pain
- Prevents arm or chest swelling (lymphedema) or helps control the swelling
- Helps your body absorb the nutrients from food to regain your health
- Improves mood to prevent and reduce depressed feelings
- Helps to prevent cancer from coming back, or other cancers from growing in your body
- Improves your level of function so you can do activities you would like to do
- Boosts your immune system so you get sick less often
- Prevents and helps to treat diabetes, heart disease and high blood pressure
- Makes you feel in control of your life and gives you confidence

Image: 123rf

Image: Clipart Library

Despite all these benefits, there are days on which it is better to skip your exercise until you feel better, or you have spoken to your healthcare provider. **If you have any new swelling, pain, fever, dizziness, headache, diarrhoea or vomiting, your body is telling you to get medical advice first** [3].

TIP: If you have been given an arm sleeve or bandages for swelling (lymphoedema), wear it while you exercise. Discuss with your lymphoedema therapist the exercise you intend doing [6].

How to ensure that it's safe to start, if you haven't done any exercise in a long time [3]

If you suffer from / if you have had any of the following, talk to your doctor before starting a new exercise routine.

- Heart problems, a heart attack or heart surgery
- Diabetes, if **not** controlled by medication
- Asthma or other lung disease, if **not** controlled by medication
- Pregnancy
- **YES** to two or more of the following questions:
  1. Do you have burning or cramping in your lower legs when walking short distances?
  2. Do you experience chest discomfort on exertion?
  3. Do you experience unusual breathlessness?
  4. Do you experience dizziness, fainting, blackouts?

Image: Emojipng

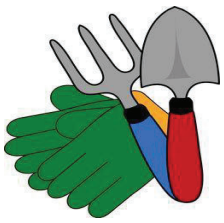


Image: Clipartix

Exercise precaution for breast cancer survivors [354]

- Be careful not to injure or overstrain your arm and chest on the affected side. This is important when you start exercising: when your arm and chest are still weak.

How to prevent the spread of viruses while you exercise [3]

- If you enjoy exercising in a group, being outside in the fresh air is preferred.
- If you haven't been vaccinated against the coronavirus (COVID-19) and you are exercising indoors in a group, wearing a mask is advised.
- When exercising indoors, keep a distance of 1.5 metres from other people.
- Wash your hands well with soap and water after your workout.
- After your workout, avoid touching your face until after you have washed hands.

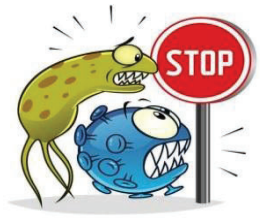


Image: Kissclipart

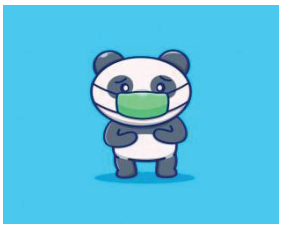


Image: Shutterstock

How to choose exercise that is right for you [3]

Think back to before you had cancer, or to when you were younger: what exercise did you enjoy? Walking, jogging, gardening, doing housework, dancing, aerobics, swimming, and cycling are exercise. If your favourite sport used to be something like netball, you could throw and catch a ball with a friend. You can join a gym or a club to exercise, but you don't have to.

There are many ways to exercise. Any activity that makes your breathing and heartbeat faster is exercise. Playing with your children or grandchildren or walking a bit further than usual are ideas for exercise.

You do not need expensive equipment or special clothing to exercise. An old t-shirt and tracksuit pants are perfect. Try the exercise routine example further on in this section because it contains all three types of general exercise: aerobic, strengthening and stretching. You can do it at home needing only two plastic bottles filled with water.

How to overcome common excuses used by breast cancer survivors [202, 354, 374, 579]

'I don't have time'

If you know that something is important, you can make time for it. Like brushing your teeth or taking your medicine. Exercise is medicine too, especially for women who have had breast cancer. You can even start by doing 10 minutes of exercise per day. Consider waking up 30 minutes earlier 5 days per week and doing your exercise in that time. **… rather say: I will make time for my workout.**

'I'm too tired'

The surgery, chemotherapy and radiation probably saved your life. But these treatments also cause muscle damage and weakening. When you become weaker you become more tired.

Becoming more tired weakens your muscles even more. But if you exercise and you repeat it often, your muscles become strong, and you become less tired. There is a kind of tiredness which only cancer survivors get: *cancer-related fatigue*. This type of fatigue can be severe, unlike any tiredness you had before your cancer. Research shows that cancer-related fatigue improves with regular exercise. **…rather say: I will do my exercise and then I will rest.**

'I exercise enough already'

You might already be quite active at work or at home. But this kind of exercise usually is not fun and not relaxing. Exercise must be something you enjoy and that recharges your batteries. Making extra time to exercise will be worth it because it makes you feel good. **…rather say: I will do a type of exercise that I enjoy, for me.**

'I get bored with exercise'

You are a unique person with unique needs and preferences. Do something that *you* enjoy. It doesn't have to be what other people are doing. If you are sociable, find a friend or a group of friends to keep you company. Do something new if your exercise session starts to get boring.

For example, you could do dancing on some days and walking on other days. **…rather say: I will make my workout fun by mixing it up.**

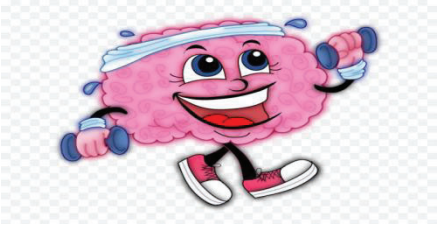


Image: FavPNG

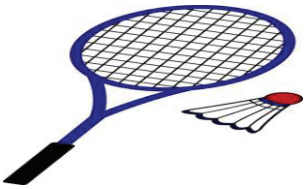


Image: Kissclipart

'Exercise hurts my arm'

Exercise can sometimes be uncomfortable, but it shouldn't be painful. If you have pain before you exercise, the exercise should not make it worse. If you have increased pain for more than 2 hours after a workout, it could be that you did too much.

Skip one session and do less the next time you exercise. Either exercise for a shorter period or less vigorously the next time. **… rather say: I will listen to my arm and get help if I need it.**

Always increase the time you spend exercising and the intensity slowly and gradually. Never exercise through pain. See your physiotherapist, clinic sister or doctor if your arm continues to be painful. You might need a different set of exercises, or your arm might have a new injury which should get treatment.

'It's too hot, it's too cold, it's too dangerous'

Try to find solutions for these problems, rather than simply making the excuses. You could move your exercise session to a different time of day, exercise indoors with music, or in a group. If it's cold and you are outside, dress in layers that are easy to take off and take along. If it's hot, wear a sun hat and light clothing.

Apply broad-spectrum sunscreen with a sun protection factor (SPF) of at least 30. Bright yellow or orange light-reflective vests and headlamps are available from hardware stores. **…rather say: I must find a way to keep including exercise in my life**

I have tried to exercise many times and stopped. Why will it be different this time?

This time we are giving you information about exercise and why it is important to continue. We are providing you with step-by-step instructions on becoming a good self-manager. You have told your family members about your plans and asked someone to exercise with you. All these things will help you. Set your exercise goals by using the steps on how to become a self-manager. Reward yourself with a treat when you achieve your goal. This motivates you to aim for your next goal [83].

Image: Download Cliparts

Image: Clipart Library

When you have walked in the evening, you get up the next morning and you feel different to the morning when you haven't been walking. You get up happy, full of life, you feel like cleaning your house. You feel like working. When you haven't walked for two or three evenings, in the mornings you feel flat, you don't feel like anything. **– Breast cancer survivor.**

Good news

Exercise helps prevent and treat chronic diseases. Research shows that breast cancer survivors who exercise are less likely to get cancer again. They usually live longer lives than those who don't exercise [6]**.**

Tasks for the week [37, 83]

Have you thought about what type of exercise you would enjoy? Write down a few options that you can imagine yourself doing again, here (e.g. walking, dancing, aerobics, etc.)

_____

_____

_____

Complete the table below with excuses you have made before not to exercise. Make a plan to overcome them!

	Excuses I have made before (please tick or comment)	How I plan to overcome this excuse
'I don't have time'		
'I'm too tired.'		
'I exercise enough already'		
'I get bored with exercise.'		
'Exercise hurts my arm.'		
'It's too hot, it's too cold, it's too dangerous.'		
Other		

Well done! You have now completed week 3. Next week, we will discuss a successful exercise plan for breast cancer survivors.

Week 4: How to start your exercise programme

HINT: This week, we are starting an exercise diary which will continue until the end of the intervention. You will find the diary at the end of week 4. You can start recording your minutes or hours for each exercise session, from today (Monday, week 4).

How to plan a successful exercise routine [3, 83, 194]

- Set a **clear goal**. Use the 4 **self-management steps** discussed last week.
- Choose something that you like to do and that you can imagine continuing.
- Decide on an exact time and place for your exercise.
- Decide for how long you will continue before changing your plan (keep going about 6 weeks before you try something else). Revise your plan about every 6 weeks.
- Keep an exercise diary so that you can see your progress over the weeks. There is one at the end of every section, and extras at the end of this workbook.
- Don't think about starting for too long. It is better to start while this information is still fresh in your head. Start now, progress slowly and gradually. Enjoy it!
- Reward yourself. It can be a special meal or a special experience. Rewards help to keep us motivated even when carrying on is hard.

How to get started [3]

Follow the steps to a successful exercise plan above. Once you know what activity or sport you would like to do, decide how much to start with. If you have not done any exercise for a long time, or you have been feeling unwell, you will have to start very slowly. A good start if you haven't been exercising is doing exercises at home for 10 minutes, every second day. Once you are no longer sore and stiff the next day, you can do those 5 days per week. Once you are comfortable exercising 10 minutes, 5 days per week, you are ready to start doing more exercise.

Increase it from there as shown under the heading **progressing your exercise.**

How to do strength and flexibility exercises correctly [3]

- Move slowly and gently, you want control of the movements.
- Move until you feel a slight pull, not pain.
- Repeat each exercise 5 times. After 1 week, increase to 7 times, the next week to 10 times.
- Always do equal amounts on your right and left sides.
- Do not hold your breath. Breathe out as you make the effort and keep breathing.

Flexibility exercises: These are slow, gentle movements that keep our joints and muscles able to move. The 25-minute exercise routine described below already contains flexibility exercises for your neck, back and legs. The shoulder exercises (week 3), which you can do after the 25-minute routine; contain flexibility exercises for the upper body.

Image: Clipart Library

Image: Dreamstime

How to ensure you are doing enough of each type of exercise [3, 18]

If you do the 25-minute example exercise routine below, and the shoulder exercises (week 5 and 6) in one day, you do not have to add anything.

Flexibility exercises: If you do a different exercise routine to the example, like 30 minutes of walking, add 10 minutes of flexibility exercises at the end of your workout.

Strengthening exercises: Remember, to make your muscles strong they must push or pull against resistance. These exercises should be done twice a week. To start, repeat every exercise 5 times. Once you can easily do an exercise 10 times, you can increase the weight (resistance). The 25-minute exercise routine below and the shoulder exercise routine (week 3) already include strengthening exercises.

Endurance exercise: Start with as much as you think you can do. If it's 5 minutes of walking, that's a good start. Gradually increase it to 30 minutes.

Always start and end off your workout with 5 minutes of slow walking, to warm up and cool down your muscles. If you do 15 minutes in the morning and 15 minutes in the evening, it still counts as 30 minutes.

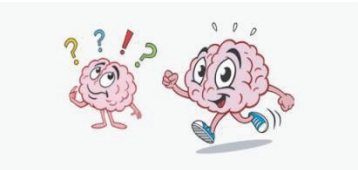


Image: Clipart Library

How to choose the right intensity for you [3]

If someone asks you while you are exercising how intense it is, you should be able to say 'quite intense'. It should be easy for you to talk while you exercise. If you can still sing you are not exercising hard enough. This is a goal to work towards. You may have to build up gradually to this *intensity*. After 8 weeks you will find you can do the same exercise with less effort. Or you may be faster than in the beginning. You will feel better generally and everyday tasks at home will become easier as you become fitter.

How to progress your exercise [18]

If you do the 25-minute general exercise routine example on one day, and the shoulder exercise routine example (week 5 and 6) the next; and you keep alternating days, you would be exercising more than 2 hours per week. **Remember, just one and a half hours of exercise per week helps to prevent or control long-term side effects of cancer, like fatigue and arm pain.** If lack of time is a problem, aim for both example routines, three days per week. That's 2 hours of exercise! Once this amount is easy, your goal is to gradually increase your exercise to total 2 and a half hours per week. There are many ways to progress your exercise safely and gradually. You can choose a method that works for you.

When you can do the example general exercise routine below (or other exercise, like walking for 20 minutes), plus the shoulder exercises in week 5 and 6, on 5 days per week, you are meeting the exercise guidelines for breast cancer survivors. Well done!

If you plan to exercise 3 days per week, you can use this table to gradually increase how long you exercise for. Start with the amount you feel comfortable doing. Example: If you can manage 25 minutes, start with week 2. Increase the amount every week as shown [580]:

Week	Exercise duration per day, in minutes
1	20
2	25
3	25
4	30
5	30
6	35
7	35
8	40
9	40
10	45
11	45
12	50

If you prefer to exercise on 5 days per week, this table can help you to progress your exercise:

Week	Exercise duration per day, in minutes
1	10
2	15
3	15
4	20
5	20
6	20
7	25
8	25
9	25
10	30
11	30
12	30

The 25-minute example routine below is a very good start, even if you do only half the exercises at first. Then gradually add more until you can do all of them in one day.

Or you can walk fast for a few minutes, then slower. Increase gradually to more fast than slow walking. Write the duration of every exercise session in your exercise diary. When you look at your exercise diary as the weeks progress, the total amount of exercise should increase.

How to complete a general exercise routine: an example [354, 358]

Below is an example of a safe general exercise routine for breast cancer survivors. It is for after your medical cancer treatment: after completing your chemo- and radiotherapy, or from 3 months after your breast surgery. It contains endurance, flexibility and strengthening exercises. Each exercise is marked as **E** for endurance, **S** for strengthening or **F** for flexibility. This helps you to combine the exercises as you like. For example, you may want to leave out the endurance exercises marked **E** and replace them with walking or jogging outside. You can then add the exercises marked **S or F** after your endurance training, to complete your workout.

Do the routine facing a clock or with your watch on, so you can count the minutes. Afterwards, do the shoulder exercise routine in week 3 to total about 35 minutes.

Special precaution for breast cancer survivors: **Exercises should not cause pain.** Ask your physiotherapist if you are unsure which exercises are suitable for you. If you have lymphoedema, get advice from your therapist before starting this routine.

1. Stand up tall and relaxed with your hands by your sides. Take a slow deep breath in through your nose, lifting your arms up above your head. Breathe out through your mouth while lowering your arms down. Repeat three times. **F**

Image: Clipart Library

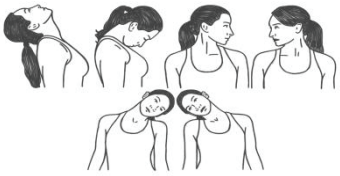
Image: PNGWing

Image: Clipart Librar

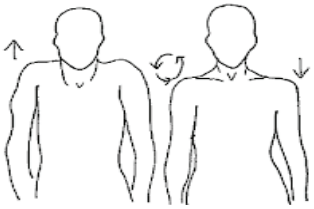
2. March on the spot for 2 minutes. Keep a steady pace where you can talk but not sing. If you can still sing, march a bit faster. This should be quite hard, not extremely hard. **E**

Image: Dreamstime

3. Stand with arms at your sides. Stretch your neck: put your ear on your right shoulder, hold for 10 seconds. Repeat on the other side. Remember to keep your shoulders relaxed. Turn your head to the right, hold 10 seconds. Then to the left, hold 10 seconds. Bring your chin to your chest, hold for 10 seconds. Now roll your shoulders forwards 10 times, and backwards 10 times. Pull your shoulders up to your ears, then away from your ears, 10 times each. **F**



Source: Prehab Exercises

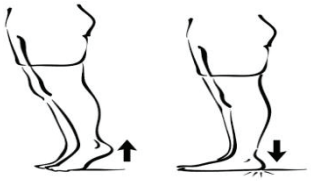


Source: Womens OK

4. March on the spot for 2 minutes: 30 Seconds normal pace, 30 seconds pull your knees up as high as you can, or jog. Repeat: 30 seconds normal pace and 30 seconds knees up or jog. **E**

Image: Dreamstime

5. In standing (hold on for balance if you need to), raise your heels off the ground to stand on your toes. Slowly lower your heels to the floor again. Keep going for 2 minutes. **S**



Source: Clipart Library

6. Stretch your body: hold each of these positions for 10 seconds. Slide your right hand down your right leg until you feel a stretch on your left side. Repeat on your left. Now lean backwards (keeping shoulders relaxed, keep breathing); and forwards trying to touch your toes. You should feel the stretch but stop there. Do not stretch into pain. Pull your belly in gently throughout. **F**

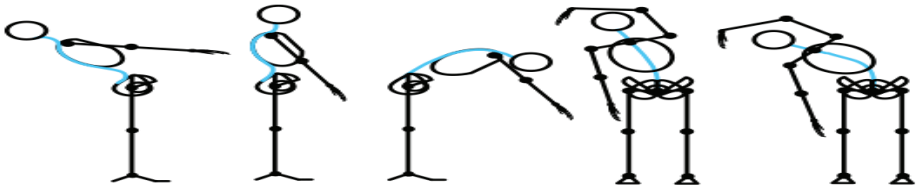


Image: Envato Tuts

7. Sit down on a chair. Stand up immediately. Keep sitting down and getting up for 2 minutes. **S**

Image: Clipart Library

8. Lie down on your back with your knees bent, feet flat on the floor. Gently pull your belly in away from your clothes and then lift your bum off the floor. Slowly lower your bum back down to the floor. Relax your shoulders and keep breathing normally. Continue for 2 minutes. **S**

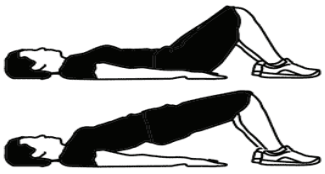


Image: FavPNG

9. March on the spot for 2 minutes. 30 seconds normal, 30 seconds jog or knees up as high as you can. Repeat. **E**

Image: Dreamstime

10. In standing, take a big step forward (*lunge)* with one leg, bending your knees so that the back knee almost touches the floor. Bring the front leg back to the starting position. Change legs and keep going for 2 minutes. **S**

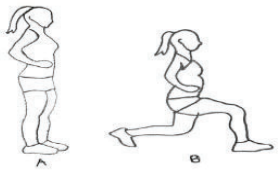


Image: Clipart Library

11. March on the spot for 2 minutes total. 30 seconds normal, 30 seconds jog or knees as high as you can. Repeat. **E**

Image: Dreamstime

12. In standing (hands by your side): take a 500 ml bottle filled with water, a tin of canned food or a small weight in each hand. Bend your elbow to bring the weights close to your face. Slowly straighten your arms again. Keep bending and straightening your arms for 2 minutes. Breathe normally and gently draw your tummy away from your clothes as you move. Can be done without weights initially, if it causes pain or is too difficult at first. **S**

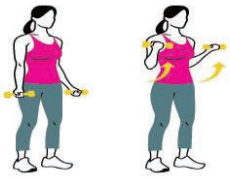


Image: Clipart Suggest

13. Stand up tall and relax. Take a deep breath in, lifting your arms up. Breathe out, lower your arms. Repeat three times. **F**

Image: Clipart Library

Image: PNGWing

Image: Clipart Library

Here is a link to the video of the example routine above:

https://drive.google.com/file/d/1Xln5dkxiqfjhI1nAYUzAWK9Xm2WSmEjf/view?usp=sharing

How to exercise – a quick summary

- ✓ Start slowly and increase gradually to an intensity of quite / somewhat intense.
- ✓ A good exercise routine should contain aerobic, strength and flexibility exercises.
- ✓ Breast cancer survivors should exercise at least 30 minutes on 3 days per week, to keep long-term side effects at bay. Then, for maximum health benefits, work towards 2 and a half hours of exercise in total, per week. This can be divided up as you prefer.
- ✓ Choose exercise that you enjoy. You can use the example above and work from there. Divide it up into manageable parts if it is too much at first.
- ✓ You can use the example routine above to design your own exercise routine, keeping in mind the special precautions for breast cancer survivors.
- ✓ Combine your general exercise routine with shoulder exercises for your arm on the affected side. An example is provided in week 5 and 6 of this handbook.
- ✓ Ask your healthcare provider to refer you to a physiotherapist if you need help or advice. During the study, please contact the researcher if you have any questions.

How to check if your fitness has improved over time [581]

Simply do the 6-minute walk test: Walk for 5 minutes at an easy pace, to warm up your muscles. Now make a mark at the starting point of the test, for example by placing a stone. Check your watch, and now walk as fast as you can for exactly 6 minutes. Make another mark at the end point of your 6-minute walk. When you repeat the test in 6 weeks or so, start from the exact same position as you did for the first test. You should, as your fitness improves, be able to walk further each time. This is a great, easy way to check your progress. Remember to cool down your muscles by walking at an easy pace for 5 minutes afterwards.

Good news: you can reward yourself for achieving your fitness goals!

Task for the week [83]

Exercise Action Plan

Use this action plan to develop a clear plan for your exercise.

This week I will:

_____ (what)

_____ (how much)

_____ (when)

_____ (how many)

(For example: this week I will walk for 20 minutes in the evening on five days)

Are you confident that you can complete this action plan? Yes / No. If you answered no, make the plan easier so you are confident that you can do it!

Now complete the minutes or hours you exercised for each day of this week (week 4). In the next few weeks of this programme, keep recording every exercise session. At the end of each week, add together the total minutes or hours for that week. Our goal is that the totals for every week should increase gradually. By week 12, you can aim for an hour and a half (90 minutes) in total if you are new to exercise, or 2 and a half hours (150 minutes) if you were already exercising before starting this programme.

TIP: Print and cut out this table. Paste it in a place where you will see it every day, so that you will remember to complete it. You can insert the date under each week, for example, 7-14 August, etc.

Exercise diary [201, 234]

Week	4	5	6	7	8	9	10	11	12
Date									
Monday									
Tuesday									
Wednesday									
Thursday									
Friday									
Saturday									
Sunday									
Total minutes or hours per week									

Week 5: How to manage your affected shoulder and arm

Concepts explained [77, 558]

A tumour is an abnormal mass that forms when cells grow and divide more than they should.

A mastectomy is when the whole breast is surgically removed.

A lumpectomy is when only the lump that formed the tumour is surgically removed.

Lymph nodes are shaped like little beans. Lymph nodes are filters for the body's immune system, to help the body fight infection and disease. They 'catch' any cells that shouldn't be in your body, including cancer cells. If your cancer starts to spread, it usually goes to these lymph nodes in your armpit first. This is why lymph nodes are often removed together with your tumour or breast.

Sentinel lymph node is the first lymph node where your cancer is likely to spread. Sometimes only the sentinel lymph node is removed if your cancer is found early.

Impingement is when a *tendon* (band of tissue that connects muscle to bone) pinches against bone as you lift your arm [582].

Cording, or axillary web syndrome: This is a possible side effect of surgical lymph node removal. Lymph vessels (tubes that carry lymph fluid) and connective tissue can harden after lymph nodes are removed. This feels and looks like tight cords that can be painful and limit movement. If you have cording, you will see bands of tissue in your armpit under the skin, especially when you raise the arm above your head [5].

Nerves are bundles of fibres in your body. They transport information between body parts to allow you to feel and move [583].

A physiotherapist is an expert in prescribing exercise, like a doctor prescribes medicine. A physiotherapist gives advice or treatment for joint and muscle problems, and for lymphoedema [352].

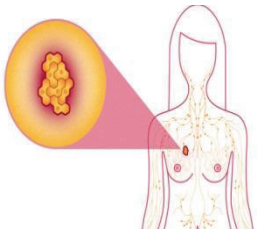


Image: Clipart Library

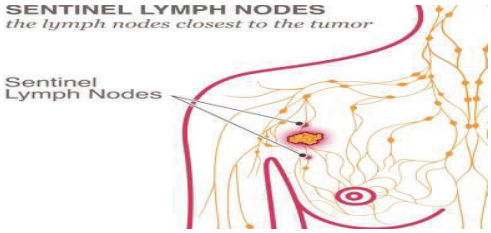


Image: National Breast Cancer Foundation

Background [77, 354]

After identifying your breast tumour and deciding if the cancer has spread to other body parts or not, your surgeon had to decide on the best way to remove the tumour. Removing a breast is major surgery.

Some breast cancer survivors assume that their arm will stay stiff and sore forever. This should not be the case if you continue with your exercises over weeks and months. Many women think that with time, the tightness and pain when they move the arm will go away by itself. This is not true.

If you don't move your arm and if you don't continue with the exercises you got in hospital, the scar will heal in a shortened position. Your arm will then get stiffer and weaker. Most of you were given exercises for your arm in hospital by a *physiotherapist*.

If your shoulder suddenly gets painful or stiff, or not getting better despite you doing the exercises, visit the clinic. You may have an injury separate to the cancer. There are many shoulder problems that can happen after breast cancer treatment.

The effects of medical cancer treatment on your affected side [6, 77, 354]

- The injury from the surgery and from removing the tissue will cause the area to feel tight and sore. It affects how well you can move your shoulder and arm.
- Radiation can be important to help cure the cancer. But it may cause hardening of the tissue under your arm and chest. This is *radiation fibrosis*. It may affect your arm and shoulder long after the end of your treatment. It contributes to the stiff, tight feeling when you use your arm. If you do not continue with your shoulder exercises, radiation fibrosis can cause your arm to become more stiff, sore, and weak.
- Months or years of changing your arm position (*posture)* to protect your shoulder may make you prone to getting *impingement*. Injuries like these need their own treatment and unique exercise programme.
- You may have a tingling feeling, burning or numbness on your arm or chest. This can happen if the surgery has irritated your *nerves*. This injury takes time to heal.

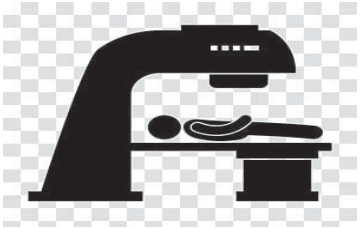


Image: Clipart Library

Image: Clipart Max

How to manage your shoulder problems [148, 164, 354]

- Research shows that shoulder exercises are very effective to keep your arm and shoulder working well. **Continue** with your exercises for as long as there is any tight or stiff feeling in your shoulder, chest, armpit, or arm when you lift the arm.
- Bear in mind that you may have to continue for years. It will be worth it if you are able to use the arm for all your daily tasks.

- Your shoulder exercises will be effective, so continue even if you suffer from nerve irritation. Stroking the area with something soft can help to reduce its sensitivity. **Ask** a physiotherapist if you need guidance.
- Cording typically gets better with physiotherapy treatment and exercises. If you think you have cording or axillary web syndrome, **show** your health provider, and **ask** to be referred to a physiotherapist who is familiar with the complications of breast cancer.
- If you suffer from radiation fibrosis, **do** your shoulder exercise routine regularly for 6 to 8 weeks. If the hardening does not improve, ask at your clinic to be referred to a physiotherapist.
- If you experience new severe pain, stiffness or swelling of your arm, **go** to your clinic. Your doctor may refer you to a physiotherapist to assess and treat your shoulder.
- **Do not hesitate to ask for the help that you need. You should not have to live with pain and stiffness for months and years!**

'I still have this pain that's been here all along, and the doctor always said it's probably from the radiation or from the chemo.' / 'I don't have power in my arms anymore. I used to be able to lift heavy things. I can't do that anymore.' / 'When I did my exercises right, I didn't have a problem with the shoulder. When I get negligent and lazy, I find the shoulder starts to pain.' **– Breast cancer survivors.**

Image: NicePNG

Image: CleanPNG

How to get the most out of your shoulder exercises [148, 164]

- If your shoulder is very stiff and sore, **do your shoulder exercises with your muscles warmed up**. Do them after the general exercise routine (week 2), after walking for 10 minutes swinging your arms, or after a warm shower.
- Do the exercises **in the sequence described below**. The routine includes exercises help to warm-up the muscles. A *warm-up* prepares your joints and muscles to work at their best.
- You might feel tightness in your chest and armpit when you exercise. The skin and muscles could have become tight and stiff from the cancer treatment. This should gradually get better as you continue doing the exercises regularly.

- Do the movements slowly until you feel a stretch. Hold the position for 5 seconds. Repeat each exercise 5 times.
- Do the exercises every day until you have your normal *flexibility* (your arm is moving freely).
- Keep breathing normally through every exercise.
- The exercises in the example routine are intended as a general guideline. If you have been given other instructions by a health provider, adhere to these as they know you individually.
- Always do the exercises **with both arms**. This way you will know how much stiffer your arm on the affected side is. It also keeps the other arm mobile.
- The shoulder exercise routine below is intended for use after you have finished your chemo- and radiotherapy, or from at least 3 months after breast surgery.

How to do your shoulder exercise routine: an example [148, 164, 354]

1. Take a deep breath in, move your arms up above your head. Exhale for at least 4 seconds, bringing your hands down. Repeat three times.

Image: Clipart Library Image: Clipart Max Image: Clipart Library

2. Standing, arms at your sides: Inhale while you move your shoulders up towards your ears. Exhale and move your shoulders away from your ears. Repeat 10 times.*

Image: Clipart Library Image: Spotebi Image: Clipart Library

3. Inhale and exhale deeply while you roll your shoulders backwards (10 times), then forwards (10 times).*

Image: Spotebi

4. Clasp your hands together, keeping your elbows straight. Lift your arms up overhead. Exhale, draw in your tummy and stretch your arms to the side. Inhale, return to the centre. Exhale and stretch over to the other side. Repeat five times each side.*

Image: Spotebi

5. Reach your hands behind your back, as if reaching for your bra strap. Move your hands up your back so that you feel a stretch. Hold 5 seconds. Return to starting position. Repeat five times each side.

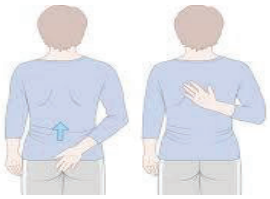


Image: The Breast Cancer Site.

6. Rest your fingertips on your shoulders. Lift your elbows up to the side as far as you can, keeping your shoulders away from your ears. Hold 5 seconds at a point of slight stretch. Repeat five times.

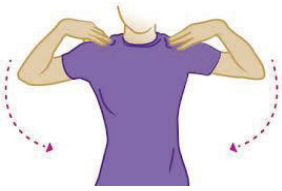


Image: Guys and St Thomas

7. Rest your fingertips on your shoulders. Point your elbows to the front and lift them up as far as you can. Keep your shoulders away from your ears. Hold 5 seconds at slight stretch. Repeat five times.

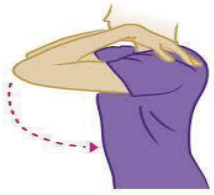


Image: Guys and St Thomas

8. Stand in front of the wall, resting your fingertips on it. Now ‘walk’ your fingertips up the wall until you feel a mild stretch in your arm. Hold 5 seconds. Repeat five times.

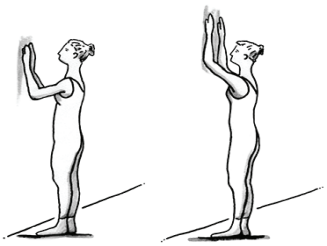


Image: Full Circle Wellness

9. Stand in a corner, placing the palms of your hands on the wall at or just above shoulder level. Keep your shoulder girdle down. Now lean in towards the wall until you feel a mild stretch in your shoulder or arm. Hold 5 seconds. Repeat five times.

Image: TN Oncology

10. Lie on your back, bend your knees with your feet flat on the floor. Reach your hands up towards the ceiling, straightening your elbows. Bend your elbows again to touch the floor, and then straighten them to reach your hands to the ceiling. You can do this exercise holding a stick at first. *Once it becomes easy, you can hold light weights (bottles of water, or cans of food). Repeat 10 times.

Image: TN Oncology

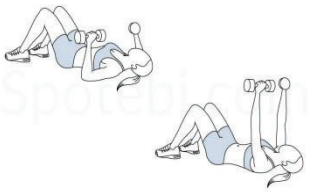


Image: Spotebi

11. Take a deep breath in, move your arms up above your head. Exhale for at least 4 seconds, bringing your hands down. Repeat three times.

Image: Clipart Library

Image: Clipart Max

Image: Clipart Library

Exercises with a * can be progressed (once they become easy to do) by holding a small weight in each hand, such as a 500 ml bottle of water or a can of food.

Here is a link to the shoulder exercise example routine:

https://drive.google.com/file/d/1cODc45vUd6imPGen0359A-EK4ezuVVjk/view?usp=sharing

How to find out if your shoulder is improving over time [362]

To help you decide if your shoulder is improving with time, answer the following questions. Score your answers and calculate the total by adding up the scores of all the questions together. Do your shoulder exercises every day, and then answer the questions again after about 8 weeks. If your shoulder is getting better, your total score should get **lower** as the weeks progress. The total score should stay low if you carry on with your daily shoulder exercise routine. If the total score suddenly increases, go to your clinic with the questions and answers. If you are doing the exercises but the total score stays the same, you can do the shoulder exercise routine twice per day for 8 weeks. Then answer the questions again. If you are still unable to lower your score (your shoulder stays sore and stiff), ask your doctor to refer you to a physiotherapist for advice.

Instructions: For each question, answer by giving a score out of 10. Example: **0 = no pain and 10 = the worst pain you can imagine**. Once you have answered all 13 questions, add up your scores to give you the total.

How severe is your pain (0 = no pain and 10 = the worst pain you can imagine)

1. At its worst? _____
2. When lying on the operated side? _____
3. Reaching for something on a high shelf? _____
4. Touching the back of your neck? _____
5. Pushing with the arm on the operated side? ____

How much difficulty do you have (0 = no difficulty and 10 = so difficult that you need help)

6. Washing your hair? _____
7. Washing your back? _____
8. Putting on a shirt? _____
9. Putting on a shirt with buttons in the front? ____
10. Putting on your pants? _____
11. Putting an object on a high shelf? ____
12. Carrying a heavy object of about 4.5 kg? ____
13. Removing something from your back pocket? ____

Total score _____ (all the scores added together)

Good news

If you persist with regular shoulder exercises and ask for help when you need it, your arm can get its full function back, and you will be able to reduce your pain [52, 194].

Task for the week [83]

Complete your exercise diary for this week (see week 4). Next, complete the table below with your own experience of shoulder problems, and your plan to manage them.

	Shoulder problem that affects me	My plan to manage this problem
Shoulder feels tight and sore		

Shoulder feels weaker than the other one or stiff		
Hardened area on chest / shoulder (radiation fibrosis)		
Tingling, burning or numbness (nerve irritation)		
Cording (tight 'cords' from chest to arm)		
Other		

Well done, you have completed week 5! Next week will be about the prevention and management of lymphoedema.

Week 6: How to detect and manage chest or arm swelling (lymphoedema)

Concepts explained [25, 364]

Lymph vessels are thin tubes that carry *lymph fluid*. This is a clear fluid filled with cells that help your body fight diseases.

Lymphoedema is when the damage from surgery and radiation, cause the lymph fluid to build up in your arm or chest and the vessels are unable to drain it away. When this happens, the area swells and can become hardened.

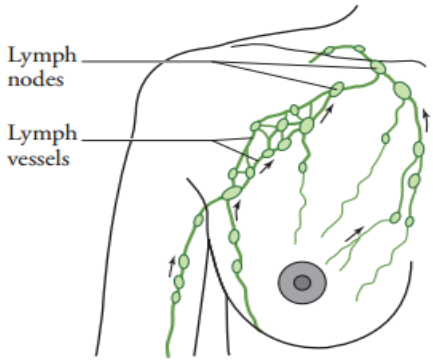
Signs of infection of your chest or arm: a rash, itching, redness, pain, your arm or chest becomes hot, or if you get a fever.

Background [364]

The *lymphatic system* is made up of your *lymph nodes* and *lymph vessels*. In your armpit there are many lymph nodes, which are connected to the lymph vessels. One or more lymph nodes are usually removed with the cancer, as cancer cells spread to the lymph nodes first. Radiation can cause scarring and damage of some of the lymph vessels.

Lymphoedema is lifelong. It can't be cured, but it can be managed. The earlier it is found and treated, the easier it will be to manage. If nothing gets done about lymphoedema, it will get worse and cause lasting damage to your arm. **Lymphoedema can start at any time after breast cancer treatment. If you think you may have lymphoedema, you should go to your clinic as soon as possible.**

If your doctor agrees that you have lymphoedema, he or she may refer you to a physiotherapist and / or to an occupational therapist. They can treat your lymphoedema with a type of massage called *manual lymphatic drainage*. They might bandage the area with special bandages and give you exercises. If necessary, they will give you an arm sleeve, which gently presses on your arm. The *compression* from the sleeve and the pumping action from your muscles as you do the exercises; help to drain excess lymph fluid out of your arm.



