Developing a Stakeholder-Driven Cancer Rehabilitation Intervention for Older Adults with Breast Cancer

by

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The number of older adult breast cancer survivors is rapidly growing. Yet with survival, this population often experiences high, persistent rates of cancer-related disability. This disability manifests in the form of activity limitations or difficulties executing daily activities that older adult breast cancer survivors need or want to do. Despite efforts to improve detection of activity limitations and referral to rehabilitation services, cancer rehabilitation remains underutilized in this population.

The focus of this dissertation was threefold. First, we examined the state of the science related to nonpharmacological interventions influencing activity limitations in older breast cancer survivors. We identified that existing interventions 1) are frequently complex in nature; 2) incorporate adaptive skills training, behavioral strategies, and exercise; 3) vary in delivery features; and 4) are associated with a wide range of effect sizes. The best combination of interventions and delivery features remain unclear.

Second, we conducted semi-structured interviews with older breast cancer survivors to identify preferences for cancer rehabilitation interventions. We learned that the choice to pursue cancer rehabilitation is influenced by emerging awareness of disability, coping styles, comparisons with others, provider interactions, perceptions of cancer as a lifelong project, social support, and cost of rehabilitation. Participants' preferences for intervention content varied but included some desire for interventions that provide peer support, healthy behavior training, and symptom

management. Participants preferred interventions delivered in outpatient clinics or community-based settings.

Third, we compiled findings from the scoping review and stakeholder interviews for expert panel review and consensus. Using a modified Delphi process, panelists rated intervention content and delivery features according to feasibility and prioritization. Our results revealed high consensus for intervention content including physical activity and adaptive skills training as well as interventions delivered in outpatient clinics or post-treatment, through a combination of in-person and virtual visits, lasting no more than 3 months, and occurring biweekly.

Overall, these findings provide important evidence-based, stakeholder-informed directions for future intervention research in cancer rehabilitation. These findings can be used to inform the development, testing, and implementation of valued and accessible interventions to address activity limitations among older breast cancer survivors.

Table of Contents

List of Tables

List of Figures

Preface

There are many individuals who have helped champion this dissertation. I would like to express my sincerest gratitude to my mentor Elizabeth Skidmore, PhD, OTR/L for her patience and guidance over the past four years. I am also grateful to the other members of my dissertation committee, Catherine Bender, PhD, RN, Natalie Leland, PhD, OTR/L, and Pamela Toto, PhD, OTR/L for their time, effort, and expertise that have helped to shape this project. I would like to acknowledge external consultants, especially Kathleen D. Lyons, ScD, OTR/L, Robert Ferguson, PhD, and Mackenzi Pergolotti, PhD, OTR/L. I would like to recognize Rachel Eilers, BS, and Madilyn Douglas, BS for their assistance in carrying out this project. I must take the opportunity to recognize the research participants, the Cancer Caring Center of Pittsburgh, and Cancer and Aging Research Group who devoted their time to recruitment and participation in these studies. I am grateful for the support provided by Laura Waterstram, the OT Cognitive Performance Laboratory, Fishbowl, and colleagues within the Department of Occupational Therapy. My dissertation was supported by research funding from the following organizations and agencies: University of Pittsburgh School of Health and Rehabilitation Sciences PhD Student Award and the Dr. Gary Kielhofner Doctoral Research Scholarship supported by the American Occupational Therapy Association. Finally, I would like to thank my family and friends, especially to Alec Smith, my parents, siblings, and grandparents for your endless love and encouragement throughout this process.

1.0 Introduction

1.1 Significance

1.1.1 Disability in older adult breast cancer survivors

The number of older adult breast cancer survivors is rapidly growing due to advancements in screening, treatment, and population aging.[1] Breast cancer is the leading cancer diagnosis in females of all races and ethnicities.[2] Currently, 50% of persons diagnosed with breast cancer are age 60 years and older.[2] An estimated 92% of adults with breast cancer have lived 5 years beyond diagnosis.[2] Yet with survival, this population often experiences high, persistent rates of comorbidity[3] and disability.[4,5]

Cancer-related disability is a multidimensional consequence of cancer and cancer-related treatments (See Figure 1) and is common throughout the cancer care continuum.[6] Cancer-related disability is comprised of impairments and activity limitations. Impairments describe changes in body structures and functions[7] such as range of motion, peripheral neuropathy, cancer-related cognitive impairment, or chronic fatigue. Although impairments frequently experienced by this population,[8] older breast cancer survivors describe activity limitations as a more meaningful outcome or consequence of cancer.[9,10] Activity limitations are difficulties a person may have when executing daily activities that he or she needs or wants to do.[7] Older breast cancer survivors report that they do not wish to compromise their engagement in daily activities in light of cancer treatment.[10] However, up to 60% of this population will experience activity limitations including difficulty and/or dissatisfaction with their performance completing with instrumental activities of daily living (e.g., money management, shopping, meal preparation)[11,12] or basic self-care tasks (e.g., bathing, dressing, eating).[13,14] For older breast cancer survivors, activity limitations can evolve and be compounded by normative aging changes, resulting in broader societal costs associated with financial toxicity,[15] hospitalization and re-hospitalization, and early retirement.[16,17]

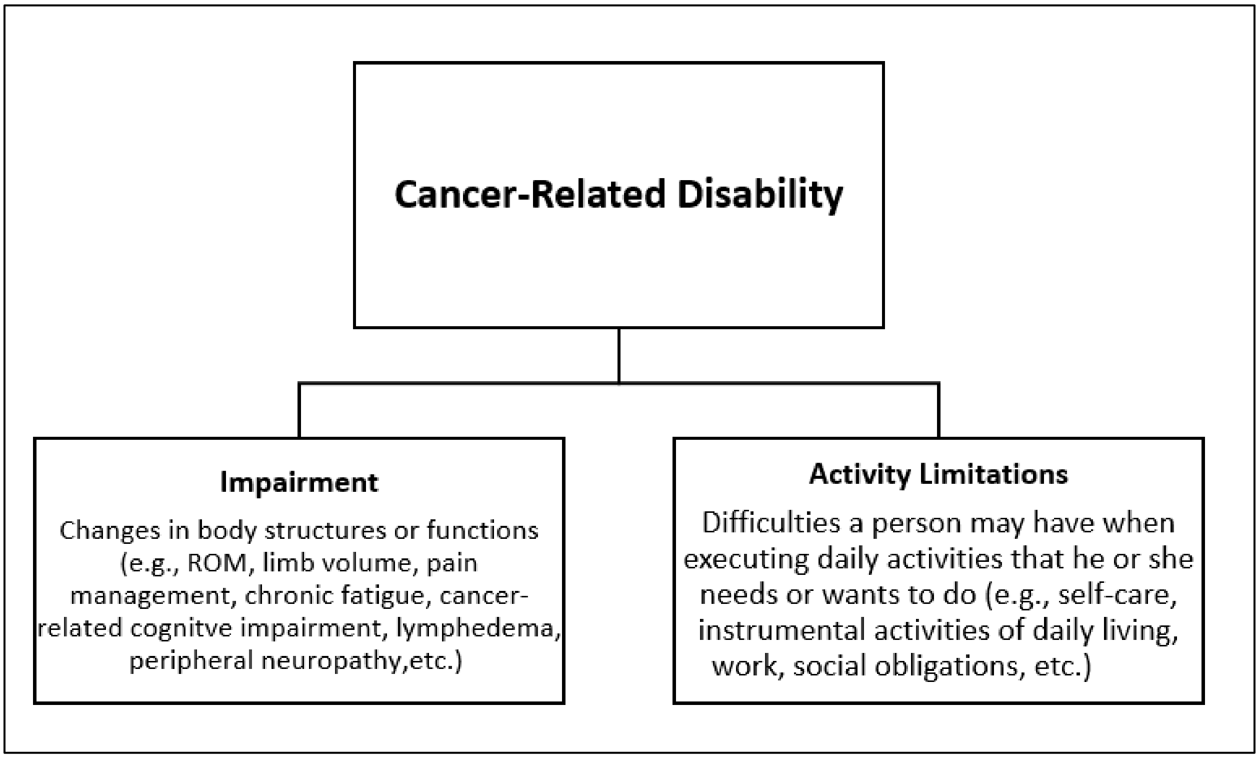


Figure 1 Dimensions of cancer-related disability

1.1.2 Referral pathways to cancer rehabilitation

The Institute of Medicine[18,19] and the National Institutes of Health[20] view cancer rehabilitation as an opportunity to address cancer-related activity limitations. Cancer rehabilitation is defined as an approach that improves the function and quality of life of patients and their families throughout the course of cancer.[21] Cancer rehabilitation encompasses multiple disciplines including but not limited to occupational therapy, physical therapy, psychology, physiatry, speech language pathology, exercise physiology, and nursing.

Scientists have already identified potential assessment batteries and procedures to improve referral of older adult breast cancer survivors to cancer rehabilitation. Most notably, the Geriatric Assessment[22] and Prospective Surveillance Model[23] provide comprehensive and systematic ways to assess and refer older adults with breast cancer for impairment and activity limitations. For example, the Geriatric Assessment can be applied in routine oncology appointments to identify potential areas of concern, such as activity limitations, in the older patient with breast cancer. Each domain within the Geriatric Assessment focuses on a specific area, such activity limitations, nutrition, fall risk, or social support.[22] Based on response to each domain, recommendations and referral strategies to applicable rehabilitation services or allied health fields are provided. Alternatively, the prospective surveillance model is most widely used with breast cancer survivors. This model has been defined as "a proactive approach to periodically examining patients and providing ongoing assessment during and after disease treatment, often in the absence of impairment, in an effort to enable early detection of and intervention"[23] (p. 2192) for disability. The goals of using this model are to promote surveillance of impairment and activity limitations associated with breast cancer treatment and to proactively introduce rehabilitation.[23]

1.1.3 Barriers in current breast cancer rehabilitation interventions

Despite efforts to improve detection of activity limitations and referral to rehabilitation services, cancer rehabilitation remains underused among older adult cancer survivors.[16] Recent reports state that less than 10% of older adult cancer survivors with identified impairments or activity limitations will receive necessary rehabilitation services.[24] In populations with metastatic breast cancer, negligible numbers (1-2%) will receive rehabilitation services despite documented impairments and activity limitations.[25]

There are multiple hypotheses about barriers to access and delivery of cancer rehabilitation services for older adult breast cancer survivors. Patients may have limited knowledge of cancer rehabilitation services or awareness of service benefits.[16] Providers also express limited knowledge on timing, access, and/or delivery of rehabilitation to older adult breast cancer survivors.[26] Furthermore, there are a limited number of interventions that address activity limitations in this population. Healthcare organizations have difficulty with scheduling of services[26] and an under recognition of cost and insurance coverage considerations for older adult survivors.[27]

1.1.4 Approaches to improve access and delivery of cancer rehabilitation interventions

One approach to overcome this fragmentation of care is to reassess the way we develop and design interventions. Interventions that consider stakeholder prioritized outcomes, intervention content, delivery features, and real world-implications are more likely to facilitate cost-effective, implementable, and sustainable effects (See Figure 2).[28] A comprehensive, stakeholder-informed approach has the ability to address several limitations in current cancer rehabilitation interventions.

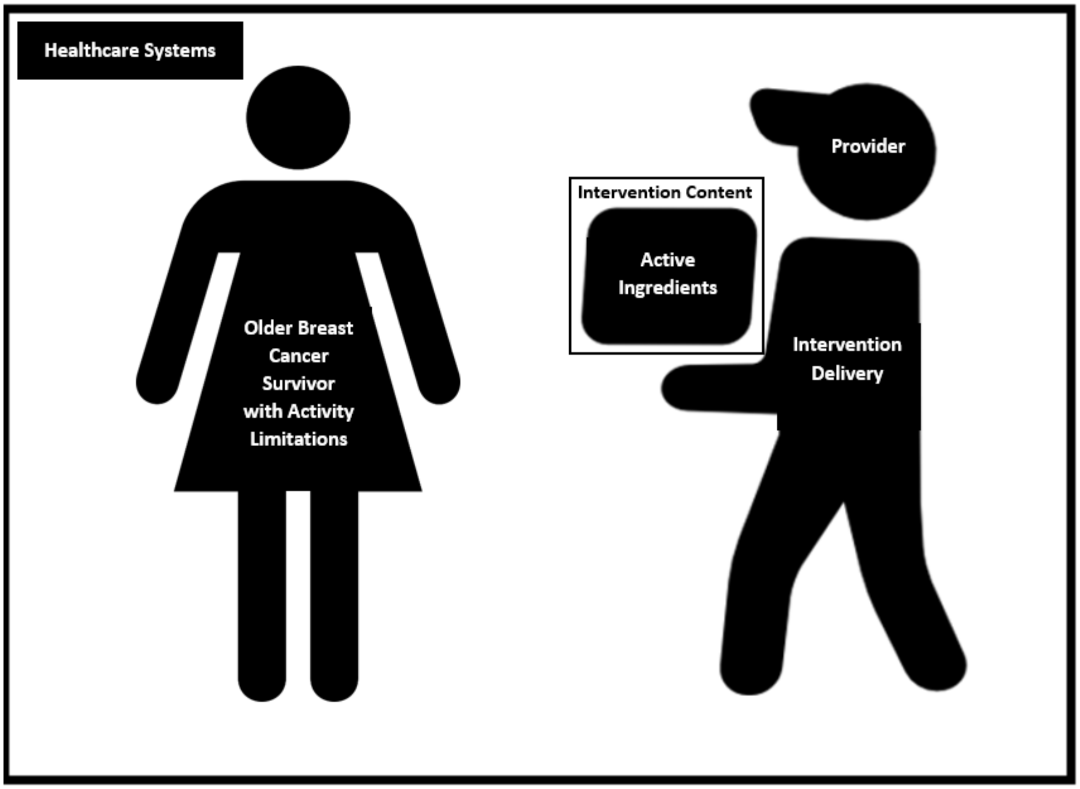


Figure 2 Characteristics of intervention development

First, current cancer rehabilitation interventions do not address the prioritized outcomes or needs of older adults with breast cancer. [6,9,10] While existing interventions target impairment-based concerns (e.g., cognitive impairment, fatigue, pain),[5] older adults breast cancer survivors prioritize performance in self-care, instrumental activities of daily living, community involvement, and quality of life.[10] Second, cancer rehabilitation interventions are complex in nature, and lack the necessary intervention content and delivery to be responsive to older adult cancer survivors' needs. Complex interventions[29,30] are interventions with several interacting components, or active ingredients, that address multidimensional outcomes. Often complex interventions have limited theoretical underpinnings, poorly operationalized mechanisms of action, and under-developed protocols specifying intervention content and delivery features.[31] Likewise, the delivery of complex interventions (i.e., location, timing, mode of delivery, duration, and frequency) often does not consider practicality, adoption, scalability, or sustainability in the community or service delivery systems.[32] Poorly specified and delivered interventions are challenging for rehabilitation professionals to implement[26] and lack of specificity may reduce the effects intervention content.[28]

Third, replicability and generalizability of current rehabilitation interventions are limited. Often, cancer rehabilitation interventions are not tested on representative samples. Few studies incorporate older adult breast cancer survivors and/or persons of color. These cancer populations are disproportionately underrepresented in research studies but are at a disproportionately high risk of cancer-related disability,[33] requiring that these populations become more prominent in intervention studies seeking to address this problem.[34] In addition, few studies consider developing interventions that can operate within current models of oncology care. Poor evaluation of interventions in context can lead to developing interventions that fail prior to use in real-world settings as too few people can deliver or use them.[28]

Most importantly, existing cancer intervention literature does not incorporate representative stakeholders' values and priorities for intervention approaches which may influence an intervention's acceptability or potency in real-world settings.[9,16,35] Stakeholder engagement is defined as an iterative process of actively soliciting the knowledge, experience, judgment and values of individuals selected to represent a broad range of interests in a particular issue, for the dual purposes of creating a shared understanding and making relevant, transparent and effective decisions.[36] By shifting intervention development to a more stakeholder-centered design,[37] we may identify and overcome barriers to intervention access and delivery earlier to allow for smoother implementation.

1.1.5 Framework to bolster effective intervention development

The design of effective, complex interventions requires a systematic approach with a strong rationale for design and intervention development process.[31] The Medical Research Council (MRC) Framework for the Development and Evaluation of Complex Interventions to Improve Health[29] provides methodological steps to develop, test, and implement evidence-based, theory-driven interventions intended for translation into real-world settings. The development phase focuses on specification of the problem, identification of the evidence-practice gaps, identifying facilitators and barriers of intervention with stakeholders, and forming possible solutions.[28,31,38]

1.2 Specific Aims

The overarching objective of this dissertation is to identify evidence-based, stakeholder-driven intervention characteristics that hold promise to reduce activity limitations in older breast cancer survivors. This will be accomplished through three aims:

1. Examine the current state of the science of cancer interventions that seek to reduce activity limitations in older breast cancer survivors **(Chapter 2).**
2. Identify stakeholder perspectives on intervention content and delivery features that show the greatest promise for reducing activity limitations among older breast cancer survivors **(Chapter 3).**
3. Generate consensus-based recommendations on intervention content and delivery features for interventions which seek to reduce activity limitations in older breast cancer survivors **(Chapter 4).**

This dissertation is important and innovative in that it examines intervention content and delivery features influencing activity limitations in this population. Few existing interventions specify activity limitations as the primary outcome. We must better understand the composition (intervention content and delivery features) and efficacy of current interventions designed to reduce activity limitations if we are to optimize development of future interventions. Second, it examines the unique intersection of key stakeholder perspectives across patient-, provider-, and healthcare organizational-levels. Integration of stakeholder knowledge and perspectives can influence intervention research and help overcome current barriers of implementation. Collectively, these aims provide the groundwork for future research focused on developing and testing interventions addressing activity limitations in older adult breast cancer survivors.

2.0 Impact of Non-pharmacological Interventions on Activity Limitations in Older Breast Cancer Survivors: A Scoping Review

2.1 Introduction

Breast cancer comprises 64% of all cancer diagnoses among females.[39] Due to advancements in screening and treatment as well as lengthened life span, older adult breast cancer survivors are living longer.[2] Nearly 50% of breast cancer survivors are over the age of 60 years old, with 19% of new cases in females 85 years and older.[40] Yet, as cancer survivors, this population experiences high rates of comorbidity and disability.[11,41] Up to 60% of this population will experience activity limitations.[42] The World Health Organization defines activity limitations as difficulties an individual may have in executing activities of daily living.[7] Activity limitations impede a survivor's ability to complete meaningful daily tasks and engage in life roles.[7] This includes difficulty[43] and dissatisfaction[11] with performing instrumental activities of daily living (e.g. money management, shopping, meal preparation) and challenges with basic self-care tasks (e.g. bathing, dressing, eating). Despite evidence of long-term activity limitations, there is little consensus on how to best intervene. If left unresolved, the costs of long-term disability in this population may culminate in excessive caregiver burden, hospitalization and re-hospitalization rates, and overall greater medical expenditures.[44]

There is an imminent need to develop and test interventions that will minimize activity limitations among older adult breast cancer survivors.[5] Reportedly only 10% of older adult survivors with documented activity limitations receive rehabilitation services, those with advanced diagnoses to an even lesser degree.[25] This may be due to a lack of available interventions, overly complicated intervention protocols, challenges with scheduling rehabilitation services, and/or lack of prioritization for these interventions in the course of cancer care.[45,46]

If we are to address these limitations in the intervention research, we must examine the relevance and feasibility of interventions in real-world settings. The Medical Research Council outlines methodological steps to develop, test, and implement evidence-based, theory-driven interventions intended for dissemination.[47] This framework recommends first identifying evidence and developing a theory about how an intervention may influence the intended outcome. This can be done by examining delivery features and intervention content, or “active ingredients,” in the existing intervention research.[28] Intervention delivery features characterize how an intervention is administered to the intended target population.[47] Active ingredients characterize what key elements of an intervention exert their effects on proposed ‘mechanisms of change’ to yield a target outcome. The examination of the delivery features and active ingredients of the studied interventions can be helpful in summarizing which elements across studies may be associated with improvements in outcomes of interest, to whom an intervention should be delivered, and potential facilitators and barriers to delivery to inform future interventions.[28]

The purpose of this scoping review was to characterize the delivery features and active ingredients of nonpharmacological interventions seeking to reduce activity limitations in older adults living with and beyond breast cancer. The effect sizes associated with these interventions were also examined. Scoping review methodology was selected as studies examining interventions addressing activity limitations in this population are relatively few, suggesting that this is an emerging body of science.

2.2 Methods

2.2.1 Search strategy

A health sciences librarian (RT) developed a comprehensive search strategy in consultation with co-authors (RB, RF, ES) using a combination of database-specific subject headings and keywords in Ovid Medline, Embase via Embase.com, EBSCO CINAHL, and Ovid PsycINFO. The full search strategy is provided in Appendix A. Search results were limited to those published from 2010-2020, English-language, and randomized controlled trials. The original search was run April 16, 2020. A final search was run October 28, 2020 to identify any new publications. Duplicates were removed using EndNote and the results were uploaded for screening into DistillerSR *(*DistillerSR, Evidence Partners, Ottawa, Canada). Bibliographies of review papers identified in both searches were examined to determine whether there were additional relevant studies not captured in the search.

2.2.2 Study inclusion

In a preliminary review of inclusion criteria, we searched for randomized controlled trials of non-pharmacological interventions that included samples of only breast cancer survivors who were 65 years and older. This search revealed only one study; therefore it was decided to re-run the search with broader criteria: 1) randomized controlled trials only; 2) samples that included participants with breast cancer, but not exclusive of other cancer diagnoses; 3) samples with mean or median age of 60 years or over OR a subgroup analysis of older adults with a mean or median age ≥ 60 years; 4) nonpharmacological interventions without use of medication or substance; and

5) inclusion of activity (limitations) as primary or secondary outcomes. Measures of activity (limitations) were based on definitions proposed by the International Classification of Functioning, Disability and Health[7] and were expected to be wide-ranging.[48] Studies were included if a primary or secondary measure assessed a person's involvement in execution of daily tasks, habits, or life roles[49] (e.g. work, leisure, instrumental activities of daily living, activities of daily living).[50]

2.2.3 Study selection

Prior to screening, duplicates were removed. A two-level screening process 1) title and abstract review, and 2) full-text review was performed using DistillerSR software (DistillerSR, Evidence Partners, Ottawa, Canada) to determine article eligibility. Pairs of trained reviewers (RB, RE, MD) were assigned to each article, after ensuring high levels of agreement ($\kappa = 0.95$) on a subset of articles (n=200). Discrepancies in article eligibility (n=5) were examined by four authors (RB, RE, MD, ES) to obtain consensus. When more than one article examined the same dataset, data from the primary and secondary analyses were combined for review.[51,52]

2.2.4 Data extraction and data analysis

Included articles were appraised for risk of bias (low concerns, some concerns, or high concerns) using the Cochrane Risk of Bias 2.0 of Randomized Controlled Trials (RB, RE, MD).[53] Data extraction characterized study designs, sample characteristics, relevant outcome measures, intervention elements, and key findings as guided by the Medical Research Council Guidelines for Developing and Evaluating Complex Interventions.[54] Intervention characteristics were categorized as 1) delivery features and 2) active ingredients. Delivery features of an intervention are the rehabilitation indications (what), timing (when), and modes of delivery (where, by whom). Active ingredients represent the key constructs of intervention content that exert an effect on the outcome of interest.[54,55] To facilitate synthesis, two independent authors (RB, ES) independently characterized delivery features and active ingredients, and discussed discrepancies until consensus was reached.

Standardized effect sizes were used to determine the threshold of outcome clinical significance. For studies that reported raw group means and standard deviations, effect sizes (Cohen's d) were computed using standardized mean differences.[56] Between-group effect sizes estimated by the differences between the mean changes of activity limitations in the intervention and control groups divided by the pooled standard deviation (SD) of activity limitations at baseline.[57] Magnitude of effect was categorized as negligible (<0.2), small (0.2 - 0.5) , medium (0.51 - 0.8), and large (> 0.8).[56] The effect size of the follow-up closest to 6 months post-intervention was selected which in most cases represented the post-intervention assessment. Studies which did not present data to calculate effect sizes but provided estimated effect sizes are noted in the table.

2.3 Results

The database searches identified a total of 15,136 potential studies for title and abstract screening after duplicates were removed; 168 articles were reviewed for full text screening. A total of 11 studies examining 14 distinct interventions were included for synthesis (Figure 3). The authors contacted 10 of the 11 corresponding authors to request additional information on sample characteristics, delivery features, active ingredients, and/or outcome data that were not in the publication. Full or partial clarification was provided by five of the 10 authors. There were nine studies with sufficient data (i.e., means and standard deviations) to compute or list published effect sizes. Five of the studies originated from Europe and three studies from the United States. Additional studies originated from Australia and Asia, along with one multi-continent study (United States and Europe).

Eight of the eleven studies were two-armed parallel group randomized controlled trials with control groups as usual care (n=5), waitlist (n=2), or another comparator intervention (n=1). Two studies were three-arm comparative effectiveness designs, and one study was a crossover randomized controlled trial. Using the Cochrane Risk of Bias 2.0,[53] seven studies demonstrated low risk of bias,[58-64] three studies demonstrated some concerns,[51,65,66] and one study demonstrated high risk of bias[67] (See Appendix B).

