

June 2021

Young Adult Cancer Survivors and Physical Activity: An Expert Consensus Study

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<https://doi.org/10.7275/22158784.0> https://scholarworks.umass.edu/dissertations_2/2204

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Young Adult Cancer Survivors and Physical Activity: An Expert Consensus Study

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Young Adult Cancer Survivors and Physical Activity: An Expert Consensus
Study

A Dissertation Presented by
ANN MARIE MORAITIS

Submitted to the Graduate School of the University of Massachusetts Amherst
in partial fulfillment of the requirements for the degree of

DOCTOR OF PHILOSOPHY

May 2021

College of Nursing

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Young Adult Cancer Survivors and Physical Activity: An Expert Consensus

Study

A Dissertation Presented by

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DEDICATION

~ *“Motion is lotion”*

Thank you Joan, for being a dear friend and teaching me what it means to
survive.

ACKNOWLEDGMENTS

I would like to extend my gratitude to my committee members, Dr. Rachel Walker, Dr. Memnun Seven and Dr. John Sirard for their contributions and support to this dissertation work. To my advisor, Dr. Rachel Walker, since our first meeting you have mentored me with your brilliant mind and passionate heart on how to incorporate principles of dignity, capability and justice into our work. Your impact and insights will travel with me. To Dr. Memnun Seven, you have been there each step of the way encouraging, advising and believing in me. Thank you for your many hours of thoughtful, patient guidance, support, laughter and friendship. To Dr. John Sirard, thank you for your time and expertise in physical activity which added depth to this dissertation work. In gratitude to the staff at the College of Nursing who welcomed and supported me, from the first day I set foot in Skinner Hall. In addition, I wish to express my appreciation to all the initial experts for this consensus study who generously volunteered their time and expertise.

A special thank you to my greatest life joys~ Phil, Elle, Anna and Julia whose support and belief in the purpose of this work and in me is unfailing. To my six siblings and mom, you were my first role models on how to be part of a team for something greater than oneself. To my dear friends whose continuous support and friendship brings me great joy and a place to rejuvenate, thank you. Finally, in gratitude to my dad, who encouraged curiosity and the pursuit of knowledge as worthy endeavors throughout life.

ABSTRACT

YOUNG ADULT CANCER SURVIVORS AND PHYSICAL ACTIVITY: AN EXPERT CONSENSUS STUDY

MAY 2021

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Directed by: Professor Rachel Walker

Annually, over 1 million adolescents and young adults (YA) are diagnosed with cancer. Cancer survivorship rates in YA are greater than 80%, yet late and long-term symptoms that impact biopsychosocial health persist for this population. Health promotion strategies, including physical activity, are being used to mitigate symptom burden in adults. Research specific to physical activity use in YA is limited. This dissertation addresses physical activity use in YA cancer survivorship. Chapter one of this dissertation introduces the critical need to understand the state of the science of physical activity use on the biological and psychosocial health of YA affected by cancer.

In chapter two, guided by the Revised Symptom Management Theory, we conducted a scoping review with the aim of exploring existing research on physical activity use in YA cancer survivors. A literature search was conducted and findings of 35 review articles were reported.

In Chapter three an overview of the study's design and methods are reported. A four-round modified Delphi study with multidisciplinary experts (Round I/II $n=18$; Round III $n=57$, Round IV $n=45$) in exercise oncology, symptom management, survivorship care, and Adolescent and

YA (AYA) cancer care was conducted. Qualitative and quantitative analyses were calculated. In addition, we report results from study aim one; to identify expert consensus areas on the impact of physical activity on the biopsychosocial health of YA cancer survivors.

In Chapter four, we report results from study aim two: to identify expert consensus areas on assessing, prescribing and implementing physical activity as a symptom management strategy in YA cancer survivorship; identify areas of clinical relevance and endorsement of physical activity as a symptom management strategy in YA cancer survivorship.

Chapter five summarizes the findings of this dissertation in the context of clinical and research implications, knowledge translation and future research needed.

Key Takeaways/Innovations/Implications

The key take away of this expert consensus study is the elevation of physical activity as a symptom management strategy at all points of the cancer care continuum.

TABLE OF CONTENTS

	Page
ACKNOWLEDGEMENTS	v
ABSTRACT	vi
LIST OF TABLES	xii
LIST OF FIGURES.....	xii
CHAPTER	
I. INTRODUCTION: PHYSICAL ACTIVITY AND YOUNG ADULT CANCER SURVIVORS.....	1
II. PHYSICAL ACTIVITY AND YOUNG ADULT CANCER SURVIVORS: A SCOPING REVIEW	5
Abstract.....	5
Introduction.....	6
Methods	7
Synthesis	10
Discussion.....	15
Conclusions.....	17
III. EXPERT CONSENSUS ON THE USE OF PHYSICAL ACTIVITY ON BIOPSYCHOSOCIAL HEALTH YOUNG ADULT CANCER SURVIVORS: A MODIFIED DELPHI STUDY	19
Abstract.....	19
Introduction.....	21
Methods.....	24
Results.....	34
Discussion	40
Conclusions.....	49

IV. YOUNG ADULT CANCER SURVIVORSHIP AND PHYSICAL ACTIVITY: EXPERT CONSENSUS STUDY RESULTS ON CLINICAL RELEVANCE AND CONSIDERATIONS.....	51
Abstract.....	51
Introduction	53
Methods	56
Results.....	57
Discussion	65
Conclusions.....	75
V. CONCLUSIONS.....	79
APPENDIX A: Tables	86
APPENDIX B: Figures	105
APPENDIX C: Matrix of Articles in Scoping Review	113
BIBLIOGRAPHY	154

APPENDIX A LIST OF TABLES

Table	Page
1. Distribution of Experts' Role in Cancer Care	86
2. Emergent Themes from Content Analysis of Qualitative Data	87
3a. Consensus: Symptom Management.....	88
3b. Consensus: Person-Centered Care.....	89
4. Interrater Reliability Scores: Symptom Management And Person-Centered Care	90
5. Statements that Lack Agreement: Symptom Management	92
6a. Consensus: Cancer Care Continuum	93
6b. Consensus: Guidance; Care Delivery Systems.....	94
7. Consensus: 'village of experts'(Assessment, Referrals, Interventions)	96
8a. Interrater Reliability Scores: Cancer Care Continuum	98
8b. Interrater Reliability Scores: Care delivery systems, Guidance	99
9. Sampling of results of conventional qualitative content analysis.....	100
10a. Delphi Round II survey modifications.....	102
10b. Delphi Round III survey modifications	103

APPENDIX B

FIGURES

Figure	Page
1. PRISMA for Scoping Review	105
2. Four Round Modified Delphi Process.....	106
3. Graphic Focus Interview Guide	107
4. Expert Recruitment and Study Process	108
5a. Key Findings	109
5b. Innovation/Implications	110

CHAPTER ONE

PHYSICAL ACTIVITY AND YOUNG ADULT CANCER SURVIVORS

Physical activity includes any form of movement from non-sedentary time to vigorous activity. Its effects can be felt in the microenvironment our cells live in to the macroenvironment we interact and function in (Wang & Zhou, 2020). Worldwide, more than one million adolescents and young adults (AYA) are diagnosed with cancer annually (Bleyer, 2011; Smith. et al., 2016). Significant improvements in AYA early diagnosis and treatments have led to increased cancer survival rates that exceed 80% (Barr, 2011; Keegan et al., 2016; Robinson et al., 2009; Roberts, et al., 2017). Cancer morbidity, however, has increased over the last two decades at a rate three times higher among 15-29-year old's than among children (Bleyer, 2007; Bleyer et al., 2017), reflecting the consequences of the cure (Kopp et al., 2016). AYA cancer survivors have a significant increased chronic disease risk than those without cancer, with more than two-thirds developing at least one chronic condition by 40 years old, limiting their full life potential (Bradford & Chen 2017; Phillips et al., 2015). Cancer and its treatments impact multiple biological and psychosocial systems resulting in late effects and long-lasting symptoms that can cause distress and disrupt social functioning at a time of critical independence for young adults (YA) (Barnett, et al., 2016; Zebrack, 2009; Smith et al., 2017; Smith et al., 2019). In adults, symptom management strategies such as physical activity, can mitigate these disruptive symptoms (Aziz, 2002, Schmitz et al., 2019; Wolin et al., 2012). The Revised Symptom Management Theory (Dodd et al., 2001), encapsulates biological, psychological and social aspects of symptoms and symptom management. By addressing all aspects of health in YA affected by cancer, this biopsychosocial approach offers improved function and quality of life (QOL).

There is a paucity of YA cancer research, with most embedded within the AYA research. This review, therefore, will encompass reference to both AYA and YA, with special attention to the YA population due to a critical need for research in this vulnerable cohort. Research in YA (age 18-39 years), a subpopulation of AYA, is limited with less than 2% of YA cancer survivors involved in clinical trials (Bleyer, 2007; Docherty, et al., 2015; Fernandez et al., 2011; Keegan et al., 2016). YA experience increased risk for cardiometabolic issues (Kopp et al., 2016; Nass et al., 2015; Rabin 2011), with cardiovascular disease being the second leading cause of death in childhood and AYA cancer survivors (Armstrong et al., 2016). Cancer and its treatment often disrupt critical emotional, cognitive, and social developmental needs in ways that can significantly impair the psychosocial health of young cancer survivors (Nass et al., 2015; Patterson, McDonald, Zebrack & Medlow 2015). Additionally, survivorship care is embedded in a fragmented care delivery models that neglect YA unique needs, leading to over 50% reporting unmet needs (Fernandez et al., 2011; Patterson et al., 2015).

Survivorship care focuses on the overall health, wellbeing, and quality of life of individuals affected by cancer (NCCN, 2020 survivorship). Survivorship care should be evidence-based, dynamic, and responsive to the unique and evolving needs of cancer survivors, which may change rapidly in relation to on-going changes in their health and life contexts (Howell 2018). Despite the numerous vulnerabilities YA face, this group is largely excluded from survivorship care research; with < 2% of YA involved with clinical trials (Bleyer, 2007; Docherty, et al., 2015; Fernandez et al., 2011; Keegan et al., 2016). Clinical experts have recognized the urgent need to develop and deliver survivorship care tailored to the unique needs and life circumstances of this understudied group of cancer survivors (Rabin, Horowitz, & Marcus, 2013). High-quality survivorship care includes support for health promotion activities designed to both mitigate negative late effects and long-term impacts of cancer treatments and reduce risk of cancer recurrence (NCCN survivorship 2020). However, in YA, there are currently

no universally accepted practice guidelines that specifically address physical activity as a precision health strategy for symptom management and improved biopsychosocial health.