Normal lymph drainage

Image: MSKCC

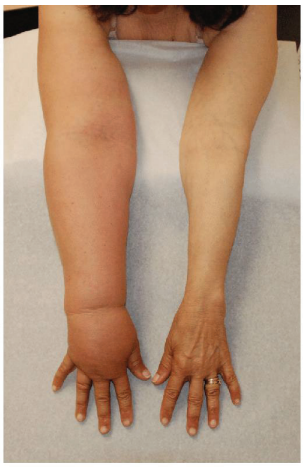


Image: Research Gate

How to detect the early signs of lymphoedema [584]

- Your arm suddenly feels heavy or achy
- Your arm or hand feels tight
- Your arm, hand or chest is noticeably swollen
- Your arm, chest, or hand swells up and then the swelling goes away
- Your shirt sleeves feel tight
- Your ring or bracelet starts to feel too tight
- Your skin makes a dent when you press into it with your finger

More signs of lymphoedema [584]

- Achiness, tingling, discomfort, or increased warmth in the arm, hand, breast, chest, or underarm.
- Tightness or decreased flexibility in nearby joints, such as the shoulder, hand, or wrist.
- Bursting or shooting pain, or pins and needles, tenderness in the elbow.
- Veins or tendons in the hand are harder to see, knuckles look less pronounced, or once-wrinkled skin that looks smoother.
- Trouble fitting the arm into a jacket or shirt sleeve that used to fit before.
- Your bra feels tighter, doesn't fit the same way as before, or leaves an indentation on your skin.
- The two sides of your back look different in size (asymmetrical).
- Changes in skin texture or appearance - tightness, redness, or hardening rash, itching, redness, pain, or skin that feels warm.
- **If left untreated, lymphoedema can cause lasting, severe damage to the tissue of your chest or arm.**

But mine didn't start immediately after radiation. It probably took about two years and then I suffered it. I was warned about the arm swelling, but at that time I was so confident I was cancer-free it was the last thing on my mind. And then just gradually, I noticed it's getting a bit swollen until one day it's like this.

Well, it was fine after the operation for two years until went flying. Nobody told me that when you fly ... if you fly in the aeroplane, you must wear a sleeve. – **Breast cancer survivors.**

How to prevent lymphoedema or make it better if you already have it [364, 584]

- Being overweight makes it more likely that you will get lymphoedema. Overweight or obesity makes the condition worse once you have it. **Keep your weight under control** by eating well (week 7).
- Start with an exercise routine (week 4). Exercise, eating nutritious food and a normal body weight lowers your chance of getting lymphoedema.
- High blood pressure or diabetes (high blood sugar) increases your risk. Work together with your health provider to keep these conditions under control.

- **Protect your chest, arm and hand from injury or infection.** An injury or infection can trigger lymphoedema, even years after your cancer treatment.
- **Avoid tight clothes, underwear, watches, or jewellery that could irritate the skin.**
- **Do not let your arm become very hot or very cold** (avoid hot baths).
- **Wear a compression sleeve** if it has been prescribed for you, also during exercise.
- If your chest or arm gets an infection rash, go to your clinic immediately. **Infections need treatment immediately to prevent lymphoedema from starting, or to prevent it from getting worse.**

Image: Rescue Legs

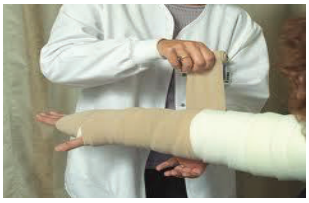


Image: Lymphedema Blog

- If you are going to fly in an aeroplane, discuss it with your healthcare provider. The cabin pressure of an aeroplane is lower than the pressure on the ground. This change in pressure may cause or worsen lymphoedema. He / she may prescribe a compression sleeve for you to wear during the flight.

- **Specific shoulder exercise** (week 5) helps to prevent lymphoedema. It also helps people who already have lymphoedema. The lymph vessels are between the muscles and the skin. Contracting and relaxing muscles next to the lymph vessels cause a 'pumping' action that helps the lymph to flow so that excess fluid is drained. Therefore, gradually training your muscles and moving your body is important to prevent lymphoedema or to improve it. Gradually training and strengthening the muscles in your chest and arm can make the arm more resistant to injury. For example, a sudden bump is more likely to injure a weak arm than a strong arm.

Image: Clipartix

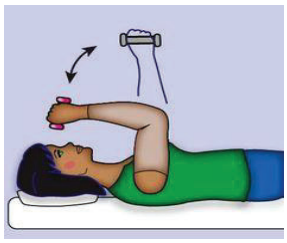


Image: Very Well Health

- If you have lymphoedema, ask to be referred to a physiotherapist or an occupational therapist who is experienced in treating this condition. Your therapist will ensure that the exercise you are doing is right for you. For example, your arm might need more rest breaks to allow the lymph fluid to drain.
- Follow the therapist's instructions carefully to benefit from the treatment. Give your therapist feedback about the treatment. This way they can help you as much as possible.

How to exercise your arm if you already have lymphoedema [67, 354]

- ✓ **Gradually** training your muscles and moving your body is important to prevent lymphedema from worsening, and to improve it.
- ✓ **Start slowly**
- ✓ **Increase your exercise gradually**
- ✓ **Listen to the arm**
- ✓ **STOP if during exercise your arm, chest or hand becomes tired, heavy, or achy.**
- ✓ As discussed above, work closely with your lymphoedema therapist to work out what works for your arm / chest and what doesn't.

How to prevent an injury or infection of your chest and arm on the affected side [421]

- ✓ Make sure the skin does not get dry or chapped.
- ✓ Apply sunscreen and insect repellent to prevent sunburn and insect stings.
- ✓ Protect your skin from cuts and injuries: wear gloves for gardening or doing dishes.
- ✓ Take care when using a razor or when cutting fingernails.
- ✓ If you need to have blood pressure or blood taken, or an injection – offer the other arm if possible. Do not assume that your doctor or nurse remember which your operated side is.

How to manage an injury to the skin of your affected arm / chest [421]

- ➢ wash the area with soap and water
- ➢ apply an antibiotic ointment (ask at your clinic or pharmacy)
- ➢ Watch the area for signs of *infection*. If there is an infection, the area will become red, painful, hot, or swollen.

How to be an excellent self-manager of your affected side [37, 83]

- ✓ You inform yourself,
- ✓ You carefully look after your chest and arm on the affected side,
- ✓ You talk to your health provider when you need help or advice
- ✓ You do your part to stay healthy and strong

Good news

Although lymphoedema cannot be cured, it can be managed if found early and treated by a lymphoedema therapist (usually either a physiotherapist, an occupational therapist or a nursing sister who has completed an extra lymphoedema management qualification) [584].

Task for the week [83]

Make an **action plan** for your shoulder. For example, this week I will do my shoulder exercise routine every day. OR today I will make an appointment at the clinic because my arm is starting to swell.

Action plan

This week I will:

_____ (what)

_____ (how much)

_____ (when)

_____ (how many)

Are you confident that you can carry out this action plan? Yes / No. If you answered no, make the plan easier so you are confident that you can do it!

Complete week 6 of your exercise diary (the exercise diary can be found at the end of week 4, or hopefully you have pasted it in the kitchen!). This week, make a special effort to add your shoulder exercise routine to your exercise programme. **Note: The shoulder exercises contribute to the total hours / minutes of exercise that you write down on your exercise diary!**

Complete the lymphoedema checklist below. Knowing the signs of lymphoedema means that you can watch out for them, without being worried. Go over this checklist every few weeks to ensure that you can catch it early and get treatment. Hint: a good plan is to **show** your healthcare provider, **ask** to be referred for treatment and keep doing your shoulder- and general **exercises** [151].

Lymphoedema signs [584, 585]

	An early sign of lymphoedema that affects me (please tick)	My plan to manage this sign
Arm suddenly feels heavy or achy		
Arm or hand feels tight		
Arm, hand or chest is noticeably swollen, swelling may come and go		
Shirt sleeves, ring or bracelet start to feel too tight		
Skin makes a dent when you press into it with your finger		
Sudden new achiness, tingling, discomfort in the arm		
Other		

Week 7: How to manage your body weight

Concepts explained [7, 369]

High blood pressure means there is extra strain on your blood vessels, heart, brain, kidneys, eyes, and other organs of the body. This increases your risk of heart disease and heart attacks.

What does BMI mean? A BMI below 20 kg/m^2 means you may be under-weight. Normal weight is 21-25 kg/m^2. Overweight is 25 – 29.9 kg/m^2, and obesity (extreme overweight) refers to a BMI of more than 30 kg/m^2.

A dietician is a health professional who gives advice on what to eat. They can design an eating plan especially for you.

Nutrients are the parts in food that are used by the body to function and stay healthy. These include proteins, fats, carbohydrates, vitamins, and minerals.

Exercise helps your body to use more energy.

To lose weight, you must eat less high energy food and exercise more, over time.

Polyphenols are special nutrients which fight cancer, heart disease and diabetes.

Proteins are the building blocks of all the essential parts of our bodies. Without protein the human body cannot function properly.

Fibre is the rough part of plants that can't be digested by your body. It helps you to feel fuller for longer and keeps your blood sugar constant. This way you won't crave sugary or starchy food as much.

Complex carbohydrates are high energy foods, but they contain valuable nutrients and fibre. For this reason, they form part of a balanced diet.

Low GI (glycaemic index) means the food releases its energy slowly. This is good to keep your blood sugar constant.

Simple carbohydrates are sugar, white bread or bread rolls, chips, cakes, muffins, cupcakes, and tarts. These have a high GI. They cause your blood sugar to rise sharply so they can cause diabetes and other illnesses. They also make you feel full without providing the nutrients your body needs to be healthy.

One alcoholic drink is 150 ml wine, 200 ml beer or 1 tot of liquor.

Image: Deposit Photos

Image: Deposit Photos

Background [24, 350]

The cancer has most likely given your body quite a knock. Now is the time to start thinking about what you put into your body. You want to be as healthy as possible, to thrive instead of just surviving. Instead of eating to get full, breast cancer survivors need to get the *nutrients* their bodies need, to become healthy and strong again.

One of the common long-term side effects of chemotherapy is weight gain. Being inactive and eating less during your cancer treatment means you lose muscle mass. Muscles keep you strong and able to do all your daily tasks. They also help your body to burn energy. Having muscles allows you to eat without putting on extra weight. These are reasons why strengthening exercise is important for breast cancer survivors.

The effects of being overweight on breast cancer survivors [365]

- Research shows that breast cancer survivors who are overweight do not survive as long as those who are a normal weight. Many breast cancer survivors are already overweight when the cancer is found.
- Overweight and obesity increases a person's chance of getting breast cancer.
- For breast cancer survivors, being overweight also increases the chance that the cancer may come back.
- It increases your risk of high blood pressure, diabetes (high blood sugar) and heart disease.

'I put on a lot of weight, then they sent me to the dietician, and it helped. I weighed more than 100. I now weigh something like... 89.' – **Breast cancer survivor**

How to find out if you are overweight [7]

- ✓ If you would like to find out if your weight is normal or if you are overweight, you can calculate your body mass index (BMI). Your BMI is your weight in kilograms, divided by your height in metres squared. (Example: a woman is 1.7 m tall and weighs 60 kg. Her BMI is 20.8 kg/m^2).
- ✓ If you don't have a scale, you can ask to be weighed and measured when you go to the clinic. Write down your weight and height so you can calculate your BMI and compare it at your next clinic visit.

How to manage your health if you are overweight [6, 233, 335]

- ✓ If you have diabetes, high blood pressure or heart failure, **find out** as much as you can about how you can make yourself better. **Ask** at your clinic for pamphlets or other reading material about your chronic disease.
- ✓ Ask your health provider to explain to you exactly about your chronic disease. **Write down** the important information they give you, like what to eat or how you can help to manage your blood pressure.
- ✓ If you are overweight, **follow** the guidelines for healthy eating below, plus the exercise routine (**week 4**) and shoulder exercise routine (**week 5**).
- ✓ After 12 weeks, **recalculate** your BMI.
- ✓ You don't have to lose a lot of weight in a short time, to get health benefits. Research shows that losing 5 to 10% can already reduce your risk of the cancer coming back and of getting chronic diseases. It is safer and healthier to lose weight gradually. To lose weight, you must eat and drink less energy than your body uses, over time. Your body then takes from your fat stores to provide the energy it needs.
- ✓ Sitting for shorter periods during the day, and rather standing, walking, and doing household tasks can help the body to use more energy. Sitting less will therefore help you to lose weight and prevent your body from putting on more weight.
- ✓ If you are unable to lose weight or if you are diabetic, your doctor can refer you to a *dietician*.

'I put on a lot of weight, then they sent me to the dietician, and it helped. I weighed more than 100. I now weigh something like... 89.' – **Breast cancer survivor**

How to choose the foods that are right for you [350, 369, 389]

Vegetables and fruit

Examples: Pumpkin, butternut, spinach, morogo, cabbage, green beans, carrots, tomatoes, onions, garlic, peas, green peppers, cauliflower, broccoli, cucumber, mushrooms, marrows
Grapes, naartjies, oranges, apples, bananas, avocado, paw-paws, guavas, watermelon, pears, peaches, apricots, lemons, berries, dates

- ✓ This is the **most important food group for cancer survivors**.
- ✓ Vegetables and fruit keep us healthy by strengthening the immune system.
- ✓ They also contain *polyphenols*.
- ✓ Research shows that women who eat at least five servings of vegetables and fruit each day survive longer than those who do not.
- ✓ A serving is roughly as big as your fist, for example a carrot, a banana, or a tomato.

Image: Freepik

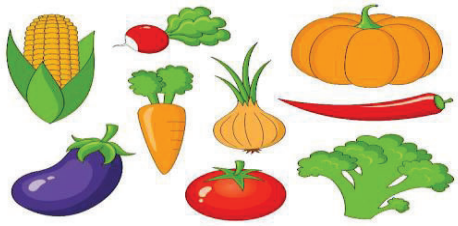


Image: Clipart Library

- ✓ Try to eat different colours of vegetables and fruits in one day, to get all the nutrients you need. Example: morogo with tomatoes (green and red); carrots and onions (orange and white).
- ✓ An easy way to get five servings per day is to eat at least one vegetable and one fruit (or two different vegetables, or two different fruits) with every meal.

Proteins

Examples: Fish (sardines, pilchards, tuna), eggs, dried or canned beans, lentils, chickpeas, peanuts, whole grains, milk, and milk products (maas), chicken, pork, beef, mutton

Image: Clipart Suggest

Image: Cook It

- ✓ To regain muscle, you must include protein in your diet.
- ✓ Aim to have at least one form of protein in every meal, for example eggs for breakfast, lentils for lunch and fish for supper.
- ✓ The best forms of protein for cancer survivors are the **plant-based** ones, like beans, lentils, peas, and chickpeas. They are also rich in *fibre*. Plant-based protein is usually also cheaper than meat.
- ✓ Try to limit red meat (beef, mutton, lamb, pork) as much as you can.
- ✓ Avoid processed meat (polony, bacon, ham, and sausages) completely. Red and especially processed meat can increase your chances of the cancer coming back.

Complex carbohydrates or starchy foods

Examples: sweet potatoes, potatoes, bread, oats, samp, pap, rice, mealies, sorghum, porridge

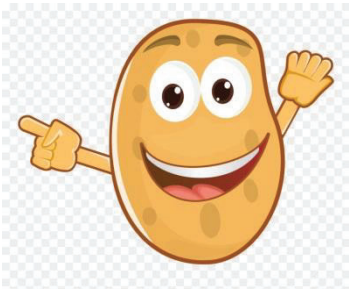


Image: Clipart Library

Image: Clipart Library

- ✓ Breast cancer survivors should focus on eating mostly vegetables and fruits, with a portion of complex carbohydrates per meal. The portion should be smaller than, or about the size of your fist, for example one medium potato.
- ✓ If your BMI is above 25 kg/m^2, eat less of this food group because excess energy you take in gets stored as fat.
- ✓ Some women find that they manage to lose weight and feel better when they eat very little carbohydrates (*low carb*). This does not work for everyone.

Most people need to reduce their refined carbohydrates, and eat wholegrain, high fibre carbohydrates, to get health benefits.

- ✓ In the supermarket you can check the labels on bread: low GI (glycaemic index) means the food releases its energy slowly. This is good to keep your blood sugar constant.
- ✓ Stay away from simple carbohydrates (too much sugar, cakes, pies, muffins, tarts, white bread, vetkoek, etc).
- ✓ Look at the labels of anything you eat often, for example cereal. If there is sugar or white flour in it, do not buy it.
- ✓ Buy low GI, wholegrain or wholewheat bread.
- ✓ Make your own porridge using oats (low GI, high fibre). For sweetness you can add a fruit like apple or banana. You will save money and be healthier if you self-manage your diet like this.

Fats and oils

Examples: canola oil, sunflower oil, seeds, margarine, olive oil, nuts, butter, lard, mayonnaise, salad dressing

Image: Clipart Library

Image: Dreamstime

- ✓ These are an important part of a healthy diet, but in small amounts.
- ✓ Just the oil used to fry vegetables or a bit of margarine on a slice of bread is enough for most people, as fats and oils are high in energy.
- ✓ Try to use plant-based fats and oils (canola oil, nuts) rather than animal-based (butter, lard) whenever possible.
- ✓ Avoid deep-fried food, as these will provide more energy than you can use. Remember that excess energy is stored as fat in the body.

Herbs and spices

Examples: rosemary, thyme, parsley, oregano, turmeric, cayenne (red pepper), ginger, basil, mint, sage, cinnamon, nutmeg, cloves, cardamom

Image: Clipart Library

Image: Jing

- ✓ Herbs and spices contain valuable vitamins and minerals which keep our bodies and minds healthy. Just like vegetables and fruit, they are full of cancer-fighting polyphenols.
- ✓ With herbs and spices, a little goes a long way.
- ✓ You can use dried herbs, but some grow well with little attention- even in a pot. Rosemary, thyme, and oregano are easy to grow, needing little water.
- ✓ Herbs and spices add flavour to your food, reducing the need for salt and sugar.

How to put together a healthy meal [350, 389]

- ➢ The perfect meal for breast cancer survivors contains one or two portions of vegetables, one portion of protein, one portion of complex carbohydrates, and some fruit for dessert.
- ➢ Add herbs and spices to taste.
- ➢ Fats and oils are already included in the cooking process.
- ➢ A portion is about as big as your fist. For example, a fried egg on whole-wheat bread with tomatoes and spinach, and a naartjie for dessert. Or a piece of chicken with cooked onions and pumpkin, a small potato, and a pear for dessert.

How to avoid foods that are unhealthy for breast cancer survivors [350, 369, 389]

- Breast cancer survivors should leave out too much sugar. Rather use a little fruit, dates, or raisins to sweeten food. Excessive sugar can cause diabetes, cancer, and infections in the body. Be careful, dates and raisins also contain a high amount of sugar. The difference is that they contain nutrients and fibre, which plain sugar does not.
- Eliminating sugar also means no sugary drinks (no cola or juice). If you must drink juice, dilute it with water. Drink plain, clean water throughout the day. For sweetness you can add a slice of fruit. Use herbal tea and rooibos without sugar or sweeteners.

That said, drinking a cup of coffee or tea with one teaspoon of sugar per day is allowed.

- Baked goods made with white flour or sugar should be avoided. This includes cakes, cupcakes, muffins, tartlets, and white bread.

Image: Deposit Photos

- No processed meat such as polony, bacon, and ham.
- Eat little or no red meat.
- Do not drink alcohol or have no more than one alcoholic drink per day. Get help to cut down if you cannot stop on your own.
- Stop smoking completely. Ask for help at the clinic if you need help to stop. Take care to stay away from other people's smoke.
- Avoid taking any nutritional supplements without checking with your doctor.
- Do not add salt to your food. Rather use herbs and spices to add flavour.
- Avoid salty food (chips, popcorn, French fries, fast food, soup powder, stock powder, ready-made cereals). Too much salt increases your blood pressure, which can damage your heart, kidneys, and other organs. A lot of food (like bread and canned food) already has added salt, even if it isn't salty. Rinse canned beans or peas to remove excess salt.
- Occasional sweet treats are allowed. Make healthy eating part of your lifestyle, your new normal. This way you will be eating well most of the time. Don't buy unhealthy food, so you do not have to try to resist eating it.

TIP: Save the money you used to spend on fast food, to buy or experience something you have always wanted.

How to ensure that your food is safe and won't make you ill [367, 369]

✓ If the tap water in your area is not safe, it can be boiled for at least one minute, then cooled before drinking.

- ✓ Wash your hands with soap and water before preparing food or eating.
- ✓ Wash vegetables and fruit thoroughly before using.
- ✓ Thoroughly clean any surface or utensil that's been in contact with raw meat or eggs. Keep raw meat and ready-to-eat foods separate.
- ✓ Cook meat, fish, or eggs well, so that there are no raw bits. Milk, fruit juices and honey should be *pasteurised*. Pasteurization means that it has been heated to a very high temperature and then sealed so it doesn't contain bacteria that can make you ill.
- ✓ Food that was in a fridge or freezer in the shop must be stored in the fridge or freezer as soon as possible. Keeping fresh food cold prevents harmful bacteria from growing in it.
- ✓ Do not eat any raw meat, fish, shellfish, poultry, or eggs. Do not eat any salads or other fresh food that may have been taken out of the fridge hours before.
- ✓ Never eat any food that has gone off, or eggs that have cracked shells. Keep leftovers in the fridge for no more than 2 days.

Image: Clipartix

Image: FavPNG

How to eat well if your weight is normal or if you are underweight [350, 369, 389]

- ✓ Because breast cancer survivors are prone to putting on weight after medical cancer treatment, the advice in this handbook focuses on ensuring that you get all the nutrients without taking in too much energy. If your BMI is in the normal range, you can still follow the advice in this book **without having to focus on eating less**.
- ✓ If your BMI is in the **underweight** range, check with your healthcare provider if you have any illness that may be the cause.
- ✓ If no cause is found, you can follow the advice in this workbook. But be sure to eat extra complex carbohydrates, up to two portions per meal. Add healthy snacks in the form of complex carbohydrates between meals.
- ✓ A person who is underweight needs to focus on trying to take in more energy. But it must be nutritious, healthy food.
- ✓ A dietician can give you individual advice.

Good news

You must not go hungry. Eating so little that you are hungry all the time will lead to severe cravings and obsessing about food. This usually results in episodes of binge eating, which is not good for any diet. What is more, you can continue to enjoy your favourite treats in small amounts, such as a block or two of chocolate.

Task for the week [7]

Work out your BMI to find out if you are under weight, normal weight, overweight or obese. Hint: see the section 'how to find out if you are overweight' for instructions on how to calculate your BMI. The first calculation is today (enter today's date). In the last week of this programme, recalculate your BMI to find out if you are closer to / in the normal range.

Today's date: _____Write down your height _____, weight _____ and your BMI: _____

Print or copy the below shopping list and put it up in the kitchen. From this week (week 7), take the list with you when you go shopping. Tick off when you buy any of the healthy items on the list. Try to continue to buy the items on the list, as the weeks go on. You can insert other items into the list. If you are unsure if an item is suitable for breast cancer survivors, you can check the cancer dietary guidelines using the following link from the World Cancer Research Fund:

https://www.google.com/url?q=https://www.wcrf.org/diet-activity-and-cancer/cancer-prevention-recommendations/&sa=D&source=docs&ust=1656622794409228&usg=AOvVaw1rMKeNNGsNiN9SctB1D12R

Well done, you have completed week 7. Next week, we will explore stress and pain management for breast cancer survivors.

Shopping list [350, 369]

	Week 7 Date:	Week 8 Date:	Week 9 Date:	Week 10 Date:	Week 11 Date:	Week 12 Date:
Cabbage, spinach, swiss chard, morogo, broccoli, cauliflower, green beans						
Pumpkin, butternut						
Tomatoes, green peppers						
Lettuce, cucumber						
Onions, garlic						
Carrots, peas, parsnips						
Mushrooms, marrows Other Other						
Naartjies, oranges, grapefruit, lemons						
Apples, pears						
Paw-paws, guavas, melons						
Avocado						
Peaches, apricots						
Grapes						
Fish: hake, snoek, sardines, pilchards, tuna						
Eggs						
Dried / canned beans, lentils, chickpeas						

Milk, yoghurt, maas, cottage cheese						
Chicken, turkey						
Wholegrain / multigrain / wholewheat / rye bread, oats, bran						
canola oil, sunflower oil, olive oil, nuts, seeds						
Herbs and spices						
Coffee, tea, rooibos tea						
Small treat, e.g. dark chocolate						
Other						
Other						
Other						

Week 8: How to manage stress and pain

Concepts explained [370, 371, 586]

Stress is when you feel emotionally or physically tense. It usually comes from a situation that makes you feel frustrated, angry, or nervous. Stress often makes your muscles tense, breathing and heart rate faster. It makes you feel irritable and angry.

Anxiety is when you feel afraid or worried most of the time, so much that it affects your daily life.

Relaxation helps you to feel calm, more in control and able to sleep well.

Progressive muscle relaxation: This is a way to relax and manage stress, where you deliberately tense one after the other muscle group in your body, then relax them and notice how this relaxation phase feels.

Deep breathing can help you to relax. With deep breathing, you focus your mind on your breathing only, for a few minutes.

Guided imagery is another useful relaxation technique, where you imagine yourself in your favourite place using all your senses, such as imagining the sound, sight, smell, taste, and the feeling of your chosen place.

Psychologists are mental health experts. They can help you to manage anxiety, depression, or other mental health problems.

Background [586]

We often stress when we feel that something is out of our control. For example, the crime that happens in our community or an unexpected illness. Feeling that your illness is beyond your control will make you feel very stressed. Excess stress that is too much to handle and not managed well can lead to anxiety or depression. Depression was discussed in week 2 of this handbook. Stress can also have a good effect on our lives, for example stressing about your illness can help you to develop healthy habits, eat healthier and look after yourself more.

Image: Clipart Library

Things that affect how stressed we feel [370, 586]

1. **The situation.** For example, if you are often feeling extremely exhausted. Does it help you to know this fatigue can be a normal side effect from your cancer treatment? Or is it better to worry about where this extreme tiredness might come from? Worrying that something serious is wrong is much more stressful, right?

2. **How we cope with the situation.** Let's say you often feel extreme tiredness (fatigue). You check with your doctor if your fatigue is caused by something other than the cancer.
   Next, you find out what you can do to make it better. Would this help your stress? Knowledge about our condition and how we can manage it helps us to cope better.

3. **Support from family, friends, and cancer support organisations.** Support can go a long way to reduce stress levels. Make sure that your closest family or friends are informed about breast cancer and what it means to be a survivor. Supporting you doesn't mean they must do everything for you and tell you to rest. This will make you weaker and more dependent in the long-term. Make sure they understand that supporting you means they should help you to get stronger, fitter, healthy and confident.

'And then she came in like an angel, and she said, oh, I'm here from CANSA for the recovery ... and you know what, how glad I am to see this woman. I cried and she prayed for me, and we talked, and she gave me all these things. That was so fantastic.'

That team that comes to me, they help a lot. You feel good again. It's because they care.'

'They come to your house and ask how you are, what have you been through, how did you experience it and things like that.'

'*Do you know what bothered me? Is that I never talked with anyone afterwards about my breast cancer, my treatment or my... nobody came to me and talked to me.'* – **Breast cancer survivors.**

How to manage your stress [37, 83, 234, 371, 587]

1. Problem solving

- **Find the problem.** The first step to deal with stress is to find out why you are feeling this way. Use the self-management steps if you are unsure why you are feeling stressed. If it is easy to deal with the problem, fix it straight away instead of worrying about it every day. For example, if your arm is feeling achy and tight, go to the clinic and tell a health provider that you are worried about lymphoedema. If the problem is something you can't do anything about, the next step is to change the way you see the problem.

- **Look at the problem in a different way.** You may be worried about your health or that your cancer comes back. Have you discussed this with a health expert who knows you?
  Or were you talking to someone whose family member had died of cancer, and that got you worried? Remember the more informed you are about *your own* health situation, the easier you will be able to manage it.

- **Get help if you need it.** Once you are familiar with the problem, you have informed yourself and looked at it in a different way; you may need to get help or support. If discussing the problem with the people closest to you is not helpful, you can ask an organisation who specialises in counselling, like FAMSA.
  If it is a health problem, speak to your clinic sister or doctor. See week 5: communicating with your healthcare provider.

Image: PNGFind

2. Relaxation

To manage stress, we need to be able to relax. Just as our bodies need exercises to adapt to our new normal, our minds often need practice to be able to adapt too. In the same way as you have been doing the physical exercises and asking for help from a physiotherapist if needed, you can do the below exercises for your mind and ask to be referred to a psychologist if you need further help.

Relaxation takes practice, so do it regularly. You will find if you practice it often, you will become able to relax even in a crowded or stressful place. Practice relaxation when you are in pain, feeling stressed or worried or when you want to go to sleep. Deep breathing, where you focus on your breathing only, is an excellent way to practice relaxation.

Practice relaxing somewhere you feel comfortable and safe. Do it at least once every day for a minute or two, more often if you are feeling stressed. You can manage your stress and prevent anxiety by practicing each, or all the below three stress management techniques (deep breathing, progressive muscle relaxation and guided imagery) every day.

- **Deep breathing:** Take a deep breath in for four *slow* counts. Hold your breath for three *slow* counts, and then take five *slow* counts to breathe out. Repeat this a few times. You can keep going for several minutes once you have practiced. **It should go like this: breathe in** - two - three - four; **hold the breath** - two - three; **breathe out** - two - three - four - five.

- **Progressive muscle relaxation:** Ask someone to read the following to you or record it and play it back to yourself every day. Repeat with the other muscle groups of your body as described below.

Take a deep breath in through your nose…hold your breath for a few seconds… now breathe out…take another deep breath through your nose… Pay attention to your body and how it feels…. Start with your right foot… squeeze all the muscles in your right foot. Curl your toes as tight as you can, hold it…good…now relax and exhale…let your foot go limp…notice the difference between the tension and the relaxation… feel the tension flow out of your foot like water… (then repeat with right lower leg and foot, entire right leg, etc.).

During the progressive relaxation exercise, you work with most major muscle groups in your body. To make it easier to remember, start with your feet and move up (or in the reverse order, from your forehead to your feet).

For example:

Foot (curl your toes downward)

Lower leg and foot (tighten your calf muscle by pulling toes towards you)

Entire leg (squeeze thigh muscles while doing the above)

(Repeat on the other side of your body)

Hand (clench your fist)

Entire right arm (tighten your biceps by drawing your forearm up towards your shoulder and "show your muscle", while clenching fist)

(Repeat on the other side of your body)

Buttocks (tighten by pulling your buttocks together)

Stomach (suck your stomach in)

Chest (tighten by taking a deep breath)

Neck and shoulders (raise your shoulders up to touch your ears)

Mouth (open your mouth wide enough to stretch the hinges of your jaw)

Eyes (clench your eyelids tightly shut)

Forehead (raise your eyebrows as far as you can)

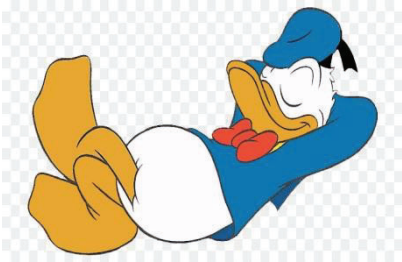


Image: Fly Clipart

Image: Clipart Library

- **Guided imagery**

Guided imagery is another excellent way to practice relaxation and to manage stress. This is where you sit or lie quietly and imagine that you are in your favourite place, such as on a tropical island, on a beach, or in a forest. Use all your senses – what does it smell like, feel the sun or the breeze on your face and think what colour the waves or the leaves are. Feel the sand on your feet and listen to the waves or the wind. What does it sound like?

3. Sleep

Sleeping well is very important for health. Some people need more sleep than others. People with chronic illnesses often have trouble sleeping because they worry about the problems their condition is causing.

How to improve your sleep:

- ✓ Follow the same routine every night before bed. It could be locking your house, washing your face, brushing your teeth, and practicing relaxation.
- ✓ If you can't sleep because you are worried, **identify and write down the problem**. Follow the problem-solving steps in **week 3**, then make an action plan to help solve it. Practice relaxation to help take your mind off your worries.
- ✓ Try to use your bed only for sleeping. Not for watching TV, reading or any daytime activities.
- ✓ Follow the same routine every morning and get up at about the same time each day. This helps to set your body's rhythm of sleeping and waking.
- ✓ Do not drink anything with caffeine such as coffee, tea, cola, or energy drinks in the last four hours before bed. Caffeine can take a long time to be digested and leave your system.
- ✓ Do not drink alcohol to help you to relax and sleep.

4. **Exercise**

Research shows that regular exercise reduces stress and depression, improves sleep, and decreases pain. It keeps your body healthy and prevents disease. Go back to **week 4** for details on safe and effective exercise for breast cancer survivors.

Good news

You can self-manage your stress to help prevent anxiety and depression from getting worse. If you are not able to manage your stress on your own, ask to be referred to a psychologist. [370]

How to manage your pain

Concepts explained

Phantom breast pain: This is when you feel pain, itching, tingling or a burning sensation in the breast that has been removed. This can happen if the brain still sends signals to nerves in the breast area that have been cut during surgery [24].

Background [24, 588, 589]

Breast cancer survivors experience a wide range of pain. You may have little or no pain, or you may have persistent, severe pain. The pain may be caused by the cancer, by the surgery, chemotherapy, radiation, Tamoxifen or by other medication. Pain from the cancer treatments can affect breast cancer survivors for years afterwards. You and your health provider should have a plan in place to address your pain. You may have to try out a few different strategies, but the effort will be worth it. You should be able to enjoy the activities of life again.

The surgery to remove your tumour can cause pain from tissue scarring, or from nerves being damaged or stretched. Speak to your doctor if you experience phantom breast pain. There is medicine that can help.

Radiation may cause lasting pain for breast cancer survivors, because of tissue and nerve damage or scarring. The injury to the muscles around where you had surgery and radiation (armpit, chest, shoulder) may cause you to tense those muscles or keep them still. This can cause the muscles to become weak and tight. The lack of movement then causes joints to stiffen. So, at first, when you do try to use the stiff muscles and joints again, it may hurt because they are no longer used to the movement. Stress, fear, anxiety and depression can also cause pain or make it worse.

Why we feel pain [358, 590]

Pain is your body's way of warning you that there may be something wrong. Sometimes there isn't really something wrong, it's just a warning. Like when you touch a surface that is very hot. You feel pain and pull your hand away. Often your hand is not damaged or burnt at all. The pain only served as a warning that you should pull your hand away to avoid getting burnt. If you have a new pain, you should pay attention to it and let a healthcare provider know. If they find the cause of the pain, they can give you medicine for it. Even if no cause is found, this does not mean that your pain isn't real. Your healthcare provider should still plan to address your pain.

Image: Vectorstock

How to manage your pain [6, 68, 158, 358, 584]

There are many things you can do to relieve pain. When you have pain, your brain is very active. Being a self-manager who learns about your condition and having support can help to decrease pain. In this way you can use your brain to your advantage, like a weapon against pain.

- **Exercise.** Research shows that people who exercise regularly have less pain than those who do not. Any type of exercise: endurance, strengthening, and stretching, is helpful.
- **Relaxation.** Relaxation helps pain because it reduces the brain's activity. Regular relaxation also improves sleep. Use the 3 relaxation techniques under 'How to manage your stress'.
- **Sleep.** Sleeping better is another powerful weapon against pain. See the tips on improving sleep under 'How to manage your stress'.
- **Heat** can be used to help relax tense muscles. This can reduce pain. You can use warm pads or compresses over any muscles in your body, EXCEPT on the arm, neck, shoulder, or upper back on your operated side. Heat brings extra fluid into that area of the body, which can overload the lymphatic system and cause lymphoedema.
  You can take a warm shower but avoid hot baths. Do not use heat on an area that is already hot, or over an open wound.

Image: Dreamstime

Image: Clipade

- **Cold** can be a good way to treat pain, but NOT around your operated breast (neck, armpit, shoulder, upper back, and arm). You can use a pack of frozen vegetables or a damp, cold cloth on a sore area, for no more than 10 minutes at a time to decrease pain.

- **Massage** is useful to improve pain. If you have bumped yourself and rubbed the area, you have done self-massage. You can gently massage a painful area if it is not hot, red, or swollen. If it is, you may have an infection. Then rather use ice on it for a day. If it doesn't improve, go to your clinic to have it examined. On your affected side, vigorous deep tissue massage should be avoided as it can cause fluid overload, just like heat and ice. The areas to avoid deep, vigorous massage are your chest, neck, armpit, arm, and upper back.
- **Support** helps to relieve pain. If you have pain and you worry about the pain a lot, this gives you stress. Stress causes your pain to get worse and it can cause sleep problems. Get clarity from your health provider about the cause of your pain. Talking to someone about the pain or your situation in general will relieve stress, which improves pain. Contact a breast cancer support organisation for emotional support and to connect with other breast cancer survivors. Sharing experiences and getting new ideas will reduce your stress. See the list of support organisations at the back of this handbook.

Image: Clipart Max

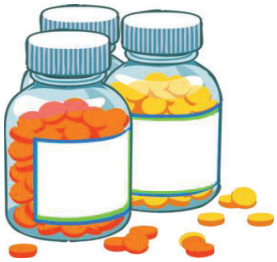


Image: Clipart Library

- **Medicine.** If you have been prescribed pain medication, you should take it regularly. Avoid waiting until the pain is severe and then taking it. If you do this the medicine will not work as well. Take it as prescribed or as soon as the pain starts.

Most of the common pain medicines can have side effects if they are used for a long time. This is why it's important that you use the other tools against pain described in the points above. Go back to your healthcare provider if your pain medicine isn't working. Sometimes the dose needs to be changed or you may need different medicine. There are medicines that are intended for other illnesses like depression or epilepsy; that can be used to treat pain over longer periods.