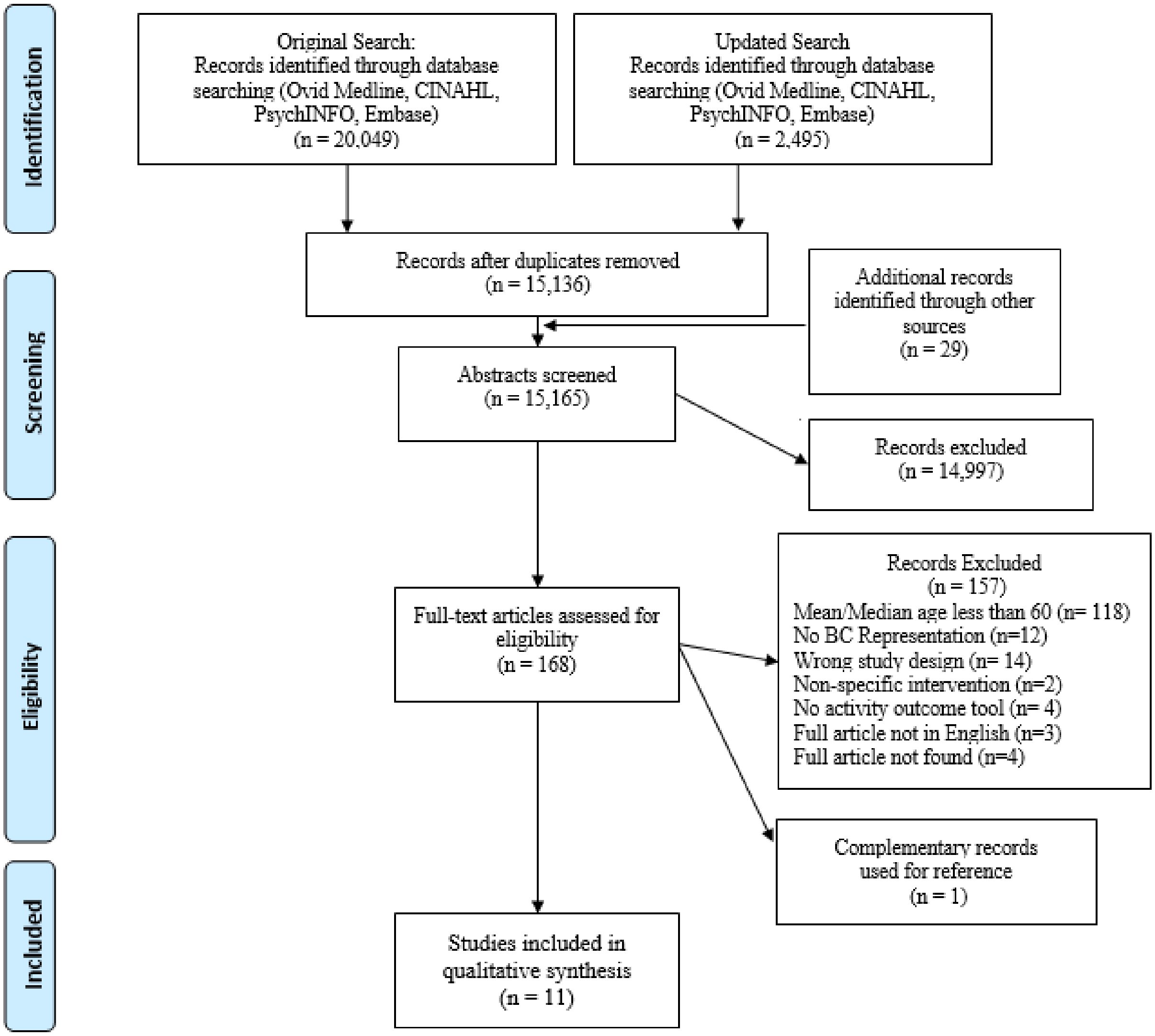


Figure 3 PRISMA flow diagram (original search 04/2020; updated search 10/2020)

2.3.1 Participants

Table 1 describes the study samples. A total of 1,631 participants were enrolled across the 11 studies with sample sizes ranging from 32 to 641 participants. Four studies enrolled participants ≥ 60 years of age, while the remaining studies enrolled adults 18 years or older, with mean or median ages higher than 60 years. There were no studies that focused on the oldest (≥75 years) or oldest-old[41] (≥85 years) despite these being fast-growing age groups in the United States.[40] Ten of the 11 studies enrolled participants with multiple cancer types and stages. Of the 1,631 participants across study samples, the five most prominent cancer diagnoses were breast (n=558), prostate (n=422), colorectal (n=165), lung (n=142), and gastrointestinal cancers (n=131). Three studies[60,61,65] focused on participants with metastatic or advanced disease exclusively. Five of the 11 studies[58,59,61,62,67] included both participants that were undergoing primary treatment and/or or were post-treatment completion at the time of intervention. On average, participants were three to five years post-diagnosis. Of the six studies[51,58,61-63,66] that reported race or ethnicity, study samples were overwhelmingly White, non-Hispanic participants (60-97.8% of participants). Of the seven studies[51,58,60,61,65,67] that included information on participant education, 39.9% of participants were college graduates.

Table 1 Participant characteristics from included studies (n=11)

Authors, (year)	Sample Size	Country	Cancer Type(s) Included	Breast Cancer, n (%)	Stage	Time since Diagnosis	Age (years), Mean (SD)	% White	Treatment Status
Poort et al., 2020[65]	134	Netherlands	Breast, Colorectal, Prostate, Renal Cell, Ovarian, Bladder, Melanoma	54 (40.3%)	Metastatic or Advanced Cancer	5.8 (5.2) years	Total Sample Mean: 62.76	Not Reported	End of Life/Palliative
Lyons et al., 2019[58]	59	USA	Hematological, Breast, Lung, Gastrointestinal, Melanoma	18 (30.5%)	All Stages	Not Reported	All over age of 65	97.0%	During Treatment; Post-Treatment
Gomersall et al., 2019[59]	36	Australia	Colorectal, Prostate, Breast	1 (2.8%)	Not Reported	57.5 months	Total Sample: 64.8 (9.6)	Not Reported	During Treatment; Post-Treatment
Pilegaard et al., 2018[60]	242	Denmark	Gastrointestinal, Lung, Breast, Prostate, Head/Neck, Bladder, Gynecological, Other	37 (15.3%)	Metastatic or Advanced Cancer	Not Reported	Total Sample: 67.16 (9.3)	Not Reported	Not Reported
Tsianakas et al., 2017[61]	42	England	Breast, Colorectal, Gynecological, Heme, Prostate, Upper GI	7 (16.7%)	Stages 3 or 4	60% between 0-2 years	Males: 65.6 (10.8) Female: 59 (11.6)	81.0%	During Treatment; Post-Treatment
Winger et al., 2014[51,52]	641	USA and Europe	Breast, Prostate, Colorectal	289 (45.1%)	Not Reported	8.5-8.7 years	Total Sample: 73.6 (5.1)	88.7%	Post-Treatment
Miki et al., 2014[62]	78	Asia	Prostate and Breast Cancers	43 (55.1%)	All Stages	56.6-68.9 months	[a]Exp: 72.97 (4.6) [b]Con: 73.1 (5.1)	100%	During Treatment; Post-Treatment
Thomas et al., 2012[63]	227	USA	Breast, Colon, Head/Neck, Lung, Myeloma, Prostate, Others	39 (17.2%)	Not Reported	30-37.5 months	[a]Exp: 61.8 (11.3) [b]Con: 62.5 (11.2)	60.0%	Not Reported
Belmonte et al., 2012[64]	32	Spain	Breast	32 (100%)	Not Reported	Not Reported	Total Sample: 67.78 (11.3)	Not Reported	Post-Treatment
Rodriguez et al., 2019[67]	94	Spain	Lung, Breast, Digestive Tract	11 (11.7%)	Not Reported	Not Reported	Total Sample: 67.9 (9.9)	Not Reported	During Treatment; Post-Treatment
Demark-Wahnefried et al., 2018[66]	46	USA	Breast, Prostate, Colorectral, Kidney, lymphoma, lung, thyroid, head and neck, multiple myeloma, pancreas	27 (58.7%)	Locoregionally staged cancers	6.7 (7.7) years	Total Sample: 70.1 (8.1)	97.8%	Post-Treatment

[a]Experimental Group; [b]Control Group

2.3.2 Activity limitations and perceived quality of life outcomes

The included studies used a variety of outcome measures (See Table 2). Eight studies (73%) had primary outcome measures assessing changes in body structures or functions such as fatigue, cognition, pain, lymphedema, dyspnea, or physical activity capacity; secondary outcome measures assessed activity limitations. Two studies had primary outcome measures assessing activity limitations. There were 12 distinct measures used to assess activity limitations. Outcome measures were divided into two categories: 1) those focused on activity limitations, i.e., difficulty performing meaningful activities; and 2) those focused on perceived quality of life, i.e., impact of difficulty performing meaningful activities.

Several measures of activity limitations assessed effects of an intervention based on frequency of performance, number of limitations, caregiver burden, and/or number of minutes allocated to an activity. The Barthel Index was used in two studies (n=2) to assess performance in activities of daily living based on amount of assistance required to complete each self-care task.[68] Other activity limitations measures included Sickness Impact Profile[69] (SIPB-8), Late Life Function & Disability Instrument[70] (LLFDI), Multimedia Activity Recall for Children and Adults (MARCA), Assessment of Motor and Process Skills[71] (AMPS), and Individually Prioritised Problem Assessment[72] (IPPA), Lawton and Brody Instrumental Activities of Daily Living[73] (Lawton IADL), and Functional Independence Measure[74] (FIM). All measures were self-report except for the AMPS and FIM which were observational assessments.

Additional measures assessed the impact of activity limitations on perceived quality of life or well-being. These self-report measures included the Functional Assessment of Cancer Therapy-General[75] (FACT-G; functional well-being subscale), Functional Assessment of Cancer Therapy-

Breast[76] (FACT-B; functional well-being subscale), Medical Outcomes Study Short-Form 36[77] (SF-36; physical function subscale), and European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire[78] (EORTC QLQ; physical function subscale).

Table 2 Summary of outcome measures

Authors, (year)	Primary Outcome	Follow-Up Assessment	Activity Limitations	Between Group Effect Size (*d*)	Perceived Health and Function	Between-Group Effect Size (*d*)
Poort et al., 2020[65]ime	Fatigue	14 weeks	[a]SIP8 (Functional Impairment Subscale)[69]	[p]GE v [m]UC: 0.46 [q]CBT v. [m]UC: 0.27	[k]EORTC QLQ[78] (Physical Function Subscale)	[p]GE v [m]UC: 0.11 [q]CBT v. [m]UC: 0.15
Lyons et al., 2019[58]	Feasibility and Disability	16 weeks	[b]LLFDI Frequency[70,79] [b]LLFDI Limitations[70,79] Modified Activity Card Sort[80]	0.08 1.82 2.67	----	----
Gomersall et al., 2019[59]	Daily Sitting Time	12 weeks	[c]MARCA [81]	----	----	----
Pilegaard et al., 2018[60]	Performance and Participation in Everyday Activities	12 weeks	[d]AMPS ADL Motor Ability [d]AMPS ADL Process Ability[71] [e]IPPA[72]	-0.07 -0.16 -0.09	----	----
Tsianakas et al., 2017[61]	Health-Related Quality of Life	24 weeks	----	----	[h]FACT-G (Functional Well-Being subscale)[75]	-0.17
Winger et al., 2014[51,52]	Perceived Physical Health	12 months	----	----	[j]SF-36 (Physical Function Subscale)[77]	2.99
Miki et al., 2014[62]	Cognition	4 weeks	Barthel Index;[68] [f]Lawton IADL [73]	0.00 0.05	----	----
Thomas et al., 2012[63]	Pain	6 months	----	----	[h]FACT-G (Functional Well-Being subscale);[75] [j]SF- 36 (Physical Function Subscale)[77]	[k]C v. [m]UC: -0.14 [l]E v. [m]UC: 0.01 C v. E: -0.12 [k]C v. mUC: 0.02 [l]E v. mUC: 0.18 [k]C v. [l]E: -0.15
Belmonte et al., 2012[64]	Lymphedema Management	4 weeks	----	----	[i]FACT-B (Functional Well-Being subscale)[76]	[n]LFLIE then MLD: -0.13 [o]MLD then LFLIE: -0.92
Rodriguez et al., 2019[67]	Dyspnea	Hospital Discharge	Barthel Index;[68] [g]FIM	----	----	----
Demark-Wahnefried et al., 2018[66]	Feasibility; Perceived Physical Function	12 months	----	----	[j]SF- 36 (Physical Function Subscale)[77]	3.95

Note: Effect sizes reported from Poort et al. were calculated by the authors; all other effects sizes were calculated using raw means and standard deviations
[a]Sickness Impact Profile; [b]Late-Life Function & Disability Instrument; [c]Multimedia Activity Recall for Children and Adults; [d]Assessment of Motor and Process Skills; [e]Individually Prioritised Problem Assessment; [f] Lawton and Brody Instrumental Activities of Daily Living; [g] Functional Independence Measure; [h]Functional Assessment of Cancer Therapy-General; [i]Functional Assessment of Cancer Therapy-Breast; [j]Medical Outcomes Study Short-Form 36; [k]European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire; [k]Coaching; [l]Education; [m]Usual Care; [n]Low-Frequency Low-Intensity Electrotherapy was received prior to Manual Lymphatic Drainage; [o]Manual Lymphatic Drainage was received prior to Low-Frequency Low-Intensity Electrotherapy; [p]Graded exercise; [q]Cognitive Behavioral Therapy

2.3.3 Delivery features of interventions

Table 3 displays a summary of the delivery features. The most common intervention structure (n=8) was in-person and one-on-one (e.g., therapist meets with participants individually to delivery intervention). Interventions ranged from one day to one year in length with the mean duration of 13 weeks. Seven interventions[59,63,64] were completed in outpatient clinical settings whereas four interventions[51,58,60,61] took place in the participant’s home. Five of the interventions met weekly;[58,59,62,65] while other studies met up to five sessions per week.[64] In-person intervention sessions ranged from 30-120 minutes in duration in comparison to remote (e.g., telephone) sessions ranged 15-30 minutes. Six interventions incorporated a remote delivery feature such as phone calls,[51,60,61,63,66] text messages,[59] or optional remote session if the participant was unable to come to the clinic.[58] Gomersall and colleagues used tailored text messages to provide exercise education and to encourage goal achievement.[59] Pilegaard and colleagues used telephone calls to reinforce strategies learned during in-person sessions and to resolve any emerging problems related to activity performance.[60] One study conducted the intervention in a fully remote format. Winger and colleagues[51] used a combination of telephone counseling and tailored print materials to encourage cancer survivors to maintain healthy eating habits and physical activity over the course of 12 months. Telephone calls and printed educational materials spanned the course of the intervention with calls lasting an average of 15-30 minutes.[51]

Table 3 Summary of delivery features

Authors, (year)	Experimental Intervention	Interventionist	Duration	Frequency	Format	Delivery Method	Setting
Poort et al., 2020[65]	Cognitive Behavioral Therapy	Psychologist	12 weeks	Up to 10, 60 minute sessions	Individual	In-person	Hospital
	Graded Exercise	Physical Therapist	12 weeks	2-hour weekly sessions	Individual	In-person	Hospital or Outpatient Clinic
Lyons et al., 2019[58]	Health through Activity	Occupational Therapist	6 weeks	6, weekly sessions	Individual	In-person	Participant Home
Gomersall et al., 2019[59]	Exercise with Tailored Text Messages	Exercise Physiologist or Physiotherapist	4 weeks	Weekly 60-minute sessions with 8 tailored text messages	Individual	In-person; Remote	Outpatient Clinic; Telehealth
Pilegaard et al., 2018[60]	Cancer-At-Home	Occupational Therapist	3 weeks	Up to 3, 60-120 minutes visits; Up to 3 calls	Individual	In-person; Remote	Participant Home; telehealth
Tsianakas et al., 2017[61]	CanWalk	Trained Researcher or Research Leaders	12 weeks	1, 15-min phone call; 3, 30-min walking session	Individual; Group	In-person; Remote	Participant Home; Community
Winger et al., 2014[51,52]	RENEW	Health Counselor	52 weeks	15 telephone calls; 8 motivational prompts; daily exercise; 4 progress reports	Individual	Remote	Participant Home; Telehealth
Miki et al., 2014[62]	Speed Feedback	Researcher	4 weeks	Weekly, 5-minute session	Individual	In-person	Hospital
Thomas et al., 2012[63]	Coaching	Advanced Practice Nurse	6 weeks	1 call every other week	Individual	In-person; Remote	Outpatient Clinic; Telehealth
	Education	Registered Nurse	1 day	Watches 1 video	Individual	In-person	Outpatient Clinic
Belmonte et al., 2012[64]	MLD	Physiotherapist	2 weeks	10, 50-minute sessions (5x/week)	Individual	In-person	Outpatient Clinic
	LFLIE	Physiotherapist	2 weeks	10 sessions (5x/week)	Individual	In-person	Outpatient Clinic
Rodriguez et al., 2019[67]	Dyspnea Intervention	Occupational Therapist	Length of hospital admission	45-minute sessions, 5x/week	Individual	In-person	Hospital
Demark-Wahnefried et al., 2018[66]	Home Gardening	Master Gardener	52 weeks	Minimum of twelve monthly remote contacts	Individual	In-person; Remote	Community

2.3.4 Active ingredients embedded in interventions

The 11 included studies reported on 14 distinct interventions. Interventions incorporated 11 discrete active ingredients: exercise, behavioral activation, cognitive behavioral therapy motivational interviewing, general behavioral strategies, environmental modification, adaptive equipment, energy conservation and work simplification, education on physical activity and sedentary behavior, adaptive skills training, and manual therapy (See Table 4). Ten of the 14 interventions combined multiple active ingredients to reduce activity limitations (See Table 5). Interventions contained an average of three active ingredients, ranging from one to six. The remaining four studies used either exercise (n=2), adaptive skill training (n=1) or manual therapies (n=1) as a sole active ingredient.

Six interventions[51,59,61,62,65,67] examined the effects of exercise alone or in-combination. Exercise programs focused on aerobic training (walking), resistance and weight training, stationary bicycling, and home exercise programs. Exercise was frequently paired with general behavioral strategies or education on physical activity or sedentary behavior. For example, Poort and colleagues[65] administered graded exercise training in combination with goal-setting for activities of daily living and educational strategies to manage fatigue and sedentary behavior. Likewise, Tsianakas and colleagues[61] devised the CanWalk intervention to combine weekly walking with motivational telephone calls and printed materials.

Behaviorally-based active ingredients were commonly included in interventions. Eight interventions[51,58,59,61,63,65,66] incorporated a combination of cognitive behavioral therapy, behavioral activation, motivational interviewing, and/or general behavioral strategies. While four interventions were primarily guided by cognitive behavioral therapy,[51,65] behavioral activation,[58] or motivational interviewing,[61] they were each augmented by additional general behavioral strategies. General behavioral strategies included activity-specific goal setting,[58,61,65] telephone encouragement,[51,66] text-message reminders or prompts,[51,59] social support through online platforms,[66] and self-monitoring logs.[51]

Often interventions incorporated adaptive equipment provision and training, general adaptative strategies, and energy conservation and work simplification strategies as adjunct or 'optional' active ingredients. Adaptive equipment provision and training occurred in three, occupational therapy-administered interventions.[58,60,67] Adaptive equipment training was used to support goal-achievement and functional independence for older adult cancer survivors with specific needs. Energy conservation and work simplification was involved in five of the interventions to promote endurance building,[58,67] injury prevention,[60,66] oxygen and energy consumption,[67] and rest.[58] Energy conservation and work simplification was delivered in the form of educational pamphlets and/or therapist directed cueing. Similarly, adaptive skills training was incorporated into seven interventions[51,58,60,63,64,66,67] to manage cancer-related impairments (E.g., pain, cognitive impairment, fatigue), modification to daily routine or performance of daily activities, and/or educational pamphlets.

Table 4 Definition of intervention active ingredients

Active Ingredient	Definition
Exercise	Activities which focus on building strength and endurance. These include both aerobic-based activities (e.g., running, swimming, walking, elliptical, NuStep, cycling, etc.) as well as non-aerobic activities (e.g., weights, resistance bands, push-ups, sit-ups).
Behavioral Activation	An approach that can empower cancer survivors to identify, schedule, engage in everyday activities and manage side effects of cancer treatment. Behavioral activation interventions must include the following four components:[82] (1) Identifying pleasurable activities that the client would like to accomplish (2) Arranging schedule to make pleasurable activities possible (3) Use of a calendar or log to examine activity engagement in relation to symptoms (e.g., fatigue, pain, mood) and activity barriers (e.g., financial, environmental, social support) (4) Development of skills required to accomplish client-centered goals (e.g., social skills, problem solving, task-specific skills)
Cognitive Behavioral Theory	A common form of talk therapy (psychotherapy) to address inaccurate or negative thinking related to current problems. It focuses on current problems, rather than focusing on issues from your past. It looks for practical ways to improve your state of mind on a daily basis.[83]
Motivational Interviewing	A form of talk therapy between a healthcare professional and person to strengthen their commitment to a specific goal based on the person's own reasons for change.
General Behavioral Strategies	This includes a variety of techniques to manage symptoms and involvement in daily activities. Examples include: - Goal setting - Rewards for achieving goals - Activity reminders - Coping strategies - Identifying unhealthy behaviors
Environmental Modification	Strategies or actions which improve the accessibility to one's physical, social, and cultural surroundings.[49] Examples include: <u>Physical</u>: This includes natural or man-made surroundings and objects in them. Modification may include rearranging furniture, adding grab bars to a shower, ramp or elevator access, adding chairs for rest breaks, universal design, increased lighting, removing clutter, adaptive computer switches. <u>Social</u>: This includes presence of relationships with and expectations of persons, groups with whom a person have contact. Examples include groups of friends, coworkers, or government agencies. It may also include community characteristics (neighborhood demographics, senior centers, transportation programs, taxes). <u>Cultural</u>: Customs, beliefs, behavior standards, and expectations accepted by the society of which a person resides. This may include family traditions or work habits
Adaptive Equipment	Devices which enable people to perform tasks they were previously unable to accomplish or had trouble doing. These devices can improve mobility, communication, comfort in the workplace, or self-care activities.
Energy Conservation and Work Simplification Strategies	Strategies to complete tasks in the most efficient way in order to have enough energy or endurance to do the activities a person enjoys the most. Strategies may include pacing, sitting while doing activities, setting priorities, chunking activities, elimination of unnecessary tasks, avoid multitasking, etc.
Physical Activity Strategies	Strategies specifically targeting an active lifestyle. This may include scheduling walks, education on consequences of sedentary lifestyle, provision of a pedometer, tracking or logging step counts, and setting healthy lifestyle goals.
Adaptive Skills Training	A general approach directed at "finding ways to simplify or ease demands of an activity to support performance This may include solutions to ease selfcare tasks, simplification of activity demands, modify clutter to reduce distractibility, etc.[49]
Manual Therapy	Techniques and/or physical agent modality to treat specific body structures or functions.

Table 5 Included studies (n=11) intervention active ingredients

		Active Ingredients												
Authors, (year)	**Experimental Intervention**	**Exercise**	**Behavioral Activation**	**Cognitive Behavioral Therapy**	**Motivational Interviewing**	**General Behavioral Strategies**	**Environmental Modification**	**Adaptive Equipment**	**Energy Conservation and Work Simplification**	**Physical Activity Strategies**	**Adaptative Skills Training**	**Manual Therapy**	**Total Active Ingredients in Intervention**	**Control Group**
Poort et al., 2020[65]	Cognitive Behavioral Therapy			●		●				●			3	Usual Care
	Graded Exercise Therapy	●				●				●			3	
Lyons et al., 2019[58]	Health through Activity		●			●	●	●	●		●		6	Usual Care
Gomersall et al., 2019[59]	Exercise with Tailored Text Messages	●				●			●				3	Exercise Alone
Pilegaard et al., 2018[60]	Cancer-At-Home						●	●	●		●		4	Usual Care
Tsianakas et al., 2017[61]	CanWalk	●			●	●				●			4	Usual Care
Winger et al., 2014[51,52]	RENEW	●		●		●				●	●		5	Waitlist
Miki et al., 2014[62]	Speed Feedback	●											1	Usual Care
Thomas et al., 2012[63]	Coaching					●					●		2	Usual Care
	Education										●		1	
Belmonte et al., 2012[64]	MLD											●	1	LFLIE
	LFLIE											●	1	MLD
Rodriguez et al., 2019[67]	Dyspnea Intervention	●						●	●		●		4	Usual Care
Demark-Wahnefried et al., 2018[66]	Home Gardening					●			●		●		3	Waitlist
Frequency of Active Ingredient		6	1	2	1	8	2	3	5	4	7	2		

2.3.5 Estimated effect sizes

Between group effect sizes (*d*) for activity limitation outcomes (See Table 2) were available for four studies. Effect sizes (*d*) were not statistically significant and ranged from 0.00 – 2.67.[58,60,62] Lyons and colleagues demonstrated negligible to large effect sizes (LLFDI Frequency: *d*=.08; LLFDI Limitations: *d*=1.82; Modified Activity Card Sort: *d*=2.67) for a complex intervention combining six active ingredients.[58] Pilegaard and colleagues used the ‘Cancer-at-Home’ intervention to reduce activity limitations in persons with advanced cancer (AMPS ADL Motor Ability: *d*=-0.07; AMPS ADL Process Ability: *d*=-0.16; IPPA: *d*=-0.09).[60] Despite being powered for this outcomes, there were no significant effects between the intervention and usual care groups. Though Miki and colleagues provided feedback on processing speed with the primary goal of reducing cognitive impairment, the intervention had negligible effects for minimizing activity limitations (Barthel Index: *d*=0.00; Lawton IADL: *d*=0.05).[62] Poort and colleagues reported small-to-moderate effects, respectively, for participants in the CBT (SIPB8: *d*=.27) and graded exercise (SIPB8: *d*=.46) intervention groups.

Between group effect sizes for perceived quality of life outcomes were available for six studies. Effect sizes ranged from -0.92 to 3.95.[51,61,63,64,66] Three of the studies were powered to detect changes in the SF-36 Physical Function subscale. The CanWalk intervention was associated with a negligible between-group effect size post-intervention (*d*=-0.17).[61] The RENEW intervention that combined lifestyle, exercise, and physical activity education was associated with a statistically (*p*=0.03) and clinically significant change (*d*=2.99) favoring the waitlist control.[51,52] Demark-Wahnefried and colleagues conducted a home gardening intervention that was associated with non-significant within group improvement functional well-being (*p*=0.29). Participants in the gardening intervention verbalized qualitative improvement in the frequency of instrumental activities of daily living and leisure activities as a result of the intervention.[66] Between group statistical significance was not assessed, but the effect size of change was large (*d*=3.95).

2.4 Discussion

This review set out to characterize nonpharmacological intervention delivery features and active ingredients that may reduce activity limitations among older breast cancer survivors. We chose to focus on older breast cancer survivors with the belief that clarification of an intervention's influence on a prevalent sub-population could help clinicians focus attention and anticipate solutions for survivors with similar disablement and treatment trajectories. While a preliminary search revealed only one randomized controlled trial of a non-pharmacological intervention that measured activity limitations with older (≥ 65 years) breast cancer survivors, a broader search strategy inclusive of multiple diagnoses and age range identified additional interventions.

Only one third of participants across included studies had a breast cancer diagnosis, after a comprehensive search. This suggests that there is limited intervention research in this population focused on activity limitations. Underrepresentation of older breast cancer survivors in research is not uncommon and is associated with stringent eligibility, transportation issues, and demands associated with trials.[34] Sedrak and colleagues recommend designing studies which consider the unique needs of older adult survivor, broaden eligibility criteria to include more representative populations (diagnosis and comorbidity), and engage often with key stakeholders to identify barriers to recruitment and retention.[34]

Older breast cancer survivors value independence with activities of daily living, work or volunteerism, leisure, and social obligations.[11,43] Despite being a prioritized health outcome in this population, the majority of studies examined activity limitations as a secondary outcome. In our review, impairment-reduction was the primary outcome in nearly three-quarters of included studies. These interventions are based on the Biomedical Model of Disability[84] which view disablement as a linear pathway originating from active pathology to impairments to activity limitations. Interventions based on this model infer that symptom management or impairment reduction will lead to improvements in more distal outcomes of health (e.g. activity limitations).[84] However, impairment reduction may not automatically lead to improvements in activity limitations.[11,50,85] Given that cancer-related sequelae and activity limitations co-occur, future intervention development may consider approaches that address and measure multidimensional presentations of cancer-related disability.