Recommendations from the National Academies of Sciences, Engineering, and Medicine cancer control call for effective and affordable interventions for preventive, screening, and diagnostic cancer care that integrates social and behavior information to develop reliable evidence (National Academies of Sciences, Engineering, and Medicine, 2019). The field of *exercise oncology* has grown exponentially in the last few decades (Jones & Albano, 2013; National Cancer Institute, 2019) to develop reliable evidence on the role of physical activity in cancer care. Nurses were involved in its pioneering stage (Jones & Albano, 2013; Winningham et al., 1989). The American College of Sports Medicine has recently published *adult* physical activity guidelines for cancer survivors (Schmitz et al., 2019). However, physical activity guidelines informed by the unique preferences (e.g. psychological, and environmental aspects) and developmental needs of YA, do not exist (Brunet et al., 2018; Munsie et al., 2019; Nass et al., 2015; Pugh et al., 2016; Rabin, 2011).

There is a critical need to understand the state of the science on how physical activity, a modifiable precision health strategy, contributes to biopsychosocial health, wellbeing, and overall quality of life, for YA cancer survivors, and how it can be feasibly and sustainably incorporated into survivorship care. Research is needed that addresses development and clinical implementation of physical activity guidelines. Physical activity can mitigate these effects and improve quality of life; however, to date, no expert consensus or clinical guidelines specific to physical activity among YA (YA) cancer survivors (age 18-39 years) have been published. Lack of clinical guidelines and limited research specific to YA cancer survivors, hinders its use as a symptom management strategy. Guidelines are needed to integrate physical activity in YA survivorship care to optimize biopsychosocial health and overall QOL. Therefore, this dissertation aims to identify expert consensus on the impact of physical activity on

biopsychosocial health, to identify expert consensus regarding assessment, prescription and implementation of physical activity as a symptom management strategy and identify areas of clinical relevance and endorsement of physical activity as a symptom management strategy in YA cancer survivorship.

CHAPTER TWO:
PHYSICAL ACTIVITY AND YOUNG ADULT CANCER SURVIVORS:
A SCOPING REVIEW

Abstract

Problem Identification: Physical activity, a precision health strategy, positively impacts biopsychosocial health in adult cancer survivors. However, physical activity's effects on YA (YA) cancer survivors are not as well-established. The purpose of this scoping review was to describe and synthesize existing research on physical activity use in YA (YA) cancer survivors.

Literature Search: CINAHL®, PubMed®, PsycINFO®, Sport Discus, Web of Science, and Cochrane Review were searched including 61 articles and 28 grey materials.

Data Evaluation: Data extraction, guided by the Revised Symptom Management Theory, included research aims, sample, design, primary outcome measures, and effects of physical activity.

Synthesis: Findings of 35 review articles were reported under three main categories.

Conclusions: Physical activity, in YA cancer survivors has shown improvements in physical function, yet there is a paucity of research. Guidelines are needed to integrate physical activity in YA survivorship care to optimize biopsychosocial health and overall quality of life (QOL).

Implications for Research: Lack of clinical guidelines and limited research specific to YA cancer survivors, hinders its use as a symptom management strategy. Research is needed that addresses development and clinical implementation of physical activity guidelines.

Knowledge Translation: Physical activity has the potential to improve QOL in YA cancer survivors.

Keywords: *symptom management, YA cancer survivors, physical activity, exercise oncology, quality of life, precision-health*

PHYSICAL ACTIVITY AND YA CANCER SURVIVORS: A SCOPING REVIEW

Introduction

Survivorship rates in the adolescent YA, ages 15-39 years, with cancer have increased over the last few decades, survivorship, however, comes with consequences of treatment that negatively impact individuals' biopsychosocial health. Adolescent and YA (AYA) affected by cancer encounter greater biological effects of cancer (e.g. elevated risk of secondary cancers, treatment related cardiotoxicities, elevated risk of chronic disease) and greater psychosocial effects (e.g. emotional distress, anxiety and depression) than their non-cancer peers. These negative effects on an individuals' biopsychosocial health represent a greater global burden to AYA more than all other age groups combined. There is a paucity of YA (YA) cancer research, with most of it being encapsulated within the AYA research. This review, therefore, will encompass reference to both AYA and YA, with special attention to the YA population due to a critical need for research in this vulnerable cohort. Research in YA (age 18-39 years), a subpopulation of AYA, is limited with less than 2% of YA cancer survivors involved in clinical trials (Bleyer, 2007; Docherty, et al., 2015; Fernandez et al., 2011; Keegan et al., 2016). YA experience increased risk for cardiometabolic issues (Kopp et al., 2016; Nass et al., 2015; Rabin 2011), with cardiovascular disease being the second leading cause of death in youth cancer survivors (Armstrong et al., 2016).

In adults, physical activity has shown to be a promising symptom management strategy to mitigate biopsychosocial effects of cancer/cancer treatments. To date, however, there is no expert consensus on physical activity guidelines or clinical considerations specific to YA (age 18-39 years) cancer survivors. Therefore, there is a critical need to understand the state of the science in how physical activity, a modifiable precision health strategy, contributes to biopsychosocial health, wellbeing, and overall quality of life, for YA cancer survivors, and how it can be feasibly

and sustainably incorporated into survivorship care. The purpose of this scoping review was to explore the existing research to date, incorporating published clinical guidelines, protocol statements and critical work in the field, to identify: 1) relationships between physical activity and cancer-related symptoms and quality of life among YA cancer survivors; 2) the measurement of physical activity in research involving YA cancer survivors and; 3) guidelines for activity among YA survivors.

Methods

Literature search/data evaluation

A scoping review is an iterative literature review process that allows for synthesis of the evidence with the aim of providing a broad overview of current scholarship on a topic of interest. In this sense, a scoping review may be more inclusive and sensitive to emergent areas of research and expert opinion than a more narrowly defined systematic review of the literature. This literature review process was chosen due to the complexity and lack of comprehensive research in physical activity among YA cancer survivors. This scoping review was performed using the following steps, as outlined by Arksey & O'Malley (2005): stage 1) identify the research question, stage 2) identify relevant studies, stage 3) perform study selection, stage 4) charting the data, stage 5) collate, summarize and report the results (Arksey & O'Malley, 2005). The purpose of this scoping review was to identify 1) relationships between physical activity and cancer-related symptoms and quality of life among YA cancer survivors. 2) the measurement of physical activity in research involving YA cancer survivors and, 3) guidelines for activity among YA survivors.

The search strategy was developed in consultation with a research librarian at the University of Massachusetts, Amherst, to include databases comprehensive enough to capture both cancer and physical activity research. The following databases were searched; CINAHL, PubMed, PsycInfo, Sport Discus, Web of Science, and Cochrane. The search terms: "YA" *and*

cancer survivor *and* exercise or physical activity or fitness or movement or activity *and* meta-analysis or meta-synthesis or systematic review or scoping review were used. Cochrane Library was searched using the following MeSH terms (all text): *young adults AND cancer survivors AND exercise OR physical activity OR fitness OR movement OR activity*. The search was limited to English language and peer-reviewed without year limitation. The most recent search was performed in December 2019.

Inclusion criteria

Systematic reviews, meta-analysis, meta-synthesis or scoping research study were considered for this scoping review if they included 1) YA aged 18-39 years; 2) both survivors diagnosed as a child and those diagnosed as YA; 3) one or more of the following movement measures: exercise, physical activity, fitness, movement or activity. An a priori decision was made not to include sedentary behavior in the search terms as this is emerging science, and the preliminary search yielded no results; however, attention to studies that included sedentary behavior was noted and summarized.

Data sources and search strategy

Titles and abstracts of retrieved articles were initially screened for relevance by one reviewer (AMM) using the defined inclusion and exclusion criteria and discussed with one other reviewer (RW). A total of 61 articles were identified through database searching as noted in figure 2.1, PRISMA for scoping review. The majority of articles retrieved spanned across multiple age ranges, with only two articles specific to YA, demanding careful consideration of what age range to include in the scoping review. In order to meet the aims of the research, a wider-age range for inclusion needed to be considered. The authors, in consultation with a reference librarian, made the decision to include articles, if > 25% or more of the studies included sampling of YA. Full texts of articles that met inclusion criteria ($n = 20$) were retrieved and reviewed by AMM, RW, and a third reviewer (MS) using the same inclusion and exclusion

criteria. Twelve peer-reviewed articles were selected for inclusion in the final analysis with consensus of all reviewers (reason for exclusions noted in PRISMA). In line with the purpose of scoping reviews, to provide literature, conceptual and policy statements that add context and comprehensively map evidence, grey literature was added in (Anderson et al., 2008; Levac, Colquhoun, & O'Brien, 2010; O'Brien et al., 2016). Grey material was identified by searching the bibliography of the included articles, identifying related documents and statements from governing and professional bodies and reviewed by AMM, RW, and MS for inclusion. A total of 23 grey materials (out of 28 retrieved) related to clinical practice guidelines, expert recommendations, policy statements, and/or critical work in YA survivorship were included. In total, 35 articles were included in this scoping review, as shown in the PRISMA-ScR diagram in *Figure 2.1*.

Data extraction

Full articles were independently read by all reviewers (AMM, RW, MS). The independent reviewers' level of consensus was 100%. Articles were abstracted by AMM using a data extraction tool, and results of this abstraction process were placed in an organizational matrix (preformatted Excel spreadsheet) to allow for easy comparison of findings across all articles. The Revised Symptom Management Theory (Dodd et al., 2001) informed the design of the organizational matrix (see supplemental table). To facilitate the analysis and synthesis of resources with methodological diversity, the data extraction tool included details about the study aims, sample and sample characteristics, study design, primary outcome measures, major findings, and the effects of physical activity on AYA. Additionally, data on variables not related to biopsychosocial health, QOL, measurement of practice guidelines were extracted and included to provide a more comprehensive understanding of the literature. The research in YA cancer survivors was limited and the majority of the articles ($n=10$) were published between 2016-2019, reflecting the emergence of this research and further warranting this scoping review.

Multiple types of research studies as well as policy and protocol statements from governing and regulatory bodies were synthesized in this scoping review including systematic review (10), systematic review and meta-analysis (4), a systematic review and narrative synthesis (1), meta-synthesis (1), scoping review (1), recommendation (6), and summary & review (12).