Quick notes on pain

- ✓ Pain can range from no pain at all to severe pain in breast cancer survivors.
- ✓ Pain can be from cancer treatments, nerve damage, or stiff and weak muscles and joints.
- ✓ Pain can be caused or worsened by stress, being anxious or afraid.
- ✓ Exercise, relaxation, cold, heat and massage and getting support can help to treat pain.
- ✓ Extreme cold, heat and vigorous, deep massage should be avoided in the chest, armpit, shoulder, arm, neck, and upper back on your operated side.
- ✓ Pain medicine works best if you take it as prescribed or as soon as the pain starts. Work with your health provider to find the best medicine for you.

Good news

Most people can get complete, or near complete relief of their pain. You do not have to suffer for the rest of your life because you had breast cancer.

Tasks for the week [35, 37, 83, 234]

- ➢ Complete your exercise diary (see week 4) for this week.
- ➢ Remember to take your shopping list (see week 8) with you when you go shopping and tick off the healthy food items that you buy.
- ➢ Complete the below table about the challenges discussed this week that affect you. Make a plan to manage your problem and then follow through with it!

	This is affecting me (please tick)	This is my plan to manage it
High levels of stress		
Anxiety		
Depression or low mood		
Poor sleep		
Pain		
I need more emotional support		
Other		

Week 9: How to find a cancer recurrence early

Concepts explained [77, 558]

A cancer recurrence is when cancer comes back.

A local recurrence means the cancer has come back close to where your previous tumour (lump) was. It can develop in the same breast after a mastectomy, even if the whole breast has been removed. Sometimes a new cancer develops in the other breast.

A regional recurrence is when the cancer starts in the same area as previously: in the lymph nodes of your armpit, above your collar bone, or in the neck of your operated side.

A distant recurrence is when the cancer has come back in the bones, lung, liver, or brain.

A mammogram is an X-ray picture is taken of your breast. This is a test to find breast cancer early, sometimes before you feel a lump or other signs.

A symptom is when you experience a noticeable change in your body or its function, that could indicate an illness.

A sign is a change in the body or its function which others can see. For example, if you experience a bloody nose (**symptom**), and other people can see the blood running from your nose (**sign**).

Background [6, 7, 83, 372]

You may be worried about your cancer coming back. Survivors must know how to find a cancer recurrence as soon as possible. Because modern cancer treatment is so effective, more survivors are alive today than ever. Survivors are also living longer lives than before. Research shows that these days, survivors are more likely to die from chronic, preventable diseases, than from cancer.

Stay aware of the information below, go over it again occasionally, and stay informed about breast cancer and your health. Be alert, but not worried about the symptoms and signs to watch out for. Let your closest family or friends read this information so they can help you to find problems early. Being alert and informed is part of being a successful self-manager. She takes care of her health by exercising regularly, eating healthy food, and going for regular check-ups at the clinic.

A higher stage of cancer means you have a higher chance of recurrence. For example, someone who had stage 3 (III) breast cancer has a higher chance of getting cancer again than someone who had stage 1 (I). This is why it is important that you know your cancer stage.

The best thing you can do to find a local recurrence early is to **do breast self-examination every month.** *The breast self-examination does not replace any of your regular clinic visits.* It's something you should do *in addition* to your medical treatment.

Whether you've had a mastectomy, lumpectomy, reconstruction, or no reconstruction; do the self-examination in the same way as you would if you hadn't had any surgery. Teach your daughters and other women how to perform breast self-examination and you could save a life.

Image: Clipart Library

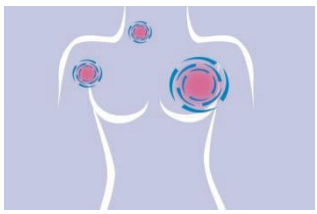


Image: Cleveland Clinic

Signs and symptoms of breast cancer [6, 7, 372]

Go to your clinic as soon as you experience any of them.

Local / regional:

- A lump or mass in the breast, chest wall, armpit, or neck
- The skin of the region around the breast is *dimpling* (making small holes)
- Your nipple suddenly starts to pull inwards (*retract)*
- Your breast suddenly gets smaller or larger
- Clear or bloody fluid runs out from the nipple on its own (spontaneously)
- A sudden change in the skin of the nipple and the area around it: redness, scaly (flaky) or thickening
- A rash on your breast that does not go away with antibiotic medicine

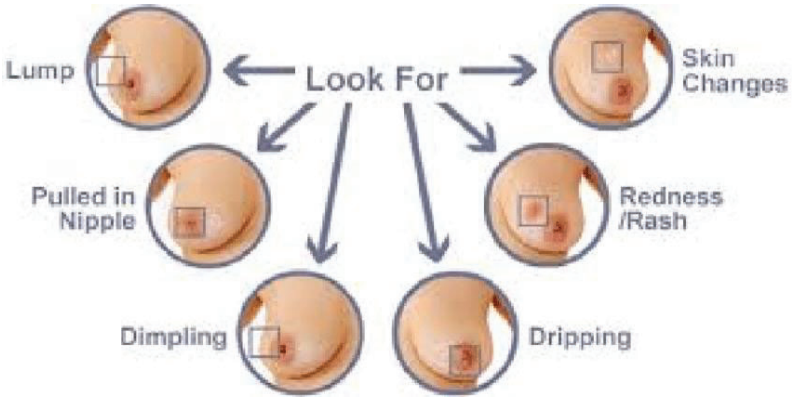


Image: Sarcasm

How to do a breast self-examination [372]

1. **Look** at yourself in the mirror without a top or a bra on. **Stand** with your hands on your hips and look for the above points **Signs and symptoms of breast cancer: local / regional.**
2. **Raise** your arms above your head and **look** for the same signs and symptoms again.
3. **Lie down** on your back and **feel** your breast / chest wall with the opposite hand (your left hand examines the right breast, and your right hand examines the left breast). Use the pads of your fingers in a circular motion to feel for any lumps or nodules. Feel if there is any new thickening along or near your surgery scar. Cover the entire area of your chest, under your armpit and up to your collarbone. To be sure that you cover the whole area side to side and top to bottom, you can move your fingers as if you are mowing a lawn.
4. **Feel** your breast / chest wall in **standing or sitting**. Use the same hand movements and cover the entire area as described in step 3.

You will find that the self-examination gets easier the more often you do it. This is because you will become familiar with the look and feel of your breast / chest regarding what is normal for you. If you are uncertain, ask your clinic sister to check for you.

What to do if you find a lump or a breast change [372]

- ✓ Don't panic, most lumps are not cancer.
- ✓ Go to your clinic as soon as possible. A health professional will do a breast examination and decide if further tests are needed, for example an ultrasound or a mammogram.
- ✓ The important thing is that you and the health professional decide on a plan for monitoring or treating the lump.
- ✓ Make sure that you get an explanation from them about the cause of the lump or breast change. If you do not feel comfortable with the advice you get, tell that or another health professional at the clinic.

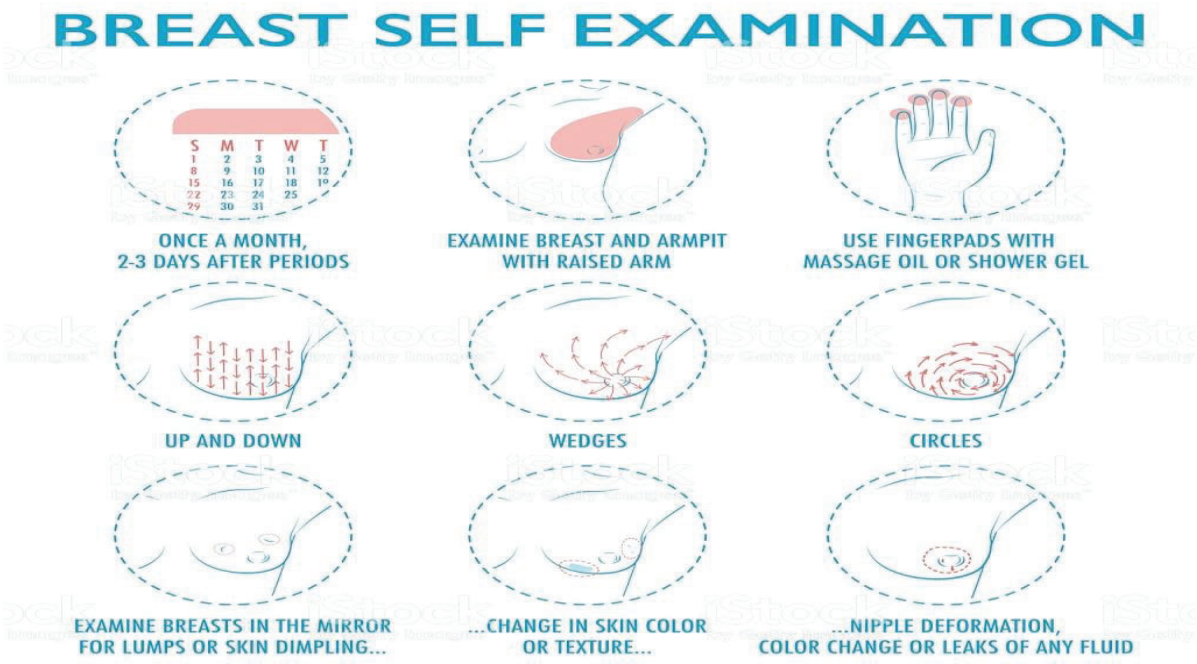


Image: Deposit Photos

Signs and symptoms of breast cancer [591]

Distant recurrence or new cancer: be aware of the below points and get medical advice if you experience any of them:

- New pain in your bones for more than 2 weeks (long bones of the arms or legs, ribs, or spine)
- Chest pain that stays (is persistent), with or without a cough
- A persistent pain in your abdomen (tummy)
- Weight loss if you haven't been trying to lose weight
- A persisting headache
- Sudden changes in your personality
- You are suddenly getting *seizures.* A seizure is when suddenly your muscles start to twitch, get stiff or limp in an uncontrollable way. If you are suddenly feeling strange behaviours, sensations, or changes in awareness that you can't control, you may be having a seizure. Seizures happen when there is temporary, uncontrolled electrical activity in the brain.
- Loss of consciousness: blackouts, where you lose awareness of yourself and others.
- Unusual spotting or vaginal bleeding that's not your monthly period

How to find a recurrence or new cancer early [372, 591]

- ✓ As an effective self-manager, check yourself often. It is a good idea to write your self-examination on the calendar and do it once every month.
- ✓ Ask someone in your household to remind you to do your self-examination monthly from now on.
- ✓ Go through each of the above points (signs and symptoms of breast cancer: distant recurrence or new cancer) after your self-examination. Look at yourself in the mirror and feel for lumps.
- ✓ Go for a check-up at the breast clinic at least once a year, and for a *mammogram*.

'I'm grateful for the second chance that I have, but I still have this doubt, will cancer come back. I asked the doctor that, and I said how will you know if the cancer is back? And she said, oh well, you will see if there's something wrong and then you can come to us.'

'The risk of whether you're prone to get it ... like already now have full blown cancer and then they say sorry, there's nothing ...It's just you want to be there, I want to see my kids marrying.'

'I would say we are cancer free but aren't there also symptoms that go with... look, you should come back if you feel this way, or you have a swollen gland in your leg....'

'And I always thought I am going to die, but that they haven't really found out about the cancer yet.'

'When I had to go for the biopsy there was a lady sitting next to me. She and I started a conversation. That woman really made me feel better. She told me no; cancer is not always about death. She says she has a friend who has been clean for 29 years and she is also clean.

She also had cancer. But then the doctor called my name, and I just thanked her. Because I thought... I don't even know the stage of my cancer.' **– Breast cancer survivors**

Good news

Staying alert and informed about the signs and symptoms to watch out for, and visiting your clinic regularly for check-ups, is vital to detect a cancer recurrence early [372, 591].

Task of the week [83, 372, 591]

- Go through the signs and symptoms of breast cancer (local / regional) and distant recurrence / new cancer above. Tick off if you experience any of them using the table below and then make an action plan to manage that problem.
- Complete your exercise diary for this week (see week 4).
- Remember to take your list of healthy food items with you when you go shopping (week 7).

Cancer signs and symptoms

	Please tick	My action plan to address this problem
Breast lump or other breast changes		
New pain in bones, chest, or abdomen		
Persistent headaches, blackouts, seizures		
Unusual vaginal bleeding not part of your period		
Sudden personality changes		
Unexpected weight loss		
Other		

Week 10: How to identify skin cancer and blood clots early; and talking to your healthcare provider

Concepts explained [7]

A blood clot is a thick, sticky clump of blood that forms in a blood vessel and blocks the blood flow.

A **deep vein thrombosis** is a blood clot that happens in an arm or a leg.

A pulmonary embolism is a blood clot in the lung.

Background [7, 374]

Breast cancer survivors have a higher risk of getting **skin cancer**, than people who have not had cancer. Apply broad spectrum, SPF 30, or higher sunscreen 20 minutes before you go out into the sun between 10 am and 4 pm. As with other cancers, skin cancer can best be treated if found early. It may be something harmless or it may need treatment, but it's important to have it checked by a doctor to make sure. Add a **routine skin check for skin cancer** to your monthly self-examination. Pay attention to the areas of your skin that are in the sun often, like your nose, forehead, hands, ears, or lower lip.

Anyone who has had cancer is more likely to develop **blood clots** than the rest of the population. This is because cancer can interfere with the normal blood clotting mechanism. A blood clot may happen at any time during your life. **Although your risk as a cancer survivor is higher than normal, blood clots are quite rare, so you don't have to worry. But being aware of the signs and symptoms of blood clots can be lifesaving.** The sooner you get medical attention, the better your chance of recovery.

Signs of skin cancer [374]

Here are the most common signs of skin cancer to look out for. Go to your clinic if you notice any of them.

- A mole that looks different than the others, changes colour, size or how it feels
- The border of a mole becomes irregular instead of round, becomes itchy or bleeds
- A painful sore that itches or burns, or doesn't heal
- A scaly patch that bleeds or becomes crusty
- A brown or black streak under a nail

Image: Clipart Library

Signs and symptoms of deep vein thrombosis [7]

If you suddenly develop

- pain
- swelling
- tenderness
- And sometimes redness or warmth in an arm or a leg, **visit your clinic immediately.**

Signs and symptoms of a pulmonary embolism [7]

- sudden shortness of breath
- chest pain when you breathe deeply
- a fast or irregular pulse
- feeling lightheaded
- Sometimes coughing up blood.

Tell the healthcare provider on duty what you are experiencing, that you have had breast cancer, and that you think you may have a blood clot.

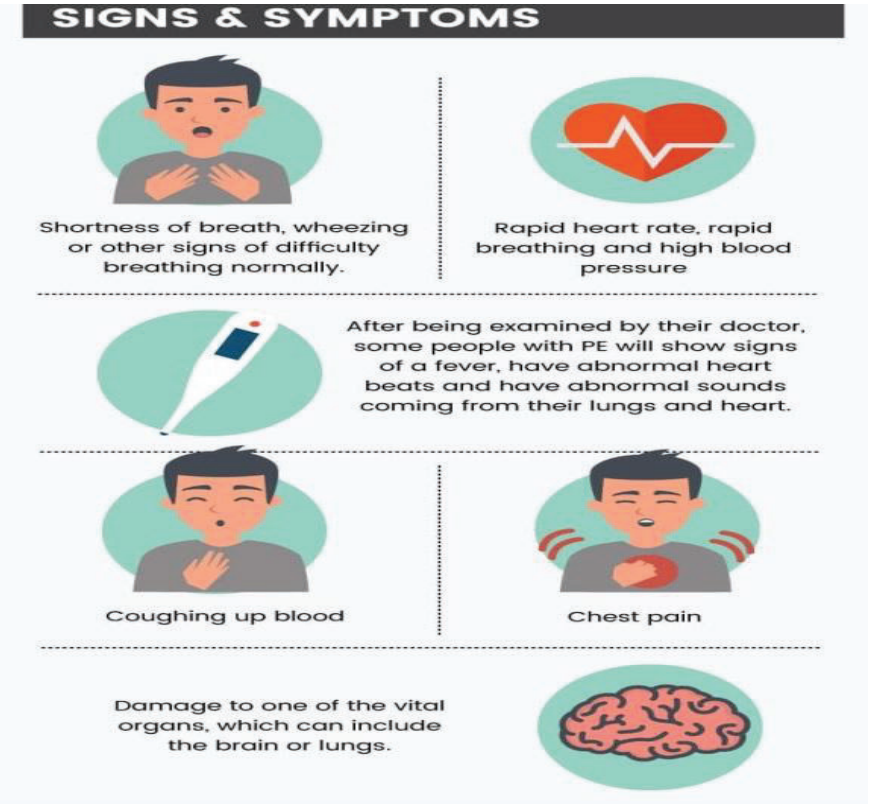


Image: Adekunleadelodun

How to prevent blood clots [7]

- ✓ Do not become overweight or obese. See the information on maintaining a healthy body weight in **week 7**.
- ✓ Get enough regular exercise. When you exercise, the movement encourages the flow of blood in the blood vessels. Remember your exercise target is 150 minutes of moderate (slightly / somewhat hard) of exercise per week. Include strengthening exercises 2 times per week. Any exercise is better than none. Even if you start with a little every day, that's good. See the exercise routine described in **week 4.** If you haven't started yet, start now.

Quick summary of your monthly self-examination [6]

- ✓ Breast self-examination to check for a local / regional recurrence
- ✓ Go through points to detect a distant recurrence or new cancer
- ✓ Check for signs of skin cancer
- ✓ Check for signs of blood clots in your arms and legs
- ✓ Check for signs of a blood clot in your lung

- ✓ Are you maintaining a healthy lifestyle: Healthy body weight, eating well, taking your medicine as prescribed and exercising regularly?
- ✓ Have you stopped unhealthy habits such as smoking and drinking too much alcohol?

Talking to your healthcare provider

Background [7]

Breast cancer survivors must visit the clinic regularly, especially if you have other chronic illnesses like diabetes, high blood pressure or heart disease. Healthcare providers are often very busy, seeing many patients each day. Communicating effectively with healthcare providers helps them to help you.

How to get the most out of your visit to the healthcare provider [233, 358, 376]

Take PART:

1. **Prepare**. **Think** about why you are going to the clinic and if there is anything you are worried about. **Write** down a list of your problems, questions, or concerns. Put the most important ones at the top of your list. Bear in mind that the healthcare provider may only have time to address one or two of the items on your list. **Take** your list with you to the appointment. Use it when the healthcare provider asks you how they can help you.

   If there is a health problem at the top of your list, prepare with some information about this problem: **where** in your body is it, **how long** has the problem been there for, **what** makes it better or worse? Have you had a similar problem before, how was it treated? Did this treatment work? Has anything changed in your life that could have caused this problem – an injury, your medicine, your diet, new exercise? Preparing this kind of information will help the healthcare provider to help you. Having it all written down prevents you forgetting anything important on the day.

   Be very clear and direct about what is worrying you and why. If you feel unhappy about how the healthcare provider is treating you, you can tell them. If you do not want to tell them directly, you can report your concern to another staff member at the clinic. Also, remember to **give positive feedback** if you have been treated well. Healthcare providers really appreciate compliments.

Image: Clipart Library

Image: DL PNG

2. **Ask.** Asking questions about your illness, test or treatment gives you information. This information helps you to be a successful self-manager of your health. Ask questions like what is wrong, is it contagious, what will happen now? If you are going to have tests or scans, ask what the tests are for. What happens if you do not go for them and what will you need to do?

   If you are getting treatment, ask about the different options, what are the benefits, risks, and side effects of the treatment? How long will you need to continue the treatment? Finally, ask questions like what you must do next and when to come back to the clinic. If you have trouble remembering it is a good idea to write things down during your visit. Or take someone you trust along with you to help you remember what was said.

3. **Repeat**. When the doctor or sister explains something important to you, repeat it back to them in your own words. This can help clear up any misunderstandings.
4. **Take action**. Make sure that you know what to do next: get medicine from the pharmacy, make another appointment, or go home and change something to improve your health. Don't assume that the next step will be done for you. Get information on what *you* can do, then do it.

Good news

If you follow the above steps, you will gain more from your visit to the healthcare provider. If you stay alert and informed about skin cancer and blood clots, you do not have to be worried about them.

Task for the week [83, 234]

- Make an **action plan** to manage your health. For example, this afternoon I will do my breast self-examination. I will check for signs of breast and skin cancer, and blood clots. I will make a note on the calendar to do it every month.

Today I will:

_____ (what)

_____ (how much)

_____ (when)

_____ (how many)

- Complete your exercise diary (see week 4) for this week: week 10 of the programme. Is your exercise increasing gradually as the weeks progress? If not, make an action plan and go back to week 4.
- Are you doing your shoulder exercise routine at least 3 times per week? If not, go back to week 5.
- Remember to take along your shopping list (see week 7) to tick off the healthy food items that you buy.

Skin cancer and blood clot checklist [7, 374]

	Sign / symptom that affects me	I plan to do _____
Mole looks / feels different to the others, uneven borders		
Sore on your skin which itches or burns, not healing		
Scaly patch on skin that bleeds / becomes crusty		
Black streak under nail		
Any deep vein thrombosis signs?		
Pulmonary embolism signs?		
Other		

Week 11: How to continue as a successful self-manager

Background [233]

In the past weeks you have learnt many new skills that will help you to thrive, rather than just survive. Breast cancer survivors sometimes feel guilty when they complain about their health problems. We are told we should just be thankful that we survived the cancer. Yes, but there's more to it than that: we experience many unique challenges as breast cancer survivors, and we have a right to receive the correct information and treatment for our health problems.

In these past few weeks, you have learnt about being a successful self-manager, about exercise, what type of exercise to do and how much. You have learnt about nutrition and about keeping your weight under control. You have learnt about the long-term side effects of breast cancer treatment and how to manage them. You have also learnt to look for signs of disease in your body and what to do about them.

How to continue as a successful self-manager [37, 83]

- If there is a problem, **get information** about the problem. You have a right to discuss your health problems or long-term cancer side effects with a health worker. They must help you to manage the problem or to find treatment for it. Your needs and your health are important, even if there are others who might be worse off than you.
- **Share** the information you have learnt among your close family, friends, and colleagues at work so they can support you.
- Through the action plans and exercise diary you have had the chance to make good changes to your lifestyle. Stick to those changes and keep setting new goals for yourself.

Image: Kind PNG

Image: Pixy

Task of the week [37, 83, 234]

- Complete your exercise diary for this week (see week 4). Is the time you spend exercising per week increasing?
- Take along your shopping list (week 7) when you go shopping. Choose to buy and eat healthy food!
- Go back to the homework sections of each of the weeks in the table below. What action plans did you make to manage your problems? Did you follow through on your action plans? If not, start doing something to manage those problem(s) today. If you are struggling with debilitating shoulder problems, fatigue, obesity, or other long-term problems despite following the advice in this book, ask at your clinic to be referred for advice or treatment.

	My action plan was ….	I did….
Week 1: long-term side effects of breast cancer affecting me		
Week 2: long-term side effects of breast cancer affecting me		
Week 3: excuses not to exercise I can associate with		
Week 5: shoulder problems affecting me		
Week 6: signs and symptoms of lymphoedema affecting me		
Week 8: signs and symptoms of stress, anxiety, depression, poor sleep, pain, or lack of emotional support affecting me		
Week 9: signs and symptoms of cancer recurrence that affect me		
Week 10: signs of skin cancer and blood clots affecting me		

Week 12: How to continue as an effective self-manager, useful contacts, and further reading

Action plans for the future [83]

Worrying about getting sick can make you feel afraid, sad, and angry. These emotions may make things feel a lot worse than they really are. Going through this workbook has encouraged you to face your fears, so you can deal with problems as they arise. Being informed is the first step to manage fear. The next step is to make an action plan, and then to do something about that fear. This can give you an enormous sense of control over everything that used to make you feel afraid. Use the action plans to identify your worries about the future and then make plans to deal with them.

Write down some of the things that may happen in the future that worry you [358]

_____

_____

_____

_____

Now write down the different things you could do, that would help plan for the things that worry you [83]. For example, you may be worried that you won't be there to see your children growing up. Things you could do for this would be to go to your healthcare provider and get information about the type and stage of your cancer. Ask them when and how often you should go to the clinic for check-ups and mammograms. Don't forget the steps to take PART discussed earlier this week.

Take along a pen and paper and write down the information your healthcare provider gives you. Another thing you could do to prepare for such a situation: talk to your partner or a trusted family member about who can take care of your children in case you die.

_____

_____

_____

_____

If you are not confident that you can carry out your plan, you need to change it. There are many organisations that can help you plan for the future. For example, the Family and Marriage Society of South Africa (FAMSA), the Cancer Association of South Africa (CANSA) or your church.

In the future

Now you have learnt to deal with many challenges you may face as a breast cancer survivor. You have learnt to be a successful self-manager, working in a team with health professionals, your family, and friends. The aim of this team is to get you to live life to the full, to thrive. Keep using the information and skills you have learnt in this handbook. Keep using action plans and exercise diaries. Staying active and involved will help you to keep improving the quality of your life. Ask at your clinic, whether there are any community exercise programmes being run in your area. For example, in the Western Cape, there is Western Cape on Wellness (WoW), a healthy lifestyle initiative. They organise many events throughout the province. Or consider taking part in your local Parkrun. This is a free, fun 5 km run / walk which happens every weekend in many outdoor locations. The contact details for these and other similar initiatives are provided at the end of this book.

Handbooks using active participation have helped many people with chronic illnesses such as cancer, HIV/AIDS, high blood pressure and osteoarthritis. This programme will be a success if you take action and make positive changes to your life [81, 233, 348, 349].

Write down here the changes to your life you have made during these 12 weeks:

_____

_____

_____

_____

Finally, write down the changes you still want to make in your life. Maybe there is something you would like to be able to do, something that would improve the quality of your life.

_____

_____

_____

Task for the week [7, 18, 83, 234]

- Complete your exercise diary for this week (see week 4). How did you do over the weeks? Any increase in exercise is worth celebrating and building upon!
- Take along your shopping list when you go grocery shopping (see week 7). Have you managed to change some of your buying habits? Well done!

- **Today's date: _____ Write down your height _____, weight _____ and your BMI: _____** Check week 7 to see what your BMI was then. Is it getting closer to the normal range: 18.5 to 24.9 kg / m^2? Don't panic if it hasn't changed. Go back to the sections on getting a normal weight and exercise, to ensure you are following all the advice. Recalculate your BMI again in about 6 to 7 weeks. If there is still no change and your weight is in the overweight or obese range, ask to be referred to a dietician for advice.
- **Use the rest of this week to sharpen the tools you have received over the past few weeks. Here is a checklist you can tick off. Go back to the relevant section in this book if you need to…**

✓ Have you gradually increased your exercise to 30 minutes, at least three times per week? ___ OR, if you had been physically active before starting this programme, did you manage to increase your weekly exercise to 2 and a half hours (150 minutes)?

✓ Are you doing your shoulder exercises at least 3 times per week? ____

✓ Have you made good changes to your diet, and are you keeping up these changes? ___

✓ Are you doing more things that you enjoy again? ____

✓ Do you check your body for signs of disease? ____

✓ Have you contacted your health provider if something about your health is worrying you? ____

✓ Are you making action plans and following them through? ____

There is another exercise diary for the next few weeks at the end of this book. Cut it out and put it in a place where you will see it often. When you run out of exercise diaries, draw your own.

You have completed this handbook. Well done! Although it contains a lot of information, your journey with cancer is unique. You might experience something that has not been covered in this handbook. Whatever it is, we encourage you to find information about your problem and to discuss it with your healthcare provider.

You have taken important steps to look after your health as a breast cancer survivor. We wish you well on this journey. Do not put this handbook away. Put it somewhere safe where you can refer to it or work through it again. Hopefully when you open it the next time you will be amazed how far you have come. We can always achieve more than we think. We just need to use the help that is offered along the way.

Image: Clipart Library

Useful organisations

Cancer Association of South Africa (CANSA) www.cansa.org.za e-mail: info@cansa.org.za

Toll-free counselling help desk: 0800 226622

WhatsApp support (free of charge): 072 197 9305 English / Afrikaans

WhatsApp support (free of charge): 071 867 3530 isiXhosa, isiZulu, Sesotho, SiSwati

Reach4Recovery: reach4recovery.org.za

Bettercare.co.za This website provides an overview of support organisations for breast cancer.

Family and Marriage Society of South Africa (FAMSA) www.famsa.org.za George (044) 874 5811

Western Cape on Wellness (WOW): WesternCape On Wellness | A healthier lifestyle

www.parkrun.co.za

Additional reading

www.cansa.org.za/womens-health

www.reach4recovery.org.za/food

www.mybreast.org.za

www.pinkparasol.co.za

www.cancer.org/cancer/breast-cancer/treatment

www.cancer.org/treatment/survivorship-during-and-after-treatment

www.breastcancer.org

www.cancer.net/cancer-types/breast-cancer/survivorship

www.nccn.org

www.nationalbreastcancer.org

Links to exercise routine examples:

General:
https://drive.google.com/file/d/1Xln5dkxiqfjhI1nAYUzAWK9Xm2WSmEjf/view?usp=sharing

Shoulder:https://drive.google.com/file/d/1cODc45vUd6imPGen0359A-EK4ezuVVjk/view?usp=sharing

Exercise diary

Week	1	2	3	4	5	6	7	8	9
Date									
Monday									
Tuesday									
Wednesday									
Thursday									
Friday									
Saturday									
Sunday									
Total minutes or hours per week									

Shopping list

	Week 1 Date:	Week 2 Date:	Week 3 Date:	Week 4 Date:	Week 5 Date:	Week 6 Date:
Cabbage, spinach, swiss chard, morogo, broccoli, cauliflower, green beans						
Pumpkin, butternut						
Tomatoes, green peppers						
Lettuce, cucumber						
Onions, garlic						
Carrots, peas, parsnips						

Mushrooms, marrows Other Other						
Naartjies, oranges, grapefruit, lemons						
Apples, pears						
Paw-paws, guavas, melons						
Avocado						
Peaches, apricots						
Grapes						
Fish: hake, snoek, sardines, pilchards, tuna						
Eggs						
Dried / canned beans, lentils, chickpeas						
Milk, yoghurt, maas, cottage cheese						
Chicken, turkey						
Wholegrain / multigrain / wholewheat / rye bread, oats, bran						
canola oil, sunflower oil, olive oil, nuts, seeds						
Herbs and spices						
Coffee, tea, rooibos tea						

Small treat, e.g. dark chocolate						
Other						
Other						
Other						

Preview Week 1 and 2: Medical cancer treatment and your body

Long-term Cancer Treatment Side Effects [24]

Breast cancer treatment includes surgery, chemotherapy, radiotherapy, and hormone blocking medicine. These are good at beating cancer and improving survival. Many side effects go away when you finish treatment. There are some problems that can happen for years. Most people do not get all of these but it's important to be aware of them.

What are common long-term side effects of treatment? [24]

- Shoulder and arm problems
- Weight gain
- Fatigue: extreme tiredness that does not get better with rest
- Lymphoedema: swelling of the arm or chest on the operated side. Can start at any time after cancer
- Difficulty with daily tasks that used to be part of your life
- Depression
- Forgetfulness

Does hormone blocking medicine (such as Tamoxifen) have side effects? [6]

Tamoxifen may be prescribed to prevent cancer from coming back. This is why you must take it for as long as your doctor advises. It can cause hot flushes, mood swings, depressed mood, less interest in sex and vaginal dryness. These effects usually go away once you finish taking Tamoxifen.

Image: After Breast Cancer

Preview Week 3 and 4: Self-management and Exercise

In the last 2 weeks, you learnt about the long-term side effects of breast cancer treatment. To make them better, you must become a good self-manager. This doesn't mean that you must do everything yourself. It means you work in a team with healthcare providers. It means that you take time to work through this handbook. You can then use the knowledge you gain from this intervention, to make good decisions about your health [200, 201].

A good self-manager [83]

- Makes action plans
- Writes down ways to achieve the action plans
- Takes action
- Regularly checks her progress
- Can change her plans if a problem arises
- Rewards herself for taking action

Exercise is like medicine for most long-term side effects of cancer treatment [18].

Even if you don't like exercise, it is important to find an activity you enjoy.

The minimum exercise to improve long-term side effects of treatment is 30 minutes, at least 3 times per week [18]. You can start with as much as you can manage. Increase it slowly and gradually from there. In this chapter, we show you how.

Image: Clipart Library

Preview Week 5 and 6: Upper limb function and lymphoedema

Cancer treatments can leave your shoulder painful, weak, and stiff. There are also many other shoulder injuries that breast cancer survivors can get [6].

The correct regular shoulder exercises can improve your shoulder and arm [148].

In this chapter of your handbook, learn about managing your shoulder and arm. Learn about shoulder injuries after cancer treatment, and when to get medical help. There is an example shoulder exercise routine designed for breast cancer survivors. There are tips and tricks to get the most out of your shoulder exercises. We show you how to use a scoring system to monitor how well your shoulder is doing, to help you decide when to get medical advice.

Lymphoedema presents as arm or chest swelling, in breast cancer survivors. It happens when lymph fluid stays in the lymph vessels and the body is not able to drain it. Breast surgery and medical cancer treatments increase your risk of getting arm or chest swelling. Lymphoedema is lifelong. It cannot be cured. The earlier it is found and treated, the easier it is to manage. If nothing gets done about lymphoedema, it will get worse and cause lasting tissue damage [584].

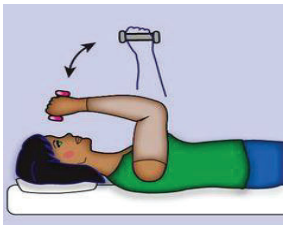


Image: Very Well Health

Lymphoedema can start at any time after breast cancer treatment [6]**. Learn more about lymphoedema, how to prevent and manage it in week 5 & 6 of your handbook.**

Preview Week 7 & 8. Eating well, body weight, stress, and pain management.

A long-term side effect of chemotherapy is weight gain. Research shows that overweight breast cancer survivors do not survive as long as those at a normal weight. Many breast cancer survivors are already overweight when the cancer is found. Overweight and obesity increases a person's chance of getting breast cancer [365, 592].

Being overweight increases the chance that your cancer may come back [335, 350]**.** In this chapter, learn about nutrition and a healthy body weight, for breast cancer survivors. Learn how to calculate your body mass index (BMI) and when to consult a dietician. There are also tips on food safety.

Stress management is important to stay healthy [6]. Learn what affects how stressed we feel and how to manage stress. There are suggestions for relaxation, and ideas to improve sleep.

Breast cancer survivors experience a wide range of pain. You may have little or no pain. Or you may have persistent, severe pain. The pain may be caused by the cancer, surgery, chemotherapy, radiation, hormone blocking, or other medicine [95].

Pain from cancer treatments can affect survivors for years. Most people can get complete or near complete relief of their pain [24]. In week 7 & 8, learn about the causes of pain in breast cancer survivors and what can be done for pain.

Image: Vectorstock

Preview Week 9 and 10: Is the cancer back? What to look out for and talking to your healthcare provider.

Breast cancer survivors should know how to find a cancer recurrence as soon as possible. A recurrence is cancer starting again. It can develop in the same breast after a mastectomy, even if the whole breast has been removed. Sometimes new cancer develops in the other breast [591].

The cancer may start in the lymph nodes of your armpit, above the collar bone, or in the neck on your operated side. There may be cancer recurrence in the bones, lung, liver, or brain.

Be informed and alert about the signs to watch out for. A good thing you can do to find a recurrence early is a breast self-examination every month [372].

Learn how to find cancer early. Learn how to do a breast self-examination in week 9 & 10 of your handbook.

Breast cancer survivors are at risk of getting skin cancer and blood clots, compared to people without cancer [7]. **In this chapter, learn about the warning signs for skin cancer and blood clots.**

As a breast cancer survivor, you must visit the clinic regularly. Healthcare providers are very busy, seeing many patients each day. Communicating with health providers helps them to help you. This week, we give you tips to get the most out of your visit to the health care worker [376].

Image: Clipart Library

Preview Week 11 and 12: Continuing as a self-manager, useful contacts, and further reading

In the past weeks, you have learnt about the long-term side effects of cancer treatment and how to manage them. You have learnt about being a successful self-manager, exercise, what exercise to do and how much. You have learnt about nutrition and keeping your weight under control. There was information on keeping your shoulder well, stress and pain management. You have learnt to look for signs of disease in your body and what to do about them.

We hope that going through this handbook has encouraged you to face your fears, to deal with problems as they arise. Being informed is the first step to manage fear. The next step is to make an action plan and to do something about that fear. This can give you control over everything that used to make you feel afraid [35, 83].

Keep using and sharing the information you have learnt in this handbook. Continue to use action plans and exercise diaries. Staying active and involved will help you to improve the quality of your life beyond these 12 weeks. **This intervention will be a success if you make positive changes to your health.**

Think about what you have learnt and achieved. Work through week 11 and 12 to identify long-term problems that must be resolved. Make action plans for these. Find useful reading material and contact details of support organisations at the end of the chapter [208, 234].

Image: Pixy

Well done for completing this handbook! We hope that it had a positive influence on your health. You can keep the handbook in a safe place for future reference.