Perhaps, interventions that prioritize engagement in meaningful daily activities may have a more favorable influence on a variety of activity outcomes. Lyons and colleagues used engagement in meaningful activities as a means to reduce activity limitations.[58] Using active ingredients of behavioral activation, adaptive skills training, and patient-centered goal-setting, participants experienced fewer activity limitations and engaged more frequently in meaningful tasks. The intervention group also saw improvements in quality of life as well as reduction in activity avoidance behaviors. Likewise, Demark-Wahnefried and colleagues devised an intervention that engaged older adult survivors in gardening. Participants were provided supplemental educational handouts on body ergonomics, lymphedema prevention, and skin protection. Participants demonstrated large improvements pertaining to perceived functioning, as well as significant reduction in pain, and improvement in gait speed. These interventions suggest that activity-focused approaches may address both impairment and activity limitations. Similar approaches have led to reductions in both impairments and activity limitations in other rehabilitation populations who experience disability similar to older breast cancer survivors.[86-88]

Overall, interventions that included behavioral strategies and adaptive skills training appeared to be associated with larger effect sizes.[58] However, we cannot conclude that these specific active ingredients independently influenced change. Eleven of the fifteen interventions were complex interventions comprised of a combination of active ingredients.[54] We were unable to detect which active ingredients had largest impact independently or which combination of active ingredients interacted to drive change. Few of the included studies suggested theoretical models that support the need for a complex intervention.[47] Without a solid theoretical understanding of an active ingredient's influence on change, there is likely to be weak change in target outcomes.[47] Future studies should rigorously examine active ingredients to identify those active ingredients that have greatest impact on activity limitations. The multiphase optimization strategy trial study design is an efficient approach to screen out ineffective active ingredients and optimize dosages of active ingredients with demonstrable effects.[89] This method can create more effective and efficient complex interventions that may improve real-world relevance and clinical meaningfulness.[89]

Intervention delivery features may also influence intervention effectiveness. For example, in this review, the mode of delivery for the same active ingredient varied across studies. A common active ingredient was exercise. Exercise was delivered in a variety of ways – remotely through educational materials,[51] in the community through walking groups,[61] or in a standard outpatient clinic.[65] Older adults confront a variety of barriers when accessing survivorship resources and cancer rehabilitation due to different social (e.g., caregiver burden, financial toxicity), environmental (e.g., limited transportation, complex medical schedules), and physiological (e.g.

age-related changes, comorbidities) challenges.[46] Intervention delivery may be optimized by seeking older breast cancer survivor and other key stakeholder input. Stakeholders are "individuals who have experience living with, caring for, advocating for, and/or treating those with a condition."[90] Stakeholders associated with this population may include older adult breast cancer survivors, caregivers, clinicians, payers, scientists, healthcare systems and administrations, and policy makers. Stakeholder input may identify key strategies to improve uptake, accessibility, implementation, and impact of intervention targeting activity limitations.[45,46] Given the breadth intervention delivery, it will be important for future research to assess stakeholder perspectives to help prioritize which delivery features will be most valued and practical.

Efforts to evaluate interventions addressing activity limitations may be limited by variation in instrumentation. Fettes and colleagues' review of disability assessment methods in individuals with advanced cancer revealed a variety of measures using binary response as to whether a participant could perform the activity without assistance or not.[91] The authors acknowledge that disability in daily activities is conceptually challenging to measure given its multidimensionality.[91] Fettes and colleagues recommended that future intervention research assess disability monthly using validated, categorically scaled outcome measures to assess sensitivity to change.[91] We also recommend measurement of multiple dimensions of disability, such as impairment *and* activity limitations, to further clarify intervention mechanisms and outcome change.

Of the studies we surveyed, few included participants of limited education. Only half of the included studies reported information pertaining to participant education, and of those studies, a large proportion were college-educated. Yet, older breast cancer survivors with lower educational levels are significantly less likely to utilize supportive care services[92] or be aware of long-term cancer and treatment risks.[93] Lack of inclusion of survivors with lower levels of education may limit generalizability, acceptability, and relevance of included interventions.

Likewise, included studies had limited representation of individuals of historically marginalized races and ethnicities. Yet, Black populations experience similar cancer incidence rates (460.4 per 100,000) as non-Hispanic white counterparts (464.6), with a similar trend for older adults with breast cancer.[94] Black, Hispanic, and Native American individuals are less likely to be diagnosed with local-stage cancer and have higher levels of comorbidity[94] which is associated with greater activity limitations.[2] Racial minorities experience early and compounding exposure to high levels of stress and health inequity that may leads to accelerated aging, chronic illness, and disablement at an earlier chronological age.[95] Our inclusion criterion of age 60 years or greater may have eliminated studies that included people of color who are experiencing the sequelae of aging at younger ages than White counterparts. And yet, these and other sociodemographic determinants of health and other cultural factors may influence the success or failure of intervention delivery and active ingredients identified in this review. To be more inclusive, future studies should consider adopting broader age criteria or alternate approaches to determining biological age.[34] Furthermore, greater efforts to recruit underrepresented populations will also be important in future intervention and implementation research. We must consider and address barriers associated with protocol design and study implementation that often perpetuate lack of diversity and underrepresentation in cancer survivorship research.

2.5 Strengths and Limitations

This scoping review was one of the first studies to characterize interventions that may reduce activity limitations with older adult cancer survivors. The use of the Medical Research Council complex intervention framework was a strength of this review. With the rapid growth of this population, we hope the findings of this scoping review inform future rehabilitation intervention development as well as research and healthcare priorities.

This review has several limitations. First, English language restrictions may add selection bias. Second, the broad definition of activity limitations led to a wide range of measures and constructs making it challenging to synthesize the finding. Third, we also restricted our search to study samples that included breast cancer survivors; thus, this could limit generalizability to other survivor populations. That said, six of the 11 included studies with sample sizes ranging 78-641 participants, included participates with cancer diagnoses other than breast cancer. Additionally, not all included studies were powered for activity limitations. Thus, we may have studies that under or over-estimated the effect sizes with respect to these outcomes.[96]

2.6 Conclusions

There have been multiple calls-to-action to consider development of cancer rehabilitation interventions that mitigate cancer-related disability.[50] Current interventions that address activity limitations in older adults cancer survivors are limited and complex in nature. As this population continues to grow and experience disablement, it will be imperative to design, test, and deliver effective interventions which influence priority outcomes. Based on the findings from this scoping review, future intervention research should consider the following recommendations: 1) clarify theoretical underpinnings of activity limitations; 2) seek stakeholder input on evidence-derived delivery features and active ingredients that should be prioritized and valued in care; 3) adopt systematic methodologies to refine complex interventions (e.g., multiphase optimization strategy); 4) prioritize and power studies for measuring activity limitations in this population; and 5) expand efforts to recruit underserved populations for enhanced generalizability of findings.

3.0 Older Breast Cancer Survivors' Perspectives on Cancer Rehabilitation: A Qualitative Study

3.1 Background

Due to advancement in screening and treatment, as well as longer life expectancies, older breast cancer survivors represent one of the fastest-growing populations in the United States.[97] The growth of this population has implications for the access and delivery of high-quality cancer care.[17] This population will require management of new and co-occurring comorbidities[14] as well as long-term cancer-related disability.[11] If left unaddressed, this disability may lead to excess medical expenditures[98] and healthcare utilization,[99] and undue accelerated aging.[100]

Growing evidence suggests that cancer rehabilitation interventions may mitigate mounting cancer-related disability.[21] However, these interventions are significantly underutilized across the cancer care continuum.[24] In 2015, representatives from the Cancer and Aging Research Group, National Cancer Institute, the National Institute on Aging, American Cancer Society, and the Patient-Centered Outcomes Research Institute met to discuss gaps and methodological issues in the design and implementation of survivorship interventions for older adult cancer survivors.[9] One recommendation from this expert gathering included redesigning intervention research to incorporate the input of patient perspectives and interdisciplinary experts throughout the development, testing, and implementation of intervention research.[9]

Understanding the priorities and preferences of older breast cancer survivors is a critical step to improve access and delivery of future cancer rehabilitation interventions. Oftentimes, findings from qualitative studies provide preliminary evidence to support development, acceptability, and implementation of complex interventions.[101] More specifically, use of an in-depth, qualitative approach may provide a richer understanding of cancer-related disability in this population and priorities for intervention.[102] In addition, it may reveal facilitators and barriers of access and delivery of rehabilitation interventions that affect implementation of intervention research.

The purpose of this qualitative study was to examine the priorities and preferences of cancer rehabilitation interventions among older breast cancer survivors. Through semi-structured interviews, we sought to address the following research questions:

1) What factors influence pursuit of rehabilitation interventions among older breast cancer survivors?
2) What constitutes valued intervention content for rehabilitation among older breast cancer survivors?
3) What constitutes preferred delivery features of rehabilitation interventions for o older breast cancer survivors?

This qualitative approach provides an opportunity to explore the dynamic factors that influence access and delivery of valued care among older breast cancer survivors. Such insights are important not only for providing reasons why existing interventions have been shown to be clinically effective (or not), but it is also integral to understanding issues concerning sustainability, value, and integration of interventions into real-world settings.[103]

3.2 Methods

3.2.1 Study design

We conducted a qualitative study using a brief, online questionnaire, and a one-time, one-on-one semi-structured interview. Telephone-based interviews were selected to optimize geographic reach, safety of participants, and a comfortable setting to discuss personal experiences. All methods were approved by the Institutional Review Board. Methodological considerations and reporting are based on the Consolidated Criteria for Reporting Qualitative Research (COREQ-32) checklist.[104]

3.2.2 Recruitment and sampling

Older adult breast cancer survivors were initially recruited through a convenience sampling technique using university-based registries (Clinical and Translational Science Institute Pitt+Me Registry; Pittsburgh Pepper Center Registry), previous breast cancer research studies at our institution, community support groups, and geriatric oncology clinics. Inclusion criteria were: 1) ≥ 65 years old; 2) initial diagnosis of breast cancer (Stages Ia – IIIc); 3) community-dwelling; 4) self-reported cancer-related disability associated with self-care or daily activities; and 5) completed primary cancer treatment (not including maintenance therapies) between 6 months and 5 years previously at the time of enrollment. Previous exposure to cancer rehabilitation services did not affect eligibility.

After recruiting ten participants, demographic and clinical features were analyzed to note gaps in participant representation related to racial or ethnic minority status and age. Remaining participants were identified through quota sampling techniques to promote inclusion of underrepresented individuals (e.g., age and race) that were more reflective of demographic composition of older adult breast cancer survivors in the United States.[105] Survivors who met eligibility criteria were contacted by the principal investigator to complete a telephone-based informed consent.

3.2.3 Data collection

Following informed consent, demographic and clinical characteristics were collected via an online questionnaire. Participants completed the questionnaire to document demographic and clinical characteristics as well as previous experience with cancer rehabilitation services. The questionnaire identified which of three semi-structured interview guides (Appendix C) would be administered during the interview. Each of the three guides was tailored to reflect a participant's previous experience with cancer rehabilitation interventions and/or desire for rehabilitation intervention (See Figure 4). For example, participants who had experienced formal cancer rehabilitation were provided additional prompts to share why they pursued rehabilitation and their experience of rehabilitation. In contrast, participants who did not have cancer rehabilitation were prompted to share a rationale and additional thoughts on desire for rehabilitation. All interview guides were structured to capture the lived experience with cancer-related disability, prior experience with cancer rehabilitation (if applicable) and preferences for future cancer rehabilitation services. More specifically, interviews facilitated conversation about preferred content of interventions (what), indications for cancer rehabilitation (for whom), timing (when), and models of delivery (where, by whom). Interviews were pilot-tested for clarity, interview length, and comprehensiveness prior to data collection.[106]

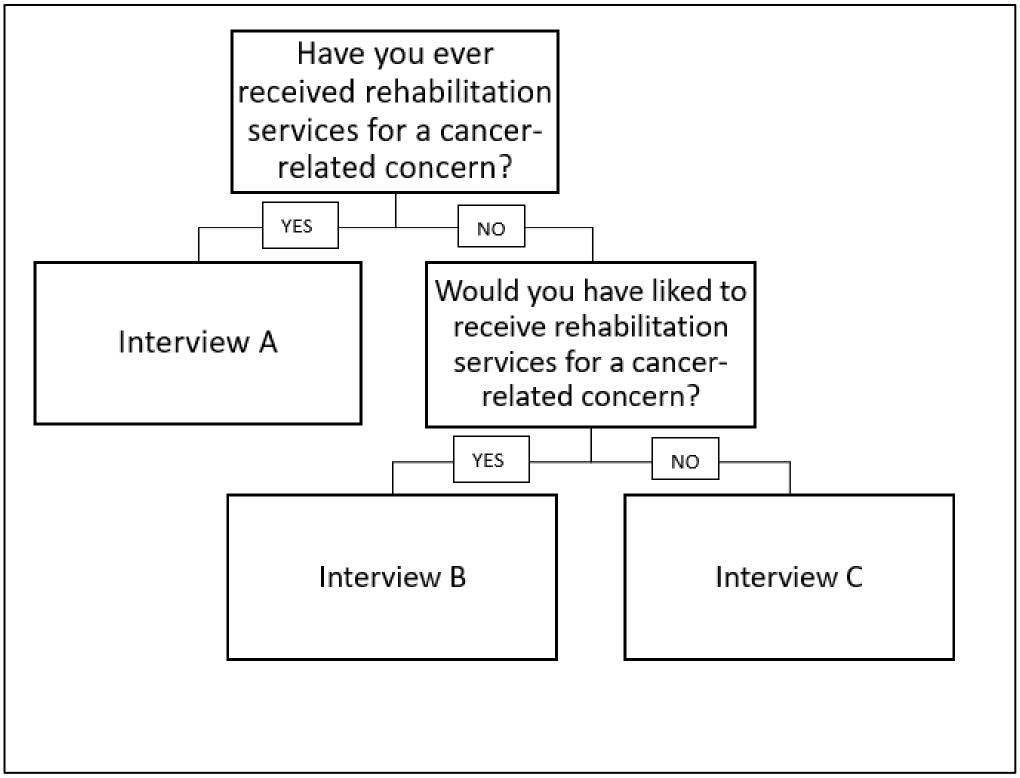


Figure 4 Interview guide determination

Interviews were scheduled for a time and date that were convenient to the participant and conducted via telephone. All interviews were conducted by the principial investigator (RB). The principal investigator is a female, PhD Candidate, licensed occupational therapist with moderate experience with in-depth interviewing and four years' clinical and research experience working with oncology populations. Interview techniques were supervised and discussed with a qualitative methods expert (NL). Participants were aware of the principal investigator's credentials and her interests in improving access and delivery of cancer rehabilitation interventions. Memos were written immediately following the interviews to capture reflections of the interview. Participants were compensated $30 for their participation.

All interviews were audio-recorded and transcribed verbatim by a trained entry-level occupational therapy student (RE). To ensure the quality and anonymity of each transcription, interviews were de-identified and proofread against the audiotape using the three-pass-per-tape policy[107] by a trained research assistant (RE) and the principal investigator (RB).

3.2.4 Data analysis

Demographic data were analyzed using descriptive statistics. Key themes were identified through inductive thematic analysis[108,109] of phrases from the transcriptions.[110] Data management and analysis were conducted using NVivo QSR Software (Version 12) [computer software]. The principal investigator (RB) read each transcript and related memo prior to coding to have a broader sense of the interview. Open codes (n=123) were generated using descriptive and in-vivo open coding approaches.[110] Open codes were condensed into patterns, defined, and formed into a codebook. Preliminary materials were reviewed by an independent reviewer (KL) with expertise in oncology, intervention development, and qualitative methods. Scientists RB and KL met to review emerging patterns, codebook definitions, and consistency of ideas. Furthermore, RB re-reviewed the transcripts and re-coded each interview in its entirety to capture quotes that fit into existing patterns, identify new ideas, and develop themes. The research team (RB, NL, ES, KL) met to discuss consensus of final themes for each research question. Dependability and credibility were maintained through an extensive audit trail of key decisions and codebooks. Discussion of data saturation of data interpretation were reviewed through weekly consensus meetings.[111] Furthermore, self-reflection on the research study was reviewed at weekly study meetings (RB and ES) to consider how experiences in occupational therapy, health services research, intervention research, and clinical experiences may have influenced interpretation of the findings.[111]

3.3 Results

3.3.1 Participants

Thirty-four potential participants completed screening; twenty potential participants were ineligible due to age (n=2), time since primary treatment completion (n=5), lack of cancer-related disability (n=11), or limited interest in study activities (n=2). Fourteen individuals provided informed consent (See Table 6). All consented participants completed the online questionnaire and scheduled interview. Telephone-based interviews ranged 24 – 48 minutes. Participants had an average age of 71.4 years old (SD = 4.7). The majority of participants were White (86%) and living in the northeast region of the United States (71%). Five participants (36%) previously received rehabilitation services for a cancer-related concern. On average, participants completed primary cancer treatment 36.5 months (SD = 18.7 months) prior to study enrollment. All participants were still receiving maintenance therapies. Across our three primary research questions, 14 themes emerged. The themes are illustrated in Figure 5.

Table 6 Participant demographic and clinical characteristics (n=14)

Age, years, Mean (SD)	71.4 (4.7)
Breast Cancer Staging, n (%)	
I	8 (57)
II	3 (21.5)
III	3 (21.5)
Time Since Diagnosis, months, Mean (SD)	36.5 (18.7)
Cancer Treatment(s) Received, n (%)	
Surgery	13 (93)
Chemotherapy	4 (29)
Radiation	12 (86)
Hormonal Therapy	14 (100)
Immunotherapy	1 (7)
Race, n (%)	
White	12 (86)
Black	1 (7)
Asian	1 (7)
State of Residence, n (%)	
Pennsylvania	10 (71)
Florida	2 (14.5)
Wisconsin	2 (14.5)
Education, n (%)	
High School or Equivalent	3 (21)
Associate or Vocational Degree	3 (21)
Bachelors Degree	3 (21)
Graduate Education (Master, Doctorate)	5 (37)
Missing	
Urbanicity, n (%)	
Rural	2 (14.5)
Suburban	10 (71)
Urban	2 (14.5)
Medications, n (%)	
4 – 6	6 (43)
7 – 9	6 (43)
10+	2 (14)
Received Cancer Rehabilitation Services*, n (%)	5 (36)
Occupational Therapy	2 (14.5)
Physical Therapy	4 (29)
Speech Language Pathology	1 (7)

*Some participants received more than one rehabilitation discipline

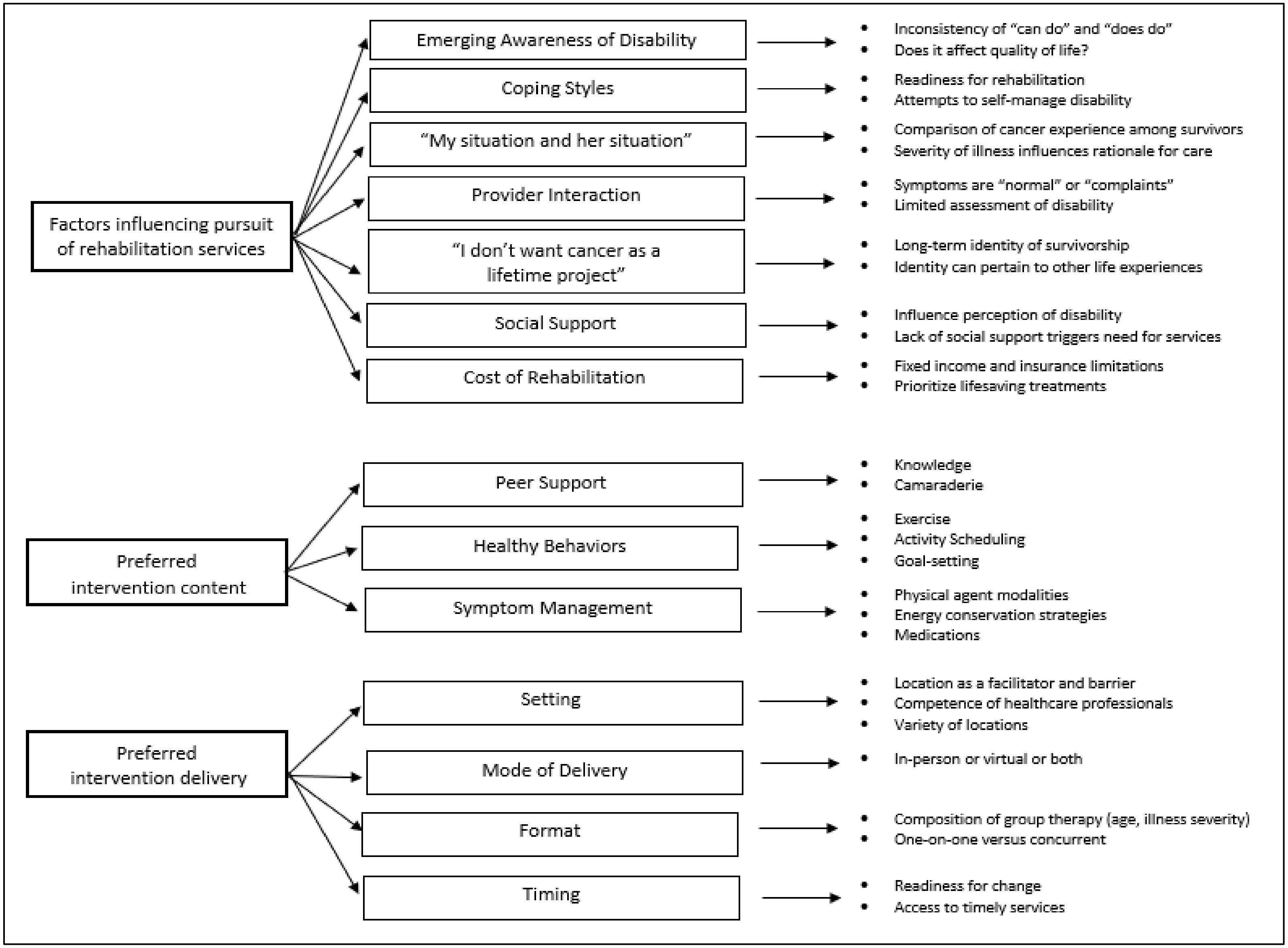


Figure 5 Major themes associated with research questions

3.3.2 Research question 1: factors influencing pursuit of or access to rehabilitation services

Interviews addressed a variety of factors such as participant’s ongoing health, physical environment, social environment, and personal factors that may influence survivors’ rationale to pursue or access rehabilitation intervention. After coding the interview transcriptions, seven themes emerged contributing to the pursuit of rehabilitation services: 1) Emerging awareness of disability; 2) Coping styles; 3) “My situation and her situation;” 4) Provider interactions; 5) “I don’t want cancer as a lifelong project;” 6) Social support; and 7) Cost of rehabilitation.

3.3.2.1 Emerging awareness of disability

All participants expressed challenges with day-to-day activities because of cancer or cancer-related treatment. Survivors shared concerns about impairments such as peripheral neuropathy, fatigue, pain, and ambulatory dysfunction in addition to activity limitations. Patient perception of disability on quality-of-life influenced pursuit of rehabilitation. For survivors who did not notice changes in quality of life, rehabilitation was a non-essential service. A 68-year-old Black survivor of Stage II breast cancer reported:

> “Well, if I had neuropathy in my feet, like I have in my hands, I could see the need for me having to learn how to move on my legs again, as a result of that. Or if I had had a mastectomy, and had to learn how to move my side, again. I would say therapy would have been something that I thought should have been recommended. But I didn't, you know, mine had shrunk enough from the chemo that it was just the lumpectomy…Because my neuropathy is in my hands, and my hands still function, they just feel funny. It doesn't limit me moving around or walking, or, you know, doing anything I even so it's just I can, you

> know, do a little bit and then when my hands get really crazy, I can't sometimes feel the needles, But so I haven't had to relearn anything. And to me, that's what those kinds of therapies do they teach you ways to function when that function has been taken away from you.” [BC9]

Interestingly, multiple participants reported activities that they “can do” but later reported problems with what they “actually do.” Participants presented themselves as “fine” or “totally back to normal,” yet later discussion revealed ongoing dissatisfaction and challenges with performance of daily activities.

> “[Cancer] did not affect me. Not at all. I kept doing everything…Um I know it cut my water ski season short because you know, once I got the surgery I wasn't on skis anymore…I really didn't…just being tired. Like if we were going to the movies my sister and I would go to the movies with a couple other ladies and I would fall asleep, you know, they’d say oh look at her she's sleeping, but I just couldn’t stay awake but yeah, other than that it was nothing that I can remember.” [BC1]
>
> “Yes, I was in the Livestrong program at the Y. I didn't realize all the stuff I really couldn't do very well till I got down there. And they, you know, they wanted you to stand on your toes, you know, like the ball of your foot and your toes and see how long you could last. You know, you did that. And then you did some other things. Just test your strength. And I couldn't believe how bad it was.” [BC7]

3.3.2.2 Coping styles

It was common for survivors to discuss coping styles, as a factor influencing pursuit of rehabilitation. For one participant, rehabilitation immediately following treatment was important to move beyond cancer. She believed the sooner that she completed therapy, the sooner her disability would resolve and end her cancer experience. For others, survivors sought additional time to process the treatment experience and/or, encounter downsides of disability before seeking rehabilitation. One survivor shared:

> “It was about a year after. They had offered it to me at one time and I wasn't ready for what it was. It was right after my treatment. And after having a whole year of not going anywhere and doing anything with my knees and then with the radiation and everything. We wanted to go away on a vacation and it was at the time we were on our vacation. So then the next time it came up I went to it. And I'm glad I did.” [BC7]

Some participants were reluctant to discuss cancer rehabilitation based on general acceptance of disability. A 77-year-old Asian survivor of Stage 1 cancer reported that her strategy to overcome disability was to give up challenging activities:

> “I have been into yoga and meditation for almost all my life. And that's what kind of uh made me go through and still was able to work even though I have lower back pain. And I’ve learned to let go the things I cannot do. Like, I don't have as many socials, if I cannot cook for a whole lot for my whole family than I won’t cook. So I know how to handle, I try to go back to the basics of what I needed just for myself.” [BC11]

Others felt confident to self-manage ongoing disability. A strong sense of self-efficacy limited rehabilitation seeking behaviors. Three survivors reported that they were proud of their self-sufficiency and general independence. Cancer was often not their first life set-back. Due to this, they had developed resilience to adversity. Factors that attributed to overall resilience included sense of self, self-efficacy, and social support.

> “Just in general, I am,. I kind of take control. Not not bossy, just in control. I'm not, I'm not afraid. You know, like, like for instance, I walked slowly so I won't fall.” [BC2]

> “So maybe my own arrogance, maybe my own feeling of um self-sufficiency, maybe didn't allow me to access something that might have actually been helpful. But I don't know, I don't know that I really needed it.” [BC8]

3.3.2.3 “My situation and her situation”

Participants’ compared their “situations” to other survivors in order to rationalize a need for rehabilitation. In general, severity of illness influenced a survivors’ decision to discuss disability with their healthcare provider. Two participants viewed their disability associated with early-stage cancer as “complaints” rather than a valid concern.