Synthesis

There are inconsistencies regarding what age defines ‘YA’ in cancer survivorship with many different cut-off points to describe this age cohort. Research specific to YA cancer survivorship and physical activity is very limited, with only two publications (Rabin, 2011; Rabin 2017) in this review. Most of the reviews (Bleyer et al., 2017; Brunet et al., 2017; Coccia et al., 2018; Docherty et al., 2015; Fernandez et al., 2011; Keegan et al., 2016; Koop et al., 2016; Nass et al., 2015; Patterson et al., 2015; Pugh et al., 2016; Smith et al., 2016; Tai et al., 2012) included in this review encompass adolescent and AYA aged 15 to 39 years affected by cancer. Due to vast biological, developmental, and psychosocial heterogeneity (Keegan et al., 2016) of YA cancer survivors, it is unclear if they are best defined by their age, cancer status, or both (Rabin, 2011). While many studies included do not report race and ethnicity data, for those that do, study samples are primarily white and English-speaking individuals (Bradford & Chen 2017; Kopp et al., 2016; Pugh, et al., 2016). All of the above factors contribute to a lack of generalizability.

Relationships between physical activity, cancer-related symptoms, and quality of life

AYA cancer survivors' psychosocial, medical, economic challenges (Bleyer, 2007), developmental needs (Spathis et al., 2015), and care transitions are unique and distinct from those of older cancer survivors (Fernandez et al., 2011). AYA cancer survivors experience higher levels of anxiety, distress, and depression (Fernandez et al., 2011; Tai et al., 2012) but are less likely to access professional mental health services (Coccia et al., 2018). There are likely multiple, interconnected mechanisms driving poor psychosocial health including sociocultural (temporary or permanent exclusion from significant socialization opportunities such as school or group

sports), and behavioral pathways (activation of the autonomic nervous system with an increase in stress hormones that increase tumor cell growth and promote angiogenesis) (Chida et al., 2008). Particular insults to self-image and bodily changes such as hair loss, weight changes, risk of infection, altered sexuality, loss of normal activities of daily living, and financial issues negatively impact psychosocial health (Bleyer 2007; Fernandez et al., 2011). AYA cancer survivors also experience financial toxicity with fewer being employed, significantly more being out of work (Nass et al., 2015) and a higher proportion not able to seek health care, due to cost, than peers without cancer (Tai et al., 2012) which negatively impact psychosocial health (Bleyer 2007; Fernandez et al., 2011). An estimated 75% of AYA cancer survivors experience cognitive changes that affect memory, learning, concentration, and decision-making (Nass et al., 2015; Treanor et al., 2016).

YA have an increased risk for cardiometabolic and pulmonary issues (Kopp et al., 2016; Nass et al., 2015; Rabin 2011; Tai et al., 2012). Treatment exposures from chemotherapy and radiation increase late effects on cardiovascular health (e.g., increased risk of myocardial infarction, stroke, congestive heart failure, valvular issues, hypertension), metabolic health (e.g., increase risk of obesity, dyslipidemia, insulin resistance, diabetes) and pulmonary health (e.g., restrictive lung disease, pulmonary fibrosis) leading to exercise intolerance; additionally, sexual dysfunction is a prominent late effect from cancer treatments (Nass et al., 2015; Tai et al., 2012).

Fatigue is a common and often debilitating symptom for YA survivors and has the most detrimental effects on the physical and functional dimensions of quality of life (Cabilan & Hines, 2017; Rabin, 2011; Spathis et al., 2015). This review indicates that fatigue can be a barrier to physical activity (Rabin, 2011; Spathis et al., 2015), and is further complicated by the beliefs of survivors, family members, and health care clinicians that resting is the best approach to manage fatigue. However, inactivity is a maladaptive behavior that can perpetuate fatigue (Spathis et al.,

2015). In adults, physical activity has shown to mitigate the symptom of cancer-related fatigue (Schmitz et al., 2019; Spathis et al., 2015).

In adult cancer survivors', higher levels of physical activity show potential to mitigate symptom burden and positively affect the quality of life, fatigue, prognostic biomarkers, secondary cancer risk, chronic disease risk, comorbidities and mortality rates (Schmitz et al., 2019; Schwartz et al., 2017). More specifically, there is strong evidence for the efficacy of physical activity on anxiety, depressive symptoms, fatigue, quality of life and perceived physical function; moderate evidence exists for the effect of exercise on sleep and bone health, but due to limited and poor methodological studies, insufficient evidence exists for cardiotoxicity, chemotherapy-induced neuropathy, cognitive function, nausea, pain, sexual function and treatment tolerance (Schmitz et al., 2019). Physical activity positively impacts certain aspects of quality of life: the ability to physically manage effects of cancer and its treatment, the psychological ability to have positive self-perceptions, social aspects of interactions, and creating purpose/meaning within a cancer diagnosis (Burke et al., 2017). Despite this, AYA cancer survivors are likely to be less physically active and have more sedentary time than non-cancer peers (Rabin, 2011; Smith et al., 2019). Research specific to the *YA* cancer population is needed (Burke et al., 2017).

Measurement of physical activity in research involving YA cancer survivors

YA cancer survivors have been vastly underrepresented in research (Bradford and Chan 2017) with less than 2% of YA survivors aged 20- 29 years and less than 15% of adolescents aged 15-19 years participating in clinical trials (Bleyer, 2007; Docherty, Kayle, Maslow, Santucroce, 2015; Fernandez et al., 2011). This is further compounded by limited studies related to physical activity and cancer survivorship (Cabilan et al., 2017). Moreover, there are methodological deficiencies, including modest effect sizes, lack of validated measures in interventional trials, heterogeneity in study designs and outcome measures, lack of control

groups, lack of longitudinal studies, lack of randomized control trials, lack of control groups, risk of bias, resulting in a lack of robust evidence and impacting both clinical effects and statistical significance (Braam et al., 2017; Bradford & Chan 2017; Brunet, et al., 2018; Caliban & Hines, 2017; Kopp et al., 2016; Munsie, et al., 2019; Neufer et al., 2015; Rabin, 2011; Rabin, 2017; Roberts, et al., 2017; Smith et al., 2016; Speck et al., 2010; Spathis et al., 2015; Treanor et al., 2016; Wurz & Brunet 2016).

There are issues on how or if physical activity is operationalized (Brunet et al., 2017), making it difficult to compare its effect across studies. Physical activity has been described as any form of activity that has the potential to promote health (Hagger, 2019). It has also been described as movement that elicits skeletal muscle contractions resulting in increased caloric requirements that exceed resting energy expenditure (Caspersen, Powell, & Christenson, 1985; Rochmis & Blackburn, 1971). There is also a wide range of physical activity outcome measures including self-report (Cabilan et al., 2017), accelerometer/ pedometer data (Brunet et al., 2017; Kopp et al., 2016), minutes/day or mets/week of moderate to vigorous exercise or calories burned (Barbaric et al., 2010; Pugh, et al., 2016), functional fitness outcome measures (Braam et al., 2016; Munsie et al., 2019) or a combination of such. Physical activity is often clustered with other health behaviors (Pugh et al., 2016), or is measured with inadequate study design to capture correlations, making it difficult to articulate its effects. Sedentary behavior, a separate risk factor from physical activity (Rabin, 2011) was discussed in some of the reviews noting that increased sedentary time increases cancer risk and fatigue (Brunet et al., 2017; Kopp et al., 2016; Rabin 2011; Roberts et al., 2017; Schmitz et al., 2019; Schwartz et al., 2017; Wolin et al., 2012). However, specific measurement of sedentary behavior was limited in the literature, other than noting that YA survivors spend more time in sedentary behavior than non-cancer peers (Rabin, 2011).

Guidelines for physical activity and clinical considerations among YA survivors

Lifelong survivorship care is the recommended standard for AYA cancer survivors. The use of physical activity in YA during and after treatment is an emerging strategy to decrease mortality and mitigate negative biopsychosocial effects of cancer treatment. Yet, there is limited scientific research in this age cohort compared to younger pediatric and adult cancer cohorts (Munsie, et al., 2019; Roberts, et al., 2017; Wurz & Brunet, 2016). In late 2019, the very first set of national physical activity guidelines specifically designed to help *adults* prevent and treat cancer-related symptoms (e.g., fatigue, anxiety, depression, physical function, and quality of life) in adults were released (Schmitz, et al., 2019). Research involving adult survivors indicates both home and community-based activity interventions before, during and after cancer treatment improve physical functioning, role functioning, social functioning aspects of health-related quality of life (Burke, et al., 2017; Mishra et al., 2015; Wurz & Brunet, 2016).

The timing of physical activity intervention should begin at the time of diagnosis, continue during treatment, and the post-treatment period to maximize the restoration and/or enhancement of the physical and functional status and promote both wellbeing and normalcy (Caliban & Hines, 2017). A study of YA hematopoietic stem cell transplant survivors indicates that individuals exercised 30 minutes/day for 76% of their 24-day hospitalization, with the majority performing walking (Munsie, et al., 2019) highlighting the feasibility of physical activity, both during treatment and hospitalization. Physical activity interventions in AYA cancer survivors are highly acceptable to study volunteers with high retention rates greater than 70% (Kopp et al., 2016). There are few behavioral interventions for YA survivors (Rabin, 2011), but of those that exist, physical activity is the most commonly targeted behavior (Pugh 2016; Wurz & Brunet 2016). Tailored physical activity programs have shown improvements in physical function and endurance (Munsie, et al., 2019), highlighting the need to assess physical activity preferences that are influenced by unique personal preferences and demographic factors (Nass et al., 2016; Patterson et al., 2015).

There is no expert consensus or guidelines specific to YA cancer survivors on physical activity. The National Comprehensive Care Network (NCCN) 2018 clinical practice guidelines call for an evaluation of 'exercise needs, hobbies and recreational activities' but offer no supportive care services or interventions (Coccia, et al., 2018). The American College of Sports Medicine recently proposed using the *Exercise is Medicine*® initiative to address practice gaps by clinicians in assessing, advising, and referring cancer survivors for activity and called on key stakeholders to create the necessary structural framework to promote and integrate physical activity for people with cancer (Schmitz et al., 2019). Advancements in AYA survivorship care have lagged behind compared to other age cohorts (Bleyer, 2017).