Bibliography of images used in the handbook 'Survivorship information for breast cancer'

1. Healthy Lifestyle Clipart. Clipart Library. https://www.clipart-library.com/clipart/8iGbAgBoT.htm. Accessed 28 July 2021.
2. Black Girl Studying. Clipart Key. https://www.clipartkey.com/view/xxbJbR_black-girl-studying-cartoon/. Accessed 28 July 2021.
3. Front View of the Breast. Johns Hopkins Medicine. http://www.hopkinsmedicine.org/health/wellness-and-prevention/anatomy-of-the-breasts. Accessed 26 July 2021.
4. Breast Cancer Awareness Pink Ribbon. IMGBIN. https://www.imgbin.com. Accessed 28 July 2021.
5. Medicine Clipart. Clipart Library. https://www.clipart-library.com/clipart/689487.htm. Accessed 28 July 2021.
6. Self-care. Clipart Key. https://www.clipartkey.com/search/self-care/. Accessed 28 July 2021.
7. Self-care day. Teen Talk. https://www.teentalk.ca/2020/07/20/international-self-care-day-2/. Accessed 28 July 2021.
8. Weight Scale. PNGTree. https://www.pngtree.com/free-png-vectors/weight-scale. Accessed 28 July 2021.
9. Cartoon Women Cliparts. Clipart Library. https://www.clipart-library.com/clipart/cartoon-women-cliparts_17.htm. Accessed 28 July 2021.
10. Tired Snail. FAVPNG. https://www.favpng.com/png_view/tired-snail-fatigue-cartoon-sleep-clip-art-png/w3pnth3. Accessed 28 July 2021.
11. Cancer Cell Cartoon. PNGTree. https://www.pngtree.com/free-png-vectors/cancer-cell-cartoon. Accessed 28 July 2021.
12. Depression Clipart. Clipart Key. https://www.clipartkey.com/view/ioxixT_depression-transparent-clipart-free-png-depression-png/. Accessed 28 July 2021.
13. Sad Stickman. Novocom Top. https://www.novocomtop.com. Accessed 28 July 2021.
14. Sad Face. Clipart Library. https://www.clipart-library.com/sad-face-clip-art-html. Accessed 28 July 2021.
15. Thumbs Up Smiley Face. Clipart Library. https://www.clipart-library.com/thumbs-up-smiley-face-html. Accessed 28 July 2021.
16. Pink Bra. After Breast Cancer. https://www.afterbreastcancer.ca. Accessed 28 July 2021.
17. Adapt a Bra to Accommodate a Prosthesis. Threads Magazine. https://www.threadsmagazine.com/2009/01/25/adapt-a-bra-to-accommodate-a-prosthesis. Accessed 26 July 2021.
18. Blue Pencil. Clipart Library. http://clipart-library.com/clipart/1354857.htm. Accessed 28 July 2021.
19. Thumbs Up. Clipart Library. https://www.clipart-library.com/thumbs-up.html. Accessed 29 July 2021.
20. Ribbon Reward. Clipart Library. https://www.clipart-library.com/ribbon-reward-cliparts.html. Accessed 29 July 2021.
21. Duggee Doing Yoga. PNG Key. https://www.pngkey.com/maxpic/u2t4u20Oe6r5u298/. Accessed 29 July 2021.
22. Exercise Clipart. Cliparting. https://www.cliparting.com/free-exercise-clip-art-28806/. Accessed 29 July 2021.
23. Vector Illustration of a Heart Exercising. 123rf. https://www.123rf.com/photo_13749208_illustration-of-a-heart-exercising.html. Accessed 29 July 2021.
24. Smiley With Weights. Clipart Library. https://www.clipart-library.com/clipart/6Tp0884kc.htm. Accessed 29 July 2021.
25. Workout Emoji. EmojiPNG. https://www.emojipng.com/preview/417305. Accessed 29 July 2021.
26. Garden Clipart. Clipartix. https://www.clipartix.com/garden-clipart-image-21432/. Accessed 29 July 2021.
27. Bacteria Cartoon. Kiss Clipart. https://www.kissclipart.com/royalty-free-bacteria-cartoon-germ-theory-of-disease-virus-oai811/. Accessed 29 July 2021.
28. Cute Panda Wear Mask. Shutterstock. https://www.shutterstock.com/image-vector/cute-panda-wear-mask-Cartoon-vector-1687264612. Accessed 29 July 2021.
29. Running Emoji Marathon Training. IMGBIN. https://www.imgbin.com/png/F8gzqhEK/running-emoji-marathon-training-exercise-png. Accessed 29 July 2021.
30. Group Exercise Clipart. Clipart Library. https://www.clipart-library.com/group-exercise-cliparts.html. Accessed 29 July 2021.
31. Workout Cliparts. Clipart Library. https://www.clipart-library.com/workout-cliparts.html. Accessed 29 July 2021.

32. Teddy Bear Fitness Icon Illustration. Freepik. https://www.de.freepik.com/vektoren-premium/teddy-bear-fitness-gym-icon-illustration-sportbaer-maskottchen-zeichentrickfigur-tierikon-konzept-isoliert_7529314.htm. Accessed 29 July 2021.
33. Brain Exercise. FavPNG. https://www.favpng.com/png_view/brain-exercise-cognitive-training-physical-fitness-clip-art-brain-png/6g1Wr7AJ. Accessed 29 July 2021.
34. Badminton Racket. Kiss Clipart. https://www.kissclipart.com/badminton-racket-clipart-racket-badminton-clip-art-7yvl5k/. Accessed 29 July 2021.
35. Reward Clip Arts. Download Cliparts. https://www.downloadcliparts.net/reward-clip-arts. Accessed 29 July 2021.
36. Turtle Running. Clipart Library. https://www.clipart-library.com/clipart/1917295.htm. Accessed 29 July 2021.
37. Fitness Man. Clipart Library. https://www.clipart-library.com/workout-cliparts.htm. Accessed 29 July 2021.
38. Orange Cartoon Character Makes Sport. Dreamstime. https://www.dreamstime.com/stock-photography-stretching-orange-cartoon-character-makes-sport-white-background-image30647672.
39. Brain Exercise. Clipart Library. https://www.clipart-library.com/brain-exercise-cliparts.htm. Accessed 29 July 2021.
40. Tall Man Clipart. Clipart Library. https://www.clipart-library.com/tall-man-clipart.htm. Accessed 29 July 2021.
41. Stick Man. PNG Wing. https://www.pngwing.com/en/search?q=happy-stick-man.htm. Accessed 29 July 2021.
42. Listening Stick Man. Dreamstime. https://www.dreamstime.com/illustration/listening-stick-man.html. Accessed 29 July 2021.
43. Prehab Exercises. https://www.prehabexercises.com. Accessed 29 July 2021.
44. Physical Therapy Exercises for Shoulder Pain. Womens OK. https://www.womensOK.com. Accessed 29 July 2021.
45. Heel Raises. Clipart Library. https://www.clipart-library.com/clipart/qiBLyGgi5.htm. Accessed 29 July 2021.
46. How To Draw A Stick Figure. Envato Tuts. https://www.design-tutsplus.com/tutorials/how-to-draw-a-stick-figure. Accessed 29 July 2021.
47. Stand Up Black and White Clipart. Clipart Library. https://www.clipart-library.com/clipart/n965396.htm. Accessed 29 July 2021.
48. Elderly Exercise. FavPNG. https://www.favpng.com-view/elderly-exercise-bridge-muscles-of-the-hip-exercise-gluteus-maximus-png/jC8y2AkT. Accessed 29 July 2021.
49. Lunge Cliparts. Clipart Library. https://www.clipart-library.com/clipart/568040.htm. Accessed 29 July 2021.
50. Standing Bicep Curl Clipart. Clipart Suggest. https://www.clipartsuggest.com/standing-bicep-curl-cliparts/. Accessed 29 July 2021.
51. Tumor Image. Clipart Library. https://www.clipart-library.com/clipart/dc456ddoi.htm. Accessed 29 July 2021.
52. Lymph Node Removal. National Breast Cancer Foundation. https://www.nationalbreastcancer.org/breast-cancer-lymph-node-removal. Accessed 29 July 2021.
53. Clipart Radiation Treatment. Clipart Library. https://www.clipart-library.com/cliparts-radiation-treatment.htm. Accessed 29 July 2021.
54. Pain In Human Body Parts. Clipart Max. https://www.clipartmax.com/middle/m2H7N4AoAod3AOK9_pain-in-human-body-parts-on-various-stiff-neck-cartoon-transparent/. Accessed 29 July 2021.
55. Shoulder Injury Clipart. NicePNG. https://www.nicepng.com/ourpic/u298u2i1y3u20Ow7_pain-relief-symptom-checker-shoulder-injury-clip-art/. Accessed 29 July 2021.
56. Physical Therapy Images. CleanPNG. https://www.cleanpng.com/free/physical-therapy.html. Accessed 29 July 2021.
57. Stick Figure. Clipart Library. https://www.clipart-library.com/stick-figure.html. Accessed 29 July 2021.
58. Stick Figure With Arms Up. Clipart Max. https://www.clipartmax.com/middle/m2i8AOH7m2b1i8AO_man-standing-with-arms-up-vector-stick-figure-hands-up/. Accessed 29 July 2021.
59. Shoulder Cliparts. Clipart Library. https://www.clipart-library.com/shoulders-cliparts.html. Accessed 29 July 2021.
60. Shoulder Shrugs. Spotebi. https://www.spotebi.com/exercise-guide/shoulder-shrugs. Accessed 29 July 2021.
61. Shoulder Rolls. Spotebi. https://www.spotebi.com/exercise-guide/shoulder-rolls. Accessed 29 July 2021.

62. Standing Side Bend. Spotebi. https://www.spotebi.com/exercise-guide/standing-side-bend. Accessed 29 July 2021.
63. Mastectomy Stretches. The Breast Cancer Site. https://blog.thebreastcancersite.greatergood.com/cs-mastectomy-stretches/. Accessed 29 July 2021.
64. Shoulder Exercises. Guys and St Thomas. https://www.guysandstthomas.nhs.uk/patients-and-visitors/patients/patient-leaflets/patient-info-leaflets.aspx. Accessed 29 July 2021.
65. Forearm Wall Slides. Full Circle Wellness. https://www.fullcirclewellness.com.au/post/exercises-for-shoulder-pain. Accessed 29 July 2021.
66. Chest Wall Stretch. TN Oncology. https://www.tnoncology.com/news/2019/05/31/exercises-after-breast-cancer-surgery/. Accessed 29 July 2021.
67. Dumbbell Chest Press. Spotebi. https://www.spotebi.com/exercise-guide/dumbbell-chest-press/. Accessed 29 July 2021.
68. Hand and Arm Care After Removal of Axillary Lymph Nodes. MSKCC. https://www.mskcc.org/cancer-care/patient-education/hand-and-arm-care-after-removal-axillary-lymph-nodes
69. Cellulitis in Right Arm of Patient with Lymphedema. Researchgate. https://www.researchgate.net/figure/Cellulitis-in-right-arm-of-patient-with-lymphedema_fig1_260372113. Accessed 29 July 2021.
70. Lymphedema Garments. Rescue Legs. https://www.rescuelegs.com/the-natural-brand/lymphedema-garments/. Accessed 29 July 2021.
71. How To Care For Short-stretch Compression Bandages. Lymphedema Blog. https://www.lymphedemablog.com/2014/10/22/how-to-care-for-short-stretch-compression-bandages/. Accessed 29 July 2021.
72. Breast Cancer Clipart Image. Clipartix. https://clipartix.com/breast-cancer-clip-art-image-24397/. Accessed 29 July 2021.
73. How to do Lymphedema Exercises. Very Well Health. https://www.verywellhealth.com/how-to-do-arm-lymphedema-exercises-430210. Accessed 29 July 2021.
74. Feet on Scale. Deposit Photos. https://depositphotos.com/vector-images/feet-on-scale.html. Accessed 29 July 2021.
75. Healthy Plate. Deposit Photos. https://depositphotos.com/vector-images/healthy-plate.html. Accessed 29 July 2021.
76. Cartoon Fruit. Freepik. https://www.freepik.com/free-photos-vectors/cartoon-fruit. Accessed 29 July 2021.
77. Vegetable Cliparts. Clipart Library. http://clipart-library.com/vegetables-cliparts.html. Accessed 29 July 2021.
78. Protein Foods. Clipart Suggest. http://www.clipartsuggest.com/protein-foods-cliparts/. Accessed 29 July 2021.
79. Find Out More About Beans and other Pulses. Cook It. http://cookit.e2bn.org/cooking2/more-628-179-find-out-more-about-beans-and-other-pulses.html. Accessed 29 July 2021.
80. Potato Cliparts. Clipart Library. http://clipart-library.com/clipart/potato-cliparts_14.htm. Accessed 29 July 2021.
81. Oat Cliparts. Clipart Library. http://clipart-library.com/oat-cliparts.html. Accessed 29 July 2021.
82. Cooking Oil Cliparts. Clipart Library. http://clipart-library.com/cooking-oil-cliparts.html. Accessed 29 July 2021.
83. Butter Illustration. Dreamstime. https://www.dreamstime.com/illustration/butter.html. Accessed 29 July 2021.
84. Herb Garden Cliparts. Clipart Library. http://clipart-library.com/herb-garden-cliparts.html. Accessed 29 July 2021.
85. Spices. Jing. https://www.jing.fm/iclipt/xwhbJJ/. Accessed 29 July 2021.
86. Healthy Habits. Deposit Photos. https://depositphotos.com/vector-images/cartoon-healthy-habits.html. Accessed 29 July 2021.
87. Washing Hands Clipart. Clipartix. https://clipartix.com/washing-hands-clipart/. Accessed 29 July 2021.
88. Food Poisoning Bacteria. FavPNG. https://favpng.com/png_view/computer-virus-food-poisoning-bacteria-probiotic-gut-flora-png/K8UrebyC. Accessed 29 July 2021.
89. Stressed Brain Clipart. Clipart Library. http://clipart-library.com/clipart/n1007518.htm. Accessed 29 July 2021.
90. People Holding Hands. PNGFind. https://www.pngfind.com/mpng/TJTJJh_group-people-holding-hands-cartoon-hd-png-download/. Accessed 29 July 2021.

91. Dreaming. Fly Clipart. https://flyclipart.com/amazing-kid-bed-clipart-girl-sleep-book-dreaming-make-your-bed-clipart-19234. Accessed 29 July 2021.
92. Sleeping Bear Clipart. Clipart Library. http://clipart-library.com/clipart/sleeping-bear-clipart_17.htm. Accessed 29 July 2021.
93. Breast Cancer Ribbon Outline. Vectorstock. https://www.vectorstock.com/royalty-free-vectors/breast-cancer-ribbon-outline-vectors. Accessed 29 July 2021.
94. African-American Woman Relaxing. Dreamstime. https://www.dreamstime.com/illustration/african-american-woman-relaxing-beach.html. Accessed 29 July 2021.
95. Clipart of a Team. Clipade. https://clipade.com/design/clip-art-of-a-team-of-three-orange-people-holding-hands-and-standing-on-blue-puzzle-pieces-with-one-man-reaching-out-to-connect-another-to-their-trio-by-3pod-321. Accessed 29 July 2021.
96. Adult Reading. Clipart Max. https://www.clipartmax.com/middle/m2i8H7H7H7b1m2d3_big-image-adult-reading-clipart/. Accessed 29 July 2021.
97. Medicine Clipart. Clipart Library. http://clipart-library.com/cartoon-medicine-cliparts.html. Accessed 29 July 2021.
98. Ninjas Fighting Cancer. Clipart Library. https://www.clipartlibrary.com/clipart/44124.htm. Accessed 29 July 2021.
99. Where Does Breast Cancer Spread? Cleveland Clinic. https://health.clevelandclinic.org/where-does-breast-cancer-spread/. Accessed 29 July 2021.
100. Signs of Breast Cancer. Sarcasm. https://www.sarcasm.co/hyped-myth-breast-cancer/. Accessed 29 July 2021.
101. Breast Examination Instruction. Deposit Photos. https://depositphotos.com/123723326/stock-illustration-breast-self-exam-instruction-breast.html. Accessed 29 July 2021.
102. Skin Check. Clipart Library. http://clipart-library.com/clipart/1309374.htm. Accessed 29 July 2021.
103. Symptoms of Pulmonary Embolism. Adekunleadelodun. https://adekunleadelodun.com/symptoms-of-pe/. Accessed 29 July 2021.
104. Paper And Pencil. Clipart Library. http://clipart-library.com/paper-and-pencil-clipart.html. Accessed 29 July 2021.
105. People Talking. DL PNG. https://dlpng.com/png/4690467. Accessed 29 July 2021.
106. Healthy Food Clipart. Kind PNG. https://www.kindpng.com/imgv/Towiim_healthy-food-pictures-clip-art-health-clipart-free/. Accessed 29 July 2021.
107. Figure Going Up Stairs. Pixy. https://pixy.org/528035/. Accessed 29 July 2021.

Appendix N: Acceptability evaluation interview guide (Chapter 4)

Semi-structured interview questions: acceptability evaluation of intervention

1. What did you like about this intervention?
2. What didn't you like about this intervention?
3. How do you feel about exercise now that you have completed the 12 week intervention?
4. How do you feel about dealing with the long-term side effects of breast cancer now that you have completed the intervention?
5. Is there anything you would have liked to add or change about the intervention?
6. Would you have preferred to receive the handbook or questionnaires in another language? Please specify.

References

Gisiger-Camata S, Adams N, Nolan TS, et al. Multi-level Assessment to Reach Out to Rural Breast Cancer Survivors. *Women's Health* 2016; 12(6):513-22.

Warner ET, Kennedy M, Maschke A, et al. Evaluation of Existing Patient Educational Materials and Development of a Brochure for Women with Dense Breasts. The Breast 2020; 50:81-4.

Parker RE. Pain in HIV/AIDS: Characteristics, Contributing Factors and the Effects of a Six-week Peer-led Exercise and Education Intervention. PhD in Physiotherapy, University of Cape Town, 2013.

Appendix O: Ethical approval letter for intervention study (Chapters 4 and 5)

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room 45 E-52-E-Floor- Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6492
Email: hrec-submissions@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

13 May 2022

HREC REF: 227/2022

A/Prof D Shamley
Human Biology
FHS
Email: Delva.shamley@uct.ac.za
Student: beutelphysio@gmail.com

Dear A/Prof Shamley

PROJECT TITLE : DEVELOPMENT AND EVALUATION OF AN EDUCATION AND EXERCISE SELF-MANAGEMENT INTERVENTION FOR BREAST CANCER SURVIVORS-SUB-STUDY LINKED TO 506/2019
(PHD CANDIDATE MS ANITA BEUTEL)

Thank you for your response letter, addressing the issues raised by the Faculty of Health Sciences Human Research Ethics Committee (HREC).

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

This approval is subject to strict adherence to the HREC recommendations regarding research involving human participants during COVID -19. Please refer to guidance letter dated 02 February 2022 on our website:
http://www.health.uct.ac.za/fhs/research/humanethics/forms

Approval is granted for one year until the 30 May 2023.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

The HREC acknowledge that the student: Ms Anita Beutel will also be involved in this study.

Please quote the HREC REF 227/2022 in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necessary, before the research may occur.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, FACULTY OF HEALTH SCIENCES HUMAN RESEARCH ETHICS COMMITTEE
Federal Wide Assurance Number: FWA00001637. Institutional Review Board (IRB) number: IRB00001938 NHREC-registration number: REC-210208-007
This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use: Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH 2020), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI), and Declaration of Helsinki (2013) guidelines. The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

Appendix P: Intervention study (Chapters 4 and 5) informed consent form

DHRS
Department of Health and Rehabilitation Sciences
FACULTY OF HEALTH SCIENCES

University of Cape Town • iYunivesithi yaseKapa • Universiteit van Kaapstad

Divisions of • Communication Sciences & Disorders • Disability Studies • Nursing & Midwifery • Occupational Therapy • Physiotherapy

F45 Old Main Building, Groote Schuur Hospital
Observatory, Cape Town, South Africa, 7925
Telephone: +27 (0) 21 406 6401
Website: www.dhrs.uct.ac.za

AN INVESTIGATION OF THE REHABILITATION NEEDS, DEVELOPMENT, AND PRELIMINARY OUTCOMES OF AN EDUCATION AND EXERCISE SELF-MANAGEMENT INTERVENTION FOR BREAST CANCER SURVIVORS

Dear breast cancer survivor

My name is Anita Beutel. I am a doctoral student at the University of Cape Town (UCT), Division of Physiotherapy. We have designed an intervention using a handbook called Survivorship Information for Breast Cancer. We want to know if working through and completing the activities in the handbook for 12 weeks, will help you to manage long-term effects of your breast cancer. This study has been approved by the Human Research Ethics Committee, Faculty of Health Sciences, University of Cape Town (reference number 227/2022).

Why is this study being done?

Some side effects of breast cancer (like hair loss and nausea) get better after your medical cancer treatment. There are also long-term side effects. Side effects like weight changes, shoulder problems, arm swelling, and extreme tiredness can happen for many years after surgery, chemotherapy, and radiation. We have done interviews with breast cancer survivors. They told us that they have many of these problems. They said they do not have enough information about these and how to make them better. They were not sure how to stay healthy and free of cancer. Therefore, we designed an intervention with a practical handbook about the management of long-term side effects of treatment, exercise, and healthy lifestyle especially for breast cancer survivors.

Why am I being asked to take part?

You have responded to our breast cancer research advertisement, sending us your contact details; OR you have let me know that you are interested in participating in breast cancer research. You may take part because you are a breast cancer survivor self-identifying as a woman. It has been six months to ten years since you completed surgery, chemotherapy and / or radiation. Taking part in this study is voluntary. You may stop participating at any time, without penalty. You do not have to give a reason if you no longer want to take part. We as researchers do not work at the hospital. Taking part will not affect your medical care or visits to the breast clinic. We want to understand if the information we will give you, is helpful.

How many people will take part in the study?

We will ask 33 breast cancer survivors to participate. If you know other breast cancer survivors who you think may be interested, please send them the leaflet advertising the study. Or you can ask them to contact me. I will send them the information about the study. My contact details are on the last page of this form.

What will I be asked to do?

1. We ask you to read this form and to sign it at the bottom. Then please return the page where you have signed to me, with your contact preferences. If you have any questions before you sign, please feel free to contact me.

2. I will phone you and ask you questions about your health, on a day and time that is convenient for you. This is to decide if you are healthy enough to participate in gradual, moderate exercise (such as walking) recommended in the handbook.

3. If you are healthy enough to participate in exercise as mentioned above, I will ask you to answer some questions about your age, breast cancer, education, and so on. This is for statistics; your name will not be on this or any other form. I will also ask questions about your pain, fatigue (tiredness), exercise, and your quality of life. It will take about 45 minutes to answer all the questions.

4. I will then send you the handbook ‘Survivorship Information for Breast Cancer’ to go through, over 12 weeks. The handbook is divided into easy to manage sections called week 1 and 2, week 3 and 4; and so on.

Read through the information and complete the tasks in the handbook. The tasks are generally about setting goals, solving problems, and making action plans to achieve your goals.

By reading the handbook, you will learn about long-term problems of breast cancer treatment, how to manage these, how to find new cancer early, when to visit the clinic, and more. I will send you the handbook via e-mail and / or WhatsApp, according to your preference. Please let me know if you have any trouble opening the e-mail or WhatsApp attachments, I will help you. I will also send you a printed copy of the handbook by courier. You can collect this when convenient, from your nearest Pep store. You will receive an SMS notification when your handbook is ready for collection.

I will send you a preview or reminder to work through the handbook, every two weeks. In the handbook there are links to two exercise videos: one for general exercise and another with upper limb exercises, especially for breast cancer survivors. You can use these example videos, you can follow the written routines in the handbook, or you can do your own exercise. I will ask you to write down every time you do your exercise, in an exercise diary (provided in the handbook). At the end of every week, you can take a picture of your exercise diary and send it to me, but you do not have to do this. Only I will see what you send to me, not anyone else. You will not need to write your name on this or on anything you send to me.

If you would like to, I can connect you with other breast cancer survivors through a WhatsApp group. You can leave this group at any time if you do not find it helpful. The exercises in the handbook have been chosen because they are safe for women with breast cancer. When you first start to do them, you may feel that your muscles are sore for a few days afterwards. This is a normal response to exercise. Your muscles should become less sore as your body gets used to the new exercises. However, if you have a question or if you are concerned about anything, please contact me or any study supervisor. **If you feel that your arm is becoming more painful, if your arm does not move as freely as before, or if you notice any extra swelling of your arm or chest, contact me or a study supervisor immediately. Our details are provided at the end of this form.**

5. After the 12 weeks of reading the handbook and doing the tasks in it, we ask you to complete the questions about your health again. These will be the same as you completed in the beginning of the programme: about pain, tiredness (fatigue), quality of life, and exercise.

For this, I will phone you on a day and time that is convenient for you. Completing these questions should take a maximum of 45 minutes.

6. [This section (6.) only applies to participants of the acceptability evaluation: After you have completed the telephone questionnaire at the end of the 12 weeks, I will phone you once more. This is to ask you some questions about how you experienced the information and tasks we gave you during the 12 week intervention. This interview will be recorded so that we can process the information you give us. The interview should take no more than 30 minutes. We will not record your name or any identifying details in the interview, or on any form. The purpose of the interview is so that we can improve the intervention according to what you tell us, before we continue with the rest of the study.]

How long will the research take?

The research will take 12 to 14 weeks. You will be asked to answer questions over the phone, two times: In the beginning and after 12 weeks. We recommend that you schedule these two phone calls when you are in a private place, at a time that is convenient. Working through the handbook will take a few hours of your time every week, for the 12 weeks. Completing the tasks and doing the exercises regularly will also take about two hours each week. You can read the handbook and do the activities in it, in your own time. This may be a lot to ask, but we feel it is important to find out if using the information is helpful.

What are the risks of taking part in this study?

There is a small physical risk of participating in this study. The handbook encourages gradual activity like walking and shoulder exercises. However, you will complete a screening questionnaire to make sure that it is safe for you to participate. It could be that reading about long-term side effects of cancer treatment may cause you to become emotional. You do not need to answer any question that you are uncomfortable with. You are allowed to stop taking part in the study at any time. If you become upset or injured, please let me or any of the study supervisors know. Our contact details are at the end of this form. We can refer you, if you agree, to a healthcare provider who will help you.

What happens if I get hurt while taking part?

Because research has shown that participating in interventions such as this one is associated with a low risk of injury, there is no insurance cover. You are requested to immediately notify us in case you get injured. If needed and if you agree, we will refer you to your healthcare provider.

What are the benefits of taking part in this study?

You will learn about breast cancer survivorship, and how to stay healthy. You can keep the handbook and re-read it at any time. We will pay you R 300 to cover your mobile data costs, after your participation. Or we will supply airtime or data bundles worth R 300, before your participation – according to your preference. We will ask for your banking / mobile service provider details once you have completed the set of telephone questions.

Will the results of the research be shared with me?

Once we have completed the study, I can send you a summary of the results if you would like.

Who will see the information about me in the study?

Only the researchers will see the information collected. Your individual identity will not be used in any report or publication. Your personal information will be given a number. Only the researchers will be able to link your name to the study number. Information on the computer will be password-protected and deleted after five years.

Who do I contact for any questions about the study?

Please feel free to contact me, Anita Beutel 082 467 0422 beutelphysio@gmail.com or any study supervisor:

Supervisor: A/Prof Delva Shamley 074 377 5287 delva.shamley@uct.ac.za

Co-supervisor: A/Prof Theresa Burgess 021 406 6171 theresa.burgess@uct.ac.za

Co-supervisor: A/Prof Niri Naidoo 021 406 6171 niri.naidoo@uct.ac.za

If you have any ethical concerns or questions about your rights or welfare as a participant of this research study, the chairperson of the Human Research Ethics Committee, University of Cape Town can be contacted: Prof Marc Blockman 021 406 6338 marc.blockman@uct.ac.za

Consent statement and contact preferences

By signing this form, you confirm that you have had an opportunity to have your questions about the study answered. You understand that you may contact us at any time if you have more questions. You understand the potential risks. You understand what the study is about and agree that I may phone you. You are allowed to stop taking part at any time without giving a reason. [This section is only for the acceptability evaluation: You agree that I may phone you to ask questions regarding what you thought about the intervention. You agree that this phone call may be audiotaped, without recording your name or other personal details.]

Full name of participant: _____

Signature of participant: _____

Witness: _____

Date: _____

E-mail address: _____

Alternative e-mail address: _____

Telephone number: _____

Alternative telephone number: _____

- How do you prefer to receive the reminders and previews, during your 12 week participation? (For example, e-mail, WhatsApp) _____

- How would you prefer to send me a picture of your exercise diary every week (optional), and / or ask any questions you may have during your participation? (Example E-mail, WhatsApp, MMS) _____

- Would you like to connect with other breast cancer survivors, even if they live far away from you, through a WhatsApp group? Yes / No _____**Note:** WhatsApp groups are optional; you do not have to join one. You are allowed to join or leave a group at any time.

- At the end of the 12 weeks, do you prefer to receive (please tick) R 300 in cash_____ OR R 300 in Airtime _____ OR data bundles _____, before you start the intervention?

Appendix Q: Intervention study advertisement leaflet

ARE YOU A BREAST CANCER SURVIVOR?

Have you completed surgery, chemotherapy, and radiation?

Are you in the remission and recovery phase of stage I, II or III breast cancer?

If you answered **yes**, please consider taking part in my Ph.D. research exploring if an education and exercise intervention can support the management of long-term side effects of breast cancer treatment. This could be an opportunity to learn about living with breast cancer long-term and develop healthy habits.

You will be asked to complete questions about your health, pain and fatigue that will take about 45 minutes. I will phone you for this when it is convenient for you. Then we will send you the handbook 'Survivorship information for breast cancer', to work through over 12 weeks. You will be encouraged to do general exercise of your choice and shoulder exercises, complete tasks (like goal setting, problem solving, making action plans) and an exercise diary. We will also send you exercise videos to inspire your exercises. After 12 weeks, we ask you to complete the questions about your health, pain, and fatigue, again.

You can complete all activities for this study, from home.

Inclusion criteria:

- Women, South African breast cancer survivors, 6 months to 10 years after surgery, chemotherapy, and radiation
- Age 18- 70 years, not participating in other breast cancer research

If you are interested to take part, please contact me.

Anita Beutel beutelphysio@gmail.com **OR** BTLANI001@myuct.ac.za

This research has been granted ethical approval by the University of Cape Town (HREC Ref 227/2022)

Appendix R: Intervention study master list

Participant Name	Study number	Date recruited	Baseline questionnaires Yes/No	Questionnaires at 12 weeks Yes/No	Acceptability evaluation participant? Yes/No. If yes, interview date	Preferred communication method for previews, reminders & questionnaires	WhatsApp group Yes/No

Appendix S: Intervention study (Chapter 4 and 5) socio-demographic questionnaire

Please complete in the right column:

Age :	
Province:	
Are you (please tick or mark with X):	
Employed	
Unemployed	
Pensioner	
Education (please tick or mark with X):	
Primary school	
High school	
Higher qualification / degree: please specify	
How many months since you completed your cancer treatment (chemo- & radiotherapy)?	

Medical cancer treatment (please tick or mark with an X):	
Chemotherapy	
Radiotherapy	
Cancer stage: I, II, III, DCIS?	
Surgical treatment:	
Lumpectomy: Left / Right / Both sides?	
Mastectomy: Left / Right / Both sides?	
Do you take hormone blocking medicine, such as Tamoxifen? Yes / No	
Other chronic medicine? Please list	

Appendix T: Adverse event form for intervention study (Chapter 4 and 5)

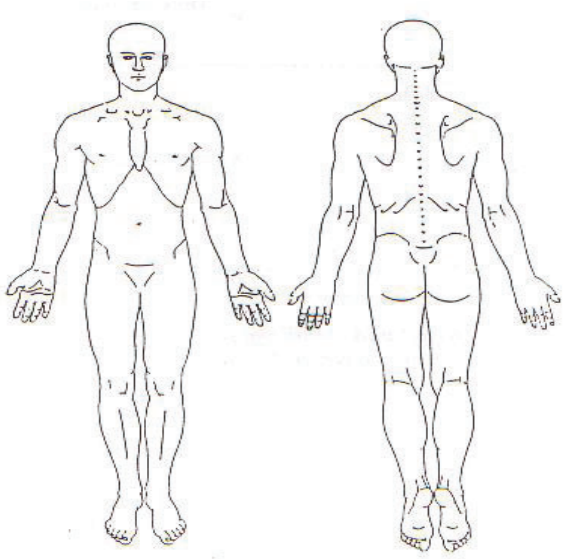
Participant number	Description of adverse event	Participant permission given for referral? Yes / No	Description of referral and outcome of treatment / rehabilitation

BRIEF PAIN INVENTORY

1. Throughout our lives, most of us have had pain from time to time (such as minor headaches, sprains, and toothaches). Have you had pain other than these everyday kinds of pain during the last week?

   Yes No

2. On the diagram, shade in the areas where you feel pain. Put an **X** on the area that hurts most.



3. Please rate your pain by circling the one number that best describes your pain at its ***worst*** in the last week.

0	1	2	3	4	5	6	7	8	9	10
No pain										Pain as bad as you can imagine

4. Please rate your pain by circling the one number that best describes your pain at its ***least*** in the last week.

0	1	2	3	4	5	6	7	8	9	10
No pain										Pain as bad as you can imagine

5. Please rate your pain by circling the one number that best describes your pain on the ***average.***

0	1	2	3	4	5	6	7	8	9	10
No pain										Pain as bad as you can imagine

6. Please rate your pain by circling the one number that tells how much pain you have ***right now.***

0	1	2	3	4	5	6	7	8	9	10
No pain										Pain as bad as you can imagine

7. What treatments or medications are you receiving for your pain? In the last week, how much ***relief*** have pain treatments or medications provided? Please circle the one percentage that most shows how much *relief* you have received.

0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
No Relief										Complete Relief

8. Circle the one number that describes how much, during the past week, **pain** has ***interfered with*** your:

A. *General Activity*

0	1	2	3	4	5	6	7	8	9	10
Does not interfere								Completely interferes		

B. Mood

0	1	2	3	4	5	6	7	8	9	10
Does not interfere									Completely interferes	

C. *Walking Ability*

0	1	2	3	4	5	6	7	8	9	10
Does not interfere									Completely interferes	

D. *Normal Work* (includes both work outside the home and housework)

0	1	2	3	4	5	6	7	8	9	10
Does not interfere									Completely interferes	

E. ***Relations with other people***

0 1 2 3 4 5 6 7 8 9 10
Does not interfere — Completely interferes

F. ***Sleep***

0 1 2 3 4 5 6 7 8 9 10
Does not interfere — Completely interferes

G. ***Enjoyment of life***

0 1 2 3 4 5 6 7 8 9 10
Does not interfere — Completely interferes

Brief Fatigue Inventory

Throughout our lives, most of us have times when we feel very tired or fatigued. Have you felt unusually tired or fatigued in the last week? Yes _____ No _____

1. **Please rate your fatigue (weariness, tiredness) by circling the one number that best describes your fatigue right NOW.**

   No Fatigue 0 1 2 3 4 5 6 7 8 9 10 As bad as you can imagine

2. **Please rate your fatigue (weariness, tiredness) by circling the one number that best describes your USUAL level of fatigue during past 24 hours.**

   No Fatigue 0 1 2 3 4 5 6 7 8 9 10 As bad as you can imagine

3. **Please rate your fatigue (weariness, tiredness) by circling the one number that best describes your WORST level of fatigue during past 24 hours.**

   No Fatigue 0 1 2 3 4 5 6 7 8 9 10 As bad as you can imagine

4. **Circle the one number that describes how, during the past 24 hours, fatigue has interfered with your:**
   - **A. General Activity**
     Does not Interfere 0 1 2 3 4 5 6 7 8 9 10 Completely Interferes
   - **B. Mood**
     Does not Interfere 0 1 2 3 4 5 6 7 8 9 10 Completely Interferes
   - **C. Walking ability**
     Does not Interfere 0 1 2 3 4 5 6 7 8 9 10 Completely Interferes
   - **D. Normal work (includes both work outside the home and daily chores)**
     Does not Interfere 0 1 2 3 4 5 6 7 8 9 10 Completely Interferes
   - **E. Relations with other people**
     Does not Interfere 0 1 2 3 4 5 6 7 8 9 10 Completely Interferes
   - **F. Enjoyment of life**
     Does not Interfere 0 1 2 3 4 5 6 7 8 9 10 Completely Interferes

Health Questionnaire

English version for South Africa

SCRIPT FOR TELEPHONE ADMINISTRATION

GENERAL INTRODUCTION

It is suggested that the telephone administrator follows the script of the EQ-5D. Although allowance should be made for the interviewer's particular style of speaking, the wording of the questionnaire instructions should be followed as closely as possible. In the case of the EQ-5D descriptive system on page 2, the precise wording must be followed.

It is recommended that the administrator has a copy of the EQ-5D in front of him or her as it is administered over the telephone. This enables the respondent's answers to be entered directly on the EQ-5D by the administrator on behalf of the respondent (i.e. the appropriate boxes on page 2 are ticked and the scale on page 3 is marked at the point indicating the respondent's "own state of health today"). If the respondent asks for clarification, the administrator can help by re-reading the question verbatim. The administrator should not try to offer his or her own explanation but suggest that the respondent uses his or her own interpretation.