> “And I mean my support was a, was a friend that had her breasts removed, you know. And she had to have reconstruction. So I looked at what she went through and I'm thinking wow, you know, I can't complain. I just can't complain. There's no way I don't have a right to complain.” [BC1]

> “I'm sort of stoic I think that's part of it but I also think I’m pretty honest and I think they just don't make, you know, it was early it’s what's called early breast cancer and I'm not sure they focus a lot on that kind of thing. I just I don't know I didn’t really feel slighted to be honest, but I also certainly nobody is making a fuss over me, you know.” [BC3]

Severity of illness also influenced survivors’ perception of who would benefit from rehabilitation services. For example, a 76 year-old White survivor of Stage 1 cancer referenced:

> “…There are people that have metastases, people who have a variety of um signs that suggest that they are going to continue to have this as a problem. So um I think those people, you’re going to treat them differently. Chronic disease is treated differently than a sort of a one-time event that you, kind of again, I consider myself cured...I consider myself

> a healthy person who is very, very lucky…If they have metastasis, they're going to need a different type of service, different type of help.” [BC8]
>
> “Absolutely someone that has more than stage one. And would have, you know, I think they call it bilateral… And I think, you know, people that um have stage two, three and four exercise helps your body heal. And I would think it would be extremely beneficial for them.” [BC14]

3.3.2.4 Provider interaction

Patient-provider interactions presented as both opportunities and barriers in the pursuit of cancer rehabilitation. Two participants noted that their physicians recommended rehabilitation to improve adherence to treatment (e.g., radiation, chemotherapy). Without rehabilitation, survivors’ felt that treatment would not be successful or influence survival. For example, a 77-year old White survivor of Stage 3 breast cancer stated:

> “I think what [physical therapy] did with me because of the pain of having to keep your shoulder and your arm up above your head to get so the so the radiologists could do what she had to do. I think they sent me to the physical therapy right away, almost right away. Because I was it was hard to keep that up there, your arm up for such a long period of time.” [BC6]

Likewise, speech language pathology services were referred to improve adherence to oral chemotherapy:

> “I couldn't swallow pills. I've never been able to swallow pills since I was five years old and chocked on a lifesaver. And I've got an asteroid Ibrance [type of chemotherapy]. Um so my primary also had speech and swallowing and the girl is lovely. And she actually has

> me swallowing some pills now with applesauce. Because Ibrance can be opened or chewed, you know, because it's chemo." [BC5]

Participants shared that healthcare team members referred to their long-term sequelae a "normal" or "complaints." Some participants felt their concerns were left unaddressed at routine medical appointments. Survivors did not know how long cancer-related disability would persist or if it would be permanent.

> "One doctor says, be patient, it'll go away. Another doctor says learn to live with it." [BC2]
>
> "No, he never no, never did. He just kind of said, yeah, that's a complaint we hear that from a lot of women, but that was all. He was sympathetic (laughing)." [BC10]
>
> "I did mention that under my arm I felt a lot of tightness and some numbness and they told me that was normal and I asked whether or not I should have any physical therapy for that. That was my initiating a question and they said probably you shouldn't need that if you just um… they showed me this sort of an exercise where you crawl your arm up the wall. That was that." [BC3]

Participants suggested that prevalence of symptoms and limited discussion influenced referral to rehabilitation interventions. Three participants attributed lack of knowledge about cancer rehabilitation by both the patient and physician as a barrier.

> "Um I think it's because it's so uh frequent that women feel this, that it's not, you know, there may be like, there's not a lot of history of women getting physical therapy for these individual things, that they don't recommend it. You know, they don't know if we'll help or not." [BC10]
>
> "Well, I thought, you know, had there been um, when I saw the word occupational therapy, I thought maybe I could do that and help my thumb. Especially, you know, had I known

> about them, I would have asked. Or maybe my doctor didn't even know, to recommend, you know...” [BC10]

Several participants mentioned they would have liked to receive more information from health care professionals prior to treatment, understand the long-standing implications of treatment, and be provided with more tailored strategies.

> “Like the Serenity Prayer, you know, that just to know, what can be changed, and what can't be changed. And be able to accept that. If there are things that can be changed…Um tell me that in the very beginning, before I go through anything, because you know, say you might end up with this, or you might have some joint pain or you might have this, you know, things might bother you. And here's some things we can do.” [BC13]

The way in which follow-up appointments were conducted often limited discussion of disability. Limited engagement from the patient created missed opportunities to discuss patient priorities, like disability.

> “You know, they don't like to put thoughts in your head, they want you to come up with it. And I can understand why. He said, do you have any, you know, pains or things like that? And I said no. And I went home and thought about it and said, you dummy. That's what you've been feeling.” [BC14]

3.3.2.5 “I don’t want cancer as a lifelong project”

Recognition and acceptance of cancer as an acute or chronic illness influenced pursuit of rehabilitation services. Participants grappled with the long-term identity as a “cancer survivor.” When cancer and related sequelae were portrayed as a “lifelong project,” participants’ declined interest in rehabilitation interventions. A 65-year-old White survivor of Stage I breast cancer shared:

> "I'm trying to think why would I not want [cancer rehabilitation]…also just I suppose the inconvenience, also just of course making a commitment to go and finding the time slot. But maybe also wanting to move on as opposed to dwell um on the therapeutic, you know, continued therapy. Which you really do. There is something about getting beyond it and feeling like okay I'm just returning to my normal life. I mean you don't want to dwell on it." [BC3]

Another participant mirrored this sentiment, sharing that she had stopped attending cancer support groups. To her, cancer was a discrete medical event rather than a chronic condition.

> "We call people diabetics [because it is chronic] and they don't call us "canceretics" or anything like that. But I think it's how self-image sort of, and at my age, I'm just being honest…But I saw some of my friends, it seems like all they do is talk about their breast cancer, having this self-image. And I've gone on just a few websites and I will never again go on any support groups. That's just, that sort of stuff…but it's me, it's not my style. I just I don't like all this poor pitiful me, I don't like all this, you need support. And I don't know for some, and I saw one of my good friends just it just became like, that's all she talked about. And like, I found that very sad." [BC8]

She continued to share that as an older adult, she had other experiences, such as being a retired pediatrician, wife, and friend, that provided her a stronger sense of identity. She placed a lower level of importance on the label of cancer and residual symptoms. Thus, she found cancer rehabilitation interventions as an excess medical expenditure:

> "[Moving away from cancer] makes them feel their first and foremost a person. So anyway, I've said it enough. But I think you have to watch that. I think over recommendation [of services] can't occur, sitting there having cancer doesn't define me."

On the other hand, the lifelong attribute of cancer survivorship meant resilience and being altruistic to one participant. Having experienced rehabilitation for lymphedema, cancer survivorship was invisible badge of duty to offer peer support, provide encouragement, and discuss strategies to overcome hardship. Just as she received help during her treatment, she described her survivorship as an opportunity to help others in similar situations:

> "Cause I know I had talked with a girl uh yesterday, no Saturday, and um she said 'I just didn't know what to do.' Because people don't know what to do. Whether they should call you, whether they shouldn't call you. You know, did you want to talk. And I was the type of person that I did want to talk. And I mean my support was a was a friend that had her breasts removed, you know." [BC1]

3.3.2.6 Social support

Availability of social support appeared to facilitate and inhibit pursuit of rehabilitation services. Those with access to social support voiced low desire or need for rehabilitation services. In contrast, participants who did not have consistent social support, funds to support paid caregivers, and/or lived alone tended to ask their physicians about rehabilitation interventions. Participants defined social support as assistance from family and friends who provided effective solutions to manage cancer-related disability such as adjustment to the condition, self-care, and instrumental activities of daily living. Social support was incorporated for physical and psychosocial benefit. Physical support included management of day-to-day chores, cooking, grocery shopping, and physical assistance with functional transfers. For example, a 69-year old White survivor of Stage IIIb breast cancer stated:

> "My husband does [what I cannot]…Uh he does the laundry. He does much of the cooking, he does the vacuuming. Um he does all the driving because I can't turn my neck.

> Um constantly schleps me to treatments, doctor's appointments...” [BC5]

A 77-year old White survivor of Stage II cancer was encouraged by her friends to hire temporary, formal caregiving services. Between care from her friends and a paid caregiver, she frequently minimized challenges that she may have encountered had support not been present:

> “I don't think I had any challenges, I have this…I am very, very lucky I have a lot of friends that are wonderful, wonderful people that went shopping for me without me even asking and brought food over and, and just always, I had people at my disposal that I didn't even have to ask at times. Kind sweet people.” [BC2]

Social support also came in forms of psychosocial or emotional assistance. It provided motivation to adhere to cancer treatment, management of long-term sequelae, and process the cancer experience. A 68-year-old White survivor of Stage 1 breast cancer reported:

> “And just be around family, my grandkids, you know they were such you know moral support. And my daughter and my son-in-law. I mean I just had so much support. And I think that’s like the main thing. I mean if someone is going through this alone, it’d be horrifying. [They provided] Just moral support, you know, just um calling me and always asking how I’m doing…”[BC1]

Conversely, social support may also perpetuate disablement and reliance on family and friends. One survivor shared that she enjoyed her involvement in an exercise group for cancer survivors. However, when she brought up the idea of continuing her exercise routine at home, her family was unsupportive:

> “I was telling my children, maybe I should raise money and get a treadmill at home. But they both are saying for older people [that a] treadmill without anybody there is dangerous because it can fall off.” [BC11]

3.3.2.7 The cost of rehabilitation

Approximately half of participants discussed cost of rehabilitation in terms of patient's insurance, financial status, and schedule availability (time). Some survivors discussed the constraints of government-supported and private insurance plans. As most were retired and living off a fixed income, survivors reported having limited flexible spending. Flexible spending included co-pays related to "optional" rehabilitation interventions. For example, one survivors stated:

> "Had insurance not covered it, I would not have [done physical therapy]. Well, I'm on a limited income, I'm on Social Security. And so cost is everything to me in regarding food, Medicare, medicine, um every everything. Cost is very, very uh means a lot to me as a senior citizen." [BC12]

After limited gains in lymphedema therapy, one survivor chose to forgo further rehabilitation services. She reported needing to prioritize money for lifesaving treatment and her spouse's quality of life. When describing the influence of cost on her cancer experience, she stated:

> "But the other thing too, I mean, there's financial concerns too which I mean, this has nothing to do with therapy. But um this is the most ridiculous thing we've ever heard. Um you know, you know, Ibrance [chemotherapy] costs about $30,000 a month…So and my feeling is, you know, I know, I'm not going to be around very long. And I want my husband to have a good life. You know, with someone else when I'm gone. I don't want him to be wiped out because of me." [BC5]

Three participants stated they enjoyed subsidized programming hosted by a local cancer wellness center which allowed them to pursue alternative therapies at a low cost. Given the community style programming, they incurred a lower cost per session. One survivor who participated in community-style yoga and acupuncture reported:

> “I don't know that [the programming] worked, I don't know that it was successful. I probably did maybe four or five sessions. And there were a couple people in the room um for a couple of sessions. And then after that I was the only one. So I don't think everybody else was as comfortable with group therapies as I was, I was just trying to avoid the cost, because at that point, it was half of the original cost to do it.” [BC9]

Cost was also attributed to the amount of time spent in rehabilitation. Most survivors referenced the importance of their schedule and time management. Survivors reported distancing themselves from complex medical schedules at the conclusion of their primary treatment. One survivor shared her experience in a hybrid home health-outpatient physical therapy. The dual settings were in place due to the COVID-19 pandemic. Despite motivation to resolve ongoing falls and ambulatory dysfunction, she reported:

> “And did I feel it was too much? I felt at the end there was too much because it wasn't working. While I was doing it, did I feel it was too much? No, I was hoping it was working. Oh, if I saw results, I would be doing it now. I would have continued it for the rest of my life. But I saw no results. It was a pain in the ass, excuse me.”

3.3.3 Research question 2: Preferences for intervention content

Our participants had different exposure to cancer rehabilitation experiences. For those who had received cancer rehabilitation services (n=5), participants were prompted to recall their experience. If applicable, participants shared additional thoughts on what they liked or what might have enhanced their rehabilitation program. All participants were asked to share patient- and provider-derived strategies used to manage disability. Through these interviews, we identified three areas of intervention content (e.g., theory, frameworks, or approaches to influence cancer-related disablement) used to manage aspects of cancer-related disability: peer support, healthy behaviors, and symptom management.

3.3.3.1 Peer support

The influence and use of social environment on cancer-related disability was a recurrent topic across interviews. Participants shared that peer support was both an advantageous and disadvantageous intervention approach. For some, peer support was leveraged to provide information, offer emotional and spiritual support, as well as encourage advocacy. One participant shared:

> “Well, you know, sometimes you when you hear other people, when they say something, you could, you could say, hey, you know what, I didn't think about it, but I feel that way too, or, or, you know…” [BC10]
>
> “I mean, my, my dearest friend would sit with me for each session, four hours. And if anything, she's very warm. She’s had cancer four times herself, so she's very knowledgeable” [BC2]

Participants acknowledged that the effectiveness of a peer support intervention would be highly dependent on peer match (e.g., peers’ age). For example, some participants shared they were not comfortable speaking with someone who is significantly younger than them. Survivors reported that younger peers may have dissimilar experiences and treatment outcomes.

> “But, you know, in a therapy group. I tended to feel sorry, for all the younger people that were sick. And I really wouldn't have focused that much on myself. And I found it, it was heartbreaking actually. I remember talking to this one beautiful woman. Um they had they offered a makeup class. And they had somebody come in with wigs and things like that…I would say she was in her late 40s. Uh and this was her second time being treated for cancer.

> And, you know, if she's young, and when you're young like that, cancer is much more aggressive. So I just, I felt bad for her. I didn't really want to be around her, or people like that. It was too hard for me. I found it sad." [BC4]
>
> "I think one of the dangers for I assume you're talking to all age, because a lot of young women have breast cancer, which is very different. Again, I have to say that right up front, I was I was 68 when I was diagnosed and it's a very different condition than when you're 40. I mean, it's completely different. You're with children and responsibilities. Um so I, in general, I don't like the I don't know. I would almost feel sorry for younger people having to interact with older people when it comes to a healthcare issue." [BC8]

Participants also reported disadvantages of an age-matched peer. Survivors worried that age-matched peers may cause them to fixate on negative aspects of aging.

> "I mean, I you know, I'd hate to be in a I'd hate to be in a group of 20 people that are hobbling around of course." [BC13]
>
> "My definition of Hell is being in a room with old people talking about their bodies. It's true. I've always hated that even when as my mother years ago when she got elderly and you would go there and all they talked about was their medicines and their doctors. My husband and I have sworn to each other we will not become those kind of old people. So to be in a group of people body focused, and that would be my Hell. But I mean, that's not to say I don't enjoy social company, and sometimes going through things with someone else." [BC8]

Survivors were indifferent toward peers of similar or varying cancer diagnoses. For example, one survivor described her experience in a cancer physical activity group:

> “So anybody that's had any type of cancer. I mean, you could have cancer of the eye or, you know, or skin cancer. Whatever you had cancer. I talked about it, where I didn't talk a lot about it, you know, you're trying to shield your family and your kids and all that stuff. But it helped bring out some of your feelings and so forth. And that was good to talk about that with other people in the same situation.” [BC7]

Another survivor without formal cancer rehabilitation expressed a similar mentality.

> “Um I don't think that would really make a difference. I don't think that would make a difference to me. It's cancer, you know, and I guess, if you have different medications, or chemo or radiation or whatever you have, it's going to give you some side effects, my side effects might not be the same as someone else. But we're all cancer survivors. So, and we're just trying to prove improve our life. So I don't think, I don't think [diagnosis] would matter. I think it might be a little easier if it was all breast cancer in the group, but I don't think I'd be upset about it being different types of cancer.” [BC13]

3.3.3.2 Healthy behaviors

Many participants described the importance of incorporating healthy behaviors such as weight management, activity scheduling, exercise, and goal-setting into daily routines. Participants integrated health promotion activities as a first attempt to prevent or resolve both impairments and activity limitations. One survivor used a combination of activity scheduling, consistent routine, and exercise to manage cancer-related disability:

> “Well, I would schedule the [exercise] sessions in the early morning. So it made me get up. It made me get moving. It made me get out. Um which sometimes when you're retired, you wake up in pain, or you wake up and you're uncomfortable, you don't want to do that. It's just easier to not do that. I scheduled my um exercise nine o'clock in the morning because

> they made me get up even if I had slept all night because of pain, it just made me get up and get moving...” [BC12]

Another participant felt that exercise allowed her to be more capable of performing portions of her daily activities. Through her involvement in a cancer exercise research study, she shared:

> “A treadmill I could hold on to it and I can do it for 20 minutes. But if I was out walking on the road or something, I cannot walk even more than three or four minutes and then the lower back starts hurting. [The treadmill helped for] getting up if the phone rings or it you have to go to the bathroom. That's like the quickness of getting up. Or if you're sitting long time I could still get up and walk a little later in the house [BC11].

Survivors initiated their own research on weight management to reduce long-term sequelae and promote a physically active lifestyle.

> “You know, one of the things that I would think about, I did a lot of research on my own. About more natural ways of treating cancer, and better ways of eating, the kinds of foods that you should avoid. I think maybe there should be more involvement of um some more natural therapies um such as maybe the healthy foods to eat, foods that cancer, keeping your weight down. This is something I researched on my own.”

Almost half of survivors who experienced cancer rehabilitation discussed goal-setting about specific impairments (e.g., ROM, limb volume, pain management) and to a lesser degree independence with meaningful daily activities (e.g., gardening, jewelry design, transfers).

> “I would have to say that the most important thing is what the patient wants in the long run, what the end result could be and to work towards that goal. Okay, so whether it be in physical therapy, in my case to walk better…But what do they want? You know, you've

> [healthcare practitioners] got to get like into survivors heads and find out where they're coming from and what's important to them." [BC2]

This survivor continued to share that despite preference for explicit goal-setting practices, she did not recall it taking place in her rehabilitation experience.

> "I don't think we did out loud. I think she must have. I don't know. We never discussed the goals." [BC2]

Another survivor reported that her rehabilitation goals were established by the provider. Without previous rehabilitation experience, she felt ill-equipped to contribute to the goal setting process. After completing rehabilitation, she wished to have had an opportunity to tailor the set goals.

> "I pretty much left it [goal-setting] up to her, because she was the expert…I mean, you lose, lose a certain amount, as soon as you have breast cancer, because you're never the same after that. And I used to make jewelry, which I can't anymore, because I don't have the strength in my hands to use the tools, or I can't feel the beads. Um so so I think maybe, you know, things like that could be addressed um early on." [BC5]

3.3.3.3 Symptom management

The participants' experienced an array of cancer-related impairments. Most frequently, survivors' reported challenges with fatigue, pain, peripheral neuropathy, lymphedema, and ambulatory dysfunction. Nearly all participants were willing to engage in self-management of symptoms using low-cost resources or strategies. Participants incorporated over-the-counter medications, topical creams, and physical agent modalities (e.g., ice, heat) to manage chronic pain.

> "Sometimes just being gentle, icepacks, heat. Uh you know, being you feel what your body is telling you want to do and let that happen. And then build on that." [BC10]

Another survivor shared that she and her provider frequently trialed medications, both prescription and over the counter, to provide short-term relief from pain and tingling.

> "Well, I went on two different medications and neither one helped…I just actually a half an hour ago called the doctor to tell them I'm going off this last medication that I've been on. I was only on both of them for like about two weeks. And I felt that I didn't give them enough time. So this time I was on Gabapentin for like about a month and a half and if anything I've gotten worse instead of better." [BC2]

To manage fatigue, participants incorporated energy conservation and work simplification strategies including taking breaks, napping, and pacing high-energy activities.

> "Well, it was towards the end of the radiation…It was almost like six weeks, I believe, of radiation. And towards the end, is when I started noticing, I just tired out. Here comes the noise. It's just I just tired out so bad. So I just made myself take rest periods… so I wouldn't fall asleep in front of people." [BC7]

Nearly one-third of the participants sought complementary or alternative medicine treatments including acupuncture, massage, mindfulness, and yoga. Participants described substantial improvement in impairments and quality of life after adopting alternative therapies. However, few connected the alternative therapies to improved performance of daily activities.

> "Well, I connected to the [Cancer] Wellness Center. So I was going for acupuncture, yoga, massage. I also got approved for medical marijuana…Acupuncture was great. Um people would always say, do you think it's helping? And my answer is it's not hurting. And I always say that, maybe if I weren't doing some of these things, the symptoms would be worse. So it was you know, it was just nice to connect with people that that understood the

> things that I was telling them, that they were real, that they were, you know, real side effects." [BC9]
>
> "I went for an entire year for acupuncture once a week. Unfortunately, they would only let you go for a year after that you couldn't go anymore.. And I don't know that it really helped a lot. It was healing. But I just felt better." [BC4]

3.3.4 Research question 3: Preferences for intervention delivery

Participants described preferences for intervention delivery including intervention settings (location), mode of delivery (in-person, virtual), formats (therapist-patient interaction), and timing (point in time when an intervention takes place).

3.3.4.1 Setting

Survivors' referenced a variety of locations that interventions could take place in including outpatient clinics, community center, patient home or hospital. Survivors found outpatient clinics advantageous as they frequently offer a variety of community-based locations. Survivors were motivated by the specialized equipment and therapist expertise within this setting.

> "Inside the clinic, they had like different machines that you could, you know, like you could ride a bike and you could leg press and things like that. Where obviously I didn't have anything [in my home]." [BC2]
>
> "Um, for what I needed to do, I would feel like it would be better for me to go there. Because here, not unless somebody came here, I might not do what was required. Um and because I'm able to get up and go like that, I could see for someone that, you know, would have trouble driving or have trouble navigating, it might be better to have somebody come

> here, but I'm not there yet. So it's just easier for me to get up and go to where the equipment is, to where the people are. It was better for me." [BC6]

Survivors' statements suggested that outpatient clinics portrayed health and a strong focus on recovery, whereas hospital or cancer center locations incited fear of cancer recurrence, illness severity, or mortality.

> "Um probably more in the community center. Um or like a physical therapy clinic location. Like [this academic medical center], has physical therapy locations around the city. But not in, in a hospital. I think it's important to um have the appearance of a healthy environment and not be a place where you might dwell on your ailment, like hospital." [BC14]

The "unlink from healthcare" was an advantage for other community centers such as local town halls, township properties, and gym facilities. However, some survivors were hesitant to attend a rehabilitation intervention in public location due to risk of contracting COVID-19.

> "I'd consider it. But considering the pandemic, I'm not sure. Because of health reasons Cause I'm 76. One of the options was to go to a health place near you. So I know that some of [the interventions] were at the JCC (Jewish Community Center). And I think there was a health center on the South Side. So more exercise places. I don't know, to be honest with you, I think sometimes the unlink from a healthcare is valuable." [BC12]

One survivor preferred a community location as it seemed less formal than a typical healthcare appointment. She reported that the community setting fostered trust and inclusion.

> "I went to the YMCA…[the Livestrong Group] that was wasn't actually therapy but well, I guess it was tell you the truth. It was therapy. I didn't think of it as therapy. I just thought

> of it as a program to get, you know, survivors there together to talk and, you know, get stronger...” [BC7]

Preference for home-based intervention were infrequent. Three survivors shared that this setting would be helpful especially for older adults that could not drive. Another survivor reported that she felt her goals could not be accomplished within the home since she did not own specialized equipment. Equally, home-based interventions were perceived as therapy for those who were severely ill or unable to leave their homes.

> “And it was, you know, great that she came because I couldn’t do I couldn't get out to do the exercises. But I preferred once I once I was able to get out. I did prefer going out rather than having them come. Because I had to do I had to do more things, there were more things that needed to be done.” [BC6]
>
> “Well like home therapy, this is probably a little crazy, but I associate that with oh you can't get out so you better have someone come to the home.” [BC3]

3.3.4.2 Mode of delivery

Participants preferences varied for the way in which interventions would be administered. The survivors shared their perspective on interventions that were delivered in-person only, virtual only, or combination. Advantages of in-person delivery included flexible scheduling and recognizable reimbursement structures using insurance. Survivors felt in-person interventions would provide them thorough care and attention.

> “I don't know. I mean, we've done a couple of doctor visits over the virtual and um I don't know. I just feel you don't really get the same as in person. when you're face to face, and they can really see your expressions, as opposed to um trying to guess what, you know

> what I'm thinking. I mean, I just think sometimes it's hard to get things out of people." [BC14]

Services delivered virtually were a common topic across survivor interviews. Almost every survivor had participated in one telehealth appointment. Participants positively described virtual interventions as safe, accessible, and convenient. Participants did not need to factor in travel time to a clinic and could fit appointments into their schedule more readily.

> "It would be great if, I'm just saying this because of this COVID-19, I really don't want to leave my house for anything. I'm very cautious. Like … I'm seeing my doctors over the internet, you know, I'm not going out. So if um if something if maybe there's a way to have like a, like, a visit over the internet, um with a therapist who can, you know, tell me that do this do that in my house that would be, that would be wonderful." [BC10]

Yet, other survivors found weaknesses of virtual programs to be the complex technology and distractibility.

> "Well, I mean…the Partridge Family boxes get old really quickly. And sometimes it's, I don't know that you'd network there as well, when, you know, it's not like you could turn to someone and talk and make your comments you have sort of wait your turn and all that sort of stuff. I think it [telehealth rehab] could work. I'm not like many people my age, I'm not, I find myself, I'm surprised that I don't like virtual things as much as I don't like that. You know, at the beginning so we've had this experience with pandemic, but having said that, it's very convenient when you don't have to leave your house." [BC8]

Interestingly, multiple participants preferred the use of a combination, or hybrid, formats, where both in-person and telehealth-based sessions were used to evaluate, progress, and boost rehabilitation outcomes. Survivors reported that this format reduced burden in terms of transportation and time and promoted face-to-face contact and communication with a therapist.

> “If it was said, say, one day a week, okay, then I was gonna, okay, maybe start with two where I was coming in one on one. And then maybe every third one visit would be virtual one…You know, like…gradually, maybe it could get to be more virtual. You know, we're going to do virtual for two weeks and see how you make out with that and then come in, and then we'll try you out on some machines or, you know, under um specific guidelines of what you're doing, how you're doing it.” [BC13]

3.3.4.3 Format

Participants shared their preferences for intervention format (e.g., one-on-one with a therapist; group-based). Participants found one-on-one interventions advantageous as they offered maximum attention from the therapist. However, two survivors shared that the execution of one-on-one therapy is not always guaranteed in real-world settings. While both survivors had been referred to outpatient rehabilitation services, they felt they were not receiving personalized attention. Each reported that the therapist juggled multiple patients at one time. The survivors did not perceive concurrent therapy as true one-one-one delivery. For example, one survivor shared:

> “I’d still prefer for it to be one-on-one, because I did go for physical therapy and I went to um a place close here. And it was like the therapist would put me on the exercise bike, keep me there for 20 minutes and then go take care of three other patients. And then come back and put me on something else and then go take care of three other patients. So I really didn’t feel like I was getting any personalized attention at all.” [BC5]

Another survivor who preferred one-on-one interventions was worried that it would not be financially feasible. Her solution was to alternate one-on-one intervention sessions with group-based sessions.

> “Well, I know therapy one-on-one would be my preference. But that's difficult to expect that every week. I mean, you know, that would be unless your insurance pays for it, it would be an expensive thing to do. So maybe, you know, one on one every other week, and then do group therapy the rest of the time.” [BC14]

Survivors shared varying opinions on group-based therapy. Advantages of group-based therapy included perceived lower cost and camaraderie. One survivor prioritized attendance in group-based alternative medicine therapies to lower the financial burden.

> “So it was nice when I had the option of splitting the cost in half, getting two sessions for the price of one because you know, as a community, they didn't charge the full amount [as a group format].” [BC9]

Reported disadvantages of group-based interventions included less individualization of care and discomfort of a group setting.

> “They did have group therapy, but it was only once a month actually. And um I considered going to it but I met several people and many of them were much younger than me. And I really was not comfortable with that. Because these people are really sick. I never thought of myself as really sick. I was older. I was very lucky that it was so small. Um and some of these people were there for the second time, and they were young. So I just, I was not comfortable there. I didn't feel it was appropriate for me.” [BC4]

3.3.4.4 Timing

Survivors preferred interventions to be delivered during treatment or post-treatment. When prompted, few survivors saw a role for prehabilitation. Participants thought rehabilitation required a specific change in their health such as decreased ROM, pain, or functional disability. Prior to treatment, they did not experience these symptoms and felt it would not be appropriate to go to therapy for “something I didn’t have.” For example, one survivor shared:

> “I guess because I didn't have that [lymphedema] before. So therapy wouldn't have done me any good. I wouldn't need to go to therapy. I mean unless it was like mental therapy, which I didn't need.” [BC1]

One survivor preferred rehabilitation intervention during active treatment as she was already in an “illness-recovery mindset.”