Discussion

There are currently no expert consensus reports or formal clinical guidelines to guide recommendations specific to assessment, prescription and implementation of activity as a symptom management strategy to mitigate biopsychosocial changes associated with cancer/cancer treatment in YA. This lack of consensus hinders both further research and efforts from integrating physical activity into supportive care survivorship practices. The lack of activity in YA survivors is an issue that affects healthcare delivery worldwide and the consensus is needed to guide clinicians (Spathis et al., 2015).

Survivorship care focuses on the overall health, wellbeing, and quality of life of individuals affected by cancer (NCCN, 2020 survivorship). Biopsychosocial health outcomes of cancer can be influenced by modifiable precision health lifestyle behaviors, such as diet, exercise and inactivity impacting quality of life (Dulaney et al., 2017; Nass et al., 2015; Rabin, 2011). Physical activity has emerged as one of the most promising foci for research and intervention to mitigate the negative effects of cancer and cancer treatment on biopsychosocial health. Physical activity is a safe, feasible and viable option throughout the cancer continuum in YA cancer survivors with retention rates greater than 70% (Bradford & Chan 2017; Kopp et al, 2016; Munsie, et al., 2019;

Pugh et al., 2016; Rabin, 2011; Wurz & Brunet 2016). Moreover, there is a strong interest in receiving information regarding physical activity with greater than 75% of those surveyed expressing interest and greater than 85% feel "able" to participate in an activity program (Belanger et al., 2012; Gupta et al., 2013; Rabin, 2011). Despite YA articulating preferences, many clinical and research facets of physical activity (measurement, intervention design and delivery) *specific* to YA survivors' have not been articulated.

Nurses have multiple opportunities to support the biopsychosocial health of YA cancer survivors at every stage in the cancer continuum (Dodd et al., 2001). Nursing scientists like Dr. Victoria Mock were early pioneers in the investigation of hospital-based and home-based physical activity intervention on sleep quality, emotional wellbeing and fatigue levels of cancer survivors in active treatment and noted increased vigor with lower levels of emotional stress and fatigue in those who exercised (Jones & Albano, 2013; Wenzel et al., 2013; Winningham et al., 1989). Professional oncology nursing associations, such as the Oncology Nursing Society, have also launched national practice initiatives designed to promote physical activity among cancer survivors in recent years. However, in a recent study, less than 9% of nurses discuss physical activity with cancer survivors (Schmitz et al., 2019).

Physical activity is an emerging precision health strategy. There is on-going debate regarding how to measure physical activity and sedentary behavior in this context. The *Nursing Science Precision Health Model* may be useful for considering a starting point for addressing the gaps in measurement, intervention design and delivery. The *Nursing Science Precision Health Model* has four precision concepts: 1) measurement, 2) characterization of (*psychosocial*) phenotype including influences from lifestyle and environment, 3) characterization of genotype (*biological markers*) and 4) intervention target, design and delivery with an emphasis on self-management techniques (Hickey et al., 2019). This model is synergistic with the pioneering work of the American College of Sports Medicine *Exercise is Medicine Initiative* to incorporate

physical activity assessments, referrals and prescriptive interventions routinely in health care as a self-management strategy.

Existing reviews and consensus statements addressing physical activity as a symptom management strategy have largely excluded YA cancer survivors. This scoping review adds to the field of physical activity and cancer research by describing and synthesizing extant research addressing physical activity among YA affected by cancer. The scoping review methodology allowed for broad lens data acquisition and synthesis from methodologically diverse data sources to address the critical gap of understanding the state of the science of physical activity use in YA cancer survivors.

The limited operationalization of physical activity in the existing research, the breadth of definitions for what constitutes YA, as well as the vast heterogeneity of developmental stages, psychosocial challenges and life contexts that the 18-39-year-old range spans posed challenges to this review. In addition, the limited research specific to YA, warranting inclusion of literature across multiple age ranges, limits the generalizability of this review. The use of a theory to guide this review, the use of a data extraction tool to describe the use of physical activity on symptoms, function and aspects of QOL add to the strength of this review.

Conclusions

Cancer survivorship rates in YA are greater than 80%, yet late and long-term symptoms persist for this population. These ‘consequences of the cure’ (Kopp et al., 2016) along with fragmented models of care, leave over 50% of YA affected by cancer with unmet needs that impact biopsychosocial health, wellbeing, and quality of life. YA experience elevated health risks due to the longevity of symptom burden, and profound disruptions of normal psychosocial and developmental milestones. In adults, strong evidence exists on the efficacy of physical activity, a modifiable precision health behavior, as a symptom management strategy for anxiety, depressive symptoms, fatigue, and perceived physical function (Schmitz et al., 2019). In addition, it

positively impacts the ability to physically manage many effects of cancer and its treatment, the psychological ability to have positive self-perceptions, social aspects of interactions, and creating purpose/meaning within a cancer diagnosis (Burke et al., 2017).

Physical activity, a precision-health strategy, in YA cancer survivors has shown improvements in physical function, yet there is a paucity of research dedicated to this vulnerable population. Compounding this is the fact that most literature that includes YA also straddles the AYA population despite biological, developmental, and psychosocial heterogeneity in those age groups. In addition, there are issues with how physical activity is operationalized and measured and a lack of clinical guidelines/recommendations specific to the unique needs of the YA.

This review elevates the call for evidence-based research and clinical guidelines, building on the American College of Sports Medicine *Exercise is Medicine*® (Schmitz et al., 2019) initiative to address practice gaps in assessing, advising, and referring cancer survivors for activity and called on key stakeholders to create the necessary infrastructure to promote physical activity that are tailored to the unique needs of YA. Collectively, results from this scoping review add to the existing literature of the utilization of physical activity among cancer survivors by addressing the YA population. Also, it highlights the need for follow-up with key stakeholders in YA survivorship and physical activity to gain insight into the state of the science and next steps in policy, clinical and research endeavors on physical activity as a symptom management strategy in YA cancer survivors.

CHAPTER THREE

EXPERT CONSENSUS ON THE USE OF PHYSICAL ACTIVITY ON YOUNG ADULT CANCER SURVIVORS BIOPSYCHOSOCIAL HEALTH: A MODIFIED DELPHI STUDY

Abstract

Significance: Cancer treatment impacts young adult (YA) biological, psychosocial health with over 50% reporting unmet needs. Physical activity (PA) offers symptom mitigation, risk reduction and critical independence to YA affected by cancer. No PA guidance/guidelines tailored to YA exist to promote integration into survivorship care.

Aim: To identify expert consensus areas on the impact of PA on the biopsychosocial health of YA cancer survivors, guided by the Revised Symptom Management Theory.

Methods: A four-round modified Delphi study was conducted with international multidisciplinary experts (Round I/II $n=18$; Round III $n=57$, Round IV $n=45$) in exercise oncology, symptom management, survivorship care, and AYA cancer care. Qualitative content analysis, descriptive statistics (% agreement, SD, mean) and interrater reliability (Kappa) were calculated.

Results: Experts reached consensus on the following: PA should be integrated into YA cancer care as part of supportive oncology to mitigate symptoms of fatigue, cardio-metabolic health, muscle mass loss, altered body composition, and anxiety/depression; PA improves functional capacity and wellbeing; at all points on the care continuum; YA should be asked if they would like guidance on PA use; to maximize survivorship adaptations, PA interventions should be tailored for personal facilitators, barriers and motivations.

Conclusions/Implications: The results of this study identified areas of consensus that warrant PA implementation in YA survivorship care to guide future research and clinical endeavors.

Keywords: *symptom management, supportive oncology, YA cancer survivorship, self-management, biopsychosocial health*

**EXPERT CONSENSUS ON THE USE OF PHYSICAL ACTIVITY ON YOUNG ADULTS
CANCER SURVIVORS BIOPSYCHOSOCIAL HEALTH: A MODIFIED DELPHI
STUDY**

Introduction

Cancer survival rates in the adolescent and YA population have increased to over 80% due to improvements in early diagnosis and treatments. (Barr, 2011; Keegan et al., 2016; Roberts, et al., 2017). However, ‘consequences of the cure’ (Kopp et al., 2016) remain, with increases in cancer morbidity over the last two decades at a rate three times higher among 15-29-year old's than among children (Bleyer, 2007; Bleyer et al., 2017). Cancer and its treatments impact multiple biological and psychosocial systems, impairing biopsychosocial health, which encompasses the interplay between biological, psychological and social systems (Engel, 1977). These impacts can cause distress and disrupt social functioning (Barnett, et al., 2016; Rabin, 2011; Smith et al., 2019; Zebrack, 2009). For YA affected by cancer, there is a longevity to these health vulnerabilities. Many of these consequences appear two or more decades after treatment (Ruddy et al., 2020) resulting in late effects and long-lasting symptoms that can last decades. Adolescent and YA (age 15-39 years) cancer survivors face a significant increased chronic disease risk, in relation to those without cancer, with more than two-thirds developing at least one chronic condition by 40 years old, limiting their full life potential (Bradford & Chen 2017; Phillips et al., 2015). YA (age 18-39 years) cancer survivors, a subpopulation of adolescent and YA cancer survivors, is an especially vulnerable population due to limited research specific to this age group and high levels of unmet needs at a transitional developmental stage. Reports indicate less than 2% of YA cancer survivors are involved in clinical trials (Bleyer, 2007; Docherty, et al., 2015; Fernandez et al., 2011; Keegan et al., 2016). The life stage of YAhood represents critical transitions to self- autonomy, adaptation, interaction and independence (Scales,

et al., 2016). Physical health and psychological wellbeing represent key indicators to healthy transition and adaptation to adulthood (Scales et al., 2016).

YA affected by cancer face unique burdens physical and psychosocial health challenges, related to cancer and treatment effects (Nass et al., 2015; Patterson et al., 2015; Rabin 2011). Increased morbidities are associated with a greater need for mental health services, greater pain management needs and reports of poorer health (Wu et al., 2015). Youth cancer survivors report worse health-related quality of life than non-cancer peers (Husson et al., 2017). The greatest challenges appear in physical and emotional domains with increased symptoms of fatigue, anxiety, depression, physical health fitness deficits, changes to body image, as well as oncofertility and sexual health problems resulting in a loss of function and sense of normalcy (Fitch et al., 2020). There is a 2-fold increased risk for cardiovascular disease versus the general population and those who develop cardiovascular disease face 11-fold increase in overall mortality than those cancer survivors without cardiovascular disease (Ruddy et al., 2020). YA cancer survivors' experiences higher levels of anxiety and depression (Fernandez et al., 2011; Tai et al., 2012) than peers without a cancer history, yet they are less likely to access supportive and preventative services (Coccia et al., 2018). They are less likely to be physically active than their peers without a cancer history (Rabin 2011). Unmet needs related to symptom management and survivorship care information are reported by over 50% of adolescent and YA cancer survivors (Fernandez et al., 2011; Patterson et al., 2015). Moreover, over 60% articulated the necessity for age appropriate support and resources related to lifestyle behavior, mental health and fertility services (Zebrack, 2009). The longevity of YA survivorship, increased morbidity, propensity of unmet needs and call for support from YA survivors make symptom management and risk reduction research critical.