If the respondent has difficulty with regard to which box to tick, the administrator should repeat the question verbatim and ask the respondent to answer in a way that most closely resembles his or her thoughts about his or her state of health today.

INTRODUCTION TO EQ-5D

We are trying to find out what you think about your health. I will first ask you a few brief and simple questions about your own state of health today. I will then ask you to do a rather different task that involves rating your health on a measuring scale. I will explain the tasks fully as I go along but please interrupt me if you do not understand something or if things are not clear to you. Please also remember that there are no right or wrong answers. We are interested here only in your personal view.

EQ-5D DESCRIPTIVE SYSTEM - PAGE 2: INTRODUCTION

First I am going to read out some questions. Each question has a choice of three answers. Please tell me which answer best describes your own state of health today.

Do not choose more than one answer in each group of questions.

(Note for administrator: it may be necessary to remind the respondent regularly that the timeframe is today)

EQ-5D DESCRIPTIVE SYSTEM - PAGE 2: TASK

MOBILITY

First I'd like to ask you about mobility.

Question 1: Would you say you have …

No problems in walking about?
Some problems in walking about?
Are you confined to bed?

So, would you say you have no problems in walking about, some problems in walking about or are you confined to bed?

(Note for administrator: tick the appropriate box on the EQ-5D questionnaire)

SELF-CARE

Next I'd like to ask you about self-care.

Question 2: Would you say you have …

1. **No problems with self-care?**
Some problems washing or dressing yourself?
Are you unable to wash or dress yourself?

So, would you say you have no problems with self-care, some problems washing or dressing yourself or are you unable to wash or dress yourself?

(Note for administrator: tick the appropriate box on the EQ-5D questionnaire)

USUAL ACTIVITIES

Next I'd like to ask you about usual activities, for example work, study, housework, family or leisure activities.

Question 3: Would you say you have …

1. **No problems with performing your usual activities?**
   Some problems with performing your usual activities?
   Are you unable to perform your usual activities?

So, would you say you have no problems with performing your usual activities, some problems with performing your usual activities or are you unable to perform your usual activities?

(Note for administrator: tick the appropriate box on the EQ-5D questionnaire)

PAIN / DISCOMFORT

Next I'd like to ask you about pain or discomfort.

Question 4: Would you say you have …

1. **No pain or discomfort?**
   Moderate pain or discomfort?
   Extreme pain or discomfort?

So, would you say you have no pain or discomfort, moderate pain or discomfort or extreme pain or discomfort?

(Note for administrator: tick the appropriate box on the EQ-5D questionnaire)

ANXIETY / DEPRESSION

Finally I'd like to ask you about anxiety or depression.

Question 5: Would you say you are …

1. **Not anxious or depressed?**
   Moderately anxious or depressed?
   Extremely anxious or depressed?

So, would you say you are not anxious or depressed, moderately anxious or depressed or extremely anxious or depressed?

(Note for administrator: tick the appropriate box on the EQ-5D questionnaire)

EQ VAS - PAGE 3: INTRODUCTION

(Note for administrator: If possible, it might be useful to send a visual aid (i.e. the EQ VAS) before the telephone call so that they can have this in front of them when completing the task)

I would now like to ask you to do a rather different task.

To help you say how good or bad your state of health is, I'd like you to try to picture in your mind a scale that looks a bit like a thermometer. Can you do that? The best state of health you can imagine is marked 100 (one hundred) at the top of the scale and the worst state you can imagine is marked 0 (zero) at the bottom.

EQ VAS - PAGE 3: TASK

I would now like you to tell me the point on this scale where you would put your own state of health today.

Thank you for taking the time to answer these questions.

Self-Efficacy for Managing Chronic Disease 6-Item Scale

We would like to know how confident you are in doing certain activities. For each of the following questions, please choose the number that corresponds to your confidence that you can do the tasks regularly at the present time.

1. How confident are you that you can keep the fatigue caused by your disease from interfering with the things you want to do?

Not at all confident | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally confident

2. How confident are you that you can keep the physical discomfort or pain of your disease from interfering with the things you want to do?

Not at all confident | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally confident

3. How confident are you that you can keep the emotional distress caused by your disease from interfering with the things you want to do?

Not at all confident | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally confident

4. How confident are you that you can keep any other symptoms or health problems you have from interfering with the things you want to do?

Not at all confident | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally confident

5. How confident are you that you can do the different tasks and activities needed to manage your health condition so as to reduce your need to see a doctor?

Not at all confident | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally confident

6. How confident are you that you can do things other than just taking medication to reduce how much your illness affects your everyday life?

Not at all confident | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally confident

Scoring
The score for each item is the number circled. If two consecutive numbers are circled, code the lower number (less self-efficacy). If the numbers are not consecutive, do not score the item. The score for the scale is the mean of the six items. If more than two items are missing, do not score the scale. Higher number indicates higher self-efficacy.

Source of Psychometric Data Stanford/Garfield Kaiser Chronic Disease Dissemination Study.

Psychometrics reported in:
Lorig KR, Sobel, DS, Ritter PL, Laurent, D, Hobbs, M. Effect of a self-management program for patients with chronic disease. Effective Clinical Practice, 4, 2001,pp. 256-262.

Comments
This 6-item scale contains items taken from several SE scales developed for the Chronic Disease Self-Management study. We use this scale now, as it is much less burdensome for subjects. It covers several domains that are common across many chronic diseases, symptom control, role function, emotional functioning and communicating with physicians. For internet studies, we add radio buttons below each number. There are 2 ways to format these items. We use the format on this document, the other is shown on the web page. A 4-item version of this scale available in Spanish.

References
Lorig KR, Sobel, DS, Ritter PL, Laurent, D, Hobbs, M. Effect of a self-management program for patients with chronic disease. Effective Clinical Practice, 4, 2001,pp. 256-262.

INTERNATIONAL PHYSICAL ACTIVITY QUESTIONNAIRE

SHORT LAST 7 DAYS TELEPHONE FORMAT

For use with Young and Middle-aged Adults (15-69 years)

The International Physical Activity Questionnaires (IPAQ) comprises a set of 4 questionnaires. Long (5 activity domains asked independently) and short (4 generic items) versions for use by either telephone or self-administered methods are available. The purpose of the questionnaires is to provide common instruments that can be used to obtain internationally comparable data on health–related physical activity.

Background on IPAQ

The development of an international measure for physical activity started in Geneva in 1998 and was followed by extensive reliability and validity testing undertaken across 12 countries (14 sites) during 2000. The final results suggest that these measures have acceptable measurement properties for use in many settings and in different languages, and are suitable for national population-based prevalence studies of participation in physical activity.

Using IPAQ

Use of the IPAQ instruments for monitoring and research purposes is encouraged. It is recommended that no changes be made to the order or wording of the questions as this will affect the psychometric properties of the instruments.

Translation from English and Cultural Adaptation

Translation from English is supported to facilitate worldwide use of IPAQ. Information on the availability of IPAQ in different languages can be obtained at www.ipaq.ki.se. If a new translation is undertaken we highly recommend using the prescribed back translation methods available on the IPAQ website. If possible please consider making your translated version of IPAQ available to others by contributing it to the IPAQ website. Further details on translation and cultural adaptation can be downloaded from the website.

Data Entry and Coding

Attached to the response categories for each question are suggested variable names and valid ranges to assist in data management and interviewer training. We recommend that the actual response provided by each respondent is recorded. For example, “120 minutes” is recorded in the minutes response space. “Two hours” should be recorded as “2” in the hours column. A response of “one and a half hours” should be recorded as either “1” in hour column and “30” in minutes column.

Further Developments of IPAQ

International collaboration on IPAQ is on-going and an *International Physical Activity Prevalence Study* is in progress. For further information see the IPAQ website.

More Information

More detailed information on the IPAQ process and the research methods used in the development of IPAQ instruments is available at www.ipaq.ki.se and Booth, M.L. (2000). Assessment of Physical Activity: An International Perspective. Research Quarterly for Exercise and Sport, 71 (2): s114-20. Other scientific publications and presentations on the use of IPAQ are summarized on the website.

Short Last 7 Days Telephone IPAQ

READ: I am going to ask you about the time you spent being physically active in the last 7 days. Please answer each question even if you do not consider yourself to be an active person. Think about the activities you do at work, as part of your house and yard work, to get from place to place, and in your spare time for recreation, exercise or sport.

READ: Now, think about all the *vigorous* activities which take *hard physical effort* that you did in the last 7 days. Vigorous activities make you breathe much harder than normal and may include heavy lifting, digging, aerobics, or fast bicycling. Think only about those physical activities that you did for at least 10 minutes at a time.

1. During the **last 7 days**, on how many days did you do **vigorous** physical activities?

   _____ Days per week [VDAY; Range 0-7, 8,9]

   8. Don't Know/Not Sure

   9. Refused

   [**Interviewer clarification**: Think only about those physical activities that you do for at least 10 minutes at a time.]

   [**Interviewer note**: If respondent answers zero, refuses or does not know, skip to Question 3]

2. How much time did you usually spend doing **vigorous** physical activities on one of those days?

   __ __ Hours per day [VDHRS; Range: 0-16]

   __ __ __ Minutes per day [VDMIN; Range: 0-960, 998, 999]

   998. Don't Know/Not Sure

   999. Refused

   [**Interviewer clarification**: Think only about those physical activities you do for at least 10 minutes at a time.]

   [**Interviewer probe**: An average time for one of the days on which you do vigorous activity is being sought. If the respondent can't answer because the pattern of time spent varies widely from day to day, ask: "How much time in total would you spend **over the last 7 days** doing vigorous physical activities?"

   __ __ Hours per week [VWHRS; Range: 0-112]

   __ __ __ __Minutes per week [VWMIN; Range: 0-6720, 9998, 9999]

   9998. Don't Know/Not Sure

   9999. Refused

READ: Now think about activities which take *moderate physical effort* that you did in the last 7 days. Moderate physical activities make you breathe somewhat harder than normal and may include carrying light loads, bicycling at a regular pace, or doubles tennis. Do not include walking. Again, think about only those physical activities that you did for at least 10 minutes at a time.

3. During the **last 7 days**, on how many days did you do **moderate** physical activities?

____ Days per week [MDAY; Range: 0-7, 8, 9]
8. Don't Know/Not Sure
9. Refused

[**Interviewer clarification**: Think only about those physical activities that you do for at least 10 minutes at a time]

[**Interviewer Note**: *If respondent answers zero*, refuses or does not know, skip to Question 5]

4. How much time did you usually spend doing **moderate** physical activities on one of those days?

__ __ Hours per day [MDHRS; Range: 0-16]
__ __ __ Minutes per day [MDMIN; Range: 0-960, 998, 999]
998. Don't Know/Not Sure
999. Refused

[**Interviewer clarification**: Think only about those physical activities that you do for at least 10 minutes at a time.]

[**Interviewer probe**: An average time for one of the days on which you do moderate activity is being sought. If the respondent can't answer because the pattern of time spent varies widely from day to day, or includes time spent in multiple jobs, ask: "What is the total amount of time you spent over the **last 7 days** doing moderate physical activities?"

__ __ __ Hours per week [MWHRS; Range: 0-112]
__ __ __ __Minutes per week [MWMIN; Range: 0-6720, 9998, 9999]
9998. Don't Know/Not Sure
9999. Refused

READ: Now think about the time you spent walking in the last 7 days. This includes at work and at home, walking to travel from place to place, and any other walking that you have done solely for recreation, sport, exercise, or leisure.

5. During the **last 7 days**, on how many days did you **walk** for at least 10 minutes at a time?

____ Days per week [WDAY; Range: 0-7, 8, 9]

8. Don't Know/Not Sure

9. Refused

[**Interviewer clarification**: Think only about the walking that you do for at least 10 minutes at a time.]

[**Interviewer Note**: *If respondent answers zero,* refuses or does not know, skip to Question 7]

6. How much time did you usually spend **walking** on one of those days?

__ __ Hours per day [WDHRS; Range: 0-16]

__ __ __ Minutes per day [WDMIN; Range: 0-960, 998, 999]

998. Don't Know/Not Sure

999. Refused

[**Interviewer probe**: An average time for one of the days on which you walk is being sought. If the respondent can't answer because the pattern of time spent varies widely from day to day, ask: "What is the total amount of time you spent walking over **the last 7 days**?"

__ __ __ Hours per week [WWHRS; Range: 0-112]

__ __ __ __Minutes per week [WWMIN; Range: 0-6720, 9998, 9999]

9998. Don't Know/Not Sure

9999. Refused

READ: Now think about the time you spent sitting on week days during the last 7 days. Include time spent at work, at home, while doing course work, and during leisure time. This may include time spent sitting at a desk, visiting friends, reading or sitting or lying down to watch television.

7. During the last 7 days, how much time did you usually spend ***sitting*** on a **week day**?

__ __ Hours per weekday [SDHRS; 0-16]

__ __ __ Minutes per weekday [SDMIN; Range: 0-960, 998, 999]

998. Don't Know/Not Sure

999. Refused

[**Interviewer clarification**: Include time spent lying down (awake) as well as sitting]

[**Interviewer probe**: An average time per day spent sitting is being sought. If the respondent can't answer because the pattern of time spent varies widely

from day to day, ask: “What is the total amount of time you spent *sitting* last **Wednesday**?”

__ __ Hours on Wednesday [SWHRS; Range 0-16]

__ __ __ Minutes on Wednesday [SWMIN; Range: 0-960, 998, 999]

998. Don't Know/Not Sure

999. Refused

Appendix V: Permission CANSA and Reach for Recovery

DHRS
Department of Health and Rehabilitation Sciences
FACULTY OF HEALTH SCIENCES

University of Cape Town • iYunivesithi yaseKapa • Universiteit van Kaapstad

Divisions of • Communication Sciences & Disorders • Disability Studies • Nursing & Midwifery • Occupational Therapy • Physiotherapy

F45 Old Main Building, Groote Schuur Hospital
Observatory, Cape Town, South Africa, 7925
Telephone: +27 (0) 21 406 6401
Website: www.dhrs.uct.ac.za

8 October 2021

To the head of research: CANSA and Reach for Recovery

PERMISSION: DISTRIBUTION OF A LEAFLET ADVERTISING PARTICIPATION IN BREAST CANCER RESEARCH.

An investigation of the rehabilitation needs, development, and preliminary outcomes of an education and exercise self-management intervention for breast cancer survivors

I am a Ph. D student at the University of Cape Town. From October 2019 until January 2020, we conducted focus group discussions with breast cancer survivors. We explored their experience of the long-term side effects of cancer treatment, and their rehabilitation needs. In the discussions, survivors confirmed that they were affected by long-term side effects. They expressed a need for information in the form of information and support to enable them to manage these problems effectively.

Informed by the results of the focus group discussions and recent breast cancer rehabilitation literature, we have designed an educational intervention on the long-term side effects of breast cancer treatment. The next step is to test its preliminary outcomes to help survivors manage long-term complications. This research has been granted ethical approval by the University of Cape Town Ethics Committee (HREC Ref 227/2022).

To this end, may I ask that a leaflet advertising the study may be distributed to breast cancer survivors in the Western Cape via your online platforms (Facebook, twitter, Instagram), your website and service delivery offerings (such as care centres, support groups and community-based home visits)? Interested patients will be invited to contact the researcher should they wish to know more about the study or to participate. The recruitment process and data collection will be the responsibility of the researchers. I will provide you with a copy of the study protocol, informed consent document and provisional ethics approval document for the study.

Data collected for this study will be confidential. Please feel free to contact any of the people involved in this research to seek further clarification or information, contact details below.

For questions, please feel free to contact me, Anita Beutel 082 467 0422 beutelphysio@gmail.com or study supervisors:
Supervisor: A/Prof Delva Shamley 074 377 5287delva.shamley@uct.ac.za
Co-supervisor: A/Prof Theresa Burgess 021 406 6171 theresa.burgess@uct.ac.za
Co-supervisor: A/Prof Niri Naidoo 021 406 6171 niri.naidoo@uct.ac.za
The chairperson of the Human Research Ethics Committee, University of Cape Town: Professor Marc Blockman marc.blockman@uct.ac.za

Thank you in advance for your assistance.

Kind regards,
Anita Beutel

Consent statement

I hereby confirm my consent to the above research project by authorising the distribution of the research advertisement leaflet via our channels.

---------- ---------- ----------

Head of research Name Date

Appendix W: Preparticipation screening questionnaire

Screening for exercise using the American College of Sports Medicine (ACSM) guidelines [3]:

1. As part of this study you will be asked to do exercises. I need to ask you some questions now to make sure that it will be safe for you to do these exercises:

a. Do you have, or have you had any of the following? (Category 1 – immediate exclusion. Yes to any of these: stop the interview and thank them for their time. They are not eligible for the study)

___ A heart attack

___ Heart surgery

___ Cardiac catheterisation

___ Coronary angioplasty (PTCA)

___ Pacemaker/implantable cardiac defibrillator/rhythm disturbance

___ Heart valve disease

___ Heart failure

___ Heart transplantation

___ Congenital heart disease

b. Screening question (see specific responses)

- Do you have diabetes?

  IF YES, is it controlled by medication? Yes – OK; No – end interview, thank you, not eligible

- Do you have asthma other lung disease?

  IF YES, is it controlled by medication? Yes – OK; No – end interview, thank you, not eligible

YES to 2 or more of the 4 following questions: not eligible, end interview, thank you for your time

1. ___ Do you have burning or cramping in your lower legs when walking short distances?

2. ___ Do You experience chest discomfort with exertion?

3. ___ Do You experience unreasonable breathlessness?

4. ___ Do You experience dizziness, fainting, blackouts?

5. Are you pregnant? Sorry but not eligible, thank you for your time.

Appendix X: TREND Checklist

Paper Section/Topic	Item No.	Descriptor	Reported? ✓	Reported? Pg #
TITLE and ABSTRACT				
Title and Abstract	1	• Information on how units were allocated to interventions	N/A	
		• Structured abstract recommended	N/A	
		• Information on target population or study sample	✓	128
INTRODUCTION				
Background	2	• Scientific background and explanation of rationale	✓	130
		• Theories used in designing behavioral interventions	✓	140
METHODS				
Participants	3	• Eligibility criteria for participants, including criteria at different levels in recruitment/sampling plan (e.g., cities, clinics, subjects)	✓	132
		• Method of recruitment (e.g., referral, self-selection), including the sampling method if a systematic sampling plan was implemented	✓	133
		• Recruitment setting	✓	133
		• Settings and locations where the data were collected	✓	142
Interventions	4	• Details of the interventions intended for each study condition and how and when they were actually administered, specifically including:		
		○ Content: what was given?	✓	141
		○ Delivery method: how was the content given?	✓	140
		○ Unit of delivery: how were subjects grouped during delivery?		N/A
		○ Deliverer: who delivered the intervention?	✓	140
		○ Setting: where was the intervention delivered?	✓	140
		○ Exposure quantity and duration: how many sessions or episodes or events were intended to be delivered? How long were they intended to last?	✓	140
		○ Time span: how long was it intended to take to deliver the intervention to each unit?	✓	140
		○ Activities to increase compliance or adherence (e.g., incentives)	✓	140
Objectives	5	• Specific objectives and hypotheses	✓	129

Outcomes	6	• Clearly defined primary and secondary outcome measures	✓	133
		• Methods used to collect data and any methods used to enhance the quality of measurements	✓	142
		• Information on validated instruments such as psychometric and biometric properties	✓	136
Sample size	7	• How sample size was determined and, when applicable, explanation of any interim analyses and stopping rules	✓	133
Assignment method	8	• Unit of assignment (the unit being assigned to study condition, e.g., individual, group, community)		N/A
		• Method used to assign units to study conditions, including details of any restriction (e.g., blocking, stratification, minimization)		N/A
		• Inclusion of aspects employed to help minimize potential bias induced due to non-randomization (e.g., matching)		N/A
Blinding (masking)	9	• Whether or not participants, those administering the interventions, and those assessing the outcomes were blinded to study condition assignment; if so, statement regarding how the blinding was accomplished and how it was assessed	✓	131, 142
Unit of Analysis	10	• Description of the smallest unit that is being analysed to assess intervention effects (e.g., individual, group, or community)	✓	133
		• If the unit of analysis differs from the unit of assignment, the analytical method used to account for this (e.g., adjusting the standard error estimates by the design effect or using multilevel analysis)		N/A
Statistical methods	11	• Statistical methods used to compare study groups for primary methods outcome(s), including complex methods for correlated data	✓	143
		• Statistical methods used for additional analyses, such as subgroup analyses and adjusted analysis		N/A
		• Methods for imputing missing data, if used	✓	144
		• Statistical software or programs used	✓	143
RESULTS				
Participant flow	12	• Flow of participants through each stage of the study: enrollment, assignment, allocation and intervention exposure, follow-up, analysis (a diagram is strongly recommended)	✓	143
		○ Enrollment: the numbers of participants screened for eligibility, found to be eligible or not eligible, declined to be enrolled, and enrolled in the study	✓	147
		○ Assignment: the numbers of participants assigned to a study condition	✓	147
		○ Allocation and intervention exposure: the number of participants assigned to each study condition and the number of participants who received each intervention		N/A
		○ Follow-up: the number of participants who completed the follow-up or did not complete the follow-up (i.e., lost to follow-up), by study condition	✓	147

		○ Analysis: the number of participants included in or excluded from the main analysis, by study condition		N/A
		• Description of protocol deviations from study as planned, along with reasons		N/A
Recruitment	13	• Dates defining the periods of recruitment and follow-up	✓	151
Baseline data	14	• Baseline demographic and clinical characteristics of participants in each study condition	✓	149
		• Baseline characteristics for each study condition relevant to specific disease prevention research		N/A
		• Baseline comparisons of those lost to follow-up and those retained, overall and by study condition		N/A
		• Comparison between study population at baseline and target population of interest	✓	162
Baseline equivalence	15	• Data on study group equivalence at baseline and statistical methods used to control for baseline differences		N/A
Numbers analyzed	16	• Number of participants (denominator) included in each analysis for each study condition, particularly when the denominators change for different outcomes; statement of the results in absolute numbers when feasible	✓	154
		• Indication of whether the analysis strategy was “intention to treat” or, if not, description of how non-compliers were treated in the analyses	✓	144
Outcomes and estimation	17	• For each primary and secondary outcome, a summary of results for each estimation study condition, and the estimated effect size and a confidence interval to indicate the precision	✓	154
		• Inclusion of null and negative findings	✓	160
		• Inclusion of results from testing pre-specified causal pathways through which the intervention was intended to operate, if any		N/A
Ancillary analyses	18	• Summary of other analyses performed, including subgroup or restricted analyses, indicating which are pre-specified or exploratory	✓	161
Adverse events	19	• Summary of all important adverse events or unintended effects in each study condition (including summary measures, effect size estimates, and confidence intervals)	✓	153
DISCUSSION				
Interpretation	20	• Interpretation of the results, taking into account study hypotheses, sources of potential bias, imprecision of measures, multiplicative analyses, and other limitations or weaknesses of the study	✓	179
		• Discussion of results taking into account the mechanism by which the intervention was intended to work (causal pathways) or alternative mechanisms or explanations	✓	178
		• Discussion of the success of and barriers to implementing the intervention, fidelity of implementation	✓	178
		• Discussion of research, programmatic, or policy implications	✓	180

Generalizability	21	• Generalizability (external validity) of the trial findings, taking into account the study population, the characteristics of the intervention, length of follow-up, incentives, compliance rates, specific sites/settings involved in the study, and other contextual issues	✓	179
Overall evidence	22	• General interpretation of the results in the context of current evidence and current theory	✓	169

From: Des Jarlais, D. C., Lyles, C., Crepaz, N., & the Trend Group (2004). Improving the reporting quality of nonrandomized evaluations of behavioral and public health interventions: The TREND statement. *American Journal of Public Health*, 94, 361-366. For more information, visit: http://www.cdc.gov/trendstatement/

Appendix Y: Data management plan

AN INVESTIGATION OF THE REHABILITATION NEEDS, DEVELOPMENT, AND PRELIMINARY OUTCOMES OF AN EDUCATION AND EXERCISE SELF-MANAGEMENT INTERVENTION FOR BREAST CANCER SURVIVORS- Student Full DMP

1. Project Details

PROJECT NAME - Replicate the title of your project, dissertation, or thesis exactly as it appears in your proposal document.

AN INVESTIGATION OF THE REHABILITATION NEEDS, DEVELOPMENT, AND PRELIMINARY OUTCOMES OF AN EDUCATION AND EXERCISE SELF-MANAGEMENT INTERVENTION FOR BREAST CANCER SURVIVORS

PERSONAL DETAILS - Indicate the name(s) and student number(s) of the student(s) who will be involved in this project, dissertation or thesis.

Anita Beutel BTLANI001

SUPERVISOR(S) DETAILS - Indicate who will supervise this project, dissertation or thesis. If you do not yet have a supervisor, leave this section blank.

A/Prof Delva Shamley A/Prof Theresa Burgess A/Prof Niri Naidoo

2. Project Summary

RESEARCH SUMMARY - Briefly summarise your study. Include the study's objectives, design, and methods.

The central premise of this thesis was that breast cancer (BC) survivors face debilitating long-term side effects (LTSE) after completing their medical cancer treatment (MCT), such as chronic pain and upper limb dysfunction, cancer-related fatigue, a reduction in health-related quality of life (HRQoL), reduced physical function, weight gain and lymphedema. It was hypothesized that BC survivors may not receive education and support to manage these and other LTSE. It was also hypothesized that LTSE of breast cancer treatment can be improved by an education and exercise self-management intervention (SMI). The thesis consists of four main components. Firstly, a qualitative study using focus group discussions was conducted to investigate the lived experience of LTSE of breast cancer treatment and the rehabilitation needs of survivors in a semi-urban region of South Africa (SA). Second, a systematic review and meta-analysis was conducted to determine the effectiveness of self-management interventions including exercise, to improve LTSE and encourage exercise participation, in BC survivors following MCT. Third, using the results of the qualitative study and the systematic review, an evidence- and theory-based education and exercise SMI was developed using published guidelines. The intervention was subsequently evaluated for acceptability through a small qualitative study. The fourth component was a single-group, pre-test-post-test study to determine the preliminary outcomes, aspects of feasibility and safety of the newly developed intervention.

3. Description of the Data

DATA REUSE DESCRIPTION - If you re-used data from third-party sources in your study, record pertinent details here such as the source of the data, the extent of the data, usage rights or restrictions pertaining to the data, and how it was incorporated into your study.

I have used existing data in my study. For the systematic review, data were extracted from published journal articles, organised, and included in meta-analyses.

DATA DESCRIPTION - Describe the data you have gathered for your study. Briefly describe the nature, scope and scale of the data you have produced.

My study produced original data (apart from the systematic review). I have collected qualitative data, in the form of five focus group interviews (first study). The data were transcribed in MS Word. Dataset = 301 KB. Quantitative data collected were in the form of descriptive demographic information of participants, they have been transferred to an

Excel spreadsheet. Size: 14.4. KB. The total number of participants for study 1:23. Study 2: socio-demographic and patient-reported outcome measures. Data have been transferred to an excel spreadsheet. Dataset is 21.6 KB in total. Acceptability evaluation nested in study 2: qualitative data have been transferred to MS Word. Dataset is 41.3 KB. Data for systematic review have been transferred to Excel spreadsheets. Dataset is 26.1 KB. Total size of dataset for this project: 404.4 KB

4. Formats and Quality Control

QUALITY CONTROL - Describe what measures you took to ensure the data you collected were of high-quality.

Data cleaning was done for quantitative data. Qualitative data were transcribed by an independent transcription company. Data were coded and re-coded several months later and were verified by another qualitative researcher. Themes and subthemes were cross-checked by a study supervisor. Triangulation was done with socio-demographic data.

FILE FORMATS - Indicate the formats in which your data will be collected and processed. Clarify whether these formats require specialised proprietary software to access or if they will be produced in or converted to more open, accessible formats for long-term accessibility and preservation. In the case of physical data objects (such as artworks or models) indicate whether these will be digitised or otherwise preserved for accessibility.

Data were transferred to MS Word and MS Excel spreadsheets. These formats do not require specialised software to access.

5. Data Management, Documentation and Curation

CURATION (MANAGING AND STORING) DATA - Describe how you organise and manage your data. Specify any file-naming conventions or community data standards you have adopted.

Data files were labelled according to the date of the focus groups. Quantitative files were labelled study 1, study 2 etc.

BACKUP AND STORAGE - Describe how your data is being stored and backed-up. If you are using a data service provider, provide details on for how long they will retain the data.

Data are backed up automatically to UCT Google Drive.

METADATA STANDARDS AND DATA DOCUMENTATION - Articulate what metadata and documentation you have produced about the data you have generated, collected or re-used.

The completed dataset will be accompanied by keywords, a short description taken from my dissertation abstract and comments on the data process taken from my methods section. I will include interview schedules and questionnaires, and codebooks for variables.

6. Data Security and Confidentiality of Potentially Disclosive Information

SECURITY - Indicate to what extent your data can be considered sensitive or at-risk. Describe how you will control access to your data. Indicate whether you anticipate a need for encryption or password-controlled access, and if so, how you will enforce that access.

All qualitative and quantitative data have been de-identified. My computer is password-secured.

ETHICS AND PRIVACY - Describe, as per your Ethics Clearance form or other similar documentation, any ethical or privacy issues that your data are subject to (if any). Summarise the main risks to the confidentiality and security of information related to human participants, the level of risk, and how this risk will be managed. If your project did not require ethical clearance, you may ignore this section.

Ethical approval was obtained for all relevant studies. Informed consent including permission to audio-tape focus groups and to access the medical records of participants. Data were de-identified using only study numbers. A master

list is kept in a locked cupboard by the researcher. Confidentiality agreements were signed prior to focus groups. Only participants and the researcher were present during focus groups.

7. Data Sharing and Open Access

USE OF EXISTING DATASETS

I have used existing data in my study

For the systematic review, data were extracted from randomized controlled trials and included in a meta-analysis.

DATA OWNERSHIP - If you have used existing datasets, note down any restrictions the data providers have indicated regarding data sharing. Otherwise, leave blank.

None.

DATA LICENCE - Indicate under which licence you intend to share your research data. If you are not sharing your data, provide the appropriate justification as per the UCT Research Data Management guidelines.

CC BY

I will share the properly de-identified data from my study under a CC BY licence.

DATA PUBLICATION - Indicate where you intend to publish your research data at the end of your project.

I will share my de-identified quantitative data on ZivaHub at the end of my project.

8. Relevant Institutional or Study Policies

Indicate the relevant departmental, unit, or institutional policies that influence your data management activities.

My project is unfunded. The following policies apply: UCT Open Access Policy, UCT Intellectual Property Policy, UCT Research Data Management Policy.

Appendix Z: Good clinical practice certification

THE GLOBAL HEALTH NETWORK

Enabling research by sharing knowledge

Hereby Certifies that

ANITA BEUTEL

has completed the e-learning course

ICH GOOD CLINICAL PRACTICE E6 (R2)

with a score of

83%

on

19/11/2023

This e-learning course has been formally recognised for its quality and content by the following organisations and institutions

*This ICH E6 GCP Investigator Site Training meets the Minimum Criteria for ICH GCP Investigator Site Personnel Training identified by **TransCelerate BioPharma** as necessary to enable mutual recognition of GCP training among trial sponsors.*

ALERRT · REDe Research Capacity Network · Global Research Nurses · THE GLOBAL HEALTH NETWORK

Global Health Training Centre
globalhealthtrainingcentre.org/elearning

Certificate Number 224d3bc9-f682-4544-b02a-73dab0e1d974 Version number 0

References

1. Le, H.V., et al., *Adhesive capsulitis of the shoulder: review of pathophysiology and current clinical treatments.* Shoulder & elbow, 2017. **9**(2): p. 75-84.
2. Shien, T. and H. Iwata, *Adjuvant and neoadjuvant therapy for breast cancer.* Jpn J Clin Oncol, 2020. **50**(3): p. 225-229.
3. Pescatello, L.S. and A.C.o.S. Medicine, *ACSM's Guidelines for Exercise Testing and Prescription*. 2014: Wolters Kluwer Health.
4. Escobar Alvarez, Y., et al., *SEOM clinical guidelines for anaemia treatment in cancer patients (2020).* Clinical and Translational Oncology, 2021. **23**(5): p. 931-939.
5. Dinas, K., et al., *Axillary web syndrome: Incidence, pathogenesis, and management.* Current Problems in Cancer, 2019. **43**(6): p. 100470.
6. Runowicz, C.D., et al., *American Cancer Society/American Society of Clinical Oncology Breast Cancer Survivorship Care Guideline.* CA Cancer J Clin, 2016. **66**(1): p. 43-73.
7. Bodai, B.I. and P. Tuso, *Breast cancer survivorship: a comprehensive review of long-term medical issues and lifestyle recommendations.* Perm J, 2015. **19**(2): p. 48-79.
8. Kahán, Z., et al., *Breast Cancer Survivorship Programme: Follow-Up, Rehabilitation, Psychosocial Oncology Care. 1st Central-Eastern European Professional Consensus Statement on Breast Cancer.* Pathology and Oncology Research, 2022. **28**: p. 1610391.
9. Nardin, S., et al., *Breast cancer survivorship, quality of life, and late toxicities.* Frontiers in oncology, 2020. **10**: p. 864.
10. Jonczyk, M.M., et al., *Surgical trends in breast cancer: a rise in novel operative treatment options over a 12 year analysis.* Breast Cancer Res Treat, 2019. **173**(2): p. 267-274.
11. Institute, N.C. *What is Cancer?* 2021 11.10.2023 [cited 2023 13.11.2023]; Available from: https://www.cancer.gov/about-cancer/understanding/what-is-cancer.
12. Thong, M.S., et al., *Cancer-related fatigue: causes and current treatment options.* Current treatment options in oncology, 2020. **21**(2): p. 1-19.
13. Berger, A.M., et al., *Cancer-Related Fatigue, Version 2.2015.* Journal of the National Comprehensive Cancer Network J Natl Compr Canc Netw, 2015. **13**(8): p. 1012-1039.
14. Organization, W.H. *Global status report on noncommunicable diseases 2014*. 2014 2023 [cited 2023 13.11.2023]; Available from: https://www.who.int/publications/i/item/9789241564854.
15. Kassam-Adams, N., et al., *A new method for assessing content validity in model-based creation and iteration of eHealth interventions.* Journal of medical Internet research, 2015. **17**(4): p. e3811.
16. Institute, N.C. *Cancer Staging*. 2022 2022 23.01.2022]; Available from: https://www.cancer.gov/about-cancer/diagnosis-staging/staging.
17. Caspersen, C.J., K.E. Powell, and G.M. Christenson, *Physical activity, exercise, and physical fitness: definitions and distinctions for health-related research.* Public health reports, 1985. **100**(2): p. 126.
18. Campbell, K.L., et al., *Exercise Guidelines for Cancer Survivors: Consensus Statement from International Multidisciplinary Roundtable.* Med Sci Sports Exerc, 2019. **51**(11): p. 2375-2390.
19. Kincaid, J.P., et al., *Derivation of new readability formulas (automated readability index, fog count and flesch reading ease formula) for navy enlisted personnel*. 1975, Naval Technical Training Command Millington TN Research Branch.
20. Painter, P., A.L. Stewart, and S. Carey, *Physical functioning: definitions, measurement, and expectations.* Advances in renal replacement therapy, 1999. **6**(2): p. 110-123.
21. Kaplan, R.M. and A.L. Ries, *Quality of life: concept and definition.* COPD: Journal of Chronic Obstructive Pulmonary Disease, 2007. **4**(3): p. 263-271.
22. Gouda, H.N., et al., *Burden of non-communicable diseases in sub-Saharan Africa, 1990–2017: results from the Global Burden of Disease Study 2017.* The Lancet Global Health, 2019. **7**(10): p. e1375-e1387.