> “Well, as time goes on, you know, you sort of forget about it. And don't think of it as. I mean, I don't go around every day saying to myself, I had cancer, I had cancer. So, you know, you might be less inclined to keep up with the therapy. Where if you did it, when you're still feeling like, man, I just had cancer, you know you might be more apt to stay on top of it.” [BC14]

More often than not, participants preferred for interventions to be delivered post-treatment. An advantage of the post-treatment rehabilitation includes distancing from illness identities. One survivor stated that during treatment, she was just focused on living and could not juggle other healthcare activities.

> “Probably very soon after I was done. And probably the best time would not have been before, because you don't want to be weighing all the side effects when you're making a decision about going forward with care. But maybe some of the first follow ups.” [BC9]

Others avoided rehabilitation to limit the number of healthcare appointments in their schedule and try to independently manage sequelae before reaching out for help.

> "Um well I do think you have to wait for a certain amount of healing, I'm sure of that…I'm just saying I was diagnosed in February I had surgery in February I started radiation in April I probably would've benefited I'm going to say like probably at the end of May um I'm guessing around the end of May because it takes a while for that scar tissue to form." [BC3]
>
> "I don't think there was a benefit [of therapy during treatment] because I was I didn't experience it until after I finished my chemo that I had this uh agitation or whatever with the standing and bending and stuff like that." [BC12]

3.4 Discussion

Access to and delivery of effective cancer rehabilitation interventions remain a challenge for older adult breast cancer survivors. Within healthcare, access can be defined as "the opportunity or ease with which consumers or communities are able to use appropriate services in proportion to their needs."[112] From the thematic analysis, older adult breast cancer survivors identified seven factors influencing pursuit to obtain appropriate cancer rehabilitation interventions: 1) Emerging awareness of disability; 2) Coping Styles; 3) "My situation and her situation;" 4) Provider interactions; 5) "I don't want cancer as a lifelong project;" 6) Social support; and 7) Cost of rehabilitation. The analysis also identified preferred intervention content and delivery features of rehabilitation interventions. These factors parallel the patient-centered dimensions of healthcare accessibility.[112] Levesque and colleagues defined patient-centered healthcare accessibility as the

1) Appropriateness of Care; 2) Affordability; 3) Acceptability; 4) Approachability; and 5) Availability and Accommodation.[112] We can use these dimensions to anchor our findings to inform the development of more accessible and valued cancer rehabilitation interventions.

Appropriateness of care denotes the fit between services and client needs, the amount of care spent in assessing health problems, and determination of the correct treatment.[112] Survivors desired earlier and more frequent discussions with healthcare providers about cancer-related impairments and activity limitations and potential solutions. However, stakeholders seemed to indicate that discussion of disability may have been limited or discounted. Survivors reported that their disability was deemed "normal." Thus, older breast cancer survivors independently sought and implemented solutions, with imperfect results. As Silver articulated, "telling cancer survivors to accept a new normal before they have optimized their functional status through cancer rehabilitation interventions essentially means that survivors are living with unnecessary disability and a suboptimal quality of life (p. 506)."[113] Adoption of a shared decision-making tool could facilitate discussion, support the identification of appropriate care solutions, and promote patient-centered care to address disability.[114] Shared decision-making may empower older breast cancer survivors to self-manage cancer-related disability and play a more active role in their survivorship care.

The cancer-based Geriatric Assessment could facilitate shared decision-making on the management of cancer-related disability.[22] The Geriatric Assessment is a valid measure that screens for multidimensional aspects of cancer-related disability and suggests supportive care referrals. This tool has been implemented in many geriatric oncology clinics[115] across the world and has been associated with improved referrals to supportive care services, fewer unanticipated hospitalizations[116] and greater health-related quality of life.[117] As providers review the results of this tool, survivors are provided an opportunity discuss emerging awareness of disability, coping styles, social support, and cost.

Previous research also supports education as a factor influencing pursuit of supportive care services. Findings from cancer-based registry data suggest that limited awareness, utilization, and need for supportive care services among breast cancer survivors is significantly associated lower education.[92] Education did not emerge as a factor influencing pursuit of rehabilitation. Lack of this finding may be due to our study sample. Over half of the participants had obtained a college-level or graduate-level education. Often individuals who participate in research are frequently of higher education.[93] Given that our sampling methods relied on research registries, limited educational variation or insights into influence of education occurred. Future models of shared-decision making should equally weigh the identified factors in addition to those previously established, such as education, to ensure opportunities for rehabilitation intervention are provided to at-risk or vulnerable individuals.

Although survivors' voiced interest in rehabilitative interventions, *affordability* influenced pursuit of rehabilitation services. Affordability reflects the economic capacity for people to spend resources and time on appropriate services.[112] Our analysis revealed that survivors consider the cost of services, insurance reimbursement, and overall use of time when assessing intervention solutions. Financial toxicity is common among older adult breast cancer survivors due to cost of treatment and long-term maintenance medications. Arastu and colleagues noted that financial toxicity among older adult cancer survivors is more likely in those who are female, college-educated, and over the age of 70 years.[15] Given that our sample represents individuals at risk for financial toxicity, we must consider the affordability of rehabilitation services. Few cancer rehabilitation intervention studies provide data regarding cost-effectiveness outcomes.[16] Future work should incorporate measures of cost-effectiveness as financial implications represent a fundamental component of clinical practice and shared decision-making about rehabilitation services.

Our data revealed several cultural or social factors contributing to survivors' pursuit of cancer rehabilitation. Levesque and colleagues described *acceptability* as the degree which personal and social values as well as cultural and gender norms align with healthcare services.[112] Our results suggest that acceptability of rehabilitation may be mediated by social support. Even though survivors may have had similar presentation of disablement, those with social networks appeared to not pursue rehabilitation services as readily. Survivors used social support to overcome disability in both physical and emotional ways. This is contradictory to a qualitative study by Yoo and colleagues who previously explored the influence of social support in older breast cancer survivors.[118] Their results revealed that older breast cancer survivors often feel a need to maintain their self-sufficiency and make it through cancer without having to depend on too many people.[118] While it is not definitive why this difference occurred, a possible explanation could be that our interviews took place with survivors nearly two to three years since diagnosis, whereas Yoo and colleagues focused on newly, diagnosed survivors. Our participants' experience of long-term sequelae may have prompted them to reach out to family and friends for support. Equally, Yoo and colleagues note that despite desire for self-sufficiency, older survivors frequently overcame their reluctance to admit vulnerabilities (emerging awareness of disability; coping styles) and ultimately reached out to family and friends for support soon after treatment began.[118]

Acceptability also relates to cultural factors which influence access to rehabilitation. Across the interviews, survivorship experiences were often compared to others with similar experiences. Participants categorized survivorship as either an acute event or a chronic illness. Kaiser (2008) explains that the ongoing label of survivorship may perpetuate an illness narrative.[119] If survivors consider cancer a discrete or acute event, they may limit opportunities to initiate conversation about disability with a healthcare provider, and vice versa. As seen in other cancer diagnostic populations,[120] it is also possible that greater length of time since diagnosis influences a survivors' ability to cope, accept, and self-manage disability. The "dynamic process of recovery and adaptation" (pg. 925),[121] or resilience, is a personal factor of those who are able to self-manage disablement without the assistance of rehabilitation services. Hurria and colleagues saw that adults lacking social support and depressive symptoms may reflect greater resilience. Moreover, understanding the risk factors for cancer-related disability and lack of resilience may influence pursuit of rehabilitation interventions.[121]

There have been many calls-to-action[16,122] to examine the beliefs and expectations of older cancer survivors regarding intervention content, delivery, and value. Further examination of such intervention constructs may improve *approachability* and *availability* of rehabilitation services. *Approachability* describes that an existing intervention will have an impact on a survivors' health.[112] Our analysis identified valued intervention content by older breast cancer survivors. Intervention content that is valued by its intended population may promote greater adherence and overall impact on a survivors' health.

Survivor's shared mixed perspectives on peer support,[123] healthy behaviors,[124] and symptom management.[125] Peer support interventions are common among oncology populations in the format of support groups. Furthermore, peer support can be leveraged to provide additional rehabilitation opportunities.[126] The use of peer support should be thoughtfully determined by an intervention's goals and desired outcomes. Among this population, peer support could be used to initiate health behaviors, improve ability to manage aspects of one's disability, and augment survivorship knowledge.[126] However, it will be important to consider reimbursement implications, service delivery characteristics, and other outcomes of implementation that may influence the impact of peer support. As seen in our data, it will be essential that peer mentors are carefully selected and trained to facilitate a productive and trusting relationship among intervention participants.[126]

Existing literature reveals that healthy behaviors and symptom management exert negligible-to-moderate effects on activity limitations (e.g., challenges or interference with day-to-day activities) (Chapter 2). Healthy behaviors embody approaches that prevent, remediate, and compensate for disability. Hurria and colleagues noted that these interventions, such as those that that promote a behavior tracking (e.g., diet) and exercise, may improve cancer-related disability in this population.[121] Our qualitative findings suggest that use of general behavioral strategies (e.g., activity scheduling, goal-setting) and physical activity strategies appear to be favored by survivors. Further testing on whether this intervention content influence activity limitations requires further testing.

Lastly, survivors shared interest in learning strategies to manage specific symptoms. Applied in models of impairment-driven rehabilitation,[127] symptom management interventions reduce distress among cancer survivors and appear to be cost-effective.[127] However, few survivors connected these strategies with strategies that improve activity limitations. Symptoms management was initiated for short-term relief rather than long-term change. Given that symptom management has demonstrated limited influence on activity limitations (Chapter 2), future intervention development should consider additional content or intervention approaches which directly influences broader activity limitations in this population.

The final dimension of healthcare access is ‘*availability and accommodation*.’ This dimension examines the degree to which health services can be reached both physically and in a timely manner. Likewise, it accounts for characteristics of healthcare facilities and characteristics of providers.[112] Even the most effective intervention content may be rendered useless if it is not delivered in a format that is available and preferred by its intended population. Across interviews, our participants had mixed preferences for intervention delivery. In this study, all interviews took place between April – July 2020 and all participants noted that their opinions of intervention delivery were informed by the COVID-19 health pandemic and care standards for high-risk patient populations. Despite this, our sample provided important insights on the context of intervention delivery and foresight into delivery methods applicable to future healthcare delivery. Understanding the context of an intervention, setting, format, and timing can significantly affect adoption of an intervention in real-world settings.[28]

Outpatient clinics and community-based settings represented health, recovery, and narratives of self-management, empowerment, and action. They were favored due to convenient location, availability of specialized equipment, and familiarity. Outpatient and community-based settings may also meet survivors’ priorities of convenience, familiarity of location, and concerns on transportation. These are all important considerations to improve overall attendance and reduce burden. Pergolotti and colleagues have begun to study the effects of outpatient rehabilitation services on cancer-related disability in older adult cancer survivors.[26,128] Their results demonstrated prevention of additional decline (e.g., grip strength, walking speed) as well as significant improvements in health-related quality of life. However, the authors noted that participants encountered several scheduling and transportation concerns which denote additional considerations interventions in these settings. While many existing interventions are studied in a hospital or cancer center,[129] our participants stated that a hospital setting perpetuated memories of illness and fear of cancer recurrence. Future intervention research may consider adapting existing and creating new interventions to reflect outpatient and community-based preferences.

Availability and accommodations also include intervention mode of delivery, format and composition. Our sample revealed mixed preferences for mode of delivery. Survivors shared that confidence to attend in-person services were largely based on the state of the COVID-19 pandemic. However, it appeared that delivery of fully virtual sessions did not meet survivors' adequacy of care standards. Future cancer rehabilitation interventions may consider a combination, or hybrid, approach to intervention delivery. This would include specific in-person sessions followed by virtual check-in appointments to ensure progress and patient-provider contact. The success of sustainable hybrid interventions will rely on access to internet, availability of internet-capable devices, and sufficient technology literacy and support for this population.[130] Future work will need to consider how technology-based delivery influences health care access and delivery for communities of lower socioeconomic status and those with limited knowledge of technology who may have increased barriers to engage virtual platforms.

Regarding format, survivors prioritized one-on-one interventions, yet were unsure if it was feasible due to financial limitations. Preference for group interventions varied. Strengths of group-based therapy included social support, networking, camaraderie. These are similar findings found in a qualitative analysis of women with breast cancer who participated in group-based community physical activity programing.[131] Wurz and colleagues[131] included participants of varying cancer diagnoses which was also valued by our study sample. Survivors resonate with the shared presentation of disability rather than fixate of differences in cancer type. However, participants reported more specific preference for group member characteristics including age limitations and illness severity. Trust and comfort among group members are necessary to ensure success of group-based intervention.[131] Additional research is needed to understand the characteristics of group participants that influence change in activity limitation outcomes, group dynamics, and intervention inclusion criteria.

Lastly, older adult breast cancer survivors' prioritized interventions that were during treatment or post-treatment. Interventions positioned in these phases reflect the Institute of Medicine's pillars of survivorship care which include prevention and surveillance of late effects and comorbidities and intervention for treatment consequences.[35] Often, our sample did not prioritize prehabilitation care. This is likely as many were unfamiliar with the concept, had no seen it implemented, or knew of its influence on disability.[132] Should future intervention development choose to adopt a prehabilitation model, scientists may seek additional stakeholder input and consider guidance from the Multiphasic Prehabilitation Conceptual Framework.[132] .

Our study presents many important considerations to influence access and delivery of cancer rehabilitation interventions among older breast cancer survivors. Our study does acknowledge a few limitations. Despite efforts to recruit a representative sample, we experienced challenges recruiting those of diverse race and ethnicities. Underrepresented populations represent nearly half of all breast cancer diagnoses.[2,94] Our primary recruitment challenge was identifying underrepresented populations who met our age criterion. While older adults are defined by "65 years and older," chronological age may be inappropriate for inclusion criteria in cancer intervention research.[133] Black women demonstrate accelerated markers of cellular aging approximately ten years earlier than White counterparts,[134] are diagnosed with more severe forms of cancer,[94] and experience significantly greater disability.[135] Adoption of broader age inclusion criteria may be warranted to capture the important perspectives of this community. The need for equitable racial and ethnic outcomes for older adult cancer survivors is critical if we are to truly create stakeholder-valued care.[136]

Furthermore, our study focused on the preferences of survivors who were post-treatment and without metastatic disease. Additional research should engage survivors undergoing treatment and/or with later stages of cancer to determine if priorities and perspectives are similar or different. Although we attempted to represent a geographically diverse sample through convenience sampling and remote data collection, selection bias may exist in this study. In addition, those who were approached and chose not to participate may have had different lived experiences, priorities, or preferences not captured.

Despite these limitations, strengths of this study lie in its in-depth exploration of older adult breast cancer survivors' priorities and preferences for cancer rehabilitation. To our knowledge, this is the first study of its kind to explore these factors among this growing population. Qualitative findings are articulated in the survivors' voices and can enhance our understanding of important intervention and implementation research questions that quantitative research may not capture.[110]

3.5 Conclusion

This study provides important perspectives influencing future cancer rehabilitation intervention development tailored to older adult breast cancer survivors with cancer-related disability. Assessment, discussion, and shared decision-making may enhance an older breast cancer survivors' pursuit of cancer rehabilitation services. Intervention research should consider frameworks of accessibility[112] to improve survivors' opportunity to participate in rehabilitation. Future interventions should consider healthy behavior strategies test such approaches within preferred delivery (outpatient clinics or community-based settings; hybrid format). Future research must consider the priorities and perspectives of underrepresented populations to enhance generalizability of findings. In addition, intervention research should continue to co-produce and develop intervention protocols with key stakeholders to facilitate greater feasibility, acceptability, efficacy, and implementation of interventions among this population.[28]

4.0 Development of an Intervention Influencing Activity Limitations in Older Breast Cancer Survivors: A Modified Delphi Study

4.1 Introduction

Older breast cancer survivors are a growing population in the United States[137] who often experience activity limitations.[13,14] Activity limitations are defined as challenges with specific tasks[7] related to self-care, instrumental activities of daily living, and life roles. The National Institutes of Health[9,18] and interest groups (American Congress of Rehabilitation Medicine Cancer Rehabilitation Networking Group;[27] Cancer and Aging Research Group[9]) have recommended for the development and implementation of interventions that address dimensions of cancer-related disability, including activity limitations. These interventions are recognized as an important component of older adult survivorship care and essential in the prevention of future disability in this population.

However, accessibility of these interventions in clinical settings remains limited.[24] Intervention accessibility is complex and guided by the opportunity to identify needs, seek intervention services, to reach, to obtain or use intervention services and to actually have the need for services fulfilled.[112] Furthermore, accessibility is also affected by patient-, provider-, and health systems factors. More specifically, older breast cancer survivors may be unaware of what cancer rehabilitation is or its therapeutic benefit,[133] have limited social support and transportation,[26,34] and have financial limitations that prevent access to interventions.[15] Provider and health systems also report difficulties implementing patient referral processes,[26] screening or measuring activity limitations,[10] efficient appointment scheduling,[26] and/or limited awareness of what cancer rehabilitation is or its therapeutic benefit.[133]

One approach to overcome these barriers is to reassess the way that we develop cancer rehabilitation interventions.[122] When developing an intervention, we must consider intervention content and delivery features. Intervention content represents the types of activities (e.g., exercise, cognitive behavioral therapy, etc.) used to address activity limitations. Intervention delivery represents ways in which intervention content is administered. Delivery features are further categorized to group similar elements (i.e., location, timing, mode, duration, frequency).

Best practices in intervention development involve partnering with key stakeholders to bridge existing evidence, patient care needs, values and priorities, as well as practical considerations of clinical settings.[9,16,28] Stakeholder engagement is defined as an iterative process of actively soliciting the knowledge, experience, judgment and values of individuals selected to represent a broad range of interests in a particular issue, for the dual purposes of creating a shared understanding and making relevant, transparent and effective decisions.[36] Stakeholders often involved in development and implementation of cancer rehabilitation interventions for older breast cancer survivors include patients, physicians (oncologist, physiatrist), patient care experts (social work, patient navigation), rehabilitation professionals (occupational therapy, physical therapy, speech language pathology), nursing, psychology, health care administrators and scientists in related fields. O'Cathain and colleagues recommend engaging stakeholders in innovative ways to solicit input on the content, format, style, and delivery of an intervention.[28] Stakeholder-driven interventions often lead to more "rapidly actionable, feasible, trustworthy, and valued" (p.1237) healthcare.[138]

There is limited consensus among stakeholders regarding intervention content and delivery intended for older breast cancer survivors with activity limitations. Obtaining stakeholder consensus on these characteristics may inform the development more accessible cancer rehabilitation interventions. We administered a modified Delphi process with an expert panel of patients, providers, healthcare administrators, and scientists. This report presents the results and implications for intervention development derived from the process.

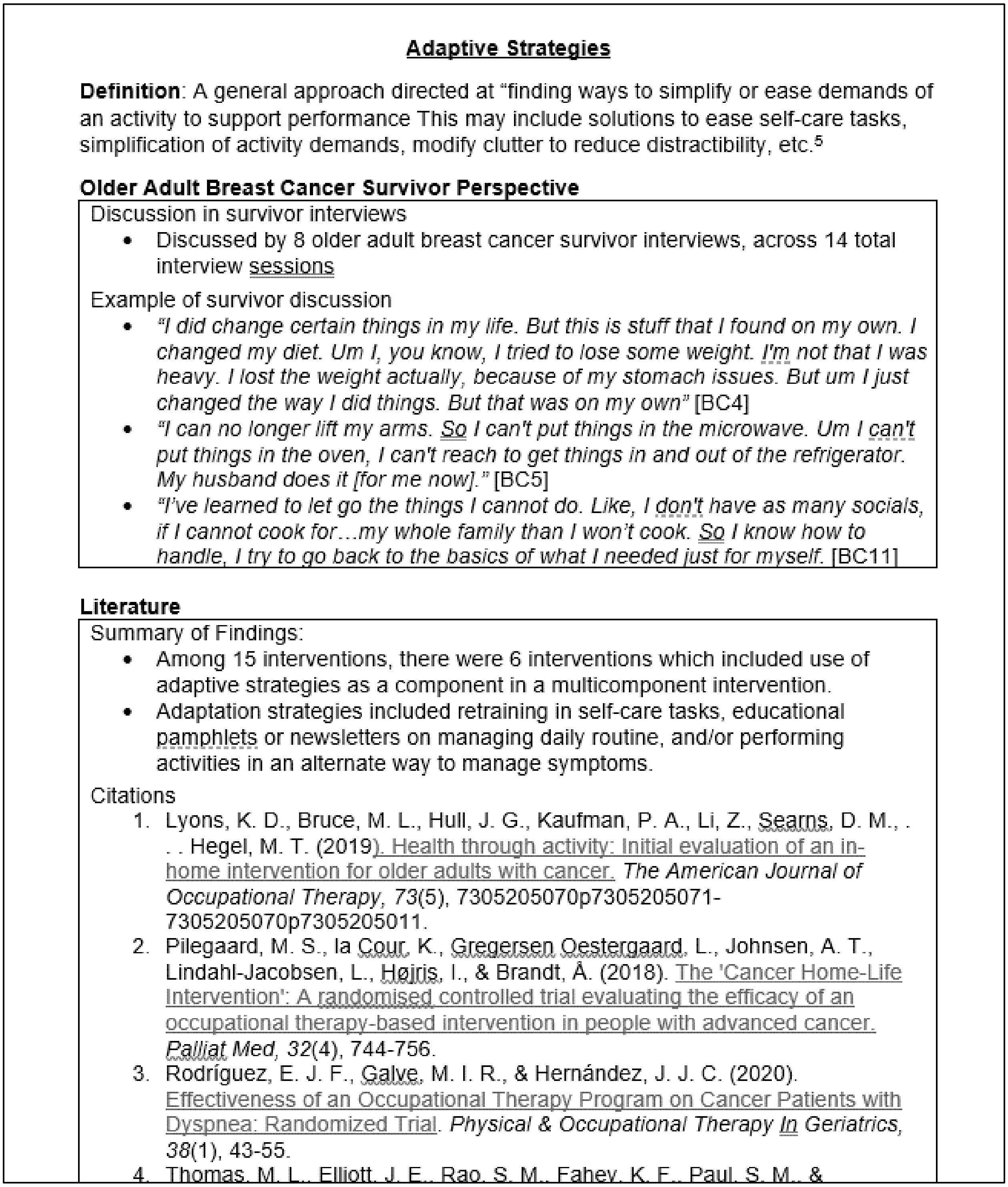
4.2 Methods

4.2.1 Overview of modified Delphi methodology

Delphi methods are used when consensus or judgment is needed to make recommendations, such as steering intervention development.[139] A standard Delphi Methodology uses structured, iterative rounds of surveys (minimum of two) to obtain anonymized feedback from respondents.[140] Traditional methods have several predefined rounds where an initial survey asks panelists a series of open-ended questions, followed by a content analysis to reduce data to core themes for panelist review.[141]

The method used in the study is comparable to classic Delphi methodologies in terms of process (two rounds with selected experts) and objectives (obtain consensus).[142] Our process was limited to two rounds a priori to maximize response rate and limit panelist burden. However, we chose to administer a modified approach. Our research team had specific interest in developing interventions intended for older breast cancer survivors with activity limitations. Whereas a first round of a Delphi process traditionally involves open-ended questionnaire to develop a list of constructs to rate, our research team provided panelists with an initial list of intervention content and delivery features.[143] The list was generated through a scoping review of existing interventions in the literature (Chapter 2) and semi-structured interviews with older adult breast cancer survivors (Chapter 3). Intervention content and delivery features are outlined in Appendices C and D, respectively.

Intervention content and delivery features were compiled and placed in a guide that integrated evidence from the scoping review with qualitative findings. Intervention content and delivery features were supported with a formal definition, stakeholder quotations, and a summary of existing evidence addressing the construct (Figure 6). In addition to lived experiences, the guide was meant to provide panelists with similar baseline knowledge of intervention content and delivery features when answering survey questions. Prior to disseminating the panelist guide, it was reviewed for comprehensiveness, usability, and readability by co-authors (RB, ES, NL) and non-participating older adults with and without cancer experience. This study was reviewed and approved by the University of Pittsburgh Institutional Review Board (STUDY20040126) and designated exempt from ongoing review.



Adaptive Strategies

Definition: A general approach directed at "finding ways to simplify or ease demands of an activity to support performance This may include solutions to ease self-care tasks, simplification of activity demands, modify clutter to reduce distractibility, etc.[5]

Older Adult Breast Cancer Survivor Perspective

Discussion in survivor interviews

- Discussed by 8 older adult breast cancer survivor interviews, across 14 total interview sessions

Example of survivor discussion

- *"I did change certain things in my life. But this is stuff that I found on my own. I changed my diet. Um I, you know, I tried to lose some weight. I'm not that I was heavy. I lost the weight actually, because of my stomach issues. But um I just changed the way I did things. But that was on my own"* [BC4]
- *"I can no longer lift my arms. So I can't put things in the microwave. Um I can't put things in the oven, I can't reach to get things in and out of the refrigerator. My husband does it [for me now]."* [BC5]
- *"I've learned to let go the things I cannot do. Like, I don't have as many socials, if I cannot cook for…my whole family than I won't cook. So I know how to handle, I try to go back to the basics of what I needed just for myself.* [BC11]

Literature

Summary of Findings:

- Among 15 interventions, there were 6 interventions which included use of adaptive strategies as a component in a multicomponent intervention.
- Adaptation strategies included retraining in self-care tasks, educational pamphlets or newsletters on managing daily routine, and/or performing activities in an alternate way to manage symptoms.

Citations

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Figure 6 Example of survey guide

4.2.2 Expert panel selection and recruitment

Given the breadth of stakeholders involved in development and implementation of cancer rehabilitation interventions, we sought to include older breast cancer survivors (≥ 65 years old), rehabilitation professionals (occupational therapy, physical therapy, speech language pathology), patient care experts (social work, patient navigation), nurses, psychologists, healthcare administrators, physicians (oncology; physiatry), as well as scientists with relevant research expertise. Ourp The research team identified a list of potential panelists (n=22) using purposive sampling techniques. Purposive sampling is a nonrandom technique that deliberately selects participants based on qualities a participant possesses.[144] It allows representation of individuals that are well-informed with a phenomenon of interest or a relevant research topic.[144] Our panel size was larger than the general recommendation of ten experts,[145] but was necessary given the breadth of stakeholder involved in the development and implementation of cancer rehabilitation interventions. Potential panelists were contacted through an individualized email inquiry and prompted to complete an electronic informed consent via Qualtrics (Qualtrics, Provo, UT) to acknowledge their understanding of the aims and their willingness to participate. Each panelist had an equal weight and anonymity.[141,143]

4.2.3 Study procedures and analysis

Following consent, panelists selected whether they wished to receive an electronic or hard copy of our guide to familiarize themselves with purpose of study, intervention content, and delivery features. Surveys were developed and administered electronically via Qualtrics (Qualtrics, Provo, UT), a digital survey platform that contains a variety of question formats, display logic, validation options, distribution methods, and data analysis features. Each round allowed a 10-day response period. Between Rounds 1 and 2, responses were quantified, summarized, and re-presented to the panelists. Data analysts were blinded to the identity of the panelist responses. Panelists were compensated $25 per survey or up to $50 for study completion.