High-quality survivorship care includes information and support for health promotion activities, including physical activity, to both mitigate negative late effects and long-term impacts of cancer treatments and reduce risk of cancer recurrence (NCCN survivorship 2020). Physical activity positively impacts effects of treatment and adaptation to survivorship. In adults, physical activity is a promising symptom management strategy on functional, cardio-metabolic, psychosocial health, with increases activity levels showing positive impact on quality of life, prognostic biomarkers, comorbidities and mortality (Schmitz et al., 2019; Schwartz et al., 2017). Physical activity is a person-centered intervention that can be self-managed by YA, offering control and critical independence at this life stage. In addition, physical activity interventions can be tailored to YA preferences, motivation, and stage in the cancer continuum to further optimize control and independence.

In YA, limited research and a lack of tailored guidelines on physical activity use in survivorship care hinder advocacy efforts and integration of physical activity in practice (Brunet et al., 2018; Moraitis, Seven, & Walker 2021; Munsie et al., 2019; Nass et al., 2015; Pugh et al., 2016; Rabin, 2011). Similarly, the healthcare team has limited discussions with cancer survivors regarding the use of physical activity in survivorship with cancer survivors (Schmitz et al., 2019; Schwartz et al., 2017; Steele et al., 2021). Yet, research indicates a majority of YA surveyed expressed an interest in physical activity both during and after cancer treatments (Belanger, Plotnikoff, Clark, & Courneya 2012; Gupta, Edelstein, Albert-Green, D'Agostino, 2013; Rabin, 2011). Expert consensus on physical activity guidelines, tailored to the unique preferences and developmental needs of YA, will facilitate dissemination and implementation of its use as a symptom management strategy. The overall goal of the study, framed by the Revised Symptom Management Theory (Dodd et al. 2001), was to generate expert consensus on the impact of

physical activity on the biopsychosocial health (symptom experience and outcome/symptom status) of YA cancer survivors.

Methods

Our study used a modified Delphi method to elicit expert opinions and to assess the extent of agreement on the use of physical activity in YA survivorship care among a panel of multidisciplinary experts with experience in one or more of the following domains: exercise oncology, survivorship care, symptom science/management, adolescent YA cancer. This study was embedded in a parent study that looked at aspects of the current state of the science related to physical activity in YA survivorship care. The methods and data analysis of the modified Delphi study are reported here in their entirety. However, the consensus results, discussion and conclusion are specific to aim 1 of the larger study.

Specific Aim 1:

To identify expert consensus areas on the impact of PA on the biopsychosocial health of YA cancer survivors, guided by the Revised Symptom Management Theory.

The Delphi Method

The modified-Delphi method was chosen due to its iterative process and its use in previous research where there is limited knowledge, information, or guidance on an emerging research topic (Hsu & Sandford, 2007; Jones & Hunter, 1995; Linstone & Turoff, 1975; Clibbens, Walters, Baird, 2012) to determine the extent of consensus on an issue (Vernon, 2009). The Delphi method originates from the RAND Corporation with the aim of achieving a level of consensus from a group of experts through intensive questionnaires and controlled feedback (Dalkey & Helmer, 1963). Previous research has used this technique to gain consensus on the development of a physical activity literacy model (Jones et al., 2018), exercise reporting (Slade, Dionne, Underwood, Buchbinder 2014; Slade et al., 2016), and exercise and anti-cancer

immunity (Shawahna & Al-Atrash, 2019). It has been used in healthcare improvement projects (Woodcock, Adeleke, Goeschel, Pronovost & Dixon-Woods, 2020), healthcare decision-making (Hasson, Keeney, McKenna, 2000) in nursing research to determine the relevance of a policy or intervention in practice (Waltz, Strickland & Lenz, 2017). It is a flexible approach used in areas where research is limited and is especially useful when linking opinions from diverse disciplines due to its iterative nature (Hasson, Keeney, McKenna, 2000; Hsu & Sanford, 2007). The majority of studies using the Delphi method are in healthcare research (Diamond et al., 2014) and can be used to indicate priorities that need to be addressed (Avery et al., 2005). Healthcare research often involves various decision-making stakeholders (Jones & Hunter, 1995), making the Delphi method ideal for harnessing multidisciplinary experts' opinions. The Delphi method allows consensus-building despite geographical dispersion (Linstone & Turnoff; Ziglio 1996). The research on the use of physical activity in cancer survivorship is emerging across the world; therefore, international experts were included in this study.

The modified Delphi, which provides preselected items to build consensus on, is one of many iterations of the Delphi Study (Hasson & Keeney, 2011) and has a range of measures including percent agreement (range 50-97%) to establish consensus (Diamond et al., 2014). Previous research is varied on the number of rounds needed to achieve consensus, but the precedent has been shown that consensus can be achieved in two to three iterations (Eubank et al., 2016, Jones et al., 2018; Ogbeifun et al., 2016). We chose the four round Delphi method for this study.

Study Design

This modified Delphi study set out to clarify initial areas of consensus, or lack thereof, to foster the establishment of consensus for physical activity guidelines and research priorities specific to YA survivors. A group of initial experts participated in all four rounds of the study. Round I consisted of recorded audio/video interviews to gather insights from a multidisciplinary

group of experts on the use of physical activity in YA survivorship care. Following transcription of interviews for thematic analysis, a Likert survey was developed to measure consensus on themes generated from Round I initial experts. This survey content became the basis for further iterations of a quantitative Likert survey that followed with a larger group of experts (Figure 3.1). In Round II, the Likert survey was used to generate consensus with initial experts' and to establish content validity. This round was considered a development survey round; therefore, it was decided *a priori* that the threshold for consensus for statement inclusion in subsequent rounds would be $\geq 70\%$ statement consensus from initial experts (1: strongly agree, 2: somewhat agree or 4: somewhat disagree, 5: strongly disagree). This agreement level has been considered appropriate in previous Delphi studies (Dalkey 1972; Diamond et al., 2014; Mc Dermott, 2016; Ramos et al., 2020). In addition, results from statements with high levels of dispersion heterogeneity were included in Round III to warrant further discovery with a larger group of experts. Each statement also included a space for open-ended responses to allow for further iteration from the initial experts and a choice of 'do not know'. Modifications were made to the Round III survey, based on open-ended responses and consensus areas. Further iterations of the survey were then disseminated in the agreement phases of Round III and IV of the study, with consensus defined more narrowly as $\geq 70\%$ of experts 1) strongly agreeing or 5) strongly disagreeing with a statement. This agreement level has been considered appropriate in previous Delphi studies (Diamond et al., 2014; Mc Dermott, 2016; Ramos et al., 2020). Descriptive statistics were calculated to assess frequencies, measures of central tendency (mean) and levels of dispersion (standard deviation). In addition, percent agreement was calculated for both initial experts only and all experts (Round III/IV) and inter-rater reliability, using the kappa statistic, accounted for chance agreement not captured in percent agreement (Hsu & Sandford, 2007;

McHugh, 2012). The study took place over a 22-week period (June- November 2020) with Likert survey rounds II-IV administered over a seven-week period (October- November 2020).

Ethical Considerations

Following approval from the University of Massachusetts, Amherst Internal Review Board (IRB), which deemed the study exempt, requests to participate were sent to potential experts with electronic consent obtained from all experts who participated in the study. The consent explicitly stated that experts could withdraw from the study at any time. Interviews were conducted by a clinical exercise physiologist and nurse scientist with research interests in activity and YA cancer survivorship. To decrease participant' burden an apriori decision of limiting the Delphi rounds to four was made. To enhance rigor and the quality of the research, careful attention to detail was taken to articulate the operationalization of consensus for each round of the study, and at the start of each subsequent consensus round, to articulate whether consensus around a particular item had been achieved in the previous round, address the reason for stopping the Delphi rounds, and share the central tendencies, level of dispersion and stability of the responses from previous rounds with the respondents (Diamond et al., 2014; Hsu & Sanford, 2007). All interviews and transcripts were kept in a locked password protected computer and available only to the research team. Experts were given a study identification number to protect anonymity. All interviews were conducted in English.

Anonymity

One of the unique characteristics of the Delphi method is the ability to provide an unbiased opinion (Goodman, 1987) while maintaining anonymity (Hasson, Keeney, McKenna 2000). It allows for consensus building in areas with limited research or agreement to generate consensus in a controlled feedback process that allows for equal representation and anonymity regardless of positionality due to anonymous nature of the study (Dalkey et al., 1972). Experts

were given a study identification number to protect anonymity. All email correspondence was done as a blinded carbon copy. All thematic results or quantitative results was noted by study ID, and consensus results were reported in aggregate form.

Defining and Selecting Multidisciplinary Experts

Multidisciplinary panels have been used in Delphi studies to gather insights from a diverse group of experts on a broad ranging topic (Avery, et al., 2005). An expert has been described in the literature as an individual with knowledge of the subject being investigated (McKenna, 1994). The sample size for the initial experts was chosen based on previous research on Delphi studies suggesting sample groups of 10-15 experts (Delbecq, Van de Ven & Gustafson 1975). In addition, when designing the study, an attempt to have equal representation for each of the four groups of expertise was considered. The sample size for expanded experts (Round III/IV) was based on previous Delphi studies that included sample sizes ranging from 3-30 participants (Mullen, 2003; Donohue & Needham, 2009) and a summary of Delphi studies (Mullen, 2003) noting varying ranges from 3-3000, including recommendation that policy geared Delphi study should have 10-50 experts (Turnoff, 1970) and concluding with the recommended sample size ultimately should reflect the purpose of the study (Cantrill, Sibbald & Buetow, 1996).

Recruitment of Initial Experts for Round I and Round II

Using purposeful sampling, we aimed to have a multidisciplinary panel using the following inclusion criteria: national/international expertise in one or more of the following: exercise oncology, survivorship care, symptom science/management, adolescent YA cancer (as noted by research publications and/or clinical expertise in guidelines/programs). For round I and II of this study equal representation was sought from the four areas of clinical/research, however, many of the experts straddled multiple roles in cancer care (Table 1).