23. Heitz, A.E., et al., *Healthy lifestyle impact on breast cancer-specific and all-cause mortality.* Breast cancer research and treatment, 2018. **167**(1): p. 171-181.
24. Lovelace, D.L., L.R. McDaniel, and D. Golden, *Long-Term Effects of Breast Cancer Surgery, Treatment, and Survivor Care.* J Midwifery Womens Health, 2019. **64**(6): p. 713-724.
25. Committee, E., *The diagnosis and treatment of peripheral lymphedema: 2016 consensus document of the International Society of Lymphology.* Lymphology, 2016. **49**(4): p. 170-184.
26. Dunne, M. and K. Keenan, *CE: Late and Long-Term Sequelae of Breast Cancer Treatment.* Am J Nurs, 2016. **116**(6): p. 36-45.
27. Prevention, C.f.D.C.a. *Measuring Physical Activity Intensity*. 2022 3 June 2022 [cited 2023 14.11.2023]; Available from: https://www.cdc.gov/physicalactivity/basics/measuring/index.html.
28. Organization, W.H. *Noncommunicable Diseases*. Fact Sheets 2023 16 September 2023 [cited 2023 14.11.2023]; Available from: https://www.who.int/news-room/fact-sheets/detail/noncommunicable-diseases.
29. Brédart, A., et al., *Interviewing to develop Patient-Reported Outcome (PRO) measures for clinical research: eliciting patients' experience.* Health and quality of life outcomes, 2014. **12**(1): p. 1-10.
30. Stout, N.L., et al., *Toward a national initiative in cancer rehabilitation: recommendations from a subject matter expert group.* Archives of physical medicine and rehabilitation, 2016. **97**(11): p. 2006-2015.
31. Wirtz, P. and F.T. Baumann, *Physical activity, exercise and breast cancer-what is the evidence for rehabilitation, aftercare, and survival A review.* Breast Care, 2018. **13**(2): p. 92-100.
32. Cheville, A.L., et al., *Integrated rehabilitation for breast cancer survivors.* American journal of physical medicine & rehabilitation, 2019. **98**(2): p. 154-164.
33. Teague, S., et al., *Retention strategies in longitudinal cohort studies: a systematic review and meta-analysis.* BMC medical research methodology, 2018. **18**: p. 1-22.
34. May, T. and G.M. Garmel, *Rotator cuff injury.* 2019.
35. Bandura, A., W.H. Freeman, and R. Lightsey, *Self-efficacy: The exercise of control*. 1999, Springer.
36. Foster, C. and D. Fenlon, *Recovery and self-management support following primary cancer treatment.* British journal of cancer, 2011. **105**(1): p. S21-S28.
37. Bandura, A., *Health Promotion by Social Cognitive Means.* Health education & behavior, 2004. **31**(2): p. 143-164.
38. Bevers, T.B., et al., *Breast Cancer Screening and Diagnosis, Version 3.2018, NCCN Clinical Practice Guidelines in Oncology.* J Natl Compr Canc Netw, 2018. **16**(11): p. 1362-1389.
39. Ganz, P.A., et al., *Supportive care after curative treatment for breast cancer (survivorship care): resource allocations in low- and middle-income countries. A Breast Health Global Initiative 2013 consensus statement.* Breast, 2013. **22**(5): p. 606-15.
40. Rugge, J.B., C. Bougatsos, and R. Chou, *Screening and treatment of thyroid dysfunction: an evidence review for the US Preventive Services Task Force.* Annals of internal medicine, 2015. **162**(1): p. 35-45.
41. Stringhini, S. and P. Bovet, *Socioeconomic status and risk factors for non-communicable diseases in low-income and lower-middle-income countries.* The Lancet Global Health, 2017. **5**(3): p. e230-e231.
42. Africa, S.S. *Rising non-communicable diseases: a looming health crisis*. 2023 [cited 2024 21.02.2024]; Available from: https://www.statssa.gov.za/?p=16729.
43. Fitzmaurice, C., et al., *Global, Regional, and National Cancer Incidence, Mortality, Years of Life Lost, Years Lived With Disability, and Disability-Adjusted Life-years for 32 Cancer Groups, 1990 to 2015: A Systematic Analysis for the Global Burden of Disease Study.* JAMA Oncol, 2017. **3**(4): p. 524-548.

44. Rich-Edwards, J.W., et al., *Sex and Gender Differences Research Design for Basic, Clinical, and Population Studies: Essentials for Investigators.* Endocrine Reviews, 2018. **39**(4): p. 424-439.
45. Sung, H., et al., *Global Cancer Statistics 2020: GLOBOCAN Estimates of Incidence and Mortality Worldwide for 36 Cancers in 185 Countries.* CA Cancer J Clin, 2021. **71**(3): p. 209-249.
46. Fitzmaurice, C., et al., *Global, Regional, and National Cancer Incidence, Mortality, Years of Life Lost, Years Lived With Disability, and Disability-Adjusted Life-Years for 29 Cancer Groups, 1990 to 2017: A Systematic Analysis for the Global Burden of Disease Study.* JAMA Oncol, 2019. **5**(12): p. 1749-1768.
47. Joko-Fru, W.Y., et al., *Breast cancer survival in sub-Saharan Africa by age, stage at diagnosis and human development index: A population-based registry study.* International journal of cancer, 2020. **146**(5): p. 1208-1218.
48. Sharma, R., *Breast cancer burden in Africa: evidence from GLOBOCAN 2018.* Journal of Public Health, 2020. **43**(4): p. 763-771.
49. Vanderpuye, V., et al., *An update on the management of breast cancer in Africa.* Infect Agent Cancer, 2017. **12**: p. 13.
50. Rivera-Franco, M.M. and E. Leon-Rodriguez, *Delays in Breast Cancer Detection and Treatment in Developing Countries.* Breast Cancer (Auckl), 2018. **12**: p. 1178223417752677.
51. UK, C.R. *Survival for Breast Cancer*. 2023 8 June 2023 [cited 2024 14 March 2024]; Available from: https://www.cancerresearchuk.org/about-cancer/breast-cancer/survival.
52. Loh, S.Y. and A.N. Musa, *Methods to improve rehabilitation of patients following breast cancer surgery: a review of systematic reviews.* Breast Cancer (Dove Med Press), 2015. **7**: p. 81-98.
53. Organization, W.H. *New global breast cancer initiative highlights renewed commitment to improve survival.* Health Topics 2021 8 March 2021 [cited 2023 15 November 2023]; Available from: https://www.who.int/news/item/08-03-2021-new-global-breast-cancer-initiative-highlights-renewed-commitment-to-improve-survival.
54. Beckjord, E.B., et al., *Population-level trends in posttreatment cancer survivors' concerns and associated receipt of care: results from the 2006 and 2010 LIVESTRONG surveys.* Journal of psychosocial oncology, 2014. **32**(2): p. 125-151.
55. Shamley, D.R., et al., *Changes in shoulder muscle size and activity following treatment for breast cancer.* Breast Cancer Res Treat, 2007. **106**(1): p. 19-27.
56. Schmidt, M.E., J. Wiskemann, and K. Steindorf, *Quality of life, problems, and needs of disease-free breast cancer survivors 5 years after diagnosis.* Quality of Life Research, 2018. **27**(8): p. 2077-2086.
57. Hauerslev, K.R., et al., *Long-term follow-up on shoulder and arm morbidity in patients treated for early breast cancer.* Acta Oncologica, 2020. **59**(7): p. 851-858.
58. Azuero, A., et al., *Co-morbidity and predictors of health status in older rural breast cancer survivors.* Springerplus, 2014. **3**: p. 102.
59. Boucheron, P., et al., *Self-reported arm and shoulder problems in breast cancer survivors in Sub-Saharan Africa: the African Breast Cancer-Disparities in Outcomes cohort study.* Breast Cancer Research, 2021. **23**(1): p. 109.
60. Bosire, E.N., E. Mendenhall, and L.J. Weaver, *Comorbid suffering: Breast cancer survivors in South Africa.* Qualitative health research, 2020. **30**(6): p. 917-926.
61. Bucciarelli, V., et al., *The role of physical exercise on endothelial dysfunction and metabolic improvement in women after breast-cancer surgery: a pilot study.* European heart journal, 2017. **38**: p. 124-.
62. Lambert, M., et al., *Health system experiences of breast cancer survivors in urban South Africa.* Women's Health, 2020. **16**: p. 1745506520949419.
63. Hamer, J. and E. Warner, *Lifestyle modifications for patients with breast cancer to improve prognosis and optimize overall health.* Cmaj, 2017. **189**(7): p. E268-E274.

64. Haykowsky, M.J., et al., *Lifestyle interventions to improve cardiorespiratory fitness and reduce breast cancer recurrence.* American Society of Clinical Oncology Educational Book, 2017. **37**: p. 57-64.
65. Montaño-Rojas, L.S., et al., *Resistance Training in Breast Cancer Survivors: A Systematic Review of Exercise Programs.* Int J Environ Res Public Health, 2020. **17**(18).
66. Hasenoehrl, T., et al., *Resistance exercise and breast cancer related lymphedema - a systematic review update.* Disabil Rehabil, 2020. **42**(1): p. 26-35.
67. Baumann, F.T., et al., *Effects of physical exercise on breast cancer-related secondary lymphedema: a systematic review.* Breast Cancer Res Treat, 2018. **170**(1): p. 1-13.
68. Boing, L., et al., *Effects of exercise on physical outcomes of breast cancer survivors receiving hormone therapy - A systematic review and meta-analysis.* Maturitas, 2020. **141**: p. 71-81.
69. Ballard-Barbash, R., et al., *Physical activity, biomarkers, and disease outcomes in cancer survivors: a systematic review.* J Natl Cancer Inst, 2012. **104**(11): p. 815-40.
70. Upshaw, J.N., et al., *Physical activity during and after breast cancer therapy and associations of baseline physical activity with changes in cardiac function by echocardiography.* Cancer Med, 2020. **9**(17): p. 6122-6131.
71. Rayne, S., et al., *The effect of access to information on beliefs surrounding breast cancer in South Africa.* Journal of Cancer Education, 2018. **33**(4): p. 806-813.
72. Singh, E., et al., *Breast cancer trends differ by ethnicity: a report from the South African National Cancer Registry (1994-2009).* Eur J Public Health, 2017. **27**(1): p. 173-178.
73. Bresick, G., K.B. Von Pressentin, and R. Mash, *Evaluating the performance of South African primary care: a cross-sectional descriptive survey.* South African Family Practice, 2019. **61**(3): p. 109-116.
74. Mutebi, M. and J. Edge, *Stigma, survivorship and solutions: Addressing the challenges of living with breast cancer in low-resource areas.* South African Medical Journal, 2014. **104**(5).
75. Moodley, J., et al., *Understanding pathways to breast cancer diagnosis among women in the Western Cape Province, South Africa: a qualitative study.* BMJ open, 2016. **6**(1): p. e009905-e009905.
76. Coughlin, S.S., et al., *Survivorship issues in older breast cancer survivors.* Breast cancer research and treatment, 2018. **174**(1): p. 47-53.
77. Society, A.C. *Breast Cancer*

Facts & Figures 2019-2020. 2019 2019 [cited 2023 5 December 2023]; Available from: https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/breast-cancer-facts-and-figures/breast-cancer-facts-and-figures-2019-2020.pdf.
78. Cheville, A.L., et al., *Cancer rehabilitation: an overview of current need, delivery models, and levels of care.* Physical Medicine and Rehabilitation Clinics, 2017. **28**(1): p. 1-17.
79. Institute, N.C., *NCI dictionary of cancer terms*. 2019, National Cancer Institute.
80. Palesh, O., et al., *Management of side effects during and post-treatment in breast cancer survivors.* Breast J, 2018. **24**(2): p. 167-175.
81. Parker, R., R.Y. Barnes, and J. Jelsma, *Improvements in health-related quality of life and function in middle-aged women with chronic diseases of lifestyle after participating in a non-pharmacological intervention programme: A pragmatic randomised controlled trial.* African journal of disability, 2019. **8**(1): p. 1-14.
82. Santana, M.J., et al., *How to practice person-centred care: A conceptual framework.* Health Expect, 2018. **21**(2): p. 429-440.
83. Lorig, K.R. and H.R. Holman, *Self-management education: history, definition, outcomes, and mechanisms.* Annals of behavioral medicine, 2003. **26**(1): p. 1-7.
84. Rimmer, B. and L. Sharp, *Implementation of Self-Management Interventions in Cancer Survivors: Why Are We Not There Yet?* J Cancer Educ, 2021. **36**(6): p. 1355-1358.
85. O'Cathain, A., et al., *Guidance on how to develop complex interventions to improve health and healthcare.* BMJ open, 2019. **9**(8): p. e029954.

86. Africa, S.S. *Census 2022*. 2023 [cited 2024 21.02.2024]; Available from: https://www.statssa.gov.za/?s=census.
87. de Villiers, K., *Bridging the health inequality gap: an examination of South Africa's social innovation in health landscape.* Infectious Diseases of Poverty, 2021. **10**(1): p. 19.
88. Africa, S.S. *Public Healthcare: how much per person?* 2017 October 2, 2017 [cited 2024 21.02.2024]; Available from: https://www.statssa.gov.za/?p=10548#:~:text=According%20to%20the%20latest%20General%20Household%20Survey%2C%20only,result%20are%20largely%20dependent%20on%20public%20healthcare.%201.
89. Abrahams, G.L., X.C. Thani, and S.B. Kahn, *South African Public Primary Healthcare Services and Challenges.* Administratio Publica, 2022. **30**(2): p. 63-85.
90. National Department of Health, S.A. *Clinical Guidelines for Breast Cancer Control and Management*. 2018 April 2018 [cited 2024 11 June 2024]; Available from: https://knowledgehub.health.gov.za/system/files/elibdownloads/2021-03/Clinical%20guidelines%20Breast%20Cancer.
91. Africa, S.S. *General Household Survey, 2021*. 2022 [cited 2024 12 April 2024]; Available from: https://www.statssa.gov.za/?p=15482.
92. Dookie, S. and S. Singh, *Primary health services at district level in South Africa: a critique of the primary health care approach.* BMC family practice, 2012. **13**: p. 1-4.
93. Government, W.C. *George Hospital: Overview*. 2023 28/03/2023 [cited 2023 14/07/2023]; Available from: https://www.westerncape.gov.za/george-hospital/.
94. McLaren, Z.M., C. Ardington, and M. Leibbrandt, *Distance decay and persistent health care disparities in South Africa.* BMC health services research, 2014. **14**(1): p. 1-9.
95. Cathcart-Rake, E.J., et al., *Advances in the care of breast cancer survivors.* bmj, 2023. **382**.
96. Duncan, M., et al., *Review of systematic reviews of non-pharmacological interventions to improve quality of life in cancer survivors.* BMJ Open, 2017. **7**(11): p. e015860.
97. Juvet, L.K., et al., *The effect of exercise on fatigue and physical functioning in breast cancer patients during and after treatment and at 6 months follow-up: A meta-analysis.* The Breast, 2017. **33**: p. 166-177.
98. Lin, Y., et al., *Effect of exercise on rehabilitation of breast cancer surgery patients: A systematic review and meta-analysis of randomized controlled trials.* Nursing open, 2023. **10**(4): p. 2030-2043.
99. Joko-Fru, W.Y., et al., *Cancer survival in sub-Saharan Africa (SURVCAN-3): a population-based study.* The Lancet Global Health, 2024. **12**(6): p. e947-e959.
100. Bradshaw, D., et al., *Strengthening public health in South Africa: building a stronger evidence base for improving the health of the nation.* South African Medical Journal, 2007. **97**(8): p. 643-651.
101. Campbell, B.C., *The physical activity levels and preferences of South African breast cancer survivors: a pilot study*. 2021, Rhodes University.
102. Joffe, M., et al., *Barriers to early presentation of breast cancer among women in Soweto, South Africa.* PloS one, 2018. **13**(2): p. e0192071-e0192071.
103. Reeves, M.M., et al., *Effect of a Remotely Delivered Weight Loss Intervention in Early-Stage Breast Cancer: Randomized Controlled Trial.* Nutrients, 2021. **13**(11).
104. Lam, W.W., et al., *The evolution of supportive care needs trajectories in women with advanced breast cancer during the 12 months following diagnosis.* Supportive Care in Cancer, 2014. **22**: p. 635-644.
105. Vuksanovic, D., et al., *Unmet needs in breast cancer survivors are common, and multidisciplinary care is underutilised: the Survivorship Needs Assessment Project.* Breast Cancer, 2021. **28**(2): p. 289-297.
106. Matthews, H. and H. Semper, *'Dropped from the system': the experiences and challenges of long-term breast cancer survivors.* Journal of Advanced Nursing, 2017. **73**(6): p. 1355-1365.

107. Magilvy, J.K., *Qualitative designs.* Nursing research secrets, 2003. **18**(3): p. 123-128.
108. Magilvy, J.K. and E. Thomas, *A first qualitative project: Qualitative descriptive design for novice researchers.* Journal for Specialists in Pediatric Nursing, 2009. **14**(4): p. 298-300.
109. Lambert, V.A. and C.E. Lambert, *Qualitative descriptive research: An acceptable design.* Pacific Rim international journal of nursing research, 2012. **16**(4): p. 255-256.
110. Twohig, P.L. and W. Putnam, *Group interviews in primary care research: advancing the state of the art or ritualized research?* Family practice, 2002. **19**(3): p. 278-284.
111. Barbour, R.S., *Making sense of focus groups.* Medical education, 2005. **39**(7): p. 742-750.
112. Tausch, A.P. and N. Menold, *Methodological aspects of focus groups in health research: results of qualitative interviews with focus group moderators.* Global qualitative nursing research, 2016. **3**: p. 2333393616630466.
113. Tong, A., P. Sainsbury, and J. Craig, *Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups.* International journal for quality in health care, 2007. **19**(6): p. 349-357.
114. Anderson, W.F., et al., *Male breast cancer: a population-based comparison with female breast cancer.* Journal of Clinical Oncology, 2010. **28**(2): p. 232.
115. Abrahams, H., et al., *Risk factors, prevalence, and course of severe fatigue after breast cancer treatment: a meta-analysis involving 12 327 breast cancer survivors.* Annals of Oncology, 2016. **27**(6): p. 965-974.
116. Lange, J.K. *Richard A. Krueger & Mary Anne Casey (2000). Focus groups. A practical guide for applied research*. in *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research*. 2002.
117. Krueger, R.A., *Focus groups: A practical guide for applied research*. 2014: Sage publications.
118. Koçak, A.T., S. Arslan, and Y. İlik. *Posttreatment Experiences of Breast Cancer Survivors in Turkey: A Qualitative Study*. in *Seminars in Oncology Nursing*. 2022. Elsevier.
119. Sander, A.P., et al., *Factors that affect decisions about physical activity and exercise in survivors of breast cancer: a qualitative study.* Physical Therapy, 2012. **92**(4): p. 525-536.
120. Kim, S., et al., *The experience of cancer-related fatigue, exercise and exercise adherence among women breast cancer survivors: Insights from focus group interviews.* Journal of clinical nursing, 2020. **29**(5-6): p. 758-769.
121. Torres, E., C. Dixon, and A.R. Richman, *Understanding the breast cancer experience of survivors: a qualitative study of African American women in rural eastern North Carolina.* Journal of Cancer Education, 2016. **31**: p. 198-206.
122. Dsouza, S.M., et al., *A qualitative study on experiences and needs of breast cancer survivors in Karnataka, India.* Clinical Epidemiology and Global Health, 2018. **6**(2): p. 69-74.
123. Posel, D. and J. Zeller, *Language shift or increased bilingualism in South Africa: Evidence from census data.* Journal of Multilingual and Multicultural Development, 2016. **37**(4): p. 357-370.
124. Daya, M., et al., *A panel of ancestry informative markers for the complex five-way admixed South African coloured population.* PloS one, 2013. **8**(12): p. e82224.
125. Wissing, D.P., *Afrikaans.* Journal of the International Phonetic Association, 2020. **50**(1): p. 127-140.
126. Lincoln, Y.S. and E.G. Guba, *Naturalistic inquiry*. 1985: sage.
127. Korstjens, I. and A. Moser, *Series: Practical guidance to qualitative research. Part 4: Trustworthiness and publishing.* European Journal of General Practice, 2018. **24**(1): p. 120-124.
128. Mabuza, L.H., et al., *African primary care research: Qualitative data analysis and writing results.* African journal of primary health care & family medicine, 2014. **6**(1): p. 1-5.
129. Quinn Patton, M., *Qualitative research and evaluation methods.* London: Sage, 2002.
130. Creswell, J.W. and D.L. Miller, *Determining validity in qualitative inquiry.* Theory into practice, 2000. **39**(3): p. 124-130.

131. Henry, P., *Rigor in qualitative research: Promoting quality in social science research.* Res J Recent Sci ISSN, 2015. **2277**: p. 2502.
132. Burnard, P., et al., *Analysing and presenting qualitative data.* British dental journal, 2008. **204**(8): p. 429-432.
133. Braun, V. and V. Clarke, *Thematic analysis*. 2012: American Psychological Association.
134. Gibbs, G.R., *Thematic coding and categorizing.* Analyzing qualitative data, 2007. **703**: p. 38-56.
135. Maguire, M. and B. Delahunt, *Doing a thematic analysis: A practical, step-by-step guide for learning and teaching scholars.* All Ireland Journal of Higher Education, 2017. **9**(3).
136. Beauchamp, T.L. and J.F. Childress, *Principles of biomedical ethics*. 2001: Oxford University Press, USA.
137. Association, W.M., *World Medical Association Declaration of Helsinki: ethical principles for medical research involving human subjects.* Jama, 2013. **310**(20): p. 2191-2194.
138. Africa, S.S. *George*. 2011 [cited 2023 6 December 2023]; Available from: https://www.statssa.gov.za/?page_id=993&id=george-municipality.
139. Africa, S.S. *Provincial Profile: Western Cape*. 2011 2011 [cited 2023 6 December 2023]; Available from: http://www.statssa.gov.za/publications/Report-03-01-70/Report-03-01-702011.pdf.
140. Cardoso, F., et al., *Early breast cancer: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up.* Annals of oncology, 2019. **30**(8): p. 1194-1220.
141. Łukasiewicz, S., et al., *Breast cancer—epidemiology, risk factors, classification, prognostic markers, and current treatment strategies—an updated review.* Cancers, 2021. **13**(17): p. 4287.
142. Trayes, K.P. and S.E. Cokenakes, *Breast cancer treatment.* American family physician, 2021. **104**(2): p. 171-178.
143. Wang, K., et al., *Prevalence of pain in patients with breast cancer post-treatment: A systematic review.* The Breast, 2018. **42**: p. 113-127.
144. DiSipio, T., et al., *Incidence of unilateral arm lymphoedema after breast cancer: a systematic review and meta-analysis.* The lancet oncology, 2013. **14**(6): p. 500-515.
145. Mustian, K.M., et al., *Comparison of Pharmaceutical, Psychological, and Exercise Treatments for Cancer-Related Fatigue: A Meta-analysis.* JAMA Oncology, 2017. **3**(7): p. 961-968.
146. Paolucci, T., et al., *The recovery of reaching movement in breast cancer survivors: two different rehabilitative protocols in comparison.* European journal of physical and rehabilitation medicine, 2021. **57**(1): p. 137-147.
147. Galantino, M.L. and N.L. Stout, *Exercise interventions for upper limb dysfunction due to breast cancer treatment.* Physical therapy, 2013. **93**(10): p. 1291-1297.
148. McNeely, M.L., et al., *Exercise interventions for upper-limb dysfunction due to breast cancer treatment.* Cochrane Database of Systematic Reviews, 2010(6).
149. Howell, D., et al., *Self-management education interventions for patients with cancer: a systematic review.* Support Care Cancer, 2017. **25**(4): p. 1323-1355.
150. Paskett, E.D., et al., *A randomized study to prevent lymphedema in women treated for breast cancer: CALGB 70305 (Alliance).* Cancer, 2021. **127**(2): p. 291-299.
151. Temur, K. and S. Kapucu, *The effectiveness of lymphedema self-management in the prevention of breast cancer-related lymphedema and quality of life: a randomized controlled trial.* European journal of oncology nursing, 2019. **40**: p. 22-35.
152. Mason, C., et al., *Long-term physical activity trends in breast cancer survivors.* Cancer epidemiology, biomarkers & prevention, 2013. **22**(6): p. 1153-1161.
153. Troeschel, A.N., et al., *Peer reviewed: physical activity in cancer survivors during "Re-entry" following cancer treatment.* Preventing chronic disease, 2018. **15**.
154. Prince, S.A., et al., *A comparison of direct versus self-report measures for assessing physical activity in adults: a systematic review.* International journal of behavioral nutrition and physical activity, 2008. **5**(1): p. 1-24.

155. Rossi, A., et al., *Effects of Theory-Based Behavioral Interventions on Physical Activity Among Overweight and Obese Female Cancer Survivors: A Systematic Review of Randomized Controlled Trials.* Integrative cancer therapies, 2018. **17**(2): p. 226-236.
156. Edge, J., et al., *The challenges of managing breast cancer in the developing world-a perspective from sub-Saharan Africa: CME-review.* South African Medical Journal, 2014. **104**(5): p. 377-379.
157. Stubblefield, M.D. and N. Keole, *Upper body pain and functional disorders in patients with breast cancer.* PM&R, 2014. **6**(2): p. 170-183.
158. De Groef, A., et al., *Pain characteristics as important contributing factors to upper limb dysfunctions in breast cancer survivors at long term.* Musculoskeletal Science and Practice, 2017. **29**: p. 52-59.
159. Nesvold, I.-L., et al., *The relation between arm/shoulder problems and quality of life in breast cancer survivors: a cross-sectional and longitudinal study.* Journal of Cancer Survivorship, 2011. **5**: p. 62-72.
160. Bao, T., et al., *Living with chronic pain: perceptions of breast cancer survivors.* Breast Cancer Research and Treatment, 2018. **169**(1): p. 133-140.
161. Bilodeau, K., D. Tremblay, and M.J. Durand, *Gaps and delays in survivorship care in the return-to-work pathway for survivors of breast cancer-a qualitative study.* Current oncology (Toronto), 2019. **26**(3): p. e414-e417.
162. Ibrahim, M., et al., *Time course of upper limb function and return-to-work post-radiotherapy in young adults with breast cancer: a pilot randomized control trial on effects of targeted exercise program.* JOURNAL OF CANCER SURVIVORSHIP, 2017. **11**(6): p. 791-799.
163. de Souza Cunha, N., et al., *Physical symptoms and components of labor tasks associated with upper limb disability among working breast cancer survivors.* Breast Cancer, 2020. **27**: p. 140-146.
164. Neto, C., P. Pezarat, and R. Oliveira, *Effects of breast cancer treatment on shoulder Function: What to expect and how to treat.* International Journal of Physical Therapy & Rehabilitation, 2018. **4**.
165. Amatya, B., F. Khan, and M.P. Galea, *Optimizing post-acute care in breast cancer survivors: a rehabilitation perspective.* Journal of multidisciplinary healthcare, 2017: p. 347-357.
166. Levkovich, I., M. Cohen, and K. Karkabi, *The experience of fatigue in breast cancer patients 1–12 month post-chemotherapy: A qualitative study.* Behavioral medicine, 2019. **45**(1): p. 7-18.
167. Ruiz-Casado, A., et al., *Cancer-related Fatigue in Breast Cancer Survivors: A Review.* Clinical Breast Cancer, 2021. **21**(1): p. 10-25.
168. Tsai, S.L., et al., *The fatigue experiences of older Taiwanese women with breast cancer.* Journal of clinical nursing, 2010. **19**(5-6): p. 867-875.
169. Schmidt, M.E., et al., *Return to work after breast cancer: The role of treatment-related side effects and potential impact on quality of life.* Eur J Cancer Care (Engl), 2019. **28**(4): p. e13051.
170. Minton, O. and P. Stone, *How common is fatigue in disease-free breast cancer survivors? A systematic review of the literature.* Breast cancer research and treatment, 2008. **112**: p. 5-13.
171. Kwok, A., C. Palermo, and A. Boltong, *Dietary experiences and support needs of women who gain weight following chemotherapy for breast cancer.* Supportive Care in Cancer, 2015. **23**: p. 1561-1568.
172. Weathers, B., et al., *Perceptions of changes in weight among African American breast cancer survivors.* Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer, 2006. **15**(2): p. 174-179.
173. Halbert, C.H., et al., *Experiences with weight change in African-American breast cancer survivors.* The Breast Journal, 2008. **14**(2): p. 182-187.
174. Binkley, J.M., et al., *Patient perspectives on breast cancer treatment side effects and the prospective surveillance model for physical rehabilitation for women with breast cancer.* Cancer, 2012. **118**(S8): p. 2207-2216.

175. Sheean, P.M., K. Hoskins, and M. Stolley, *Body composition changes in females treated for breast cancer: a review of the evidence.* Breast cancer research and treatment, 2012. **135**: p. 663-680.
176. Demark-Wahnefried, W., K.L. Campbell, and S.C. Hayes, *Weight management and its role in breast cancer rehabilitation.* Cancer, 2012. **118**(S8): p. 2277-2287.
177. Dean, L.T., et al., *Race or Resource? BMI, Race, and Other Social Factors as Risk Factors for Interlimb Differences among Overweight Breast Cancer Survivors with Lymphedema.* Journal of obesity, 2016. **2016**: p. 8241710.
178. Iwase, T., et al., *Body composition and breast cancer risk and treatment: mechanisms and impact.* Breast cancer research and treatment, 2021. **186**: p. 273-283.
179. Simonavice, E., et al., *Body composition, muscular strength, and physical function in breast cancer survivors.* International journal of body composition research, 2011. **9**(2).
180. Winters-Stone, K.M., M.E. Medysky, and M.A. Savin, *Patient-reported and objectively measured physical function in older breast cancer survivors and cancer-free controls.* Journal of geriatric oncology, 2019. **10**(2): p. 311-316.
181. Foulkes, S., et al., *Persistent impairment in cardiopulmonary fitness after breast cancer chemotherapy.* 2019.
182. Petrick, J.L., et al., *Functional status declines among cancer survivors: trajectory and contributing factors.* Journal of geriatric oncology, 2014. **5**(4): p. 359-367.
183. Crouch, A., V.L. Champion, and D. Von Ah, *Comorbidity, cognitive dysfunction, physical functioning, and quality of life in older breast cancer survivors.* Supportive Care in Cancer, 2022. **30**: p. 359-366.
184. Kabała, M. and J. Wilczyński, *Evaluation of equivalent reactions in women after mastectomy using biodex balance system.* Journal of Education, Health and Sport, 2017. **7**(12): p. 565-578.
185. Atanes Mendes Peres, A.C., et al., *Body posture after mastectomy: comparison between immediate breast reconstruction versus mastectomy alone.* Physiotherapy Research International, 2017. **22**(1): p. e1642.
186. Głowacka-Mrotek, I., et al., *Assessment of postural balance in women treated for breast cancer.* Medicina, 2020. **56**(10): p. 505.
187. Zabojszcz, M., et al., *Influence of Complex Physical Therapy on Physical Fitness and Balance in Women After Unilateral Mastectomy Due to Cancer Treatment.* Medical Rehabilitation, 2022. **26**(4): p. 28-35.
188. Fretta, T.B., et al., *Mat pilates method improve postural alignment women undergoing hormone therapy adjunct to breast cancer treatment. Clinical trial.* Complementary therapies in clinical practice, 2021. **44**: p. 101424.
189. Altas, E.U. and Ü.S. Demirdal, *The effects of post-mastectomy lymphedema on balance, Kinesiophobia and fear of falling.* Journal of community health nursing, 2021. **38**(2): p. 130-138.
190. Williams, F. and S.C. Jeanetta, *Lived experiences of breast cancer survivors after diagnosis, treatment and beyond: qualitative study.* Health expectations, 2016. **19**(3): p. 631-642.
191. Schmitz, K.H., et al., *Prospective evaluation of physical rehabilitation needs in breast cancer survivors: a call to action.* Cancer, 2012. **118**(S8): p. 2187-2190.
192. Kramer, N., J. Ramjith, and D. Shamley, *Prevalence of shoulder morbidity after treatment for breast Cancer in South Africa.* Support Care Cancer, 2019. **27**(7): p. 2591-2598.
193. Groen, W.G., W.H. van Harten, and J.K. Vallance, *Systematic review and meta-analysis of distance-based physical activity interventions for cancer survivors (2013–2018): We still haven't found what we're looking for.* Cancer Treatment Reviews, 2018. **69**: p. 188-203.
194. Olsson Möller, U., et al., *A comprehensive approach to rehabilitation interventions following breast cancer treatment-a systematic review of systematic reviews.* BMC cancer, 2019. **19**(1): p. 1-20.

195. Bloom, J.R., et al., *Addressing the needs of young breast cancer survivors at the 5 year milestone: can a short-term, low intensity intervention produce change?* Journal of cancer survivorship, 2008. **2**(3): p. 190-204.
196. Brick, R., et al., *Factors influencing utilization of cancer rehabilitation services among older breast cancer survivors in the USA: a qualitative study.* Supportive care in cancer, 2021. **30**(3): p. 2397-2405.
197. Royak-Schaler, R., et al., *Exploring patient-physician communication in breast cancer care for African American women following primary treatment.* Oncology Nursing Forum, 2008. **35**(5): p. 836-843.
198. Blom, K.Y., et al., *Early intervention with compression garments prevents progression in mild breast cancer-related arm lymphedema: a randomized controlled trial.* Acta Oncologica, 2022. **61**(7): p. 897-905.
199. Handberg, C. and T. Maribo, *Why cancer survivorship care needs assessment may lead to no clear patient pathway-Based on patients' experiences and perspectives.* European Journal of Oncology Nursing, 2020. **48**: p. 101824.
200. Boogaard, L., et al., *Efficacy of self-management programs in managing side effects of breast cancer: a systematic review and meta-analysis of randomized control trials.* Rehabilitation Oncology, 2016. **34**(1): p. 14-26.
201. Van Dijck, S., et al., *The effects of physical self-management on quality of life in breast cancer patients: A systematic review.* The Breast, 2016. **28**: p. 20-28.
202. Clifford, B.K., et al., *Barriers and facilitators of exercise experienced by cancer survivors: a mixed methods systematic review.* Supportive Care in Cancer, 2018. **26**(3): p. 685-700.
203. Rosenberg, J., P.N. Butow, and J.M. Shaw, *The untold story of late effects: a qualitative analysis of breast cancer survivors' emotional responses to late effects.* Supportive care in cancer, 2021. **30**(1): p. 177-185.
204. Denny, L., et al., *Interventions to close the divide for women with breast and cervical cancer between low-income and middle-income countries and high-income countries.* The Lancet, 2017. **389**(10071): p. 861-870.
205. Dietrich, L., et al., *Effectiveness of a survivorship program: An assessment of patients with breast cancer in a community setting.* Journal of oncology practice, 2016. **12**(6): p. e688-e696.
206. Halpern, M.T. and K.E. Argenbright, *Evaluation of effectiveness of survivorship programmes: how to measure success?* The Lancet Oncology, 2017. **18**(1): p. e51-e59.
207. Abdollahzadeh, F., et al., *Un-met supportive care needs of Iranian breast cancer patients.* Asian Pacific Journal of Cancer Prevention, 2014. **15**(9): p. 3933-3938.
208. Cuthbert, C.A., et al., *Self-management interventions for cancer survivors: A systematic review and evaluation of intervention content and theories.* Psychooncology, 2019. **28**(11): p. 2119-2140.
209. Moore, H.C. *Breast cancer survivorship*. in *Seminars in Oncology*. 2020. Elsevier.
210. Aunan, S.T., G.C. Wallgren, and B. Sætre Hansen, *Breast cancer survivors' experiences of dealing with information during and after adjuvant treatment: A qualitative study.* Journal of clinical nursing, 2019. **28**(15-16): p. 3012-3020.
211. Statista. *Digital population in South Africa as of January 2023*. 2023 2023 [cited 2023 18 December 2023]; Available from: https://www.statista.com/statistics/685134/south-africa-digital-population/.
212. Mbunge, E., et al., *Virtual healthcare services and digital health technologies deployed during coronavirus disease 2019 (COVID-19) pandemic in South Africa: a systematic review.* Global health journal, 2022. **6**(2): p. 102-113.
213. Spector, D., et al., *Do breast cancer survivors increase their physical activity and enhance their health-related quality of life after attending community-based wellness workshops?* Journal of Cancer Education, 2012. **27**: p. 353-361.

214. Ruiz-Vozmediano, J., et al., *Influence of a multidisciplinary program of diet, exercise, and mindfulness on the quality of life of stage IIA-IIB breast cancer survivors.* Integrative Cancer Therapies, 2020. **19**: p. 1534735420924757.
215. Gharzai, L.A., et al., *Financial Toxicity During Breast Cancer Treatment: A Qualitative Analysis to Inform Strategies for Mitigation.* JCO Oncology Practice, 2021. **17**(10): p. e1413-e1423.
216. Aristokleous, I., et al., *The Role of Social Media in Breast Cancer Care and Survivorship: A Narrative Review.* Breast Care, 2023. **18**(3): p. 193-199.
217. Hu, J., et al., *Peer support interventions for breast cancer patients: a systematic review.* Breast Cancer Research and Treatment, 2019. **174**: p. 325-341.
218. Ammitzbøll, G., et al., *Physical activity and survival in breast cancer.* European journal of cancer, 2016. **66**: p. 67-74.
219. Hirschey, R., et al., *Exploration of Exercise Outcome Expectations Among Breast Cancer Survivors.* Cancer nursing, 2017. **40**(2): p. E39-E46.
220. Hirschey, R., et al., *What do breast cancer survivors expect from exercise?* Cancer nursing, 2019. **42**(1): p. E15.
221. Tarasenko, Y., C. Chen, and N. Schoenberg, *Self-reported physical activity levels of older cancer survivors: results from the 2014 National Health Interview Survey.* Journal of the American Geriatrics Society, 2017. **65**(2): p. e39-e44.
222. Avancini, A., et al., *Exercise levels and preferences in cancer patients: a cross-sectional study.* International journal of environmental research and public health, 2020. **17**(15): p. 5351.
223. Elshahat, S., C. Treanor, and M. Donnelly, *Factors influencing physical activity participation among people living with or beyond cancer: a systematic scoping review.* International Journal of Behavioral Nutrition and Physical Activity, 2021. **18**: p. 1-20.
224. Sturgeon, K.M., et al., *Patient preference and timing for exercise in breast cancer care.* Support Care Cancer, 2018. **26**(2): p. 507-514.
225. Sweegers, M.G., et al., *Which exercise prescriptions improve quality of life and physical function in patients with cancer during and following treatment? A systematic review and meta-analysis of randomised controlled trials.* British journal of sports medicine, 2018. **52**(8): p. 505-513.
226. Paxton, R.J., et al., *African-American breast cancer survivors' preferences for various types of physical activity interventions: A Sisters Network Inc. web-based survey.* Journal of Cancer Survivorship, 2014. **8**(1): p. 31-38.
227. Behzadnia, B., A. Kiani, and S. Babaei, *Autonomy-supportive exercise behaviors promote breast cancer survivors' well-being.* Health promotion perspectives, 2020. **10**(4): p. 409.
228. Hefferon, K., et al., *Understanding barriers to exercise implementation 5-year post-breast cancer diagnosis: a large-scale qualitative study.* Health education research, 2013. **28**(5): p. 843-856.
229. Schmidt, M.E., et al., *Self-reported physical activity behavior of breast cancer survivors during and after adjuvant therapy: 12 months follow-up of two randomized exercise intervention trials.* Acta oncologica (Stockholm, Sweden), 2017. **56**(4): p. 618-627.
230. Boland, L., K. Bennett, and D. Connolly, *Self-management interventions for cancer survivors: a systematic review.* Support Care Cancer, 2018. **26**(5): p. 1585-1595.
231. Murdoch, J., et al., *Implementing supportive exercise interventions in the colorectal cancer care pathway: a process evaluation of the PREPARE-ABC randomised controlled trial.* BMC Cancer, 2021. **21**(1): p. 1137.
232. Kim, S.H., K. Kim, and D.K. Mayer. *Self-Management Intervention for Adult Cancer Survivors After Treatment: A Systematic Review and Meta-Analysis*. in *Oncology nursing forum*. 2017.
233. McCorkle, R., et al., *Self-management: Enabling and empowering patients living with cancer as a chronic illness.* CA: a cancer journal for clinicians, 2011. **61**(1): p. 50-62.
234. Rimmer, B., et al., *Characteristics and Components of Self-Management Interventions for Improving Quality of Life in Cancer Survivors: A Systematic Review.* Cancers, 2023. **16**(1): p. 14.