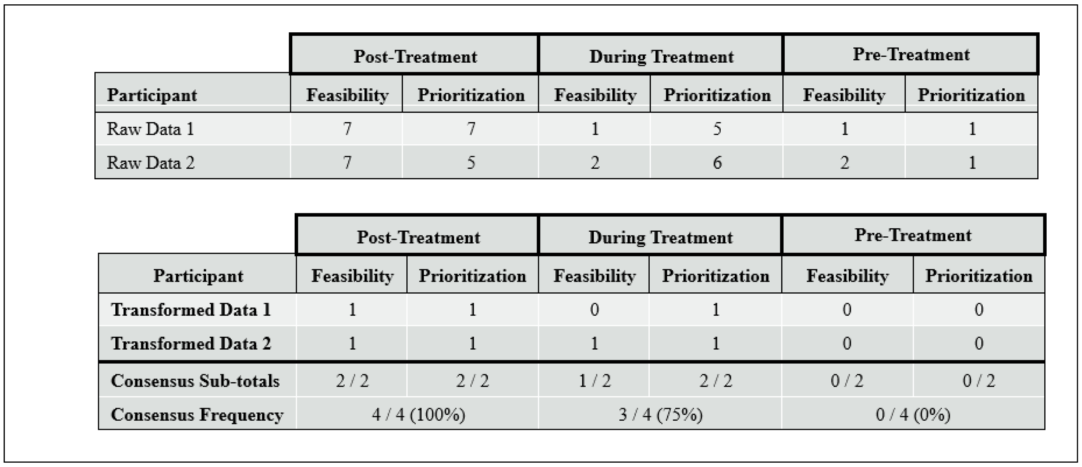
4.2.3.1 Round 1 survey

The panelists provided demographic information (e.g., stakeholder expertise, occupational roles, geographic location, and race). Based on existing evidence, interviews, and personal experience, panelists rated intervention content (Appendix D) and delivery features (location, timing, mode, duration, frequency) (Appendix E) according to feasibility and prioritization. *Feasibility* was defined as the degree to which an intervention content or delivery feature can be implemented in models of cancer care that stakeholders had experienced. Feasibility was rated on a 7-point Likert scale where 1 represented "very feasible" and 7 represented "not at all feasible." *Prioritization* was defined as the belief that an intervention or delivery feature should be incorporated in a future intervention based on personal experience, scientific evidence, and older adult breast cancer survivor preferences. Prioritization was rated on a 7-point Likert scale where 1 represented "high priority" and 7 represented "low priority." After rating intervention content and delivery features, panelists had the opportunity to suggest additional content, delivery features, and/or to provide justification for decisions using open-ended comment boxes.

4.2.3.2 Round 1 analysis

For Round 1, intervention content and delivery features were rated according to the feasibility and prioritization. Raw panelist ratings were transformed where positive ratings (ratings of 5-7) were given one point, and those with negative or neutral scores (ratings of 1-4) were given

0 points. Transformed point values were subtotaled according to feasibility and prioritization, respectively. Both the feasibility and prioritization subtotals were summed together to represent total points received out of total points possible. This proportion was reported as a percentage of consensus. Figure 7 provide an example of this procedure using the “timing” delivery feature. Points assigned to the feasibility and prioritization ratings for each “timing” option were transformed and subtotaled. Subtotals for each option were then summed and reported as total points received out of total points possible. The proportion was reported as a percentage of consensus.[146]



	Post-Treatment		During Treatment		Pre-Treatment	
Participant	**Feasibility**	**Prioritization**	**Feasibility**	**Prioritization**	**Feasibility**	**Prioritization**
Raw Data 1	7	7	1	5	1	1
Raw Data 2	7	5	2	6	2	1

	Post-Treatment		During Treatment		Pre-Treatment	
Participant	**Feasibility**	**Prioritization**	**Feasibility**	**Prioritization**	**Feasibility**	**Prioritization**
Transformed Data 1	1	1	0	1	0	0
Transformed Data 2	1	1	1	1	0	0
Consensus Sub-totals	2 / 2	2 / 2	1 / 2	2 / 2	0 / 2	0 / 2
Consensus Frequency	4 / 4 (100%)		3 / 4 (75%)		0 / 4 (0%)	

Figure 7 Example of Round 1 data transformation to calculate consensus frequencies using simulated data

Given the breadth of intervention content, we made an a priori decision to move content with greater than 70% consensus[147] into the next round for further review.[143,148] Delivery features required consensus of greater than or equal to 50% to move into the next round for further review. Panelists’ written comments were reviewed by the research team. If more than one panelist suggested intervention content or delivery feature, it was included in Round 2.

4.2.3.3 Round 2 survey

Based on results of Round 1, panelists were asked to rank or confer agreement of intervention content and delivery features. Ranking was used for intervention content and delivery features that had more than one option with sufficient consensus for review. Ranking scales were based on the number of potential options in the selected category. For delivery features that had consensus on only one option for Round 2 review, panelists were asked to indicate agreement (agree/disagree). For all questions, panelists were asked to share rationale for their response using open-ended comment boxes.

4.2.3.4 Round 2 analysis

To interpret questions using ranking methods, we calculated the median rank. Consensus of the median rank was defined as a percentage of panelists that ranked an option within one unit of the median.[147] For example, the median rank exercise was "4." The percentage of panelists who ranked exercise as a "3, 4, or 5" was calculated to determine consensus. To interpret questions using agreement methods, the proportion of agreement across panel was calculated and reported as percent agreement. For both types of questions, consensus was classified as high (70% or higher that fell within the median score), moderate (60% or higher), and low (50% or lower).

4.3 Results

4.3.1 Participants

Twenty-one panelists consented to participate. Response rates were 95% for Rounds 1 and 2 (n=20) due to loss to follow-up of one panelist soon after consent (See Table 7). Panelists included older breast cancer survivors (25%), physicians (geriatric oncologist, physiatrist) (20%), rehabilitation practitioners (occupational therapist, physical therapist, speech language pathologist) (30%) and other related professions (nursing, healthcare administration, psychology, scientists). Primary roles of panelists were patient (25%), clinical (25%), and administrative (25%); however, 70% of panelists had secondary roles. Panelists were primarily White (70%) and resided in the northeast (65%) or southeast (20%) regions of the United States.

Table 7 Description of panelists

Characteristics	Survey 1 (n=20)
Expertise, n (%)	
Older Breast Cancer Survivor	5 (25%)
Physician (Oncology or Physiatry)	4 (20%)
Occupational Therapy	3 (15%)
Physical Therapy	2 (10%)
Speech Language Pathology	1 (5%)
Psychology or Neuropsychology	1 (5%)
Nursing	1 (5%)
Patient Care Expert (Navigator or Social Work)	2 (10%)
Research in related field	1 (5%)
Primary Role, or Affiliation, n (%)	
Patient / Survivor	5 (25%)
Administrator	5 (25%)
Clinician	5 (25%)
Educator	1 (5%)
Scientist	3 (15%)
Other	1 (5%)
Secondary Role or Affiliations, n (%)	
Administrator	1 (5%)
Clinician	4 (20%)
Educator	3 (15%)
Scientist	4 (20%
Other	2 (10%)
Not applicable	6 (30%)
Race, n (%)	
White	14 (70%)
Black	3 (15%)
Asian	3 (15%)
Ethnicity, Hispanic, Latino/a, or Spanish Origin, n (%)	1 (5%)
Education, n (%)	
Associates	2 (10%)
Bachelor	3 (15%)
Masters	4 (20%)
Doctoral	11 (55)
Region of Residence in United States, n (%)	
Northeast	13 (65%)
Pacific	1 (5%)
Southeast	4 (20%)
Southwest	2 (10%)

4.3.2 Round 1 results

The aim of Round 1 was to evaluate stakeholders' beliefs of intervention content and delivery features that are feasible and a priority (Table 8). Intervention content that met greater than 70% consensus were: 1) physical activity and sedentary behavior strategies (92.5%), adaptive skills training (85%), energy conservation and work simplification strategies (85%), general behavior strategies (82.5%), and exercise (82.5%). Panelists wrote in additional intervention content including peer support (n=3), cognitive rehabilitation activities (n=1), and web-based education resources (n=1). Based on a priori criteria, peer support was moved to Round 2 for additional review.

Delivery features included location, timing, mode, duration, and frequency. Reported are the delivery features met greater than or equal to 50% consensus. All intervention locations [outpatient clinic (82.5%), hospital (75%), community (67.5%), patient home (65%)] and timing [post-intervention (97.5%), during intervention (80%); pre-intervention (50%)] met consensus criteria. Combination of in-person and virtual delivery met consensus criteria (92.5%) for the mode of delivery. Intervention duration of three months of less (62.5% -75%) and frequencies of one (82.5%) or two (65%) times per week met consensus. The most common comment about delivery features was the role of COVID-19 in delivery of current and future care. Four panelists reported that their responses about location and mode of delivery were highly dependent on safety of high-risk populations given the pandemic.

Table 8 Round 1 consensus (n=20)

Intervention Construct	Consensus Frequencies
Intervention Activity	
Physical Activity and Sedentary Behavior Strategies	92.5%
Energy Conservation and Work Simplification	85.0%
Adaptive Skills Training	85.0%
General Behavioral Strategies	82.5%
Exercise	82.5%
Adaptive Equipment	70.0%
Motivational Interviewing	67.5%
Environmental Modification	65.0%
Cognitive Behavioral Therapy	52.5%
Intervention Location	
Outpatient Clinic	82.5%
Hospital	75.0%
Community	67.5%
Patient Home	65.0%
Timing of Intervention	
Post-Treatment	97.5%
During Treatment	80.0%
Pre-Treatment	50.0%
Modes of Delivery	
Combination	92.5%
Virtual Only	50.0%
In-Person Only	40.0%
Intervention Duration	
Less than 4 weeks	62.5%
1 to 3 months	75.0%
4 to 6 months	45.0%
6 to 12 months	27.5%
12 months or more	10.0%
Intervention Frequency	
1 time per week	82.5%
2 times per week	65.0%
3 times per week	30.0%
4 or more times per week	5.0%

4.3.3 Round 2 results

The aim of Round 2 clarified consensus for intervention content and delivery features. Table 9 displays median prioritization rankings, level of agreement, consensus classification and stakeholder qualitative data. Additional qualitative data justifying panelist rankings can be found in Appendix F. Intervention content with highest rankings were physical activity strategies (high consensus) and adaptive skills training (moderate consensus). Panelists prioritized interventions delivered in outpatient clinics (high consensus). Likewise, panelists prioritized timing of interventions to be delivered post-treatment (high consensus). Lastly, interventions delivered using a combination format (virtual and in-person), a duration of three months or less, and occurring one to two times per week were prioritized with high consensus.

Table 9 Round 2 rankings (n=20)

	Median (Range)	Consensus Percentage	Consensus Classification	Panelist Qualitative Reflections
Intervention Content[a]				
Physical Activity Strategies	2 (1 - 5)	85%	High	“Physical activity/Sedentary behavior has a cascading effect on physical function, mood, sleep, fatigue, cognition, and potentially nutrition. It has significant impact across multiple domains for a single intervention.” “I chose adaptive strategies. After fighting and beating breast cancer, there are still changes that need to be made to a person's lifestyle. From a social work perspective, it makes sense that the patient overall "adapt" to their "new normal" I feel it encompasses some of the other intervention activities.”
Adaptive Skills Training	3 (1 - 5)	65%	Moderate	
Behavioral Strategies	4 (1 - 6)	65%	Moderate	
Energy Conservation	4 (1 - 6)	55%	Low	
Exercise	4 (1 - 6)	60%	Moderate	
Peer Support	6 (1 - 6)	50%	Low	
Intervention Delivery Features				
Location[a]				“My highest priority with outpatient clinic is the patient will get the best care in a facility that is built and structured for their specific needs without feeling like they are in an actual hospital.” “Outpatient is typically the most convenient for the patient and sites by which patients would most likely remain compliant short and long term.”
Outpatient Clinic	1 (1 - 3)	100%	High	
Community	3 (1 - 4)	95%	High	
Hospital	3 (1 - 4)	90%	High	
Patient Home	4 (1 - 4)	70%	High	
Timing[a]				“Post-treatment is my highest priority, mainly because to do it pre or during treatment doesn't take into consideration what changes they body will continue to make after treatment is over. Which I feel is when most of the changes will take place.”
Post-Treatment	1 (1 - 2)	100%	High	
During Treatment	2 (1 - 3)	100%	High	
Pre-Treatment	3 (1 - 3)	85%	High	
Mode of Delivery[b]				“While COVID-19 has facilitated the use of virtual modalities for therapy, adjustment and quirks are often easier to manage when an in-person relationship established. Moreover, components of assessment can be challenging online and measures may be less precise. Thus, I think the combination is optimal for both patient and clinician.”
Combination	---	100%	High	
Duration[b]				“I think 1-3 months is a good amount of time to introduce certain interventions. It is enough time for the patients to get used to the intervention and show they can implement it on their own moving forward to the future.”
1 to 3 months in length	---	75%	High	
Frequency[b]				“That's what our healthcare system will allow and most people can manage in their daily lives.”
1-2 times per week	---	100%	High	

[a] Outcomes were based on % consensus at median ranking, plus/minus one rank

[b] Outcomes were based on confirmation of agreement (agree or disagree)

4.4 Discussion

The modified Delphi process was used to inform the development of interventions addressing activity limitations in older breast cancer survivors. This process enabled our study team to provide guidance on intervention content and delivery features based on existing evidence and stakeholder perspectives. Collectively, our findings suggest that interventions prioritizing physical activity and adaptive skills may be valued for addressing activity limitations. Panelists prioritized post-treatment interventions that could be delivered in outpatient clinics, post-treatment, and using a combination of in-person and virtual visits. We also found that panelists preferred interventions of shorter duration and bi-weekly frequency. These findings have implications for the ways we develop and test new interventions and modify existing interventions for older breast cancer survivors.

Panelists prioritized physical activity strategies and adaptive skills training with high and moderate degrees of consensus. Interestingly, panelist commentary suggests that prioritization of these components may be due to their multidimensional influence on cancer-related disability. For example, strategies to promote physical activity are thought to affect a variety of body structures and functions. Various physical activities have led to improvements in muscle strength, gait speed, and mental health as well as reduction in falls.[149] Since physical activity has a moderate association with activities of daily living and strong association with social interactions,[150] we might infer that physical activity strategies may also promote the capacity of older breast cancer survivors to more successfully overcome limitations in self-care, social obligations, and leisure activities. Adaptive skill training was also prioritized for its multidimensional effects. This intervention content was perceived to be generalizable to a variety of activity limitations. Adaptive skills training can teach older breast cancer survivors to identify challenging daily activity, generate personalized processes to overcome the challenge, and generalize these skills to future daily challenge encounters.[82] In other words, adaptive skills training was perceived to promote self-management of ongoing and new sequelae that may affect overall activity engagement in this population.

Limited consensus was found for the remaining intervention content. This may be due to a few reasons. First, peer support represents a wide range of programs that capitalize on the experiential knowledge of cancer survivors to enhance health, participation, and quality of life among other cancer survivors.[126] Peer support was based on panelist feedback and had only one application from our scoping review (Chapter 2). While more commonly used in community settings, there is limited infrastructure to support such peer or group interventions within existing models of cancer rehabilitation or geriatric oncology.[151] In addition, older breast cancer survivors report mixed feelings on peer support interventions, noting that success of such an intervention may be highly dependent on peer match (Chapter 3). Thus, peer support bears further investigation.

Equally important, panelists did not reach consensus on the use of behavioral strategies, energy conservation and work simplification strategies, and exercise in Round 2. Comments from individuals raised concerns that the effects of these interventions might vary greatly based on delivery. Other panelists stated that these interventions may be more costly to implement. Future research may pursue further clarification of how specific combinations for intervention content and delivery models are perceived by stakeholders and evaluate their cost-effectiveness. Additional intervention content that did not achieve consensus in Round 1 included adaptive equipment, motivational interviewing, environmental modification, cognitive rehabilitation (panelist comment), and web-based support tools (panelist comment). Limited consensus may be due to underdeveloped theory in relation to activity limitations and/or limited evidentiary or stakeholder support.

As suggested earlier, delivery features are important to consider in intervention development. Panelists highly prioritized outpatient clinics as the setting location for interventions. Panelists shared that outpatient clinics facilitate delivery of skilled services without the ongoing reminders of cancer recurrence or appearance of illness that a hospital may convey. Likewise, panelists shared that outpatient clinics are convenient to older adults with limited transportation and/or live within rural communities. As oncology care moves toward community-based models, Kent and colleagues suggest adopting outpatient settings within research designs to accelerate implementation of research.[152] Intervention locations representative of current healthcare models are likely to be accessible and result in recruitment of more representative samples, including those who are in underserved communities.[152,153] Future intervention research should consider adoption of outpatient or settings aligned with community-based models to meet stakeholder preferences and health care policy priorities.

There was strong consensus for interventions that take place post-treatment. Post-treatment interventions are more widely accepted and utilized than services pre-treatment or during treatment.[127] Panelists commented that interventions delivered post-treatment provided time for survivors to become aware of functional decline, experience greater flexibility in their schedules, as well as focus energy on recovery rather than treatment. Post-treatment also represents the longest phase of cancer survivorship when survivors must adjust to biological, psychological, and social changes.[154] Older breast cancer survivors on the expert panel shared qualitative comments that demonstrated shared about uncertainty about use of prehabilitation. This may suggest a need for further education on disability prevention and models of prehabilitation care.[155] Given this, future intervention development and health services research need to further investigate models of care delivery that may best support chronic and/or long-term surveillance and treatment of cancer-related sequelae.[154]

The mode of delivery, duration, and frequency of intervention had early and consistent consensus in both Delphi rounds. Stakeholders prioritized interventions combining both in-person and virtual delivery. It is possible that this mode of delivery received consensus influenced by the COVID-19 pandemic.[156] Eleven of 20 panelists reported that a hybrid delivery affords convenient appointment scheduling, increases patient safety, reduces transportation burden, provides ongoing progress, and may provide problem-solving within the patient's home context. However, one stakeholder noted that training in technology among older populations will be critical to optimize value of the virtual component. Since March 2020, the shift to telemedicine was made to promote safety of high-risk populations,[156,157] such as older breast cancer survivors. Practitioners, administrators, and patients in our study reported similar beliefs that forms of virtual rehabilitation will remain intact post-pandemic. Thus, developing, testing, and implementing hybrid models of care will be imperative.

Stakeholders fully agreed on the duration (no more than three months) and frequency (one to two times per week) of intervention. Stakeholder feedback suggested that this duration and frequency were manageable within existing reimbursement structures, limited patient burden, and provided enough time to affect health outcomes. Ensuring that interventions are not overly burdensome is important for stakeholder buy-in and patient adherence.[28] As healthcare and research teams refine content of an intervention, they may also consider use of multiphase optimization designs,[89] particularly time-varying adaptive models, which investigate optimal intervention length. This way, existing interventions that are longer than three months and/or more frequent than two times per week can be modified to meet preferences of key consumers while maintaining clinically meaningful outcomes.

Limitations of our study should be considered when interpreting our results. Our panel included stakeholders with variation in roles and geography to ensure that intervention content and delivery features were acceptable, relevant, and valued by widespread stakeholders. However, our results may not fully reflect the values and needs of all survivors of metastatic breast cancer and/or those among underrepresented populations. The pre-defined constructs were based on a scoping review and stakeholder interviews which had a limited representation of populations with advanced disease or populations of color.

We also encountered various challenges in the recruitment of panelists from underrepresented populations. This may be largely due to the lack of diversity among key stakeholder workforces. A recent report from the American Society of Clinical Oncology stated that there is a ‘persistent pattern of reduced diversity” (pg. 3697) among oncology residency programs leading to serious implications for delivery of quality cancer care.[158] Lack of diversity is further magnified by the limited representation of prominent stakeholder groups such as physiatry,[159] rehabilitation professionals,[160,161] and research participants.[162] We also encountered challenges recruiting diverse patient stakeholders due to age criteria. While older adults are often assumed as “65 years and older,” using chronological age may be inappropriate for underrepresented populations who demonstrated accelerated markers of cellular aging.[133] Adoption of broader age inclusion criteria may be warranted to capture the important perspectives of diverse patient perspectives.

Future expert panels and intervention research should capture the necessary perspectives of underrepresented patients and providers who may have unique lived experiences. Moving forward, scientists should consider adopting frameworks of co-design[163] which seek to integrate representative stakeholder feedback throughout intervention design, development, and testing to reduce healthcare inequities. Lastly, our panel did not come to consensus on all intervention content. This may reflect the limited evidence on existing interventions influencing functional decline intended for this population and lack of familiarity with types of intervention content among various stakeholders.

4.5 Conclusions

The findings from this study represent the first attempt at specifying intervention characteristics influencing activity limitations among older breast cancer survivors. The recommendations were grounded in existing evidence and stakeholder-driven priorities. Adoption of interventions involving physical activity and adaptive skills training may improve value and acceptability of interventions. Delivery of interventions post-treatment, within an outpatient clinic, and using both in-person and virtual visits may improve relevance and accessibility for older breast cancer survivors. Future intervention research should incorporate and test these intervention characteristics to ensure their effectiveness and utility in real-world settings.

5.0 Discussion

There is a critical need to develop interventions that address activity limitations in older breast cancer survivors. With current growing rates of older breast cancer survivors,[137] we cannot afford long-standing delays such as a 17-year gap between intervention development and implementation.[164] Barriers to implementation of intervention research have been connected to traditional models of intervention development.[153] Traditional models use a linear pathway of pre-intervention studies, intervention development, feasibility and efficacy testing, effectiveness, and then wider implementation.[30,153] In these models, initial intervention development often fails to consider elements of implementation.[165] Without earlier consideration, we miss opportunities to refine and improve an intervention's fit for real-world setting,[153] thus perpetuating healthcare disparities.[166,167]

This dissertation applied a novel approach to integrate components of implementation into pre-intervention development research.[165] Through a scoping review, we examined intervention content and delivery features of existing interventions that influence activity limitations in older breast cancer survivors (Chapter 2). Following this, we explored older breast cancer survivors experience of cancer rehabilitation interventions and well as preferences for intervention content and delivery features (Chapter 3). We compiled and presented the findings to an expert panel of stakeholders involved in the care of older breast cancer survivors. The panel represented multiple levels of influence including the patient (older breast cancer survivor), provider (healthcare professionals), systems (administrators and healthcare organizations), and society (scientists and national agencies). The panel participated in a modified Delphi process to generate consensus-based recommendations to guide intervention development intended for older breast cancer survivors with activity limitations (Chapter 4). As such, this dissertation explored some important first steps toward blended intervention and implementation studies.[153,165] However, to begin to understand the implications of our findings, we must examine this research in the larger context of health and health care delivery.

5.1 Importance of Integrated Approaches to Enhance Intervention Development and Implementation

Over 50% of breast cancer survivors are considered older adults.[2] Multiple reports have documented that older breast cancer survivors have unique and complex needs, including chronic and late effects of cancer and comorbid conditions and cancer-related disability.[11,14,121,122,168,169] The United States is currently struggling to identify a coordinated medical and public health approach to meet these diverse survivorship needs.[122]

Traditional linear processes of intervention development, derived from pharmaceutical development models, have often resulted in complex behavioral interventions that are challenging to adopt in real-world settings.[34] This is because pre-intervention and efficacy trials designed to maximize health outcomes often limit our understanding of "noise in the system (patient comorbidities, competing demands and skill variance of clinicians, resource limitations, varying motivations of patients)" (p. 2).[153] Forgoing early investigation of "the noise" has left us with interventions that are poorly structured to address the complex needs of representative samples and settings. Alfano and colleagues recommend that we adapt the process of developing and testing survivorship interventions to improve communication, collaboration, evaluation, and integration.[122] Brown and colleagues share specific recommendations to accomplish the adapted process by blending design components of implementation into pre-intervention development, efficacy, and effectiveness trials[32,165] (See Figure 8).

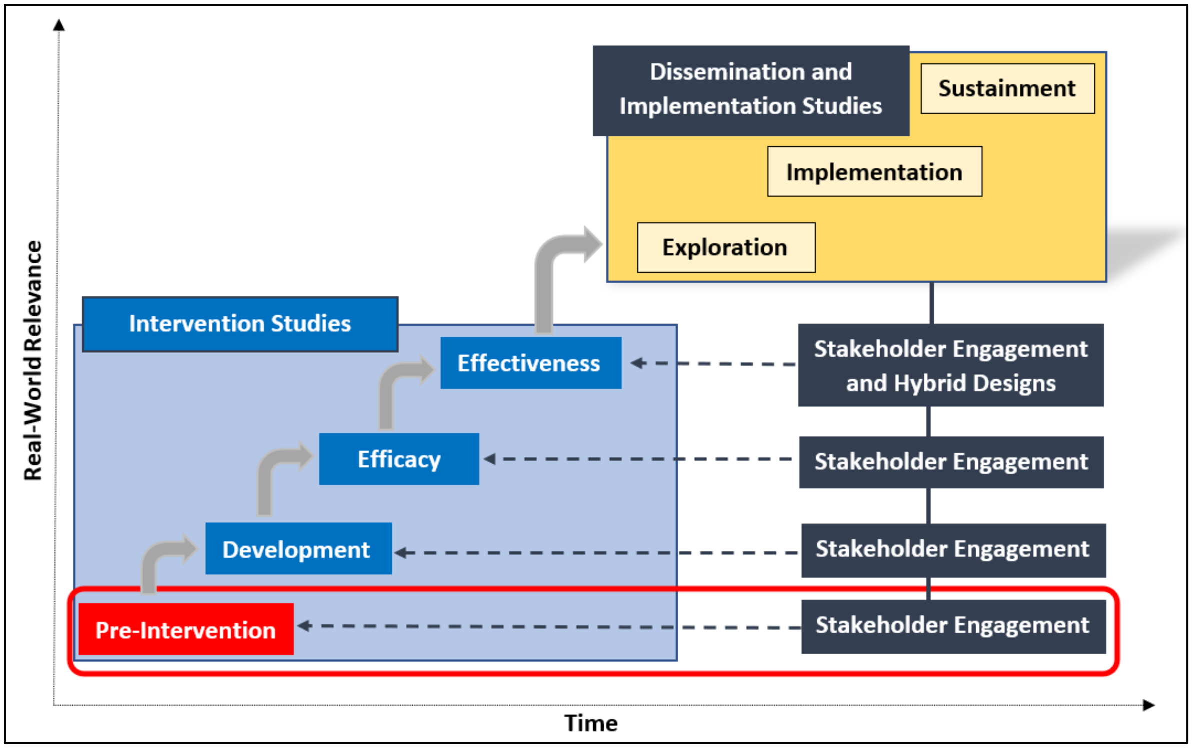


Figure 8 Blending design components of implementation with intervention development (Adapted from Figure 1 in Brown et al. 2017)

Findings from this dissertation focus on the pre-intervention phase depicted in Figure 8 (bolded in red). This research supports that use of both quantitative and qualitative research methods is an important and effective way to integrate components of intervention development and implementation. Whereas pre-intervention trials typically measure health outcomes quantitatively, qualitative data collection can “precede, confirm, complement, or extend quantitative evaluation” (p.2).[32]

The addition of qualitative methodologies in the pre-intervention phase integrates important and necessary perspectives of older breast cancer survivors and other related stakeholders. Stakeholders share insights that are distinct from scientists[90] as they are representative of the intended users of such interventions. Stakeholders may provide a deeper understanding of feasibility, efficiency, safety, equity, timeliness, and sustainability of an intervention that are not typically captured by quantitative analyses alone.[37] For example, large registry data depicts limited uptake of cancer rehabilitation interventions among older breast cancer survivors.[24] Yet, quantitative statistics of adherence did not fully reveal causation of limited uptake. Our qualitative findings uncovered that poor uptake of cancer rehabilitation interventions may be due to lack of shared decision-making tools, cost, and limited assessment of activity limitations. Likewise, our scoping review revealed that evidence-based interventions addressing activity limitations in older breast cancer survivors are typically delivered in-person only. However, qualitative findings from semi-structured interviews and Delphi process suggest that older breast cancer survivors and related stakeholders prefer and prioritize interventions that combine in-person and virtual delivery. Specifically, stakeholders found the combination delivery more feasible and accessible to in-person alone. This finding demonstrates that intervention delivery must evolve as stakeholder preferences adapt and change. Had we not used both quantitative and qualitative approaches to investigate mode of delivery, we may have continued to create interventions that have limited relevance and accessibility to end consumers. Incorporation of both methodologies may help us to understand the context for implementation and allow earlier and continual refinement an intervention to promote greater clinical benefit and acceptability.