A potential group of initial experts identified by the primary investigator ($n = 49$) were contacted via email to inform them of the study. The email included a description of the study design and a figure outlining steps for each round of data generation and estimated time commitments. We provided a link to an online informed consent form. The informed consent reviewed potential risk/benefits of study participation, confidentiality procedures, voluntary participation, the opportunity to terminate involvement in the study at any time, and to answer any questions they may have. An affirmative response indicated a commitment to participate in the study. All consents were received prior to scheduling individual interviews for a 30-minute time slot that was convenient for the initial expert. All interviews were conducted in English and occurred over 15-weeks (June – September 2020). Interviewees were given a study identification number, which was used to analyze all data throughout the study. A central list linking the expert to their study identification was kept on a password-protected computer and available to the dissertation team.

Recruitment of Additional Experts for Round III & IV

All initial experts were invited to participate in round III & IV. A pool of additional experts for round III and IV were identified ($n = 137$), using purposeful sampling that fit the following inclusion criteria: expertise/experience in one or more of the following: exercise oncology, YA cancer, symptom science/management, cancer survivorship care (as noted by research publications and/or clinical expertise in guidelines/programs and/or experience in AYA cancer care, physical activity in cancer survivors). Recruitment efforts were as noted in round I/II and additional efforts included: posting a survey link on social media (Twitter), review of investigators listed on the NIH grant RePorter site with research grants in symptom management, survivorship care, behavioral health related to adolescent YA cancer research), and an invitation for initial experts to share round III survey link with individuals who fit the inclusion criteria.

Potential experts were informed about the ongoing Delphi study and invited to participate in the final rounds with an estimated 15-minute time commitment for each round. Experts who participated in round III had the option of providing their email if they wished to participate in round IV.

Data Collection and Analyses

Delphi Round I

The first round was an explorative phase (Adler & Ziglio, 1996; Holey et al., 2007) consisting of qualitative interviews conducted to establish the content from the initial group of experts (Hsu & Sandford, 2007). Thematic analysis of the interviews was performed, and the qualitative data was used to create an initial Likert survey. To foster flexibility and inductive reasoning from the initial experts, we created a focus-specific interview guide with an accompanying graphic diagram to be used as a measurement tool. Focus-structured interview questions/graphic was used in this exploratory round. Focus-structured interview questions have been used in exploratory research and are useful when interviewing groups with diverse backgrounds by allowing flexibility of responses (Moore et al., 2013; Waltz, Strickland & Lanz 2017). The graphic diagram included the following domains adapted from constructs of the Revised Symptom Management Theory: outcomes (e.g., morbidity/mortality), care continuum, symptom outcomes, symptom experience, symptom management, guidelines, barriers/facilitators, care delivery systems, and integration (Figure 3.2). To establish face validity and estimate participant burden, the survey was designed with input and expertise from the dissertation committee.

Recruitment emails were sent out to potential experts ($n = 49$) with 24 responses for a response rate of 49% (18 consented experts and six declining). Reasons for declining included initial time commitment ($n = 5$), but they requested to be considered for further rounds III, and no longer

active in clinical/research ($n=1$). Individual focused interviews were conducted for each of the national/international multidisciplinary initial experts ($n = 18$) using the graphic diagram to gain insights into physical activity as a symptom management strategy. Audio/video-based interviews, which averaged 30-45 minutes, were conducted and recorded using a secure online platform. All interviews were audio/video recorded and transcribed in their entirety. In order to increase trustworthiness, a clear decision trail was documented via memos maintained by the PI throughout the study process (Hasson & Keeney, 2011). Qualitative interviews were transcribed and analyzed using conventional qualitative content analysis (Hseith & Shannon, 2005) for theme extraction with consensus achieved by the research team. This method of analysis allowed for subjective interpretation of the content text contained in the measurement tools (i.e., focus-structured interview questions/graphic diagram and open-ended questions) to explore the qualitative research questions and identify information that informed the development of the Likert survey used as a measurement tool in round II using MAXQDA (VERBI Software, 2019) for analysis. More specifically, using the conventional qualitative content analysis approach (Hseith & Shannon, 2005), open-ended probes in response to interviews/case study responses were used (e.g., can you tell me more about that). Initial analysis included reading all transcripts to achieve immersion for overarching themes. All data was then reread word to word first to derive codes using exact words and then identify key concepts. Field notes were kept by the researcher for each participant to journal impressions and thoughts both during each interview and again after initial analysis to facilitate critical reflection needed to identify overarching themes, ideas, and biases and areas for further clarification. The process continued with labeling initial codes. Codes were then sorted into categories based on how they were linked and related. Meaningful clusters were made from these preliminary categories. Further review and synthesis of the categories resulted in the identification of potential themes.

Qualitative data from Round I was used to inform the creation of a 5-point Likert (Likert, 1932) statement and open-response survey with 104 statements clustered around overarching themes, categories, and codes that were articulated by the initial experts to build consensus. A 5-point Likert scale (1=strongly agree, 2= somewhat agree, 3 = neither agree nor disagree, 4 = somewhat disagree, 5 = strongly disagree) provides adequate reliability and is less taxing than a higher point Likert scale (Dawes, 2008). Additionally, open text spaces were embedded in the survey to allow for initial experts an opportunity for further iteration, clarification or comments to inform subsequent rounds. This technique has been used in previous modified Delphi studies (Vogel et al., 2019).

Delphi Round II

A link to the online survey was disseminated via email to all eighteen initial experts to establish initial consensus, as a form of member-checking and to establish construct validity. Qualtrics software, Version XM of Qualtrics. Copyright © 2020 Qualtrics was used for data collection on all online survey administration. Complete responses ($n = 18$) were analyzed using quantitative and qualitative methods. Data from all online surveys was exported into SPSS for data cleaning and analysis using IBM *SPSS* Statistics for Mac, version 27 (IBM Corp., Armonk, N.Y., USA). Quantitative analysis was performed using descriptive statistics, % agreement, measures of central tendency (mean) and dispersion (standard deviation) for areas with $\geq 70\%$ consensus. Analysis software indicated the average time to complete the survey was < 14 minutes. Qualitative analysis of open-text responses was performed as outlined in round I. Following analysis, the Likert survey was modified for Round III based on the level of consensus and input from open-text responses. Briefly, ten questions were reworded for clarity, six questions were removed, and 9 questions were added to the survey for Round III iteration. Full details reported in results below.

Delphi Round III

Following analysis from Round II, a 107 statement 5-point Likert (1-strongly agree, 2-somewhat agree, 3-neither agree nor disagree, 4-somewhat disagree, 5-strongly disagree) and open-response survey was created for dissemination to initial experts and a larger sample of experts for consensus building (total $n = 137$ invited, including all 18 initial experts). Seventeen of the initial experts participated (94% retention) in round III. Complete responses from the Round III survey ($n = 56$) were analyzed for % agreement, measures of central tendency (mean), and level of dispersion (standard deviation). Thirty-seven statements were removed due to a lack of consensus ($< 70\%$ agreement). Areas with lack of consensus and levels of dispersion were noted for reporting in the study results.

Delphi Round IV

Following analysis of round III survey data, a 71 statement 5-point Likert (1-strongly agree, 2-somewhat agree, 3-neither agree nor disagree, 4-somewhat disagree, 5-strongly disagree) survey was developed for round IV that reflected areas with $\geq 70\%$ consensus. Two additional questions were added to collect further data on the experts role in cancer and years in this role. The survey link was disseminated via email to previous experts who provided their email in Round III ($n = 56$). Complete responses from experts ($n = 45$) were analyzed for descriptive statistics (% agreement, mean, standard deviation) for areas with $\geq 70\%$ agreement (Table 3a, 3b, 6a, 6b, 7). In addition, weighted Kappa scores were calculated to quantify inter-rater reliability among all experts (table 4a, 4b, 8a, 8b).

Data Cleaning

Data cleaning included: removal of duplicate survey responses by one expert, connecting data with email and study ID's from two of the initial experts for future comparison, removal of incomplete surveys (12 incomplete surveys: 9 ended survey at consent, 3 at 65% completion).

One respondent completed the survey but did not provide an email address, therefore was unable to complete round IV.

Expert Recruitment/Retention Rates

Of the 49 experts invited to participate as initial experts, 24 responded (49% response rate) with 18 participants completing Round I. All initial experts included in round I ($n = 18$) were retained for round II (100% response rate), which enhanced the reliability of the Likert survey. Round III included a total of 56 experts, including seventeen of the initial experts (94% retention of initial experts from round II). Experts who participated in round III had the option of providing their email if they wished to participate in round IV ($n = 56$). In round IV, fifteen of the eighteen initial experts (83% retention) and 30 of the 39 additional experts from round III (77% retention) participated. The descriptive characteristics of experts are given in table 1.

Consensus Results

Round I

Expert distribution. The distribution of initial experts was as follows: exercise oncology (50.0%), survivorship care (55.6%), symptom science/management (38.9%), adolescent YA cancer (33.3%). Specialists in YA cancer care, a subdivision of adolescent YA cancer care, are limited in the field and our study reflects such.

Qualitative results. Inductive thematic saturation, the point at which even with new data, no new core categories or themes emerged (Given, 2015; Morse, 1995; Saunders et al., 2018), was reached at interview 15, however data collection continued with all eighteen scheduled interviews. The coding process continued, resulting in a list of initial codes (e.g., fatigue, pain, well-being, functional status, tailored care, unmet needs, measurement, control, motivation, flexible care models, cancer care continuum, health disparities, telehealth, health care providers). These initial codes were then combined into seven broader thematic categories (symptom

outcome, symptom status, person-centered care, village of experts, guidance/guidelines, cancer care continuum, care delivery systems) based on meaning and how they were linked. Clustering of codes resulted in 3 overarching themes (Table 2): the effect of physical activity on symptom management in YA (aim 1); person-centered YA survivorship care (aim 1); clinical considerations of integrating physical activity into YA survivorship care (aim 2). Results related to aim 2 are discussed elsewhere.

Round II

Expert distribution. The distribution of expertise of the initial experts was as follows: exercise oncology (50.0%), survivorship care (55.6%), symptom science/management (38.9%), adolescent YA cancer (33.3%).