235. Dorri, S., et al., *A Systematic Review of Electronic Health (eHealth) interventions to improve physical activity in patients with breast cancer.* Breast Cancer, 2020. **27**(1): p. 25-46.
236. Xu, A., Y. Wang, and X. Wu, *Effectiveness of e-health based self-management to improve cancer-related fatigue, self-efficacy and quality of life in cancer patients: Systematic review and meta-analysis.* Journal of Advanced Nursing, 2019. **75**(12): p. 3434-3447.
237. Martín-Núñez, J., et al., *Systematic review of self-management programs for prostate cancer patients, a Quality of life and self-efficacy meta-analysis.* Patient Education and Counseling, 2022: p. 107583.
238. Dittus, K.L., R.E. Gramling, and P.A. Ades, *Exercise interventions for individuals with advanced cancer: a systematic review.* Preventive medicine, 2017. **104**: p. 124-132.
239. Jiang, M., et al., *Exercise for fatigue in breast cancer patients: An umbrella review of systematic reviews.* International Journal of Nursing Sciences, 2020. **7**(2): p. 248-254.
240. Lahart, I.M., et al., *Physical activity for women with breast cancer after adjuvant therapy.* Cochrane Database of Systematic Reviews, 2018(1).
241. Page MJ, M.J., Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al., *The PRISMA 2020 statement: an updated guideline for reporting systematic reviews.* BMJ, 2021. **372**(n71).
242. Organization, W.H. *Global Recommendations on Physical Activity for Health*. 2010 [cited 2023 23 October 2023]; Available from: https://www.who.int/publications/i/item/9789241599979.
243. Dong, B., et al., *Yoga has a solid effect on cancer-related fatigue in patients with breast cancer: a meta-analysis.* Breast Cancer Research and Treatment, 2019. **177**(1): p. 5-16.
244. Odynets, T., et al., *Effectiveness of individualized physical rehabilitation programs on post-mastectomy pain in breast cancer survivors.* Physiotherapy quarterly, 2018. **26**(3): p. 1-5.
245. Collaboration, T.C., *Cochrane Handbook for Systematic Reviews of Interventions Version 5.1.0*, G.S. Higgins JPT, Editor. 2011.
246. Sterne JAC, S.J., Page MJ, Elbers RG, Blencowe NS, Boutron I, Cates CJ, Cheng H-Y, Corbett MS, Eldridge SM, Hernán MA, Hopewell S, Hróbjartsson A, Junqueira DR, Jüni P, Kirkham JJ, Lasserson T, Li T, McAleenan A, Reeves BC, Shepperd S, Shrier I, Stewart LA, Tilling K, White IR, Whiting PF, Higgins JPT. , *RoB 2: a revised tool for assessing risk of bias in randomised trials.* . BMJ, 2019. **366**(14898).
247. Higgins, J., et al., *Cochrane Handbook for Systematic Reviews of Interventions: Cochrane;, 2022.* Available from: www. train ing. cochr ane. org/handb ook, 2022.
248. Schünemann, H.J., et al., *GRADE Guidelines: 16. GRADE evidence to decision frameworks for tests in clinical practice and public health.* Journal of clinical epidemiology, 2016. **76**: p. 89-98.
249. Team, R.C., *R: A language and environment for statistical computing.* 2022, R Foundation for Statistical Computing: Vienna, Austria.
250. Guolo, A. and C. Varin, *Random-effects meta-analysis: the number of studies matters.* Statistical methods in medical research, 2017. **26**(3): p. 1500-1518.
251. Borenstein, M., et al., *A basic introduction to fixed-effect and random-effects models for meta-analysis.* Research synthesis methods, 2010. **1**(2): p. 97-111.
252. Yang, F.L., L. Hsiao-Hsuan, and L. Man-Ting, *Effects of nutrition intervention on nutritional status, physical activity and life quality of breast cancer survivors.* FASEB journal, 2017. **Conference: Experimental Biology 2017, EB. United States. 31**(1 Supplement 1).
253. Pollard, A., et al., *The role of psychosocial interventions in modifying health behaviours: findings from a randomised controlled pilot to test the effects of a behavioural intervention (Theory-Based Information and Advice) on uptake of physical activity in breast cancer survivors.* Psycho-oncology, 2011. **20**: p. 88.
254. Segal, R., et al., *Randomized trial of a lifestyle intervention for women with early-stage breast cancer (BC) receiving adjuvant hormone therapy: initial results.* Journal of clinical oncology, 2011. **29**(15 SUPPL. 1).

255. Yuen, H.K. and D. Sword, *Home-based exercise to alleviate fatigue and improve functional capacity among breast cancer survivors.* Journal of allied health, 2007. **36**(4): p. e257-75.
256. Fu, M.R., et al., *A Web-and mobile-based intervention for women treated for breast cancer to manage chronic pain and symptoms related to lymphedema: Randomized clinical trial rationale and protocol.* JMIR Research Protocols, 2016. **5**(1).
257. Wang, Y.J., et al., *Effects of a 6-week walking program on Taiwanese women newly diagnosed with early-stage breast cancer.* Cancer Nurs, 2011. **34**(2): p. E1-13.
258. Basen-Engquist, K.M., et al., *Feasibility and efficacy of a weight gain prevention intervention for breast cancer patients receiving neoadjuvant chemotherapy: a randomized controlled pilot study.* Support Care Cancer, 2020. **28**(12): p. 5821-5832.
259. Allicock, M., et al., *A Pilot and Feasibility Mobile Health Intervention to Support Healthy Behaviors in African American Breast Cancer Survivors.* J Racial Ethn Health Disparities, 2021. **8**(1): p. 157-165.
260. Hatchett, A., J.S. Hallam, and M.A. Ford, *Evaluation of a social cognitive theory-based email intervention designed to influence the physical activity of survivors of breast cancer.* Psycho-Oncology, 2013. **22**(4): p. 829-836.
261. Chapman, J., et al., *Pilot randomized trial of a volitional help sheet-based tool to increase leisure time physical activity in breast cancer survivors.* Br J Health Psychol, 2018. **23**(3): p. 723-740.
262. Holtdirk, F., et al., *Results of the Optimune trial: A randomized controlled trial evaluating a novel Internet intervention for breast cancer survivors.* PLOS ONE, 2021. **16**(5).
263. Short, C.E., et al., *Main outcomes of the Move More for Life Trial: a randomised controlled trial examining the effects of tailored-print and targeted-print materials for promoting physical activity among post-treatment breast cancer survivors.* Psychooncology, 2015. **24**(7): p. 771-8.
264. Butler, L.D., et al., *Effects of supportive-expressive group therapy on pain in women with metastatic breast cancer.* Health psychology, 2009. **28**(5): p. 579-587.
265. Cunningham, A.J., *A new approach to testing the effects of group psychological therapy on length of life in patients with metastatic cancers.* Advances in Mind-Body Medicine, 2002. **18**(2): p. 5-9.
266. Uhm, K.E., et al., *Effects of exercise intervention in breast cancer patients: is mobile health (mHealth) with pedometer more effective than conventional program using brochure?* Breast Cancer Res Treat, 2017. **161**(3): p. 443-452.
267. Henry, N.L., et al., *Pilot study of an internet-based self- management program for symptom control in patients with early-stage breast cancer.* JCO Clinical Cancer Informatics, 2018. **2018**(2): p. 1-12.
268. Meneses, K., et al., *Preliminary evaluation of psychoeducational support interventions on quality of life in rural breast cancer survivors post-primary treatment.* Cancer Nursing, 2009. **32**(5): p. 385.
269. Hirschey, R., et al., *A randomized phase II trial of MOVING ON: an intervention to increase exercise outcome expectations among breast cancer survivors.* Psycho-oncology, 2018. **27**(10): p. 2450-2457.
270. Vallance, J.K., et al., *Randomized controlled trial of the effects of print materials and step pedometers on physical activity and quality of life in breast cancer survivors.* Journal of clinical oncology, 2007. **25**(17): p. 2352-2359.
271. Stolley, M., et al., *Efficacy of a Weight Loss Intervention for African American Breast Cancer Survivors.* JOURNAL OF CLINICAL ONCOLOGY, 2017. **35**(24): p. 2820-+.
272. Bower, J.E., et al., *Mindfulness meditation for younger breast cancer survivors: a randomized controlled trial.* Cancer, 2015. **121**(8): p. 1231-1240.

273. Phillips, S.M., et al., *Optimization of a technology-supported physical activity promotion intervention for breast cancer survivors: results from Fit2Thrive.* Cancer, 2022. **128**(5): p. 1122-1132.
274. Jeffs, E. and T. Wiseman, *Randomised controlled trial to determine the benefit of daily home-based exercise in addition to self-care in the management of breast cancer-related lymphoedema: a feasibility study.* Support Care Cancer, 2013. **21**(4): p. 1013-23.
275. Fillion, L., et al., *A brief intervention for fatigue management in breast cancer survivors.* Cancer nursing, 2008. **31**(2): p. 145-159.
276. Hartman, S.J., et al., *Randomized controlled trial of increasing physical activity on objectively measured and self-reported cognitive functioning among breast cancer survivors: The memory & motion study.* Cancer, 2018. **124**(1): p. 192-202.
277. Cadmus, L.A., et al., *Exercise and quality of life during and after treatment for breast cancer: results of two randomized controlled trials.* Psychooncology, 2009. **18**(4): p. 343-52.
278. Heim, M.E., M.L. v d Malsburg, and A. Niklas, *Randomized controlled trial of a structured training program in breast cancer patients with tumor-related chronic fatigue.* Onkologie, 2007. **30**(8-9): p. 429-434.
279. Owen, J.E., et al., *Randomized pilot of a self-guided internet coping group for women with early-stage breast cancer.* Annals of Behavioral Medicine, 2005. **30**(1): p. 54-64.
280. Short, C., et al., *How do different delivery schedules of tailored web-based physical activity advice for breast cancer survivors influence intervention use and efficacy?* Journal of Cancer Survivorship, 2017. **11**(1): p. 80-91.
281. Sheng, J.Y., et al., *The impact of weight loss on physical function and symptoms in overweight or obese breast cancer survivors: results from POWER-remote.* Journal of cancer survivorship, 2022. **16**(3): p. 542-551.
282. Pope, Z.C., et al., *Effectiveness of combined smartwatch and social media intervention on breast cancer survivor health outcomes: a 10-week pilot randomized trial.* Journal of clinical medicine, 2018. **7**(6).
283. Park, J.H., et al., *Quality of life and symptom experience in breast cancer survivors after participating in a psychoeducational support program: a pilot study.* Cancer Nurs, 2012. **35**(1): p. E34-41.
284. Kim, S.H., et al. *Randomized pilot test of a simultaneous stage-matched exercise and diet intervention for breast cancer survivors*. in *Oncology nursing forum*. 2011. Oncology Nursing Society.
285. Lahart, I.M., et al., *Randomised controlled trial of a home-based physical activity intervention in breast cancer survivors.* BMC cancer, 2016. **16**(1): p. 1-14.
286. Sturgeon, K.M., et al., *Commercially available lifestyle modification program: randomized controlled trial addressing heart and bone health in BRCA1/2+ breast cancer survivors after risk-reducing salpingo-oophorectomy.* Journal of Cancer Survivorship, 2017. **11**(2): p. 246-255.
287. Befort, C.A., et al., *Weight Loss Maintenance Strategies Among Rural Breast Cancer Survivors: The Rural Women Connecting for Better Health Trial.* OBESITY, 2016. **24**(10): p. 2070-2077.
288. Harrigan, M., et al., *Randomized trial comparing telephone versus in-person weight loss counseling on body composition and circulating biomarkers in women treated for breast cancer: the lifestyle, exercise, and nutrition (LEAN) study.* Journal of Clinical Oncology, 2016. **34**(7): p. 669.
289. Ergun, M., et al., *Effects of exercise on angiogenesis and apoptosis-related molecules, quality of life, fatigue and depression in breast cancer patients.* Eur J Cancer Care (Engl), 2013. **22**(5): p. 626-37.
290. Lee, M.K., et al., *A Web-based self-management exercise and diet intervention for breast cancer survivors: Pilot randomized controlled trial.* INTERNATIONAL JOURNAL OF NURSING STUDIES, 2014. **51**(12): p. 1557-1567.

291. Pinto, B.M., et al., *Home-based physical activity intervention for breast cancer patients.* Journal of clinical oncology, 2005. **23**(15): p. 3577-3587.
292. Wang, L.F., et al., *Effects of a personal trainer-led exercise intervention on physical activity, physical function, and quality of life of breast cancer survivors.* Breast Cancer, 2021. **28**(3): p. 737-745.
293. Aaronson, N.K., et al., *The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology.* JNCI: Journal of the National Cancer Institute, 1993. **85**(5): p. 365-376.
294. Brady, M.J., et al., *Reliability and validity of the Functional Assessment of Cancer Therapy-Breast quality-of-life instrument.* Journal of clinical oncology, 1997. **15**(3): p. 974-986.
295. Hays, R.D., et al., *Development of physical and mental health summary scores from the patient-reported outcomes measurement information system (PROMIS) global items.* Quality of life Research, 2009. **18**(7): p. 873-880.
296. Fallowfield, L.J., et al., *Assessment of quality of life in women undergoing hormonal therapy for breast cancer: validation of an endocrine symptom subscale for the FACT-B.* Breast cancer research and treatment, 1999. **55**(2): p. 187-197.
297. Craig, C.L., et al., *International physical activity questionnaire: 12-country reliability and validity.* Medicine and science in sports and exercise, 2003. **35**(8): p. 1381-1395.
298. Jones, L.W. and W. Demark-Wahnefried, *Diet, exercise, and complementary therapies after primary treatment for cancer.* The lancet oncology, 2006. **7**(12): p. 1017-1026.
299. Brown, J.K., et al., *Nutrition and physical activity during and after cancer treatment: an American Cancer Society guide for informed choices.* CA: a cancer journal for clinicians, 2003. **53**(5): p. 268-291.
300. Warburton, D.E., C.W. Nicol, and S.S. Bredin, *Prescribing exercise as preventive therapy.* Cmaj, 2006. **174**(7): p. 961-974.
301. BLAIR, S.N., et al., *Assessment of habitual physical activity by a seven-day recall in a community survey and controlled experiments.* American journal of epidemiology, 1985. **122**(5): p. 794-804.
302. Kriska, A.M., et al., *Development of questionnaire to examine relationship of physical activity and diabetes in Pima Indians.* Diabetes care, 1990. **13**(4): p. 401-411.
303. Kohl, H.W., et al., *A mail survey of physical activity habits as related to measured physical fitness.* American journal of epidemiology, 1988. **127**(6): p. 1228-1239.
304. Terranova, C.O., et al., *Dietary and Physical Activity Changes and Adherence to WCRF/AICR Cancer Prevention Recommendations Following a Remotely Delivered Weight Loss Intervention for Female Breast Cancer Survivors: The Living Well after Breast Cancer Randomized Controlled Trial.* Journal of the Academy of Nutrition and Dietetics, 2022. **122**(9): p. 1644-1664. e7.
305. Boyd, N., et al., *Measurement of the clinical status of patients with breast cancer: evidence for the validity of self assessment with linear analogue scales.* Journal of Clinical Epidemiology, 1988. **41**(3): p. 243-250.
306. Mendoza, T.R., et al., *The rapid assessment of fatigue severity in cancer patients: use of the Brief Fatigue Inventory.* Cancer, 1999. **85**(5): p. 1186-1196.
307. Butt, Z., et al., *Measurement of fatigue in cancer, stroke, and HIV using the functional assessment of chronic illness therapy—fatigue (FACIT-F) scale.* Journal of psychosomatic research, 2013. **74**(1): p. 64-68.
308. Kline, C., et al., *Estimation of from a one-mile track walk, gender, age and body weight.* Med. Sports Exerc, 1987. **19**: p. 253-259.
309. Rikli, R.E. and C.J. Jones, *Development and validation of a functional fitness test for community-residing older adults.* Journal of aging and physical activity, 1999. **7**(2): p. 129-161.
310. Foster, C., et al., *Generalized equations for predicting functional capacity from treadmill performance.* American heart journal, 1984. **107**(6): p. 1229-1234.

311. Marcus, B.H. and B.A. Lewis, *Physical Activity and the Stages of Motivational Readiness for Change Model.* President's Council on Physical Fitness and Sports Research Digest, 2003.
312. Marcus, B.H., et al., *Self-efficacy and the stages of exercise behavior change.* Research quarterly for exercise and sport, 1992. **63**(1): p. 60-66.
313. Maybon, L., et al. *Identification of tools to measure changes in musculoskeletal symptoms and physical functioning in women with breast cancer receiving aromatase inhibitors*. in *Oncology nursing forum*. 2013. Oncology Nursing Society.
314. Friedberg, J.P., S.R. Lipsitz, and S. Natarajan, *Challenges and recommendations for blinding in behavioral interventions illustrated using a case study of a behavioral intervention to lower blood pressure.* Patient education and counseling, 2010. **78**(1): p. 5-11.
315. Lahart, I.M., et al., *The effects of a home-based physical activity intervention on cardiorespiratory fitness in breast cancer survivors; a randomised controlled trial.* J Sports Sci, 2018. **36**(10): p. 1077-1086.
316. Lee, M.K., et al., *A Web-based self-management exercise and diet intervention for breast cancer survivors: pilot randomized controlled trial.* International journal of nursing studies, 2014. **51**(12): p. 1557-1567.
317. Dettori, J.R., D.C. Norvell, and J.R. Chapman, *Seeing the Forest by Looking at the Trees: How to Interpret a Meta-Analysis Forest Plot.* Global Spine J, 2021. **11**(4): p. 614-616.
318. Lorig, K.R., et al., *Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: a randomized trial.* Medical care, 1999: p. 5-14.
319. Bruinsma, T.J., et al., *Effects of diet and exercise-induced weight loss on biomarkers of inflammation in breast cancer survivors: A systematic review and meta-analysis.* Cancer Epidemiology Biomarkers and Prevention, 2021. **30**(6): p. 1048-1062.
320. Salam, A., et al., *Effect of post-diagnosis exercise on depression symptoms, physical functioning and mortality in breast cancer survivors: A systematic review and meta-analysis of randomized control trials.* Cancer Epidemiology, 2022. **77**.
321. Spei, M.-E., et al., *Physical activity in breast cancer survivors: A systematic review and meta-analysis on overall and breast cancer survival.* Breast (Edinburgh), 2019. **44**: p. 144-152.
322. Anbari, A.B., A. Wanchai, and J.M. Armer, *Breast cancer-related lymphedema and quality of life: A qualitative analysis over years of survivorship.* Chronic illness, 2021. **17**(3): p. 257-268.
323. Arndt, V., et al., *Quality of life in long-term and very long-term cancer survivors versus population controls in Germany.* Acta Oncologica, 2017. **56**(2): p. 190-197.
324. Roine, E., et al., *Long-term health-related quality of life of breast cancer survivors remains impaired compared to the age-matched general population especially in young women. Results from the prospective controlled BREX exercise study.* Breast, 2021. **59**: p. 110-116.
325. Ammitzbøll, G., et al., *Effect of progressive resistance training on health-related quality of life in the first year after breast cancer surgery - results from a randomized controlled trial.* Acta Oncol, 2019. **58**(5): p. 665-672.
326. Di Meglio, A., et al., *A phase III randomized trial of weight loss to reduce cancer-related fatigue among overweight and obese breast cancer patients: MEDEA Study design.* Trials, 2022. **23**(1): p. 193.
327. Emili, R., et al., *Health-related quality of life, heart rate variability and physical fitness in breast cancer patients during the COVID-19 lockdown: the impact of a lifestyle program ('MoviS Project, movement and health beyond the care' (CESU approval n. 21/10.07.2019).* Tumori, 2020. **106**(2 SUPPL): p. 212-213.
328. Hagstrom, A.D., et al., *Resistance training improves fatigue and quality of life in previously sedentary breast cancer survivors: a randomised controlled trial.* European journal of cancer care, 2016. **25**(5): p. 784-794.
329. Schmidt, M., et al., *Longterm quality of life, problems and needs of breast cancer survivors.* Oncology research and treatment, 2018. **41**: p. 142-.

330. Madigan, C.D., et al., *Effectiveness of weight management interventions for adults delivered in primary care: systematic review and meta-analysis of randomised controlled trials.* Bmj, 2022. **377**: p. e069719.
331. Ross, R., et al., *Waist circumference as a vital sign in clinical practice: a Consensus Statement from the IAS and ICCR Working Group on Visceral Obesity.* Nat Rev Endocrinol, 2020. **16**(3): p. 177-189.
332. Sweeney, F.C., et al., *Aerobic and Resistance Exercise Improves Shoulder Function in Women Who Are Overweight or Obese and Have Breast Cancer: A Randomized Controlled Trial.* Phys Ther, 2019. **99**(10): p. 1334-1345.
333. Dieli-Conwright, C.M., et al., *Aerobic and resistance exercise improves physical fitness, bone health, and quality of life in overweight and obese breast cancer survivors: a randomized controlled trial.* Breast Cancer Research, 2018. **20**(1): p. 124.
334. Schutz, S., et al., *Different Methods of Physical Training Applied to Women Breast Cancer Survivors: A Systematic Review.* Front Physiol, 2021. **12**: p. 639406.
335. Shaikh, H., et al., *Body weight management in overweight and obese breast cancer survivors.* Cochrane Database Syst Rev, 2020. **12**(12): p. Cd012110.
336. Agbejule, O.A., et al., *Self-management support for cancer-related fatigue: A systematic review.* International Journal of Nursing Studies, 2022. **129**: p. 104206.
337. Strifler, L., et al., *Identifying and selecting implementation theories, models and frameworks: a qualitative study to inform the development of a decision support tool.* BMC Med Inform Decis Mak, 2020. **20**(1): p. 91.
338. Yang, G.S., et al., *Interventions for the Treatment of Aromatase Inhibitor–Associated Arthralgia in Breast Cancer Survivors: A Systematic Review and Meta-analysis.* Cancer Nursing, 2017. **40**(4).
339. Kim, S.H., et al., *Effects of a partnership-based, needs-tailored self-management support intervention for post-treatment breast cancer survivors: A randomized controlled trial.* Psycho-Oncology, 2022. **31**(3): p. 460-469.
340. Puklin, L.S., et al. *Randomized Trial Evaluating a Self-Guided Lifestyle Intervention Delivered via Evidence-Based Materials versus a Waitlist Group on Changes in Body Weight, Diet Quality, Physical Activity, and Quality of Life among Breast Cancer Survivors*. Cancers, 2023. **15**, DOI: 10.3390/cancers15194719.
341. Cheng, L. and G. Kotronoulas, *How effective are self-management interventions in promoting health-related quality of life in people after primary treatment for breast cancer? A critical evidence synthesis.* European Journal of Oncology Nursing, 2020. **47**: p. 101776.
342. Motsoeneng, P.M., et al., *Breast Cancer Rehabilitation Services in South Africa and Survivor Experience of These Services in Two Dedicated Cancer Units.* 2022.
343. Pinto, M., et al., *Breast Cancer Survivorship: the Role of Rehabilitation According to the International Classification of Functioning Disability and Health-a Scoping Review.* Curr Oncol Rep, 2022. **24**(9): p. 1163-1175.
344. Araújo-Soares, V., et al., *Developing behavior change interventions for self-management in chronic illness.* European Psychologist, 2018.
345. Skivington, K., et al., *A new framework for developing and evaluating complex interventions: update of Medical Research Council guidance.* bmj, 2021. **374**.
346. Campbell, M., et al., *Framework for design and evaluation of complex interventions to improve health.* Bmj, 2000. **321**(7262): p. 694-696.
347. Shabangu, N., et al., *Chronic pain in female breast cancer survivors - prevalence, characteristics and contributing factors: a cross-sectional pilot study.* BMC Women's Health, 2023. **23**(1): p. 613.
348. Hendricks, C., *Osteoarthritis in women living in Cape Town: prevalence, characteristics, and the effects of a non-pharmacological intervention*. 2022, Faculty of Health Sciences.

349. Parker, R., J. Jelsma, and D.J. Stein, *Managing Pain in Women Living With HIV/AIDS: A Randomized Controlled Trial Testing the Effect of a Six-Week Peer-Led Exercise and Education Intervention.* The Journal of Nervous and Mental Disease, 2016. **204**(9).
350. Rock, C.L., et al., *American Cancer Society nutrition and physical activity guideline for cancer survivors.* CA: A Cancer Journal for Clinicians, 2022. **72**(3): p. 230-262.
351. Cabanes, A., et al., *Supportive care interventions for cancer patients in low- and middle-income countries (LMICs): a scoping review.* Supportive Care in Cancer, 2022. **30**(11): p. 9483-9496.
352. Stubblefield, M.D., *The Underutilization of Rehabilitation to Treat Physical Impairments in Breast Cancer Survivors.* Pm r, 2017. **9**(9s2): p. S317-s323.
353. Kantelhardt, E.J., et al., *A review on breast cancer care in Africa.* Breast Care, 2015. **10**(6): p. 364-370.
354. Society, A.C. *Exercises After Breast Cancer Surgery*. 2024 2024 [cited 2024 14.02.2024]; Available from: https://www.cancer.org/cancer/types/breast-cancer/treatment/surgery-for-breast-cancer/exercises-after-breast-cancer-surgery.html.
355. Kruger-Jakins, T., et al., *The development of an intervention to manage pain in people with late-stage osteoarthritis.* The South African journal of physiotherapy, 2016. **72**(1): p. 311-311.
356. Khajoei, R., et al., *Breast cancer survivors-supportive care needs: systematic review.* BMJ Support Palliat Care, 2023. **13**(2): p. 143-153.
357. Dickens, C., et al., *Stage at breast cancer diagnosis and distance from diagnostic hospital in a periurban setting: a South African public hospital case series of over 1,000 women.* International journal of cancer, 2014. **135**(9): p. 2173-2182.
358. Parker, R., *Pain in HIV/AIDS : characteristics, contributing factors and the effects of a six-week peer-led exercise and education intervention.*, in *Department of Psychiatry and Mental Health*. 2013, University of Cape Town: Cape Town, South Africa.
359. Barnes, R.Y., *An investigation into the nature and prevalence of musculoskeletal conditions among women attending a community clinic, and the effectiveness of an intervention programme for these patients*. 2016, University of Cape Town.
360. Leclerc, A.F., et al., *Multidisciplinary rehabilitation program after breast cancer: benefits on physical function, anthropometry and quality of life.* European journal of physical and rehabilitation medicine, 2017. **53**(5): p. 633-642.
361. Petito, E.L., et al., *Application of a domicile-based exercise program for shoulder rehabilitation after breast cancer surgery.* Revista latino-americana de enfermagem, 2012. **20**: p. 35-43.
362. Roach, K.E., et al., *Development of a shoulder pain and disability index.* Arthritis & Rheumatism: Official Journal of the American College of Rheumatology, 1991. **4**(4): p. 143-149.
363. Giacalone, A., P. Alessandria, and E. Ruberti, *The physiotherapy intervention for shoulder pain in patients treated for breast cancer: Systematic review.* Cureus, 2019. **11**(12).
364. Gillespie, T.C., et al., *Breast cancer-related lymphedema: risk factors, precautionary measures, and treatments.* Gland surgery, 2018. **7**(4): p. 379-403.
365. Rock, C.L., et al., *American Cancer Society guideline for diet and physical activity for cancer prevention.* CA: a cancer journal for clinicians, 2020. **70**(4): p. 245-271.
366. Jacobs, I., et al., *Degree of food processing and breast cancer risk in black urban women from Soweto, South African: the South African Breast Cancer study.* British Journal of Nutrition, 2022. **128**(11): p. 2278-2289.
367. Miller, M., W. Oldewage-Theron, and C. Napier, *Eat clean and safe food: a food-based dietary guideline for the elderly in South Africa.* South African Journal of Clinical Nutrition, 2021. **34**(1): p. 41-50.
368. Seethaler, B., et al., *Potential impact of a mediterranean diet-based nutrition education within a lifestyle intervention study (LIBRE 1) on fatty acid profiles in erythrocytes.* Aktuelle Ernahrungsmedizin, 2017. **42**(3).

369. (CANSA), C.A.o.S.A. *Fact Sheet on Nutrition for Individuals Diagnosed with Breast Cancer*. 2021 April 2021 [cited 2023 16.06.2023]; Available from: https://cansa.org.za/files/2021/04/Fact-Sheet-on-Nutrition-for-Individuals-Diagnosed-with-Breast-Cancer-April-2021.pdf.
370. Andersen, B.L., et al., *Management of Anxiety and Depression in Adult Survivors of Cancer: ASCO Guideline Update.* Journal of Clinical Oncology, 2023. **41**(18): p. 3426-3453.
371. Sinha, M.K., et al., *Progressive Muscle Relaxation and Guided Imagery in Breast Cancer: A Systematic Review and Meta-analysis of Randomised Controlled Trials.* Indian J Palliat Care, 2021. **27**(2): p. 336-344.
372. Breastcancer.org. *Breast Self-exam*. 2022 04.10.2022 [cited 2023 14.06.2023]; Available from: https://www.breastcancer.org/screening-testing/breast-self-exam-bse.
373. UK, C.R. *Skin Cancer Symptoms*. 2022 16.12.2022 [cited 2023 14.06.2023]; Available from: https://www.cancerresearchuk.org/about-cancer/skin-cancer/symptoms.
374. CANSA. *Be SunSmart Everywhere*. 2012 02.12.2022 [cited 2023 14.06.2023]; Available from: https://cansa.org.za/be-sunsmart/.
375. Prevention, C.f.D.C.a. *Blood Clots (Deep Vein Thrombosis)*. 2023 15.05.2023 [cited 2023 14.06.2023]; Available from: https://www.cdc.gov/cancer/survivors/patients/blood-clots.htm#.
376. CANSA. *Questions to ask Healthcare Providers*. 2008 11.03.2021 [cited 2023 14.06.2023]; Available from: https://cansa.org.za/questions-to-ask-healthcare-providers/.
377. Bodenheimer, T., et al., *Patient self-management of chronic disease in primary care.* Jama, 2002. **288**(19): p. 2469-75.
378. Mazzoni, A.S., et al., *Effect of self-regulatory behaviour change techniques and predictors of physical activity maintenance in cancer survivors: a 12-month follow-up of the Phys-Can RCT.* BMC cancer, 2021. **21**(1): p. 1272.
379. Williams, S.L. and D.P. French, *What are the most effective intervention techniques for changing physical activity self-efficacy and physical activity behaviour—and are they the same?* Health education research, 2011. **26**(2): p. 308-322.
380. Forum, W.E. *This is the most popular messaging app in Africa*. 2018 16 February 2018 [cited 2024 18 April 2024]; Available from: https://www.weforum.org/agenda/2018/02/why-whatsapp-is-the-most-popular-messaging-app-in-africa/.
381. Stacey, F.G., et al., *A systematic review and meta-analysis of social cognitive theory-based physical activity and/or nutrition behavior change interventions for cancer survivors.* Journal of cancer survivorship, 2014. **9**(2): p. 305-338.
382. Mama, S.K., et al., *Mediated effects of social cognitive theory variables on physical activity in Hispanic breast cancer survivors.* Cancer epidemiology biomarkers and prevention, 2015. **24**(10).
383. Auster-Gussman, L.A., et al., *Social cognitive variables and physical activity during chemotherapy for breast cancer: An intensive longitudinal examination.* Psycho-oncology (Chichester, England), 2022. **31**(3): p. 425-435.
384. Phillips, S.M. and E. McAuley, *Physical activity and quality of life in breast cancer survivors: the role of self-efficacy and health status: Physical activity and QOL in breast cancer survivors.* Psycho-oncology (Chichester, England), 2014. **23**(1): p. 27-34.
385. Awick, E.A., et al., *Physical activity, self-efficacy and self-esteem in breast cancer survivors: a panel model: Physical activity and self-esteem in breast cancer survivors.* Psycho-oncology (Chichester, England), 2017. **26**(10): p. 1625-1631.
386. Peek, K., et al., *Interventions to aid patient adherence to physiotherapist prescribed self-management strategies: a systematic review.* Physiotherapy, 2016. **102**(2): p. 127-135.
387. Pudkasam, S., et al., *Motivational strategies to improve adherence to physical activity in breast cancer survivors: A systematic review and meta-analysis.* Maturitas, 2021. **152**: p. 32-47.
388. Borg, G. and D. Ottoson, *Perception of exertion in physical exercise*. 1986: Springer.

389. International, W.C.R.F. *Cancer Prevention Recommendations*. 2023 2023 [cited 2023 15.06.2023]; Available from: https://www.wcrf.org/diet-activity-and-cancer/cancer-prevention-recommendations/.
390. Reeves, D., et al., *The contribution of social networks to the health and self-management of patients with long-term conditions: a longitudinal study.* PloS one, 2014. **9**(6): p. e98340.
391. Green, L.W. and M.W. Kreuter, *Health promotion planning: An educational and ecological approach*, in *Health promotion planning: An educational and ecological approach*. 1993, McGraw-Hill.
392. Ayala, G.X. and J.P. Elder, *Qualitative methods to ensure acceptability of behavioral and social interventions to the target population.* Journal of public health dentistry, 2011. **71**: p. S69-S79.
393. Connelly, L.M., *Pilot studies.* Medsurg nursing, 2008. **17**(6): p. 411.
394. Rogers, C., D. Shamley, and S. Amosun, *Older adults' experience of an exergaming intervention to improve balance and prevent falls: a nested explanatory qualitative study.* Applied Sciences, 2021. **11**(24): p. 11678.
395. Schreier, M., *Qualitative content analysis in practice.* Qualitative content analysis in practice, 2012: p. 1-280.
396. Vaismoradi, M., et al., *Theme development in qualitative content analysis and thematic analysis.* 2016.
397. Johnson, V.L., et al., *The development of a self-management intervention for stroke survivors–my life after stroke (MLAS).* Disability and Rehabilitation, 2022: p. 1-9.
398. Eldredge, L.K.B., et al., *Planning health promotion programs: an intervention mapping approach*. 2016: John Wiley & Sons.
399. Wight, D., et al., *Six steps in quality intervention development (6SQuID).* J Epidemiol Community Health, 2016. **70**(5): p. 520-525.
400. Graham, I.D., et al., *Lost in knowledge translation: time for a map?* Journal of continuing education in the health professions, 2006. **26**(1): p. 13-24.
401. Czajkowski, S.M., et al., *From ideas to efficacy: The ORBIT model for developing behavioral treatments for chronic diseases.* Health Psychology, 2015. **34**(10): p. 971.
402. Arnold, M., et al., *Current and future burden of breast cancer: Global statistics for 2020 and 2040.* The Breast, 2022. **66**: p. 15-23.
403. McCormack, V., et al., *Breast cancer survival and survival gap apportionment in sub-Saharan Africa (ABC-DO): a prospective cohort study.* Lancet Glob Health, 2020. **8**(9): p. e1203-e1212.
404. Gray, J.R., S.K. Grove, and S. Sutherland, *Burns and grove's the practice of nursing research-E-book: Appraisal, synthesis, and generation of evidence*. 2016: Elsevier Health Sciences.
405. Bowen, D.J., et al., *How we design feasibility studies.* American journal of preventive medicine, 2009. **36**(5): p. 452-457.
406. Pfledderer, C.D., et al., *Consolidated guidance for behavioral intervention pilot and feasibility studies.* Pilot and Feasibility Studies, 2024. **10**(1): p. 57.
407. Stratton, S.J., *Quasi-experimental design (pre-test and post-test studies) in prehospital and disaster research.* Prehospital and disaster medicine, 2019. **34**(6): p. 573-574.
408. Harris, A.D., et al., *The use and interpretation of quasi-experimental studies in medical informatics.* Journal of the American Medical Informatics Association, 2006. **13**(1): p. 16-23.
409. Knapp, T.R., *Why Is the One-Group Pretest–Posttest Design Still Used?* Clinical Nursing Research, 2016. **25**(5): p. 467-472.
410. Hiam-Galvez, K.J., B.M. Allen, and M.H. Spitzer, *Systemic immunity in cancer.* Nature Reviews Cancer, 2021. **21**(6): p. 345-359.
411. Khosravi, N., et al., *Exercise training, circulating cytokine levels and immune function in cancer survivors: a meta-analysis.* Brain, behavior, and immunity, 2019. **81**: p. 92-104.
412. Santa-Maria, C.A., et al., *The Effects of a Remote-based Weight Loss Program on Adipocytokines, Metabolic Markers, and Telomere Length in Breast Cancer Survivors: the POWER-Remote Trial.* Clinical cancer research, 2020. **26**(12): p. 3024-3034.