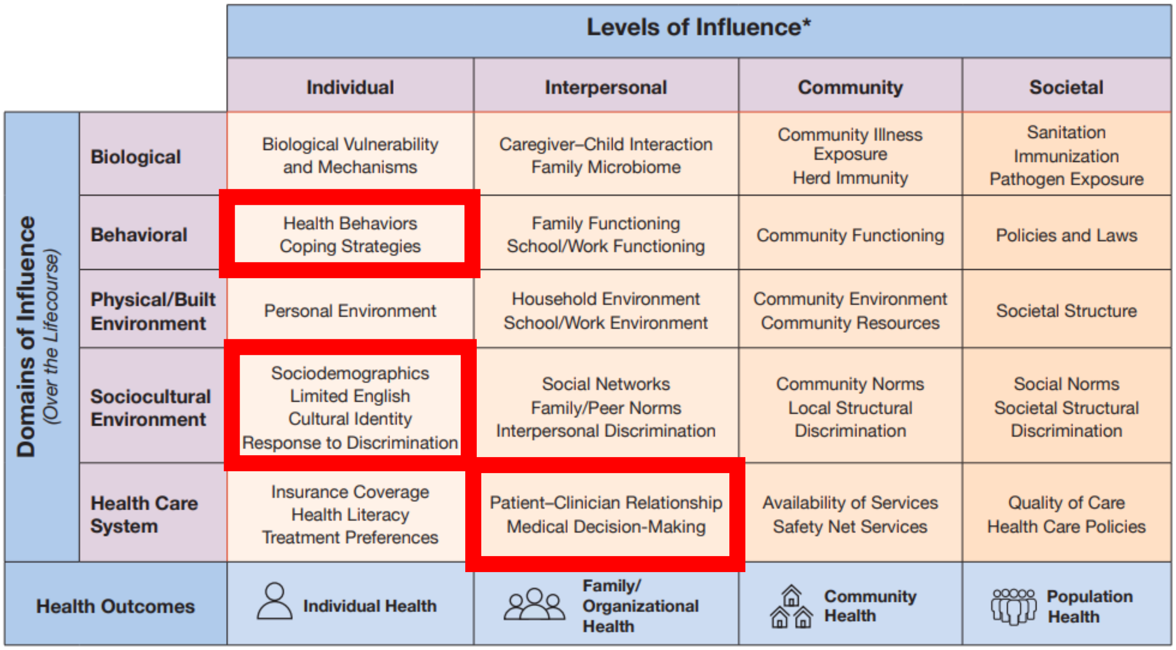
By blending intervention development and implementation approaches, we also afford mutually beneficial opportunities to both scientists and stakeholders.[170] Scientists have reported positive insights into their work and gaining a greater understanding of intervention context.[171] They have also found ways to improve recruitment, improve the quality and relevance of data collection, and expand dissemination of their research results.[172] Likewise, stakeholders have reported feelings of empowerment and value, a sense of cohesiveness, and having a better understanding of research, which collectively resulted in positive attitudes toward clinical research as well.[171] These positive experience may motivate stakeholders during and after the intervention studies to continue involvement in research.[171] Positive research experiences may lead to improvements in recruitment and study participation across older breast cancer survivors.[34]

Based on these dissertation findings, our future research will involve developing an intervention protocol and efficacy testing informed by stakeholder input. Once we determine that the intervention has strong face validity, relevance to this population, and supports application in broader settings, we can consider use of hybrid research designs.[165] Hybrid designs simultaneously test elements of intervention effectiveness and implementation to enhance public health impact.[165] Hybrid designs focus on gathering information on an intervention delivery and/or testing implementation strategies during an effectiveness trial. These trials may help us to understand if the clinical intervention effects might be susceptible to change during implementation in a new setting or under conditions less controlled (e.g. real world settings; new populations).[165] Through this work, we may achieve an earlier understanding of who (does not) qualifies, who (does not) benefits, what barriers exist to implementation, what problems were associated with delivery, and what intervention modifications may enhance implementation.

5.2 Health Care Disparities in Intervention Research Addressing Activity Limitations Among Older Breast Cancer Survivors

Findings from this dissertation also revealed health care disparities within this scope of research. From a broad view, older breast cancer survivors have limited representation across clinical trials.[34] Lack of inclusivity is further magnified for older breast cancer survivors of color. Females of color represent half of new breast cancer diagnoses.[94] However, findings from our scoping review suggest that existing data are largely based on homogenous study samples of White, non-Hispanic, college-educated women. Likewise, we experienced challenges recruiting diverse older breast cancer survivors and related stakeholders in Chapters 3 and 4. Lack of representation may influence our understanding of intervention value, relevance, and implementation.[34]

The National Institute on Minority Health and Health Disparities published a research framework that conceptualizes ways that intervention scientists can approach development of more equitable interventions.[173] Specifically, the framework demonstrates how healthcare disparities arise due a combination of many factors. [174] The framework divides health across levels of influence such as individual, interpersonal, community, and society.[174] Within each level of influence are domains of health including biological, behavioral, physical environment, sociocultural, and health care system. This matrix characterizes 20 distinct factors that influence healthcare disparities.[173,174] Intervention development that considers these multi-level, multi-domain factors may allow us to create more accessible, valued, and effective interventions.[174] Findings from this dissertation (bolded in red) can be examined within this framework to depict what factors have been addressed by this dissertation and factors that require additional investigation (See Figure 9; Appendix G).



		Levels of Influence*			
		Individual	Interpersonal	Community	Societal
Domains of Influence *(Over the Lifecourse)*	**Biological**	Biological Vulnerability and Mechanisms	Caregiver–Child Interaction Family Microbiome	Community Illness Exposure Herd Immunity	Sanitation Immunization Pathogen Exposure
	Behavioral	Health Behaviors Coping Strategies	Family Functioning School/Work Functioning	Community Functioning	Policies and Laws
	Physical/Built Environment	Personal Environment	Household Environment School/Work Environment	Community Environment Community Resources	Societal Structure
	Sociocultural Environment	Sociodemographics Limited English Cultural Identity Response to Discrimination	Social Networks Family/Peer Norms Interpersonal Discrimination	Community Norms Local Structural Discrimination	Social Norms Societal Structural Discrimination
	Health Care System	Insurance Coverage Health Literacy Treatment Preferences	Patient–Clinician Relationship Medical Decision-Making	Availability of Services Safety Net Services	Quality of Care Health Care Policies
Health Outcomes		**Individual Health**	**Family/ Organizational Health**	**Community Health**	**Population Health**

Figure 9 NIMHD Research Framework. Reproduced from National Institute on Minority Health and Health Disparities (2018)

5.2.1 Dissertation findings and applications

The findings from this dissertation primarily addressed *individual-* and *interpersonal-levels* of influence. *Individual-level* factors are directly related to older breast cancer survivors whereas *interpersonal-level* factors represent the connection between older breast cancer survivors with other individuals, life roles, and their environment. Intervention research that addresses *individual-* and *interpersonal-level* factors are common among cancer rehabilitation intervention literature[175] and broader healthcare disparity research.[174] These levels of influence inform foundational components of a manualized intervention, testing of theory and mechanisms of action, identification of outcomes of interest, and explorations of interventions in relation to health systems and organizational contexts.

5.2.1.1 Individual-behavioral factors

Findings from Chapters 3 and 4 primarily relate to the *Individual-Behavioral* factor. We explored preferred intervention content and coping strategies to address activity limitations in this population. Specifically, Chapter 3 revealed that older breast cancer survivors prefer to combine a variety of healthy behaviors (physical activity/exercise; adaptive skills training; goal-setting) to manage activity limitations. Use of multiple healthy behaviors parallels the complex, multi-component structure of existing intervention identified in Chapter 2. Furthermore, physical activity and adaptive skills training were prioritized by an expert panel. Intervention content that incorporates activity planning, problem-solving and/or practice of daily activities may be critical to overcome activity limitations. Physical activity and adaptive skills training represent patient-centric approaches that can be tailored to incorporate *Individual-Sociocultural Environment* considerations.[82,176] Future work should rigorously examine this intervention content to identify which approach or combination of approaches is most clinically meaningful and feasible to implement with populations that are more representative of the demographics of older breast cancer survivors.

5.2.1.2 Individual-sociocultural environment

Study samples included in the scoping review (Chapter 2), qualitative analysis (Chapter 3), and Delphi study (Chapter 4) were primarily White and non-Hispanic, and thus limit generalizability of the priorities and values in this dissertation to those of minority populations. In the United States, variations in cancer incidence, tumor phenotypes, and outcomes are associated with racial and ethnic identity.[177] A recent narrative review of health disparities among underrepresented breast cancer populations states that any possible genetic explanations for these associations are confounded by socioeconomic, cultural, and lifestyle pattern.[177] Understanding how *Individual-Sociocultural Environment* factors interact to influence access to and delivery of cancer rehabilitation interventions may help clinicians, researchers, and policy makers identify more effective strategies to address breast cancer disparities going forward.

Sociocultural factors may also contribute to the inadvertent exclusion of people of color from current studies. Our studies were focused on older adult breast cancer survivors and we used the broadly accepted chronological age of 60 or 65 as an inclusion criterion. However, this criterion may have inadvertently excluded Black women who have a higher incidence of breast cancer at a younger age than White women. For example, Black women less than 50 years old have a higher incidence of breast cancer than White women in the same age group. Around the time of menopause, this trend reverses, and older white women have higher breast cancer incidence.[178] Likewise, Black women are more likely to develop triple negative breast cancer, a highly invasive pre-menopausal tumor that is associated with different cancer treatments and poor outcomes.[177] Use of a socially defined cut-point as an inclusion criterion may have prevented inclusion of Black women in the reviewed and prospectively conducted studies in this dissertation. And yet, younger Black breast cancer survivors may have similar needs for cancer rehabilitation services as older White breast cancer survivors. In addition, environmental stressors such as poverty and financial insecurity, lack of transportation, poor access to care, low educational attainment, and lack of health insurance contribute to poor health-related quality of life and disease severity which confound chronological age, among Black breast cancer survivors.[178,179] To ensure greater representation in research and access to rehabilitation intervention services, we should consider additional ways to define “age” to enhance inclusion of underrepresented populations in future research.

Stakeholder engagement and study recruitment strategies may increase the enrollment of underrepresented populations through specific understanding of and respect for sociocultural beliefs and values of these communities.[180] Strategies should also seek to overcome documented barriers to recruitment and intervention adherence including influence from family, religious leaders or friends, work constraints, transportation, and language barriers.[181] Connection of sociocultural environment factors to healthcare access may make certain research participation and rehabilitation interventions more attractive and instill trust compared to options which do not consider these factors.[182]

Furthermore, *Individual-Sociocultural Environment* factors may also inform intervention content and delivery for underrepresented populations. A scan of the literature conveys that identified intervention content including peer support,[183] healthy behaviors,[124], and physical activity strategies,[124] are valued and/or demonstrate modest effects on dimensions cancer-related disability in underrepresented populations. However, poor patient-provider communication and inequitable care delivery may perpetuate poor engagement in intervention, promote mistrust, and prevent future utilization of services.[124] Concerted time and funding must be dedicated to collaborating with stakeholders of underrepresented populations to adapt delivery of an intervention to accommodate for these *Individual-Sociocultural* factors. For example, efforts can be made to leverage intervention locations that are familiar and accessible to black survivors including churches, civic organizations, parks, and recreation centers to provide support systems and venues for programmatic activities.[184] Strategically designing interventions to consider input and sociocultural values from underrepresented persons may strengthen appropriateness, accessibility, overall benefit and sustainability of an intervention within real-world settings.[112]

5.2.1.3 *Interpersonal-Healthcare System*

Lastly, our findings revealed a deeper understanding of the relationship between older breast cancer survivors and healthcare system (*Interpersonal-Healthcare System)*. Pursuit of cancer rehabilitation interventions were based on multiple factors including cost and patient-provider interaction. Survivors shared that insurance coverage and out-of-pocket costs weighed into their decision to use rehabilitation services, yet few studies incorporate outcomes of cost-effectiveness.[16] Likewise, survivors wanted additional opportunities to engage in conversations with healthcare providers about benefits of cancer rehabilitation or strategies to mitigate activity limitations. According to Lawhon and colleagues, older breast cancer survivors prefer that they and their doctor share responsibility for deciding care solutions.[185] Future research efforts may consider creating and/or adapting a shared decision-making tool that is sensitive to the specific needs of breast cancer survivors. As stated previously, the tool should comprise sociocultural considerations that are relevant and comprehensive to all breast cancer survivors. Sutton and colleagues also recommend leveraging the knowledge and insight of patient navigators and/or community health workers, as opposed to physicians, to improve provider-patient relationships, communication about disability, and combat healthcare inequities among underrepresented breast cancer survivors.[186] Through implementation of these communication strategies, we may be able to examine patient characteristics to determine whether there were differences between those who chose to participate in the shared decision-making, who triggers need for rehabilitation, who pursues rehabilitation services, and how the tool affects healthcare provider communication.[187] Implementation may also reflect the degree to which we equitably apply shared decisions making and rehabilitation opportunities among older breast cancer survivors. Evaluation of these constructs is necessary to ensure that shared-decision making is feasible, equitable, and sustainable.

5.2.2 Future Directions

These dissertation findings revealed important considerations to inform cancer rehabilitation strategies for older breast cancer survivors with activity limitations. However, to ensure that intervention research addressing activity limitations is accessible and equitable in this population, future research might consider designs that consider multi-level and multi-domain factors. This research may span to include community or societal-level factors which influence scalability, sustainability, and widespread translation of future interventions. Likewise, intervention research should continue to explore influence of sociocultural environment on intervention priorities, delivery, and relevance.

5.3 Conclusion

This dissertation identifies intervention content and elements of delivery to inform future interventions for the older breast cancer survivors with activity limitations. The findings advance our knowledge in the fields of rehabilitation and geriatric oncology to better understand priorities and preferences of key stakeholders that may lead to more acceptable, valued, and appropriate cancer rehabilitation interventions. Next steps include development of an intervention protocol that incorporates and tests the mechanisms among the prioritized content and delivery features. Intervention protocols should be co-produced with representative older breast cancer survivors to ensure acceptability and value. Furthermore, early intervention testing can include *Community*- and *Societal-level* outcomes to simultaneously understand implications of the intervention within real world settings.

Appendix A Search Strategy

Ovid Medline

#	**Searches**
1	exp neoplasms/ or exp antineoplastic agents/ or exp antineoplastic protocols/ or cancer pain/ or cancer survivors/ or integrative oncology/ or exp medical oncology/ or oncology service, hospital/ or exp radiotherapy/
2	(anticancer or antineoplastic* or cancer* or carcinoma* or carcinosarcoma* or chemotherap* or fibrosarcoma* or germinoblastoma* or germinoma or gonadoblastoma or hemangioma or hemangiopericytoma or hemangiosarcoma* or hodgkin granuloma or hodgkins granuloma or hodgkin's granuloma or immunoblastoma* or leukemia* or oncological or oncologyor neoplas* or tumor or tumors or tumour or tumours or sarcoma*).ti,ab,kw.
3	1 or 2
4	exp behavior therapy/ or counseling/ or directive counseling/ or motivational interviewing/ or occupational therapy/ or person-centered psychotherapy/ or problem solving/ or psychotherapy, brief/ or psychotherapy, group/ or psychotherapy, multiple/ or psychotherapy, rational-emotive/ or psychotherapy/ or reality therapy/ or rehabilitation/ or self care/ or self efficacy/ or self-help groups/ or social participation/ or socioenvironmental therapy/
5	((behavior* or behaviour*) adj3 (activation* or intervention or interventions or management or modification* or rehab* or strateg* or technique or techniques or therapeutic or therapies or therapy or training or trainings or treatment or treatments)).ti,ab,kw.
6	(activity monitoring or activity planning or activity scheduling or cognitive behavioral or cognitive behavioural or cognitive therap* or contingency management or coping behavior or coping behaviors or coping skill or coping skills or counseling or counselling or group therap* or metacognitive strateg* or occupational rehabilitation or occupational therap* or planned behavior or problem solving therap* or psychoeducational intervention* or psychosocial intervention* or psychotherap* or rehab* or scheduled exercise or self help group* or self management intervention* or skills training or solution focused).ti,ab,kw.
7	(exp motivation/ or planning techniques/ or (engage or reengage or re engage or engaged or engagement or plan or planning or scheduling or self monitoring).ti,ab,kw.) and (exp leisure activities/ or exp activities of daily living/ or exp exercise/ or (exercise or leisure or meaningful activit* or pleasant activit* or meaningful event* or meaningful activit* or physical activit* or recreation or recreational or social activit*).ti,ab,kw.)
8	4 or 5 or 6 or 7
9	randomized controlled trial.pt.

10	controlled clinical trial.pt.
11	randomized.ab.
12	placebo.ab.
13	drug therapy.fs.
14	randomly.ab.
15	trial.ab.
16	groups.ab.
17	9 or 10 or 11 or 12 or 13 or 14 or 15 or 16
18	exp animals/ not humans.sh.
19	17 not 18
20	3 and 8 and 19
21	limit 20 to yr="2010 -Current"

EBSCO CINAHL

#	Query
S33	S32 Limiters - Published Date: 20100101-20201231
S32	S3 AND S8 AND S31
S31	S30 NOT S29
S30	S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23
S29	S27 NOT S28
S28	(MH "Human")
S27	S24 OR S25 OR S26
S26	TI (animal model*)
S25	(MH "Animal Studies")
S24	(MH "Animals+")
S23	AB (cluster N3 RCT)
S22	(MH "Crossover Design") OR (MH "Comparative Studies+")
S21	AB (control N5 group)
S20	PT ("randomized controlled trial")
S19	(MH "Placebos")

S18	(MH "Sample Size") AND AB (assigned OR allocated OR control)
S17	TI (trial)
S16	AB (random*)
S15	TI (randomised OR randomized)
S14	(MH "Cluster Sample+")
S13	(MH "Pretest-Posttest Design+")
S12	(MH "Random Assignment")
S11	(MH "Single-Blind Studies")
S10	(MH "Double-Blind Studies")
S9	(MH "Randomized Controlled Trials+")
S8	S4 OR S5 OR S6 OR S7
S7	((MH "Motivation") OR (MH "Planning Techniques") OR TI engage OR AB engage OR TI reengage OR AB reengage OR TI "re engage" OR AB "re engage" OR TI engaged OR AB engaged OR TI engagement OR AB engagement OR TI plan OR AB plan OR TI planning OR AB planning OR TI scheduling OR AB scheduling OR TI "self monitoring" OR AB "self monitoring") AND ((MH "Leisure Activities+") OR (MH "Activities of Daily Living+") OR (MH "Exercise+") OR TI exercise OR AB exercise OR TI leisure OR AB leisure OR TI "meaningful activit*" OR AB "meaningful activit*" OR TI "pleasant activit*" OR AB "pleasant activit*" OR TI "meaningful event*" OR AB "meaningful event*" OR TI "meaningful activit*" OR AB "meaningful activit*" OR TI "physical activit*" OR AB "physical activit*" OR TI recreation OR AB recreation OR TI recreational OR AB recreational OR TI "social activit*" OR AB "social activit*")
S6	(TI "activity monitoring" OR AB "activity monitoring" OR TI "activity planning" OR AB "activity planning" OR TI "activity scheduling" OR AB "activity scheduling" OR TI "cognitive behavioral" OR AB "cognitive behavioral" OR TI "cognitive behavioural" OR AB "cognitive behavioural" OR TI "cognitive therap*" OR AB "cognitive therap*" OR TI "contingency management" OR AB "contingency management" OR TI "coping behavior" OR AB "coping behavior" OR TI "coping behaviors" OR AB "coping behaviors" OR TI "coping skill" OR AB "coping skill" OR TI "coping skills" OR AB "coping skills" OR TI counseling OR AB counseling OR TI counselling OR AB counselling OR TI "group therap*" OR AB "group therap*" OR TI "metacognitive strateg*" OR AB "metacognitive strateg*" OR TI "occupational rehabilitation" OR AB "occupational rehabilitation" OR TI "occupational therap*" OR AB "occupational therap*" OR TI "planned behavior" OR AB "planned behavior" OR TI "problem solving therap*" OR AB "problem solving therap*" OR TI "psychoeducational intervention*" OR AB "psychoeducational intervention*" OR TI "psychosocial intervention*" OR AB

	"psychosocial intervention*" OR TI psychotherap* OR AB psychotherap* OR TI rehab* OR AB rehab* OR TI "scheduled exercise" OR AB "scheduled exercise" OR TI "self help group*" OR AB "self help group*" OR TI "self management intervention*" OR AB "self management intervention*" OR TI "skills training" OR AB "skills training" OR TI "solution focused" OR AB "solution focused")
S5	((TI behavior* OR AB behavior* OR TI behaviour* OR AB behaviour*) N3 (TI activation* OR AB activation* OR TI intervention OR AB intervention OR TI interventions OR AB interventions OR TI management OR AB management OR TI modification* OR AB modification* OR TI rehab* OR AB rehab* OR TI strateg* OR AB strateg* OR TI technique OR AB technique OR TI techniques OR AB techniques OR TI therapeutic OR AB therapeutic OR TI therapies OR AB therapies OR TI therapy OR AB therapy OR TI training OR AB training OR TI trainings OR AB trainings OR TI treatment OR AB treatment OR TI treatments OR AB treatments))
S4	(MH "Behavior Therapy+") OR (MH "Counseling") OR (MH "Motivational Interviewing") OR (MH "Occupational Therapy") OR (MH "Psychotherapy") OR (MH "Behavior Modification+") OR (MH "Psychotherapy, Brief") OR (MH "Psychotherapy, Psychodynamic") OR (MH "Psychotherapy, Group") OR (MH "Reality Therapy") OR (MH "Socioenvironmental Therapy+") OR (MH "Rehabilitation") OR (MH "Rehabilitation, Psychosocial") OR (MH "Community Reintegration") OR (MH "Problem Solving") OR (MH "Self Care") OR (MH "Self-Efficacy") OR (MH "Social Participation") OR (MH "Support Groups")
S3	S1 OR S2
S2	(TI anticancer OR AB anticancer OR TI antineoplastic* OR AB antineoplastic* OR TI cancer* OR AB cancer* OR TI carcinoma* OR AB carcinoma* OR TI carcinosarcoma* OR AB carcinosarcoma* OR TI chemotherap* OR AB chemotherap* OR TI fibrosarcoma* OR AB fibrosarcoma* OR TI germinoblastoma* OR AB germinoblastoma* OR TI germinoma OR AB germinoma OR TI gonadoblastoma OR AB gonadoblastoma OR TI hemangioma OR AB hemangioma OR TI hemangiopericytoma OR AB hemangiopericytoma OR TI hemangiosarcoma* OR AB hemangiosarcoma* OR TI "hodgkin granuloma" OR AB "hodgkin granuloma" OR TI "hodgkins granuloma" OR AB "hodgkins granuloma" OR TI "hodgkin's granuloma" OR AB "hodgkin's granuloma" OR TI immunoblastoma* OR AB immunoblastoma* OR TI leukemia* OR AB leukemia* OR TI oncological OR AB oncological OR TI "oncologyor neoplas*" OR AB "oncologyor neoplas*" OR TI tumor OR AB tumor OR TI tumors OR AB tumors OR TI tumour OR AB tumour OR TI tumours OR AB tumours OR TI sarcoma* OR AB sarcoma*
S1	(MH "Neoplasms+") OR (MH "Antineoplastic Agents+") OR (MH "Cancer Care Facilities") OR (MH "Cancer Fatigue") OR (MH "Cancer Survivors") OR (MH "Cancer Patients") OR (MH "Cancer Pain") OR (MH

	"Oncology Care Units") OR (MH "Oncology+") OR (MH "Oncologic Care+") OR (MH "Radiotherapy+")

Used a search filter to identify randomized controlled trials in CINAHL developed by Glanville et al. See: Glanville J, Dooley G, Wisniewski S, Foxlee R, Noel-Storr A. Development of a search filter to identify reports of controlled clinical trials within CINAHL Plus. Health Information & Libraries Journal. 2019 Mar;36(1):73-90.