Analysis of open-text responses. Open text responses included insights on the use of family members, peer mentors, patients and physiotherapists as “village of experts” to provide physical activity referrals, assessments and interventions. It noted that while clinical professionals such as nurses, advanced practice nurses, medical doctors, and physician assistants could refer and assess, ‘that may not be the best use of their time’ and therefore should not be relegated to them. It suggested that education endeavors about the use of physical activity in YA cancer survivors, could include exercise professionals, peer coaches and pharmacists. It was noted that while supportive oncology “should be part of supportive oncology”, it is “not regularly included”.

Symptom management. Experts agreed physical activity integration in YA cancer care was part of supportive oncology (72.3%). There was consensus on the recommendation of physical activity for the following symptoms: fatigue (88.9%), cardio-metabolic health (94.4%), loss of muscle mass (100%), excess body fat (88.9%), low bone mineral mass (72.2%), anxiety/depression (83.3%), cognitive health (72.2%). Improvements in functional capacity (72.2%) and wellbeing (72.2%) were noted. Areas with lesser agreement included recommending

physical activity for pain (22.2%), chemotherapy induced peripheral neuropathy (44.4%), mitigating inflammatory processes (50%), nausea/vomiting (11.1%) and creating a sense of normalcy (66.7%). It should be noted that when ranking included both ‘strongly agree’ and ‘somewhat agree’, there was greater consensus as follows: pain (72.2%), chemotherapy induced peripheral neuropathy (72.2%), mitigating inflammatory processes (72.2%), nausea/vomiting (38.9%) and creating a sense of normalcy (88.9%).

Person-centered cancer care. To address concepts of control critical to this life stage related to the use of physical activity as a person-centered self-management intervention highlighted in the qualitative interviews, a series of statements related to agreement if YA should be asked if they would like guidance on physical activity stages at the various stages on the cancer care continuum, showed strong consensus: prehabilitation (83.3%), active treatment phase (88.9%), post-treatment phase (94.4%), long term survivorship (88.9%). Statements related physical activity facilitating adaptation to cancer survivorship showed strong consensus (83.3%). The identification of both facilitators (94.4%) and barriers (94.4%) to physical activity received consensus. There was consensus on conducting tailored physical activity assessments (72.2%), interventions (77.8%) as well as conducting motivational assessments (77.8%) to provide tailored physical activity interventions to YA cancer survivors.

Lack of consensus. Areas of lesser agreement included: early interventions to reduce inactivity are essential to mitigate long-term effects (50%), the use of physical activity to lessen frailty from cancer treatment (61.1%) and the use of person centered physical activity interventions to aid in adaptation in the prehabilitation phase (44.4%, active treatment phase (44.4%). However, when ratings were clustered to include ‘strongly agree’ and ‘somewhat agree’, consensus was achieved on the following statements: early interventions to reduce inactivity are essential to mitigate long-term effects (94.4%), the use of physical activity to lessen frailty from

cancer treatment (100%), use of person centered physical activity interventions to aid in adaptation in the prehabilitation phase (77.8%, active treatment phase (77.8%).

Survey modification. Ten statements were reworded for clarity, six statements were removed, and 9 statements were added to the survey for Round III iteration (Table 10a). Statements that represented consensus were retained for the round III iteration. Ninety-eight statements were retained, 9 statements were added and the option for additional comments was placed as an open text for Round III of the Likert survey. Fifty-eight statements reflected consensus of $\geq 70\%$ of initial experts chose a rank of 1 (strongly agree), 2 (somewhat agree) or 4 (strongly disagree) or 5 (somewhat disagree).

Round III

The survey was modified following analysis from Round II, resulting in a 107 statement 5-point Likert (1-strongly agree, 2-somewhat agree, 3-neither agree nor disagree, 4-somewhat disagree, 5-strongly disagree) survey with open-response options for every item. The Round III survey was disseminated to initial experts and a larger sample of experts for consensus building ($n = 137$ experts invited).

Complete responses ($n = 56$) were analyzed for descriptive statistics. Analysis looked at descriptive statistics: % agreement, measures of central tendency (mean), level of dispersion (standard deviation). 37 statements were removed due to a lack of consensus ($< 70\%$ agreement). Areas with lack of consensus and levels of dispersion were noted for reporting in the study results.

Symptom Management. There was consensus that physical activity integration in YA cancer care was part of supportive oncology (94.7%). There was consensus on the recommendation of physical activity for the following symptoms: fatigue (89.5%), cardio-metabolic health (91.2%), loss of muscle mass (86.0%), excess body fat (75.4%), low bone

mineral mass (70.2%), anxiety/depression (91.2%), cognitive health (80.7%). Improvements in functional capacity (82.5%) and wellbeing (78.9%) were noted. Areas with lesser agreement included recommending physical activity for pain (30.4%), chemotherapy induced peripheral neuropathy (35.7%), mitigating inflammatory processes (46.4%) and creating a sense of normalcy (66.1%).

Person-centered Cancer Care. To address concepts of control critical to this life stage related to the use of physical activity as a person-centered self-management intervention highlighted in the qualitative interviews, a series of statements related to agreement if YA should be asked if they would like guidance on physical activity stages at the various stages on the cancer care continuum, showed strong consensus: prehabilitation (80.7%), active treatment phase (86.0%), immediate post-treatment phase (87.7%), long term survivorship (93.0%). Statements related to physical activity facilitating adaptation to cancer survivorship showed consensus in the immediate post-treatment phase (75.4%) and in long-term survivorship (87.7%). The identification of both facilitators (86.0%) and barriers (93.0%) to physical activity received consensus. There was consensus on conducting tailored physical activity assessments (75.4%), interventions (77.2%). Consensus on conducting motivational assessments to provide tailored physical activity interventions to YA cancer survivors lessened in round III (64.9%). Areas of lesser agreement also included: early interventions to reduce inactivity are essential to mitigate and long-term effects (66.1%), the use of physical activity to lessen frailty from cancer treatment (53.6%) and the use of person centered physical activity interventions to aid in adaptation in the prehabilitation phase (66.1%), active treatment phase (62.5%). Areas that lacked consensus are found in table 5.

Survey Modification

Thirty-six statements were removed due to a lack of consensus (table 10b).

Round IV

Complete responses from experts ($n = 45$) were analyzed for descriptive statistics: % agreement, measures of central tendency (mean), level of dispersion (standard deviation) for areas with $\geq 70\%$ agreement. Percent consensus was established in 53 of the 62 remaining statements in round IV ($14 \geq 90\%$; $23 \geq 80\%$; $16 \geq 70\%$ and nine statements not achieving consensus).

Symptom Management. There was consensus that physical activity integration in YA cancer care was part of supportive oncology (91.1%). There was consensus on the recommendation of physical activity for the following symptoms: fatigue (91.1%), cardio-metabolic health (88.9%), loss of muscle mass (86.7%), excess body fat (77.8%), anxiety/depression (77.8%), Improvements in functional capacity (86.7%) and wellbeing (86.7%) were noted. Areas with lesser agreement included recommending physical activity for low bone mineral mass (60.0%) and cognitive health (55.6%).

Person-centered Cancer Care. To address concepts of control critical to this life stage related to the use of physical activity as a person-centered self-management intervention highlighted in the qualitative interviews, a series of statements related to agreement if YA should be asked if they would like guidance on physical activity stages at the various stages on the cancer care continuum, showed strong consensus: prehabilitation (88.9%), active treatment phase (86.7%), immediate post-treatment phase (91.1%), long term survivorship (97.9%). Statements related to physical activity facilitating adaptation to cancer survivorship showed consensus in the immediate post-treatment phase (73.3%) and in long-term survivorship (86.7%). The identification of both facilitators (91.10%) and barriers (95.6%) to physical activity received consensus. There was consensus on conducting tailored physical activity assessments (71.1%), interventions (80.0%) and conducting motivational assessments to provide tailored physical

activity interventions to YA cancer survivors (71.1%). All areas related to person-centered cancer care for YA achieved expert consensus in round IV.

Interrater reliability. In addition, weighted Kappa scores were calculated between round III and round IV to assesses inter-rater reliability among all experts and account for a chance agreement not captured in percent agreement (Holey, Feeley, Dixon & Whittaker 2007; Mc Dermott, 2016; McHugh, 2012). Results of interrater reliability (Kappa score) for all experts were as follows (Table 4a, 4b): 10 statements exhibited poor interrater reliability (.00 -.20); 5 statements exhibited minimal interrater reliability (.21-.39); 12 statements exhibited weak interrater reliability (.40 -.59); 9 statements exhibited moderate interrater reliability (.60 -.79); 1 statement exhibited strong interrater reliability (.80-.90). Results of interrater reliability (Kappa score) for initial experts were as follows: 12 statements exhibited poor interrater reliability (.00 -.20); 7 statements exhibited minimal interrater reliability (.21-.39); 12 statements exhibited weak interrater reliability (.40 -.59); 10 statements exhibited moderate interrater reliability (.60 -.79); 1 statement exhibited strong interrater reliability (.80-.90).

Discussion

With over 50% of YA survivors reporting unmet needs, survival itself is not an adequate or just outcome measure (Ness et al., 2018; Wong et al., 2017). Lifelong survivorship care that focuses on overall health, wellbeing, and quality of life of individuals affected by cancer is the recommended standard of care (NCCN, 2020 survivorship). Supportive oncology is care that is given to prevent or treat symptoms to improve quality of life in those affected by cancer (NCI, no date). This study established consensus that physical activity should be integrated into YA cancer care as part of supportive oncology. The integration of physical activity as part of supportive oncology was fostered in 2009 by a round table of American College of Sports Medicine (ACSM) experts who issued guidelines on exercise for adult cancer survivors (Wolin et al.,

2012). The benefits and recommendations of physical activity on biopsychosocial health in cancer survivorship were highlighted as well as barriers to facilitation and implementation. While the research in exercise oncology has exploded since the 2009 ACSM roundtable, reliable integration of physical activity into supportive oncology care remains elusive. In adult cancer survivors, physical activity has emerged as a promising target for the management of late effects of cancer and its treatment that impact biopsychosocial health (Aziz, 2002; Schmitz et al., 2019; Wolin et al., 2012). In YA cancer survivors, use of physical activity in the management of psychosocial effects of cancer and its treatment is being investigated (Wurz & Brunet, 2017) as a strategy to both mitigate vulnerabilities and support resilience. Multifocal health promotion interventions (behavioral, cognitive and social) need to be investigated in long-term and understudied cancer populations (Antoni, 2013; Aziz, 2002).