413. Sattar, S., et al., *Feasibility of a remotely delivered strength and balance training program for older adults with cancer.* Current oncology (Toronto, Ont.), 2021. **28**(6): p. 4408-4419.
414. Zhu, J.W., et al., *What Is Known about Breast Cancer in Young Women?* Cancers, 2023. **15**(6): p. 1917.
415. Buzaglo, J.S., et al., *Evaluation of the efficacy and usability of NCI's Facing Forward booklet in the cancer community setting.* J Cancer Surviv, 2013. **7**(1): p. 63-73.
416. Doege, D., et al., *Health-related quality of life in long-term disease-free breast cancer survivors versus female population controls in Germany.* Breast cancer research and treatment, 2019. **175**: p. 499-510.
417. Heins, M.J., et al., *Adverse health effects after breast cancer up to 14 years after diagnosis.* Breast, 2022. **61**: p. 22-28.
418. Tommasi, C., et al., *Long-Term Effects of Breast Cancer Therapy and Care: Calm after the Storm?* J Clin Med, 2022. **11**(23).
419. Mascheroni, E., et al., *Exploring differences in psychological aspects during pregnancy between cancer survivors and women without a history of cancer.* Supportive Care in Cancer, 2020. **28**: p. 2255-2263.
420. Lambertini, M., et al., *Pregnancy after breast cancer: a systematic review and meta-analysis.* Journal of Clinical Oncology, 2021. **39**(29): p. 3293-3305.
421. Donahue, P.M.C., et al., *Advances in the prevention and treatment of breast cancer-related lymphedema.* Breast Cancer Research and Treatment, 2023. **200**(1): p. 1-14.
422. Chow, S.-C., et al., *Sample size calculations in clinical research*. 2017: CRC press.
423. Miller-Matero, L.R., et al., *A Brief Psychological Intervention for Chronic Pain in Primary Care: A Pilot Randomized Controlled Trial.* Pain Medicine, 2021. **22**(7): p. 1603-1611.
424. Hensen, B., et al., *Remote data collection for public health research in a COVID-19 era: ethical implications, challenges and opportunities.* Health Policy Plan, 2021. **36**(3): p. 360-368.
425. Eldridge, S.M., et al., *CONSORT 2010 statement: extension to randomised pilot and feasibility trials.* bmj, 2016. **355**.
426. Haynes, R.B., D.W. Taylor, and D.L. Sackett, *Compliance in health care.* 1979.
427. Hall, A.M., et al., *Measurement Tools for Adherence to Non-Pharmacologic Self-Management Treatment for Chronic Musculoskeletal Conditions: A Systematic Review.* Archives of Physical Medicine and Rehabilitation, 2015. **96**(3): p. 552-562.
428. Tomlinson, M., et al., *The use of mobile phones as a data collection tool: a report from a household survey in South Africa.* BMC medical informatics and decision making, 2009. **9**: p. 1-8.
429. Burnand, H.G., et al., *The EQ-5D-3L administered by text message compared to the paper version for hard-to-reach populations in a rural South African trauma setting: a measurement equivalence study.* Archives of Orthopaedic and Trauma Surgery, 2021. **141**(6): p. 947-957.
430. Papaioannou, D., et al., *Recommendations on recording harms in randomised controlled trials of behaviour change interventions.* Bmj, 2024. **387**: p. e077418.
431. Cleeland, C. and K. Ryan, *Pain assessment: global use of the Brief Pain Inventory.* Annals of the Academy of Medicine, Singapore, 1994. **23**(2): p. 129-138.
432. Center, T.U.o.T.M.A.C. *The Brief Fatigue Inventory*. 2023 [cited 2023 22.09.2023]; Available from: https://www.mdanderson.org/research/departments-labs-institutes/departments-divisions/symptom-research/symptom-assessment-tools/brief-fatigue-inventory.html.
433. Center, U.o.T.M.A.C. *The Brief Pain Inventory*. 2023 2023 [cited 2023 22.09.2023]; Available from: https://www.mdanderson.org/research/departments-labs-institutes/departments-divisions/symptom-research/symptom-assessment-tools/brief-pain-inventory.html.
434. So, W.K., et al., *Symptom clusters experienced by breast cancer patients at various treatment stages: A systematic review.* Cancer Medicine, 2021. **10**(8): p. 2531-2565.

435. Bjerkeset, E., K. Röhrl, and I. Schou-Bredal, *Symptom cluster of pain, fatigue, and psychological distress in breast cancer survivors: prevalence and characteristics.* Breast cancer research and treatment, 2020. **180**: p. 63-71.
436. Ferreira, V.T., et al., *Assessing the impact of pain on the life of breast cancer survivors using the Brief Pain Inventory.* J Phys Ther Sci, 2015. **27**(5): p. 1361-3.
437. Parker, R., J. Jelsma, and D.J. Stein, *Pain in amaXhosa women living with HIV/AIDS: Translation and validation of the Brief Pain Inventory–Xhosa.* Journal of pain and symptom management, 2016. **51**(1): p. 126-132. e2.
438. Edries, N., J. Jelsma, and S. Maart, *The impact of an employee wellness programme in clothing/textile manufacturing companies: a randomised controlled trial*. 2013, BioMed Central Ltd.
439. Shi, Q., et al., *Determination of mild, moderate, and severe pain interference in patients with cancer.* Pain, 2017. **158**(6): p. 1108-1112.
440. Gebremariam, G.T., et al., *Validation of the amharic version of the brief fatigue inventory for assessment of cancer-related fatigue in Ethiopian cancer patients.* Journal of pain and symptom management, 2018. **56**(2): p. 264-272.
441. Nugusse, T., et al., *Prevalence of fatigue and associated factors among cancer patients attending Tikur Anbessa Specialized Hospital, Addis Ababa, Ethiopia.* Cancer Management and Research, 2021: p. 1909-1916.
442. Gok Metin, Z., et al., *The effects of progressive muscle relaxation and mindfulness meditation on fatigue, coping styles, and quality of life in breast cancer patients receiving adjuvant paclitaxel regimen: an assessor blinded, three-arm randomized controlled trial.* Annals of oncology, 2019. **30**: p. v840-v841.
443. Yao, L.-Q., et al., *The effect of an evidence-based Tai chi intervention on the fatigue-sleep disturbance-depression symptom cluster in breast cancer patients: A preliminary randomised controlled trial.* European Journal of Oncology Nursing, 2022. **61**: p. 102202.
444. Torres, D.M., et al., *Effectiveness of mat pilates on fatigue in women with breast cancer submitted to adjuvant radiotherapy: randomized controlled clinical trial.* Supportive Care in Cancer, 2023. **31**(6): p. 362.
445. Group, T.E., *EuroQol-a new facility for the measurement of health-related quality of life.* Health policy, 1990. **16**(3): p. 199-208.
446. Kimman, M.L., et al., *Patient satisfaction with nurse-led telephone follow-up after curative treatment for breast cancer.* BMC Cancer, 2010. **10**: p. 174.
447. Group, E. *EQ-5D-3L User Guide*. 2023 [cited 2024 23 March 2024]; Available from: https://euroqol.org/wp-content/uploads/2023/11/EQ-5D-3LUserguide-23-07.pdf.
448. Dolan, P., et al., *A social tariff for EuroQol: results from a UK general population survey*. 1995.
449. Kim, S.-H., et al., *Validity and reliability of EQ-5D-3L for breast cancer patients in Korea.* Health and quality of life outcomes, 2015. **13**(1): p. 1-7.
450. Zeng, X., et al., *Measurement properties of the EQ-5D-5L and EQ-5D-3L in six commonly diagnosed cancers.* The Patient-Patient-Centered Outcomes Research, 2021. **14**: p. 209-222.
451. DING, H., *Reliability and validity of EQ-5D-3L and FACT in Beijing's patients with cancer and precancerosis.* Tumor, 2017: p. 953-959.
452. Jelsma, J., et al., *The reliability and validity of the Xhosa version of the EQ-5D.* Disability and rehabilitation, 2004. **26**(2): p. 103-108.
453. Shiroiwa, T., et al., *Long-term health status as measured by EQ-5D among patients with metastatic breast cancer: comparison of first-line oral S-1 and taxane therapies in the randomized phase III SELECT BC trial.* Quality of Life Research, 2017. **26**: p. 445-453.
454. Park, H.-Y., et al., *Real-Time Interactive Digital Health Care System for Postoperative Breast Cancer Patients: A Randomized Controlled Trial.* Telemedicine and e-Health, 2023. **29**(7): p. 1057-1067.

455. Greene, B.L., et al., *Factors affecting physical activity behavior in urban adults with arthritis who are predominantly African-American and female.* Physical Therapy, 2006. **86**(4): p. 510-519.
456. Woby, S.R., M. Urmston, and P.J. Watson, *Self-efficacy mediates the relation between pain-related fear and outcome in chronic low back pain patients.* European Journal of Pain, 2007. **11**(7): p. 711-718.
457. Wideman, T.H. and M.J. Sullivan, *Differential predictors of the long-term levels of pain intensity, work disability, healthcare use, and medication use in a sample of workers' compensation claimants.* PAIN®, 2011. **152**(2): p. 376-383.
458. Lorig, K.R., et al., *Effect of a self-management program on patients with chronic disease.* Effective clinical practice: ECP, 2001. **4**(6): p. 256-262.
459. İncirkuş, K. and N. Nahcivan, *Validity and reliability study of the Turkish version of the self-efficacy for managing chronic disease 6-item scale.* Turkish journal of medical sciences, 2020. **50**(5): p. 1254-1261.
460. Ritter, P.L. and K. Lorig, *The English and Spanish self-efficacy to manage chronic disease scale measures were validated using multiple studies.* Journal of clinical epidemiology, 2014. **67**(11): p. 1265-1273.
461. Singleton, A.C., et al., *Supporting women's health outcomes after breast cancer treatment comparing a text message intervention to usual care: the EMPOWER-SMS randomised clinical trial.* Journal of Cancer Survivorship, 2022: p. 1-13.
462. Gao, Y., et al., *The mediating role of self-efficacy of managing chronic disease between the dual-mode of self-control and the fatigue in breast cancer patients undergoing postoperative chemotherapy.* Journal of Cancer Research and Therapeutics, 2021. **17**(7): p. 1643-1650.
463. Foster, C., et al., *Cancer survivors' self-efficacy to self-manage in the year following primary treatment.* Journal of Cancer Survivorship, 2015. **9**: p. 11-19.
464. Saw, M., *The effects of a six-week physiotherapist-led exercise and education intervention in patients with osteoarthritis, awaiting an arthroplasty in the South Africa*, in *Department of Physiotherapy*. 2015, University of Cape Town: Cape Town, South Africa.
465. Questionnaire, I.P.A., *International Physical Activity Questionnaire Short Form.* 1998.
466. Lee, P.H., et al., *Validity of the international physical activity questionnaire short form (IPAQ-SF): A systematic review.* International journal of behavioral nutrition and physical activity, 2011. **8**(1): p. 1-11.
467. Oyeyemi, A.L., et al., *The Short International Physical Activity Questionnaire: cross-cultural adaptation, validation and reliability of the Hausa language version in Nigeria.* BMC medical research methodology, 2011. **11**(1): p. 1-11.
468. Oyeyemi, A.L., et al., *Measurement of physical activity in urban and rural South African adults: a comparison of two self-report methods.* BMC Public Health, 2016. **16**: p. 1-13.
469. Ewah, P.A., et al., *Cross-cultural adaptation, reliability, and validation of the international physical activity questionnaire short form in languages in Africa: A systematic review.* 2023.
470. Gavala-González, J., A. Torres-Pérez, and J.C. Fernández-García, *Impact of Rowing Training on Quality of Life and Physical Activity Levels in Female Breast Cancer Survivors.* International Journal of Environmental Research and Public Health, 2021. **18**(13): p. 7188.
471. Park, S.W., et al., *Factors associated with physical activity of breast cancer patients participating in exercise intervention.* Supportive care in cancer, 2019. **27**(5): p. 1747-1754.
472. Kuijpers, W., et al., *eHealth for Breast Cancer Survivors: Use, Feasibility and Impact of an Interactive Portal.* JMIR Cancer, 2016. **2**(1): p. e3.
473. Ruiz-Casado, A., et al., *Validity of the physical activity questionnaires IPAQ-SF and GPAQ for cancer survivors: insights from a Spanish cohort.* International journal of sports medicine, 2016: p. 979-985.

474. Wanchai, A. and J.M. Armer, *Effects of weight-lifting or resistance exercise on breast cancer-related lymphedema: A systematic review.* International Journal of Nursing Sciences, 2019. **6**(1): p. 92-98.
475. Committee, I.R., *Guidelines for data processing and analysis of the International Physical Activity Questionnaire (IPAQ)-short and long forms.* http://www. ipaq. ki. se/scoring. pdf, 2005.
476. ten Broeke, P., et al., *Why do people sit? A framework for targeted behavior change.* Health Psychology Review, 2022: p. 1-14.
477. Howard-Jones, G., et al., *Influence of social networks on cancer survivors' self-management support: A mixed methods study.* Eur J Cancer Care (Engl), 2022. **31**(3): p. e13578.
478. Green, E.K., et al., *Perceptions of Support Groups Among Older Breast Cancer Survivors: "I've Heard of Them, but I've Never Felt the Need to Go".* Cancer Nurs, 2018. **41**(6): p. E1-e10.
479. Des Jarlais, D.C., et al., *Improving the reporting quality of nonrandomized evaluations of behavioral and public health interventions: the TREND statement.* American journal of public health, 2004. **94**(3): p. 361-366.
480. Pembury Smith, M.Q.R. and G.D. Ruxton, *Effective use of the McNemar test.* Behavioral Ecology and Sociobiology, 2020. **74**(11): p. 133.
481. Teresi, J.A., et al., *Guidelines for Designing and Evaluating Feasibility Pilot Studies.* Med Care, 2022. **60**(1): p. 95-103.
482. Leysen, L., et al., *Risk factors of pain in breast cancer survivors: a systematic review and meta-analysis.* Supportive Care in Cancer, 2017. **25**(12): p. 3607-3643.
483. Zainordin, N.H., et al., *Physical Activity, Sitting Time, and Quality of Life among Breast and Gynaecology Cancer Survivors.* Asian Pac J Cancer Prev, 2021. **22**(8): p. 2399-2408.
484. Biering, K., et al., *The long-term course of fatigue following breast cancer diagnosis.* J Patient Rep Outcomes, 2020. **4**(1): p. 37.
485. Gavin, K.L., et al., *Sedentary behavior after breast cancer: motivational, demographic, disease, and health status correlates of sitting time in breast cancer survivors.* Cancer Causes Control, 2019. **30**(6): p. 569-580.
486. O'Connell, N.S., et al., *Methods for Analysis of Pre-Post Data in Clinical Research: A Comparison of Five Common Methods.* J Biom Biostat, 2017. **8**(1): p. 1-8.
487. Wikipedia. *WhatsApp*. 2024 14 April 2024 [cited 2024 18 April 2024]; Available from: https://en.wikipedia.org/wiki/WhatsApp#.
488. Wikipedia. *Pep (Store)*. 2024 22 February 2024 [cited 2024 18 April 2024]; Available from: https://en.wikipedia.org/wiki/Pep_(store).
489. Jaeschke, R., J. Singer, and G.H. Guyatt, *Measurement of health status: ascertaining the minimal clinically important difference.* Controlled clinical trials, 1989. **10**(4): p. 407-415.
490. Reed, D.E., et al., *Comparable Minimally Important Differences and Responsiveness of Brief Pain Inventory and PEG Pain Scales across 6 Trials.* The Journal of Pain, 2024. **25**(1): p. 142-152.
491. Raman, S., et al., *Minimal clinically important differences in the EORTC QLQ-C30 and brief pain inventory in patients undergoing re-irradiation for painful bone metastases.* Quality of Life Research, 2018. **27**(4): p. 1089-1098.
492. Nixon, A., A. Williams, and C. Theodore-Oklota, *PRO80 PSYCHOMETRIC VALIDATION OF THE BRIEF FATIGUE INVENTORY (BFI) IN ADULT X-LINKED HYPOPHOSPHATEMIA (XLH).* Value in Health, 2020. **23**: p. S343.
493. Sari, N.P.W.P., *Fatigue Intensity in Cervical and Breast Cancer Survivors: Difference in Each Stage of Cancer Survivorship.* Indonesian Journal of Cancer, 2019. **13**(1): p. 5-12.
494. Makgalemele, K.T., *The relationship between education and vulnerability to poverty in South Africa*. 2022: University of Johannesburg (South Africa).
495. Reddy, V. and B. Mncwango, *Education and Labour Market Inequalities in South Africa*, in *Social Justice and Education in the 21st Century: Research from South Africa and the United*

States, W. Pearson Jr and V. Reddy, Editors. 2021, Springer International Publishing: Cham. p. 29-52.
496. Kelly, G., L. Mrengqwa, and L. Geffen, *"They don't care about us": older people's experiences of primary healthcare in Cape Town, South Africa.* BMC geriatrics, 2019. **19**(1): p. 1-14.
497. Bresick, G., K.B.V. Pressentin, and R. Mash, *Evaluating the performance of South African primary care : a cross-sectional descriptive survey.* South African Family Practice, 2019. **61**(3): p. 109-116.
498. Fransman, T. and D. Yu, *Multidimensional poverty in South Africa in 2001–16.* Development Southern Africa, 2019. **36**(1): p. 50-79.
499. Parker, R., et al., *Barriers to implementing clinical trials on nonpharmacological treatments in developing countries: lessons learnt from addressing pain in HIV.* Pain reports, 2019. **4**(6): p. e783-e783.
500. Cubasch, H., et al., *Breast conservation surgery versus total mastectomy among women with localized breast cancer in Soweto, South Africa.* PLoS One, 2017. **12**(8): p. e0182125.
501. Choong, G.M., G.D. Cullen, and C.C. O'Sullivan, *Evolving standards of care and new challenges in the management of HER2-positive breast cancer.* CA: a cancer journal for clinicians, 2020. **70**(5): p. 355-374.
502. Frazelle, M.L. and P.J. Friend, *Optimizing the Teachable Moment for Health Promotion for Cancer Survivors and Their Families.* J Adv Pract Oncol, 2016. **7**(4): p. 422-433.
503. Bluethmann, S.M., et al., *Grasping the 'teachable moment': time since diagnosis, symptom burden and health behaviors in breast, colorectal and prostate cancer survivors.* Psychooncology, 2015. **24**(10): p. 1250-1257.
504. Jia, G., J.R. Sowers, and A.T. Whaley-Connell, *Obesity in Hypertension: The Role of the Expanding Waistline Over the Years and Insights Into the Future.* Hypertension, 2024. **81**(4): p. 687-690.
505. Hasumi, T. and K.H. Jacobsen, *Healthcare service problems reported in a national survey of South Africans.* International Journal for Quality in Health Care, 2014. **26**(4): p. 482-489.
506. Headley, J.A., K.K. Ownby, and L.D. John, *The effect of seated exercise on fatigue and quality of life in women with advanced breast cancer.* Oncology nursing forum, 2004. **31**(5): p. 977-983.
507. Phillips, S., et al., *A technology-based physical activity intervention for patients with metastatic breast cancer (Fit2ThriveMB): Protocol for a randomized controlled trial.* JMIR Research Protocols, 2021. **10**(4).
508. Mock, V., et al., *Fatigue and quality of life outcomes of exercise during cancer treatment.* Cancer Pract, 2001. **9**(3): p. 119-27.
509. Gil, K.M., et al., *Uncertainty management intervention for older African American and Caucasian long-term breast cancer survivors.* Journal of Psychosocial Oncology, 2005. **23**(2-3): p. 3-21.
510. Ashing, K.T. and M. George, *Exploring the efficacy of a paraprofessional delivered telephonic psychoeducational intervention on emotional well-being in African American breast cancer survivors.* Supportive Care in Cancer, 2020. **28**(3): p. 1163-1171.
511. Christy, S.M., et al., *Long-term dietary outcomes of the FRESH START intervention for breast and prostate cancer survivors.* Journal of the American Dietetic Association, 2011. **111**(12): p. 1844-1851.
512. Wagner, L.I., et al., *Targeted eHealth Intervention to Reduce Breast Cancer Survivors' Fear of Recurrence: Results From the FoRtitude Randomized Trial.* J Natl Cancer Inst, 2021. **113**(11): p. 1495-1505.
513. Bannell, D.J., et al., *Adherence to unsupervised exercise in sedentary individuals: A randomised feasibility trial of two mobile health interventions.* DIGITAL HEALTH, 2023. **9**: p. 20552076231183552.

514. Sohn, H., et al., *Costing the implementation of public health interventions in resource-limited settings: a conceptual framework.* Implement Sci, 2020. **15**(1): p. 86.
515. Huynh, L., et al., *Cost-effectiveness of health research study participant recruitment strategies: A systematic review.* Clinical Trials, 2014. **11**(5): p. 576-583.
516. Kaper, J., et al., *Encouraging smokers to quit: the cost effectiveness of reimbursing the costs of smoking cessation treatment.* Pharmacoeconomics, 2006. **24**: p. 453-464.
517. Gordon, L.G., et al., *Cost-effectiveness of a pragmatic exercise intervention for women with breast cancer: results from a randomized controlled trial.* Psycho-Oncology, 2017. **26**(5): p. 649-655.
518. Wang, L., et al., *Breast cancer-related lymphoedema and resistance exercise: An evidence-based review of guidelines, consensus statements and systematic reviews.* Journal of Clinical Nursing, 2023. **32**(9-10): p. 2208-2227.
519. Riis, C.L., et al., *Are patient-reported outcomes useful in post-treatment follow-up care for women with early breast cancer? A scoping review.* Patient Related Outcome Measures, 2019: p. 117-127.
520. Anderson, K.O., et al., *Automated pain intervention for underserved minority women with breast cancer.* Cancer, 2015. **121**(11): p. 1882-90.
521. Lagendijk, M., et al., *Patient reported outcome measures in breast cancer patients.* European Journal of Surgical Oncology, 2018. **44**(7): p. 963-968.
522. Whisenant, M.S., et al., *Identification of breast cancer survivors with high symptom burden.* Cancer nursing, 2022. **45**(4): p. 253-261.
523. Ibrahim, M., et al., *The long-term effects of posttreatment exercise on pain in young women with breast cancer.* The Journal of community and supportive oncology, 2018. **16**(3): p. e145-e151.
524. Al Maqbali, M., et al., *Prevalence of fatigue in patients with cancer: a systematic review and meta-analysis.* Journal of pain and symptom management, 2021. **61**(1): p. 167-189. e14.
525. Joly, F., et al., *Long-term fatigue and cognitive disorders in breast cancer survivors.* Cancers, 2019. **11**(12): p. 1896.
526. Berger, A.M., et al., *Usual and worst symptom severity and interference with function in breast cancer survivors.* The journal of supportive oncology, 2012. **10**(3): p. 112-118.
527. Bean, H.R., et al., *Insomnia and fatigue symptom trajectories in breast cancer: a longitudinal cohort study.* Behavioral Sleep Medicine, 2021. **19**(6): p. 814-827.
528. Kessels, E., O. Husson, and C.M. van der Feltz-Cornelis, *The effect of exercise on cancer-related fatigue in cancer survivors: a systematic review and meta-analysis.* Neuropsychiatric disease and treatment, 2018. **14**: p. 479-494.
529. Hughes, R., et al., *Health-state utility values in breast and prostate cancer measured using the EQ-5D: a systematic review of the literature.* Value in Health, 2014. **17**(7): p. A645-A646.
530. Wang, L., et al., *Health-related quality of life and utility scores of patients with breast neoplasms in China: A multicenter cross-sectional survey.* The Breast, 2018. **39**: p. 53-62.
531. Criscitiello, C., et al., *Health-related quality of life among patients with HR+/HER2–early breast cancer.* Clinical Therapeutics, 2021. **43**(7): p. 1228-1244. e4.
532. Janssen, M.F., et al., *Population norms for the EQ-5D-3L: a cross-country analysis of population surveys for 20 countries.* The European Journal of Health Economics, 2019. **20**: p. 205-216.
533. Montagnese, C., et al., *Quality of Life in Women Diagnosed with Breast Cancer after a 12-Month Treatment of Lifestyle Modifications.* Nutrients, 2020. **13**(1).
534. El Sayed, E., et al., *Perceived quality of life in a cohort of Egyptian breast cancer survivors in Alexandria as measured by EQ-5D-3L: a cross-sectional study.* The Egyptian Journal of Surgery, 2021. **40**(4): p. 1081-1086.
535. Hamer, J., et al., *Quality of life (QOL) and symptom burden (SB) in patients with breast cancer.* Supportive Care in Cancer, 2017. **25**: p. 409-419.

536. Excellence, N.I.f.H.a.C. *How NICE measures value for money in relation to public health interventions*. 2013 1 September 2013 [cited 2024 31 May 2024]; Available from: https://www.nice.org.uk/Media/Default/guidance.
537. Baik, S.H., et al., *Cancer-relevant self-efficacy is related to better health-related quality of life and lower cancer-specific distress and symptom burden among Latina breast cancer survivors.* International journal of behavioral medicine, 2020. **27**(4): p. 357-365.
538. Adams, R.N., et al., *Avoidant coping and self-efficacy mediate relationships between perceived social constraints and symptoms among long-term breast cancer survivors.* Psychooncology, 2017. **26**(7): p. 982-990.
539. Somayyeh, B., et al., *Exploring the Role of Self-Efficacy for Coping With Breast Cancer: A Systematic Review.* Archives of breast cancer, 2017. **4**(2).
540. Saw, M.M., et al., *Significant improvements in pain after a six-week physiotherapist-led exercise and education intervention, in patients with osteoarthritis awaiting arthroplasty, in South Africa: a randomised controlled trial.* BMC Musculoskeletal Disorders, 2016. **17**(1): p. 1-14.
541. Scott, J.M., et al., *Efficacy of Exercise Therapy on Cardiorespiratory Fitness in Patients With Cancer: A Systematic Review and Meta-Analysis.* Journal of clinical oncology : official journal of the American Society of Clinical Oncology, 2018. **36**(22): p. 2297-2305.
542. Ortiz, A., et al., *Relationship between physical activity, disability, and physical fitness profile in sedentary Latina breast cancer survivors.* Physiotherapy Theory and Practice, 2018. **34**(10): p. 783-794.
543. Igwesi-Chidobe, C.N., et al., *Physical activity containing behavioural interventions for adults living with modifiable chronic non-communicable diseases in Africa: a systematic mixed-studies review.* International health, 2018. **10**(3): p. 137-148.
544. Pinto, B., S. Dunsiger, and K. Stein, *Does a peer-led exercise intervention affect sedentary behavior among breast cancer survivors?* Psychooncology, 2017. **26**(11): p. 1907-1913.
545. Dempsey, P.C., et al., *Sedentary behavior and chronic disease: mechanisms and future directions.* Journal of Physical Activity and Health, 2020. **17**(1): p. 52-61.
546. Ortiz, A., et al., *Differences in physical fitness, disability, and health-related quality of life between physical active and sedentary Hispanic breast cancer survivors.* Cancer epidemiology biomarkers and prevention. Conference: 7th AACR conference on the science of health disparities in racial/ethnic minorities and the medically underserved san antonio, TX united states. Conference start: 20141109 conference end: 20141112. Conference publication: (var.pagings), 2015. **24**(10 SUPPL. 1) (no pagination).
547. Ng, N., A. Santosa, and P. Kowal, *Sitting time and obesity among older adults in low-and middle-income countries: Nawi Ng.* The European Journal of Public Health, 2017. **27**(suppl_3): p. ckx186. 042.
548. Ekelund, U., et al., *Dose-response associations between accelerometry measured physical activity and sedentary time and all cause mortality: systematic review and harmonised meta-analysis.* bmj, 2019. **366**.
549. Mclaughlin, M., et al., *Worldwide surveillance of self-reported sitting time: a scoping review.* International Journal of Behavioral Nutrition and Physical Activity, 2020. **17**(1): p. 111.
550. Sanders, J.P., et al., *Devices for self-monitoring sedentary time or physical activity: a scoping review.* Journal of medical Internet research, 2016. **18**(5): p. e90.
551. Shelby, R.A., et al., *Self-efficacy for coping with symptoms moderates the relationship between physical symptoms and well-being in breast cancer survivors taking adjuvant endocrine therapy.* Supportive care in cancer, 2014. **22**: p. 2851-2859.
552. Seo, M.H. and K.H. Lim, *The effects of fatigue and distress on self-efficacy among breast cancer survivors.* Korean Journal of Adult Nursing, 2016. **28**(4): p. 378-387.

553. Fisher, M.I. and D. Howell, *The power of empowerment: An ICF-based model to improve self-efficacy and upper extremity function of survivors of breast cancer.* Rehabilitation Oncology, 2010. **28**(3): p. 19-25.
554. Geng, Z., et al., *Gauging the effects of self-efficacy, social support, and coping style on self-management behaviors in Chinese cancer survivors.* Cancer nursing, 2018. **41**(5): p. E1-E10.
555. Kenzik, K.M., et al., *Changes in Body Mass Index and Physical Activity Predict Changes in Vitality During a Weight Loss Trial in Breast Cancer Survivors.* Ann Behav Med, 2018. **52**(12): p. 999-1009.
556. Allahqoli, L., et al., *The global incidence, mortality, and burden of breast cancer in 2019: correlation with smoking, drinking, and drug use.* Frontiers in Oncology, 2022. **12**: p. 921015.
557. Santos, J.C., et al., *The biopsychosocial approach: towards holistic, person-centred psychiatric/mental health nursing practice.* European Psychiatric/Mental Health Nursing in the 21st Century: A Person-Centred Evidence-Based Approach, 2018: p. 89-101.
558. (CANSA), C.A.o.S.A. *Breast Cancer*. 2024 2024 [cited 2024 06.03.2024]; Available from: https://cansa.org.za/breast-cancer/.
559. National Department of Health, S.A. *Budget Vote 2023/2024*. 2023 [cited 2024 31 May 2024]; Available from: https://www.health.gov.za/wp-content/uploads/2023/05/Draft-Minister-of-Health-Budget-Vote-Speech.
560. Garton, E.M., et al., *An analysis of survivorship care strategies in national cancer control plans in Africa.* Journal of Cancer Survivorship, 2023. **17**(3): p. 634-645.
561. Gupta, A., et al., *Perception, magnitude, and implications of cancer-related fatigue in breast cancer survivors: Study from a developing country.* Journal of Cancer Research and Therapeutics, 2021. **17**(4).
562. Poorkiani, M., et al., *The effect of rehabilitation on quality of life in female breast cancer survivors in Iran.* Indian journal of medical and paediatric oncology, 2010. **31**(4): p. 105-109.
563. Ahmadi, M., et al., *Development of a mobile-based self-care application for patients with breast cancer-related lymphedema in Iran.* Applied Clinical Informatics, 2022. **13**(05): p. 935-948.
564. Powell-Wiley, T.M., et al., *Obesity and Cardiovascular Disease: A Scientific Statement From the American Heart Association.* Circulation, 2021. **143**(21): p. e984-e1010.
565. Manafe, M., P.K. Chelule, and S. Madiba, *The Perception of Overweight and Obesity among South African Adults: Implications for Intervention Strategies.* Int J Environ Res Public Health, 2022. **19**(19).
566. Stanton, A.L., et al., *Outcomes From the Moving Beyond Cancer Psychoeducational, Randomized, Controlled Trial With Breast Cancer Patients.* Journal of Clinical Oncology, 2005. **23**(25): p. 6009-6018.
567. Pope, Z., et al., *Feasibility of smartphone application and social media intervention on breast cancer survivors' health outcomes.* Translational behavioral medicine, 2019. **9**(1): p. 11-22.
568. Webb, J., et al., *A mixed methods process evaluation of a print-based intervention supported by internet tools to improve physical activity in UK cancer survivors.* Public Health, 2019. **175**: p. 19-27.
569. Kapoor, A., P. Nambisan, and E. Baker, *Mobile applications for breast cancer survivorship and self-management: A systematic review.* Health Informatics J, 2020. **26**(4): p. 2892-2905.
570. Louw, Q.A., et al., *Rehabilitation Capacity in South Africa-A Situational Analysis.* Int J Environ Res Public Health, 2023. **20**(4).
571. Motsei, A.S. and P.A. Phindane, *Multiculturalism, Orality, and Folklore in South Africa*, in *The Palgrave Handbook of African Oral Traditions and Folklore*, A. Akinyemi and T. Falola, Editors. 2021, Springer International Publishing: Cham. p. 489-507.
572. Kellner, K., et al., *Southern African Arid Lands: Current Status and Future Prospects*, in *Climate Variability Impacts on Land Use and Livelihoods in Drylands*, M.K. Gaur and V.R. Squires, Editors. 2018, Springer International Publishing: Cham. p. 243-260.

573. Tan, Y., et al., *Effectiveness of peer support on quality of life and anxiety in breast cancer patients: a systematic review and meta-analysis.* Breast Care, 2023. **18**(1): p. 49-59.
574. Shamley, D. and K. Robb, *An early warning surveillance programme for detecting upper limb deterioration after treatment for breast cancer: A novel technology supported system.* BMC Cancer, 2015. **15**(1): p. 635.
575. Park, J.H., et al., *The effect of oncologists' exercise recommendations on the level of exercise and quality of life in survivors of breast and colorectal cancer: a randomized controlled trial.* Cancer, 2015. **121**(16): p. 2740-2748.
576. Winters-Stone, K.M., et al., *Enhancing an oncologist's recommendation to exercise to manage fatigue levels in breast cancer patients: a randomized controlled trial.* Supportive care in cancer, 2017: p. 1-8.
577. Pramesh, C.S., et al., *Priorities for cancer research in low- and middle-income countries: a global perspective.* Nat Med, 2022. **28**(4): p. 649-657.
578. Jablotschkin, M., et al., *Benefits and challenges of cancer peer support groups: A systematic review of qualitative studies.* European Journal of Cancer Care, 2022. **31**(6): p. e13700.
579. Vd Wiel, H.J., et al., *Characteristics of participants and nonparticipants in a blended internet-based physical activity trial for breast and prostate cancer survivors: Cross-sectional study.* JMIR Cancer, 2021. **7**(4).
580. Rogers, L.Q., et al., *Effects of the BEAT Cancer physical activity behavior change intervention on physical activity, aerobic fitness, and quality of life in breast cancer survivors: a multicenter randomized controlled trial.* Breast Cancer Res Treat, 2015. **149**(1): p. 109-19.
581. Enright, P.L., *The six-minute walk test.* Respiratory care, 2003. **48**(8): p. 783-785.
582. Lang, A.E., et al., *Impingement pain affects kinematics of breast cancer survivors in work-related functional tasks.* Clinical Biomechanics, 2019. **70**: p. 223-230.
583. Teran-Wodzinski, P., et al., *Effects of home-based exercise intervention in breast cancer survivors with chemotherapy-induced peripheral neuropathy: study protocol.* Rehabilitation oncology, 2021. **39**(2): p. E25-.
584. McLaughlin, S.A., C.L. Brunelle, and A. Taghian, *Breast cancer–related lymphedema: risk factors, screening, management, and the impact of locoregional treatment.* Journal of Clinical Oncology, 2020. **38**(20): p. 2341.
585. Pappalardo, M., et al., *Breast cancer-related lymphedema: recent updates on diagnosis, severity and available treatments.* Journal of Personalized Medicine, 2021. **11**(5): p. 402.
586. Tang, M., et al., *The Effects of Cognitive-Behavioral Stress Management for Breast Cancer Patients: A Systematic Review and Meta-analysis of Randomized Controlled Trials.* Cancer Nursing, 2020. **43**(3).
587. Noyes, K., et al., *Problem-solving skills training in adult cancer survivors: Bright IDEAS-AC pilot study.* Cancer Treat Res Commun, 2022. **31**: p. 100552.
588. Haenen, V., et al., *Pain prevalence and characteristics in survivors of solid cancers: a systematic review and meta-analysis.* Supportive Care in Cancer, 2023. **31**(1): p. 85.
589. Hamood, R., et al., *Chronic pain and other symptoms among breast cancer survivors: prevalence, predictors, and effects on quality of life.* Breast cancer research and treatment, 2018. **167**(1): p. 157-169.
590. IASP, *IASP taxonomy.* 2012.
591. Breastcancer.org. *Understanding Breast Cancer Recurrence*. Types of Breast Cancer 2023 21 December 2023 [cited 2024 20 May 2024]; Available from: https://www.breastcancer.org/types/recurrent.
592. Playdon, M.C., et al., *Weight gain after breast cancer diagnosis and all-cause mortality: systematic review and meta-analysis.* JNCI: Journal of the National Cancer Institute, 2015. **107**(12).