Ovid PsycINFO

Searches	Results
1	exp Neoplasms/ or exp Antineoplastic Drugs/ or exp Oncology/ or exp Chemotherapy/ or exp Radiation Therapy/
2	(anticancer or antineoplastic* or cancer* or carcinoma* or carcinosarcoma* or chemotherap* or fibrosarcoma* or germinoblastoma* or germinoma or gonadoblastoma or hemangioma or hemangiopericytoma or hemangiosarcoma* or hodgkin granuloma or hodgkins granuloma or hodgkin's granuloma or immunoblastoma* or leukemia* or oncological or oncology or neoplas* or tumor or tumors or tumour or tumours or sarcoma*).ti,ab,id.
3	1 or 2
4	exp Behavior Therapy/ or counseling/ or group counseling/ or psychotherapeutic counseling/ or rehabilitation counseling/ or exp Cognitive Behavior Therapy/ or Motivational Interviewing/ or occupational therapy/ or exp psychotherapy/ or rehabilitation/ or problem solving/ or exp self-care skills/ or self-efficacy/ or exp Behavior Change/ or behavior modification/ or Support Groups/ or Self-Help Techniques/ or social interaction/
5	((behavior* or behaviour*) adj3 (activation* or intervention or interventions or management or modification* or rehab* or strateg* or technique or techniques or therapeutic or therapies or therapy or training or trainings or treatment or treatments)).ti,ab,id.
6	(activity monitoring or activity planning or activity scheduling or cognitive behavioral or cognitive behavioural or cognitive therap* or contingency management or coping behavior or coping behaviors or coping skill or coping skills or counseling or counselling or group therap* or metacognitive strateg* or occupational rehabilitation or occupational therap* or planned behavior or problem solving therap* or psychoeducational intervention* or psychosocial intervention* or psychotherap* or rehab* or scheduled exercise or self help group* or self management intervention* or skills training or solution focused).ti,ab,id.
7	(motivation/ or behavioral intention/ or exp motivation training/ or planned behavior/ or (engage or reengage or re engage or engaged or engagement or plan or planning or scheduling or self monitoring).ti,ab,id.) and (exp recreation/ or exp daily activities/ or exp "Activities of Daily Living"/ or exp Exercise/ or meaning/ or meaningfulness/ or (exercise or leisure or

	meaningful activit* or pleasant activit* or meaningful event* or meaningful activit* or physical activit* or recreation or recreational or social activit*).ti,ab,id.)
8	4 or 5 or 6 or 7
9	randomized controlled trials/ or randomized clinical trials/ or random sampling/ or placebo/ or exp Treatment Effectiveness Evaluation/ or exp Treatment Outcomes/ or (randomly or randomized or placebo or groups or controlled or "comparative stud*" or trial or trials or (research adj3 design) or (evaluat* adj3 stud*) or (prospectiv* adj3 stud*) or ((singl* or doubl* or trebl* or tripl*) adj3 (blind* or mask*))).ti,ab.
10	3 and 8 and 9
11	limit 10 to yr="2010 -Current"

Embase (Embase.com)
Saved as “SR_Brick_CancerBA_2020”

o.	Query
30	#29 NOT 'conference abstract'/it
29	#3 AND #8 AND #27 AND [2010-2020]/py
28	#3 AND #8 AND #27
27	#23 NOT #26
26	#24 OR #25
25	'animal experiment'/de NOT ('human experiment'/de OR 'human'/de)
24	(rat:ti OR rats:ti OR mouse:ti OR mice:ti OR swine:ti OR porcine:ti OR murine:ti OR sheep:ti OR lambs:ti OR pigs:ti OR piglets:ti OR rabbit:ti OR rabbits:ti OR cat:ti OR cats:ti OR dog:ti OR dogs:ti OR cattle:ti OR bovine:ti OR monkey:ti OR monkeys:ti OR trout:ti OR marmoset$:ti) AND 'animal experiment'/de
23	#9 OR #10 OR #11 OR #12 OR #13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20 OR #21 OR #22
22	trial:ti
21	volunteer:ti,ab OR volunteers:ti,ab
20	(controlled NEAR/7 (study OR design OR trial)):ti,ab
19	assigned:ti,ab OR allocated:ti,ab

18	((assign* OR match OR matched OR allocation) NEAR/5 (alternate OR group*1 OR intervention*1 OR patient*1 OR subject*1 OR participant*1)):ti,ab
17	crossover:ti,ab OR 'cross over':ti,ab
16	'parallel group$':ti,ab
15	((double OR single OR doubly OR singly) NEAR/1 (blind OR blinded OR blindly)):ti,ab
14	(open NEAR/1 label):ti,ab
13	(evaluated:ab OR evaluate:ab OR evaluating:ab OR assessed:ab OR assess:ab) AND (compare:ab OR compared:ab OR comparing:ab OR comparison:ab)
12	compare:ti OR compared:ti OR comparison:ti
11	placebo:ti,ab
10	random*:ti,ab
9	'randomized controlled trial'/exp OR 'controlled clinical trial'/exp OR 'randomization'/de OR 'intermethod comparison'/de OR 'double blind procedure'/de OR 'human experiment'/de
8	#4 OR #5 OR #6 OR #7
7	('motivation'/de OR 'planning'/de OR engage:ti,ab,kw OR reengage:ti,ab,kw OR 're engage':ti,ab,kw OR engaged:ti,ab,kw OR engagement:ti,ab,kw OR plan:ti,ab,kw OR planning:ti,ab,kw OR scheduling:ti,ab,kw OR 'self monitoring':ti,ab,kw) AND ('recreation'/exp OR 'daily life activity'/exp OR 'exercise'/exp OR exercise:ti,ab,kw OR leisure:ti,ab,kw OR 'pleasant activit*':ti,ab,kw OR 'meaningful event*':ti,ab,kw OR 'meaningful activit*':ti,ab,kw OR 'physical activit*':ti,ab,kw OR recreation:ti,ab,kw OR recreational:ti,ab,kw OR 'social activit*':ti,ab,kw)
6	'activity monitoring':ti,ab,kw OR 'activity planning':ti,ab,kw OR 'activity scheduling':ti,ab,kw OR 'cognitive behavioral':ti,ab,kw OR 'cognitive behavioural':ti,ab,kw OR 'cognitive therap*':ti,ab,kw OR 'contingency management':ti,ab,kw OR 'coping behavior':ti,ab,kw OR 'coping behaviors':ti,ab,kw OR 'coping skill':ti,ab,kw OR 'coping skills':ti,ab,kw OR counseling:ti,ab,kw OR counselling:ti,ab,kw OR 'group therap*':ti,ab,kw OR 'metacognitive strateg*':ti,ab,kw OR 'occupational rehabilitation':ti,ab,kw OR 'occupational therap*':ti,ab,kw OR 'planned behavior':ti,ab,kw OR 'problem solving therap*':ti,ab,kw OR 'psychoeducational intervention*':ti,ab,kw OR 'psychosocial intervention*':ti,ab,kw OR psychotherap*:ti,ab,kw OR rehab*:ti,ab,kw OR 'scheduled exercise':ti,ab,kw OR 'self help group*':ti,ab,kw OR 'self management intervention*':ti,ab,kw OR 'skills training':ti,ab,kw OR 'solution focused':ti,ab,kw

5	((behavior* OR behaviour*) NEAR/3 (activation* OR intervention OR interventions OR management OR modification* OR rehab* OR strateg* OR technique OR techniques OR therapeutic OR therapies OR therapy OR training OR trainings OR treatment OR treatments)):ti,ab,kw
4	'directive counseling'/de OR 'e-counseling'/de OR 'motivational interviewing'/de OR 'patient counseling'/de OR 'patient guidance'/de OR 'occupational therapy'/de OR 'psychotherapy'/de OR 'behavior modification'/de OR 'behavior contracting'/de OR 'client centered therapy'/de OR 'cognitive therapy'/de OR 'acceptance and commitment therapy'/de OR 'group therapy'/de OR 'rational emotive behavior therapy'/de OR 'reality therapy'/de OR 'short term psychotherapy'/de OR 'rehabilitation'/de OR 'self care agency'/de OR 'self help'/de OR 'self esteem'/exp OR 'social participation'/de
3	#1 OR #2
2	anticancer:ti,ab OR antineoplastic*:ti,ab OR cancer*:ti,ab OR carcinoma*:ti,ab OR carcinosarcoma*:ti,ab OR chemotherap*:ti,ab OR fibrosarcoma*:ti,ab OR germinoblastoma*:ti,ab OR germinoma:ti,ab OR gonadoblastoma:ti,ab OR hemangioma:ti,ab OR hemangiopericytoma:ti,ab OR hemangiosarcoma*:ti,ab OR 'hodgkin granuloma':ti,ab OR 'hodgkins granuloma':ti,ab OR immunoblastoma*:ti,ab OR leukemia*:ti,ab OR oncological:ti,ab OR 'oncologyor neoplas*':ti,ab OR tumor:ti,ab OR tumors:ti,ab OR tumour:ti,ab OR tumours:ti,ab OR sarcoma*:ti,ab,kw
1	'neoplasm'/exp OR 'antineoplastic agent'/exp OR 'antineoplastic protocol'/exp OR 'cancer pain'/de OR 'cancer survivor'/de OR 'oncology'/exp OR 'cancer center'/de OR 'radiotherapy'/exp OR 'cancer therapy'/exp OR 'oncological procedure'/exp

RCT filter adapted from https://www.cochranelibrary.com/central/central-creation

Appendix B Quality Appraisal

	Randomization	**Deviation from Intended Intervention**	**Missing Outcome Data**	**Measurement of Outcome**	**Selection of the Reported Result(s)**	**Overall Appraisal**
Poort et al., 2020[65]	Low	Low	Some	Some	Low	Some Concerns
Lyons et al., 2019[58]	Low	Low	Low	Low	Low	Low Risk
Gomersall et al., 2019[59]	Low	Low	Low	Low	Low	Low Risk
Pilegaard et al., 2018[60]	Low	Low	Low	Low	Low	Low Risk
Tsianakas et al., 2017[61]	Low	Low	Low	Low	Low	Low Risk
Winger et al., 2014[51,52]	Some	Low	Low	Some	Low	Some Concerns
Miki et al., 2014[62]	Low	Low	Low	Low	Low	Low Risk
Thomas et al., 2012[63]	Low	Low	Low	Low	Low	Low Risk
Belmonte et al., 2012[64]	Low	Low	Low	Low	Low	Low Risk
Rodriguez et al., 2019[67]	Low	Low	High	Low	Low	High Risk
Demark-Wahnefried et al., 2018[66]	Low	Some	Low	Low	Low	Some Concerns

Appendix C Interview Guides

Version A: Participant Who Received Cancer Rehabilitation Services

Introduction: Thank you for doing this interview with me today. Today's interview will be audio-recorded and will take approximately 60 minutes. Only approved study team members will have access to the recording. Today's conversation with help me understand more about the answers from your survey. Mainly, I am hoping to learn more about your experiences with cancer rehabilitation, challenges you may have encountered as a result of your cancer experience, and potential ways that we can improve the delivery of future cancer rehabilitation. Before we begin, do you have any questions?

1. Please describe any challenges you may have experienced since your diagnosis.
    a. How would you say cancer affected your body? What are the symptoms you experienced as a result of your cancer?
    b. How has cancer affected your daily routine and responsibilities?
        i. Probe fluctuations in challenges over course of cancer experience (pre-treatment, during treatment, post-treatment)

2. What are any strategies you used to overcome these challenges you mentioned?
    a. Another wording: How did you manage for these changes in your _______________ (symptoms/Day-to-day routine)?
    b. Did you feel confident in your ability to manage your cancer-related disability?

3. On the questionnaire, I saw you completed cancer rehabilitation in _______________. Tell me more about your cancer rehab experience?
    a. Probe: Tell me about the activities or exercises you did during your ___________ (hospital, inpatient, outpatient, home health) rehabilitation experience?
    b. Probe: What are/were you hoping to get out of your rehabilitation? What were your expectations of your cancer rehabilitation program?

    c. Probe: How did you and your therapist determine your goals or priorities for therapy?
    d. Probe: During therapy, did you ever experience X and y? (insert scoping review intervention content)
    e. Probe: Is there anything you would want to be done differently in your therapy experience?
    f. Probe: What elements of rehabilitation did you enjoy the most/least?
    g. Probe: How soon after your referral did you start your cancer rehab…if delayed why?
    h. Probe: What do you think is the purpose of cancer rehabilitation?
    i. Probe: What do you think are some of the benefits of cancer rehab?
    j. Probe: What thoughts/feelings did you have when participating in rehab?
    k. In your opinion, what should an ideal rehab program look like?

4. Having experienced the rehabilitation process, what things should therapists consider or prioritize when delivering care?
    a. Potential Examples: transportation barriers, social support, timing of day, etc.

5. We are constantly trying to improve the way we deliver therapy. There are many ways for us to deliver cancer rehabilitation. Where would you like to receive rehabilitation services? What do you like about this setting?
    a. If participant unsure of responses, provide examples of hospital, community, outpatient, virtual, etc.
    b. Probe: What do you like/dislike about other settings?
    c. Probe: How often would you commit to going?

6. What are some of your thoughts on doing therapy ________________ (before treatment, after treatment, etc.)?
    a. Potential Variations: When do you think you benefit most from cancer rehab? Given your cancer experience, when do you think it would be most practical to do cancer rehabilitation?

Conclusion: Thank you again for discussing these topics with me today. I have learned quite a bit and hope it guides us to deliver quality care to those who need it in the future. Before we wrap up, do you have any last questions for me?

Version B: Participant Who Did Not Receive Cancer Rehab But Wanted It

Introduction: Thank you for doing this interview with me today. Today's interview will be audio-recorded and should take no more than 60 minutes. Only approved study team members will have access to the recording. Today's conversation with help me understand more about the answers from your survey. Mainly, I am hoping to learn more about your cancer experience. Before we begin, do you have any questions?

To get us started,

1. Please describe any challenges you may have experienced since your diagnosis.
    a. How would you say cancer affected your body? What are the symptoms you experienced as a result of your cancer?
    b. How has cancer affected your daily routine and responsibilities?
    c. Probe fluctuations in challenges over course of cancer experience (pre-treatment, during treatment, post-treatment)

2. What are any strategies you used to overcome these challenges you mentioned?
    a. Another wording: How did you manage for these changes in your _______________ (symptoms/Day-to-day routine)?

3. You marked that you want or would have wanted cancer rehabilitation. Tell me about your desire to have cancer rehabilitation?
    a. Potential Follow-Up Questions:
        i. Had you every heard of cancer rehabilitation services before?
            1. Probe how, where, and who told them about it.
        ii. Why do you think you did not receive it?
        iii. What are/were you hoping to get out of your rehabilitation?
        iv. When do you think you would have benefitted the most from it?
        v. How often would you commit to going?

4. We are constantly trying to improve the way we deliver therapy. There are many ways for us to deliver cancer rehabilitation. Where would you like to receive rehabilitation services? What do you like about this setting?
    a. If participant unsure of responses, provide examples of hospital, community, outpatient, virtual, etc.
    b. Probe: What do you dislike about other settings?

        c. Probe: How often would you commit to going?
        d. Probe: What types of activities would you want as a part of your rehabilitation experience?
            i. Provide definitions or examples of options from scoping review if they are unable to identify independently.

5. What are your thoughts on the best timing of therapy _________________ (before treatment, after treatment, etc.)?
    a. Potential Variations: When do you think you benefit most from cancer rehab? Given your cancer experience, when do you think it would be most practical to offer or do cancer rehabilitation?

6. Thinking about your cancer experience, what would be reasons for you not to attend cancer rehabilitation?

Conclusion: Thank you again for discussing these topics with me today. I have learned quite a bit and hope it guides us to deliver quality care to those who need it in the future.

Version C: Participant Who Didn’t Receive Cancer Rehab And Doesn’t Want It

Introduction: Thank you for doing this interview with me today. Today’s interview will be audio-recorded and should take no more than 60 minutes. Only approved study team members will have access to the recording. Today’s conversation with help me understand more about the answers from your survey. Mainly, I am hoping to learn more about your cancer experience. Before we begin, do you have any questions?

To get us started,

1. Please describe any challenges you may have experienced since your diagnosis.
    a. How would you say cancer affected your body? What are the symptoms you experienced as a result of your cancer?
    b. How has cancer affected your daily routine and responsibilities?
    c. Probe fluctuations in challenges over course of cancer experience (pre-treatment, during treatment, post-treatment)

2. What are any strategies you used to overcome these challenges you mentioned?
    b. Another wording: How did you manage for these changes in your _______________ (symptoms/Day-to-day routine)?

3. I saw that you would not have wanted/benefited from cancer rehabilitation. Tell me more about why you selected this answer.
    a. Potential Follow-Up Questions:
        i. What would be the reasons why you would consider cancer rehabilitation services?
        ii. What are some of the reasons why you wouldn’t consider cancer rehabilitation?
        iii. Were cancer rehabilitation services ever offered to you?
        iv. Tell me about why you think you did not receive it?
        v. Who do you think cancer rehabilitation services would benefit the most?
        vi. Provide an example of what type of cancer survivor would benefit most from cancer rehabilitation?

4. We are constantly trying to improve the way we deliver therapy. Given your experience, I was hoping you could share with me what ways cancer rehab could be done to make it more accessible to cancer survivors. I saw that you would prefer therapy to be delivered through ________________________. What do you like about this setting?

    b. Potential Follow-Up Questions:
        i. What do you dislike about other settings?
        ii. How often would a cancer survivor be able to commit to going?
        iii. Who should tell cancer survivors about cancer rehabilitation services?
        iv. Would cancer survivors prefer to attend one-on-one sessions or groups?
        v. Probe: Based on your treatment experience, what types of rehabilitation activities do you think would be beneficial for older breast cancer survivors?
            1. Note: Provide definitions or examples of options from scoping review if they are unable to identify independently.

5. What are some of your thoughts on the timing of therapy _________________ (before treatment, after treatment, etc.)?
    c. Potential Variations: When do you think you benefit most from cancer rehab? Given your cancer experience, when do you think it would be most practical to do cancer rehabilitation?

Conclusion: Thank you again for discussing these topics with me today. I have learned quite a bit and hope it guides us to deliver quality care to those who need it in the future.

Appendix D Intervention Content Definitions

Intervention Content	Definition
Exercise	Activities which focus on building strength and endurance. These include both cardio-based activities (e.g., running, swimming, walking, elliptical, NuStep, cycling) as well as resistance activities (e.g., weights, resistance bands, push-ups).
Cognitive Behavioral Theory	A common form of talk therapy (psychotherapy) to address inaccurate or negative thinking related to current problems. It focuses on current problems, rather than focusing on issues from your past. It looks for practical ways to improve your state of mind on a daily basis.
Motivational Interviewing	A form of talk therapy between a healthcare professional and person to strengthen their commitment to a specific goal based on the person's own reasons for change.
General Behavioral Strategies	This includes a variety of techniques to manage symptoms and involvement in daily activities. Examples include: - Goal setting: Identifying activities that the client needs or wants to accomplish - Rewards for achieving goals - Activity reminders - Coping strategies - Identifying unhealthy behaviors - Arranging schedule to make pleasurable activities possible - Use of a calendar or log to examine activity engagement in relation to symptoms (e.g., fatigue, pain, mood) and activity barriers (e.g., financial, environmental, social support) - Development of skills required to accomplish client-centered goals (e.g., social skills, problem solving, task-specific skills)
Environmental Modification	Strategies or actions which improve the accessibility to one's physical, social, and cultural surroundings. Examples include: <u>Physical</u>: This includes natural or man-made surroundings and objects in them. Modification may include rearranging furniture, adding grab bars to a shower, ramp or elevator access, adding chairs for rest breaks, universal design, increased lighting, removing clutter, adaptive computer switches. <u>Social</u>: This includes presence of relationships with and expectations of persons, groups with whom a person have contact. Examples include groups of friends, coworkers, or government agencies. It may also include community characteristics (neighborhood demographics, senior centers, transportation programs, taxes). <u>Cultural</u>: Customs, beliefs, behavior standards, and expectations accepted by the society of which a person resides. This may include family traditions or work habits

Adaptive Equipment	Training or provision of devices which enable people to perform tasks they were previously unable to accomplish or had trouble doing. These devices can improve mobility, communication, comfort in the workplace, or self-care activities. Examples include walkers, reacher, sock aid, hearing aids, Google Home or Amazon Alexa, adjustable desk, etc.
Energy Conservation and Work Simplification Strategies	Strategies to complete tasks in the most efficient way in order to have enough energy or endurance to do the activities a person enjoys the most. Strategies may include pacing, sitting while doing activities, setting priorities, chunking activities, elimination of unnecessary tasks, avoid multitasking, etc.
Physical Activity and Sedentary Behavior Strategies	Strategies specifically targeting an active lifestyle. This may include scheduling walks, education on consequences of sedentary lifestyle, provision of a pedometer, tracking or logging step counts, and setting healthy lifestyle goals.
Adaptive Skills Training	A general approach directed at “finding ways to simplify or ease demands of an activity to support performance This may include solutions to ease self-care tasks, simplification of activity demands, modify clutter to reduce distractibility, etc.

Appendix E Delivery Features

Category	Category Definition	Specific Delivery Features
Format	Is the therapist working one-on-one with a patient? Is the therapist working with a group of patients at the same time? Or, does the intervention combine both individual and group sessions across the intervention?	- One-on-One - Group - Combination of One-on-One and Group
Frequency	How often does the intervention occur in a given week?	- 1 time per week - 2-3 times per week - 3 times per week - 4 or more times per week
Length	How long is does the intervention last from the first session to the last session?	- Less than 4 weeks - 1 – 3 months - 4 – 6 months - 6 – 12 months - 12 months or longer
Location	A particular place where the intervention occurs.	- <u>Patient Home</u>: The therapist provides an intervention in the context of a person's preferred residence (apartment, house, condominium, personal care home, etc.) - <u>Community</u>: A non-medical facility within a local neighborhood. Examples may include senior center, community center, library, restaurant meeting rooms, and/or faith-based buildings. - <u>Outpatient Clinic</u>: a facility for diagnosis and treatment of a health-related concerns. Outpatient clinics are specifically placed throughout the community to improve convenience. They may be in strip malls, office centers, or stand-alone buildings. - <u>Hospital or Cancer Center</u>: All-inclusive healthcare facility which tends to both emergent and ongoing health concerns. This is an institution which provide comprehensive clinical care.

Mode	The way in which a therapist administers an intervention.	- In-Person - Telehealth (delivery through video call, website, telephone, mobile application, etc.) - Combination of in-person and telehealth modes
Timing	A particular point or period when an intervention takes place	- <u>Pre-Treatment</u>: An intervention is delivered prior to a person receiving treatment (surgery, radiation, chemotherapy, etc.) for cancer. - <u>During Treatment</u>: An intervention is delivered while a person is actively receiving targeted treatment (surgery, radiation, chemotherapy, etc.) for cancer. - <u>Post-Treatment</u>: An intervention is delivered while a person has completed primary treatment (surgery, radiation, chemotherapy, etc.) for cancer. The patient may be taking maintenance medications (e.g., tamoxifen, Arimidex, Femara, Armomasin) to lower the chance of the cancer returning.

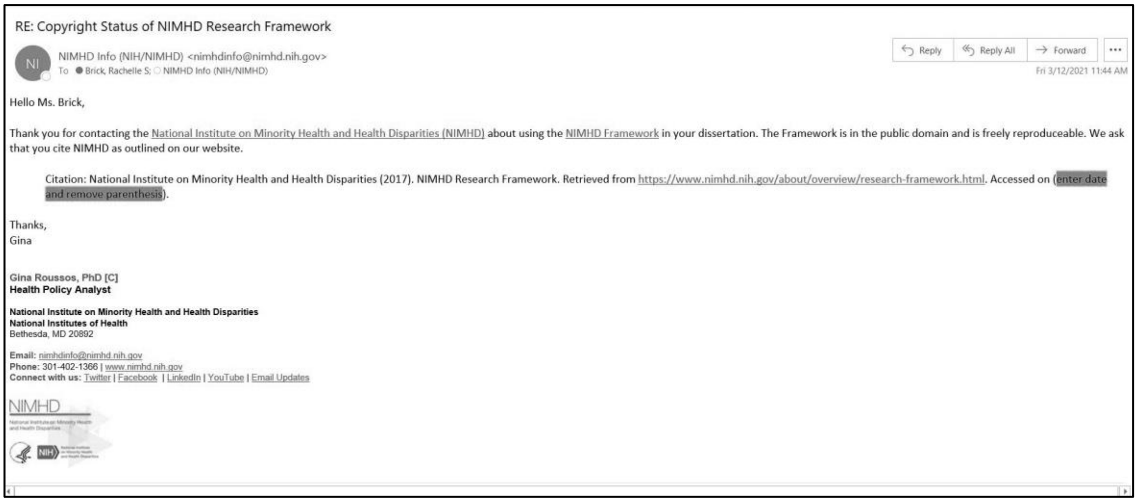
Appendix F Additional Panelist Commentary

Characteristics	Panelist Qualitative Reflections
<u>Intervention Content</u>	
Physical Activity Strategies	"It is the most impactful in terms of data supported outcomes, and the easiest to develop an intervention." "My reasoning is that most older adults become more and more sedentary as they age. The physical activity and movement will allow them to stay healthier physically and something to look forward to each day."
Adaptive Skills Training	"before, during and after treatment, there are many changes and it is very important to be able to navigate life, as close to normal as possible while adjusting to these changes." "Adaptive strategies include problem solving and overcoming obstacles to participation in other strategies such as exercise
Behavioral Strategies	"Behavior change is the biggest barrier we see to patients implementing the recommendations we make. It requires a lot of sessions to make the behavior change occur."
Energy Conservation	"Energy Conservation is important to understand early in cancer treatment to maximize the balance and ability to maintain involvement in chosen occupations. Once this is prioritized, patients/clients can then start to implement avoiding sedentary behaviors and look to increase physical activity when able." "Clients discuss not having any energy and do not know that there are ways to conserve energy"
Exercise	"Exercise offers manifold health benefits, making it the place to invest for greatest potential return with each individual. It can be expensive to execute if it is always with a skilled professional or needs a lot of equipment."
Peer Support	No comments reported

Characteristics	Panelist Qualitative Reflections
<u>**Intervention Delivery Features**</u>	
Location	
Outpatient Clinic	“ As more and more cancer care moves to the outpatient setting and with the growing focus on pre-hab, interventions must be available for patients within the outpatient setting.” “I chose outpatient clinic as best intervention location because it is most feasible to incorporate interventions during follow up visits with the doctor. I feel most patients want to address all concerns "in one stop" as opposed to additional appointments/trips.” “In outpatient, I can address many of the intervention strategies like energy conservation, adaptive strategies, and durable medical equipment as needed.” “the most important info for me was received during aftercare, outpatient appointments. a more relaxed arena than the hospital or during treatments” “Access to variety of machines and ancillary use of modalities, one on one supervision”
Community	“Community could be a site but many patients prefer individualized sessions in either their home or an official office.”
Hospital	“ Out of home-more relaxing than the hospital but still in a medical facility”
Patient Home	“ Perhaps best is combination ... community medical/exercise or clinic site, with in-home virtual followup.” “ Home is the place where people live their lives. Helping them do what we recommend in their own environments is key.”
Timing Post-Treatment During Treatment Pre-Treatment	**“**Post-treatment is my highest priority, mainly because to do it pre or during treatment doesn't take into consideration what changes they body will continue to make after treatment is over. Which I feel is when most of the changes will take place.”
Mode of Delivery Combination	“Regardless of pandemic constraints, the flexibility in intervention allows for greatest patient/client participation in therapy services.” “Transportation is a barrier for some patients. For others, internet access is a barrier. I think combination intervention allows us to work with all patients and meet them where they are at. Some patients prefer in person interventions while others prefer to remain in the comfort of their own homes. Combination is all encompassing.” “In person hold the patient accountability, and virtual can serve as a touchpoint” “There are times when a virtual demonstration does not provide enough information so an in-person session can clarify what you don’t understand. A virtual demonstration has the benefit of being replayed whereas the in person session cannot.”
Frequency 1-2 times per week	“Cancer survivors have busy lives like all of us and a lower frequency with opportunity to practice between sessions may increase participation.” “Patients have several appointments and challenges with transportation; if goals can be accomplished with less frequency they will be more willing to participate.” “More may be problematic for cost/travel issues. Less doesn’t give enough feedback from the therapist to correct some issues. 2 per week gives the patient a chance to ask questions and to hear about progress/regression issues. I personally start with 2x weekly and scale down to 1x before “graduating”

Characteristics	Panelist Qualitative Reflections
Duration 1 to 3 months in length	“ I initially thought that 4 weeks or less would be the best duration. But when dealing with older adults they may need more time to get acclimated to the what they are learning which may take more time. So I do agree that 1-3 months would now be more appropriate.” “Longer term commitments may be perceived as difficult and the timeframe of 1-3 months seems plenty of time for an effective intervention.” “I worry that, for true carryover, most people need more than 3 months of support” “Based on my experience, I feel the duration should be 6 to 12 months. It took me this time period to get my life back to normal.”

Appendix G Permission to Reproduce NIMHD Research Framework Figure



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Thanks,
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