Symptom Management

Results of this study support that physical activity should be recommended to mitigate some of the unmet physical and mental health needs of YA cancer survivors. Previous research has indicated physical activity use is a promising priority for intervention development to promote health behavior change based on its promising effects on quality of life of YA survivors (Pugh et al, 2016; Rabin, 2011; Signorelli et al., 2018; Wurz & Brunet, 2016). The research is clear, in adults, on quality of life being a predictor of mortality in cancer survivorship (Signorelli et al., 2018) although the exact mechanisms for such remain elusive (Burke et al., 2017). Studies specific to the adolescent YA population are feasible and acceptable, however, larger randomized control trials are needed (Munsie, Joske & Ackland, 2019).

Fatigue is a common and often debilitating symptom for YA survivors and has the most detrimental effects on the physical and functional dimensions of quality of life (Cabilan & Hines, 2017; Rabin, 2011; Spathis et al., 2015). YA cancer survivors describe fatigue as both physical

and psychological (Hauken, Grue, & Dyregrov, 2019). The symptom of fatigue often leads to inactivity, a maladaptive behavior that in turn can perpetuate fatigue (Rabin, 2011; Spathis et al., 2015). This behavior is further complicated by the beliefs of healthcare clinicians, family members and survivors themselves that resting is the best approach to manage fatigue. Experts in this study found consensus that physical activity should be recommended to mitigate the symptom of fatigue (91.1%). Previous research in adult cancer survivors has shown physical activity mitigates the symptom of cancer-related fatigue (Schmitz et al., 2019; Spathis et al., 2015). In a meta-analysis of adult cancer survivors ($n = 3254$), those who completed resistance exercise exhibited improvement in cancer related fatigue (Brown, et al., 2011).

Altered body composition, most notably excess body fat, reduced bone mineralization resulting in an increased risk for both metabolic syndrome, osteoporosis and fragility often seen in young cancer survivors contribute to symptom burden and mortality (Barr et al., 2016). Risks to metabolic, bone and muscle health have, often seen in young cancer survivors, contribute to symptom burden and mortality (Barr et al., 2016.) Previous research indicates that treatment exposures from chemotherapy and radiation increase late effects on metabolic health (e.g., increase risk of obesity, dyslipidemia, insulin resistance, diabetes) (Nass et al., 2015; Tai et al., 2012). Higher levels of anxiety, distress, and depression are experienced by adolescent and YA cancer survivors (Fernandez et al., 2011; Tai et al., 2012) yet they are less likely to access professional mental health services (Coccia et al., 2018). In particular insults to self-image and bodily changes such as hair loss, weight changes, risk of infection, altered sexuality, loss of normal activities of daily living, and financial issues negatively impact psychosocial health (Bleyer 2007; Fernandez et al., 2011). Physical activity offers a self-managed intervention to provide mitigate of some of these changes. Experts in this study found consensus that physical

activity should be recommended for both excess body fat (77.8% consensus), loss of muscle mass (86.7% consensus), and anxiety/depression (77.8% consensus).

It is estimated that 75% of AYA cancer survivors experience cognitive changes that impact memory, learning, concentration, and decision-making (Nass et al., 2015; Treanor et al., 2016). A higher proportion of these individuals are unable to seek health care, due to cost, than peers without cancer (Tai et al., 2012) which negatively impact psychosocial health and adaptations (Antoni, 2013; Bleyer 2007; Fernandez et al., 2011) and further increases their risk to biopsychosocial health. Experts in this study lacked consensus on the use of physical activity to mitigate cognitive health issues (55.6%). Observational research in a large study ($n=6199$) of adult childhood cancer survivors, indicates those with vigorous exercise regimes exhibited less depression and cognitive health insults (Tonorezos et al., 2019).

The effects of cancer and its treatment impair physical and mental health outcomes, with long term insults on AYA wellbeing (Bradford & Chan, 2017). Unmet needs correlate to worse outcomes and higher symptom burden. In order for YA to reach their full potential, the optimization of health and wellbeing need to be supported throughout survivorship (Bradford & Chan, 2017). In this Delphi study, the symptoms of cognitive health, chemotherapy induced peripheral neuropathy, mitigation of cellular inflammation, low bone mineral mass, frailty, normalcy and distress did not meet the set consensus threshold. However, as we analyzed the data and looked at the measures of central tendency and dispersion, we noticed a homogenous spread with clustering around the rankings of strongly and somewhat agree. The symptom of frailty is a clustering of symptoms (Gee et al., 2019) and in as such needs to be further investigated. There is the dangerous symptom clustering of sarcopenia, osteopenia and altered BMI seen in adolescent and YA cancer survivors that manifests as frailty (Barr et al., 2016). Physical activity can positively impact all of these symptoms. Gee and colleagues looked at the biological

underpinnings of frailty, seen here as physical dimensions, and expanded our understanding to include psychosocial and functional dimensions that manifest (Gee et al, 2019). By looking at multiple outcome measures, we see a more complete picture of the frailty syndrome. The initial experts established consensus on the use of physical activity on frailty, but subsequent rounds lacked consensus. Symptoms of frailty may relate to the multitude of unmet physical and emotional needs in YA, therefore warrant further investigation.

Person-centered Care

YA survivors are understudied and often straddle pediatric and adult care systems resulting in fragmented cancer care experiences (Bleyer et al., 2017; Fernandez et al., 2011; Patterson et al., 2015). In addition, they have unique needs related to their developmental stage (e.g. oncofertility, transition to emotional and financial independence, body image, social impacts, control) that are often unmet and not understood in their survivorship care (Smith et al., 2019). In a recent study, young survivors articulated the need for care that ‘fits me’ (Wong et al., 2017). Person-centered care is care centered and responsive to individual needs, preferences and values that treats and individual as a whole entity (Institute of Medicine 2008). To address a lack of person-centered care for adolescents and YA, the National Cancer Institute supported the Health Outcome and Patient Experience (HOPE) study to understand their unique unmet needs. The results of this study were broad and wide reaching of the need for more clinical trials and greater awareness for the many unmet needs, including the need for physical fitness, of this vulnerable and resilient population (Keegan et al., 2012; Smith et al., 2019). Compared with healthy age controls, adolescent and YA cancer survivors experience worse mental and physical health with the greatest discrepancies related to physical and emotional roles, physical and social functioning and fatigue (Smith et al., 2013). In this study, there was expert consensus on statements as they relate to providing person-centered care. Results indicated consensus that YA

should be asked if they would like guidance on the use of PA at all stages of the cancer care continuum as part of person-centered care. Interventions tailored by and for YA and support the critical independence associated with this developmental stage (Barnett et al., 2016). Experts in this study showed consensus regarding the need to ask YA us they would like guidance on physical activity during the prehabilitation (88.9%), active treatment (86.7%), immediate post-treatment (91.1%) and long-term survivorship (97.9%) phases of the cancer care continuum. In addition, expert consensus results indicated that identification of personal barriers (95.6%) and personal facilitators (91.1%) to physical activity need to be identified. Experts in this study found consensus that the tailoring of physical activity interventions facilitated its integration into survivorship care (80.0%). In addition, there was consensus that culturally and environmentally tailored programs also facilitate integration (82.2%).

The aims of this study involved insights from multidisciplinary disciplines to identify consensus areas where further research and advocacy regarding the use of physical activity in YA cancer survivorship care. The research design included the use of Kappa values to measure interrater reliability and add to the robustness of the modified Delphi study by measuring the change of an expert's opinion over time (McHugh, 2012; Ogbeifun et al, 2016). However, a limitation of this study is that the expanded group of experts only took part in Rounds III and IV, limiting the ability to measure change in all experts' opinions over time. Kappa scores of initial experts, who took place in round II/III and IV were also calculated to measure change over time, with higher levels of interrater reliability noted when compared to all experts in round III/IV. Overall the Kappa results yielded low or moderate response reliability. Subsequent rounds with the expanded group of experts would have provided a better description of interrater reliability (McHugh, 2012). There is opinion from previous researchers that low Kappa scores are not indicative of poor interrater reliability, since the goal of the Delphi study is to converge on consensus

(involving the Kappa statistic (Ogbeifun et al., 2016). To assess interrater reliability on emerging areas of consensus, taking into account changes of measures of central tendency and dispersion may offer a more accurate assessment (McHugh 2012). In addition, the multi-disciplinary experts changed over subsequent rounds as noted in table 1, diluting the interpretation of the results.

As with other methodologies, establishing rigor measured by reliability, validity, and trustworthiness is essential (Hasson & Keeney, 2011). Credibility, dependability, confirmability and transferability (Lincoln & Guba 1985; Polit, Beck & Hungler, 2001) perhaps are better measures of trustworthiness (Hasson & Keeney, 2011). In this study credibility was enhanced by the origins of the measurement tool from the experts themselves, through the use of a graphic interview guide; the multiple iterations of the survey with space for open-text to allow the experts a place to provide feedback; providing the experts previous consensus results between round III and IV. Dependability was enhanced by representation from multidisciplinary experts in both their expertise and their positionalities in the cancer care delivery system. Confirmability was enhanced by establishing and communicating a clear description of the research process and articulating our decision-making. More specifically, careful attention to detailed decision rules was taken in study design to 1) articulate the operationalization of consensus for each round of the study *a priori*, articulate on whether consensus was achieved, address the reason for stopping the Delphi rounds, and assess the central tendencies, level of dispersion and stability of the responses (Diamond et al., 2014; Hsu & Sanford, 2007; Miller 2006). The multiple rounds in the modified Delphi process could enhance transferability, as a form of verification. However, the use of a modified Delphi method aims to predict and therefore verification can only relate to verification of emerging consensus from clinical and research experts. Perhaps the biggest limitation to transferability is that the most valued expert, the YA cancer survivor, was not

explicitly included in this study of clinical and research professionals' perspectives on physical activity. Previous research indicates that YA want information and support regarding physical activity use in survivorship (Belanger et al., 2012; Fitch 2020; Smith et al., 2019; Wong et al., 2017). This study sought to investigate insights on structural systems that may foster/inhibit the support of such. Any findings contained herein should be validated with YA cancer survivors for their critical and lived experience.

The analysis could have been enhanced to achieve additional aims of psychometric measurement validity by the use of ranking including content validity index for analysis. In addition, we were unable to measure interrater reliability on questions related to consensus on who should provide physical activity assessments, referrals and intervention due to select all that apply vs. forced response question. The 'select all' format is less taxing on survey participants (Lau & Kennedy, 2019), therefore was chosen to minimize participant burden.

The strengths of this research include online data collection which allowed for a geographically dispersed multidisciplinary expert panel inclusive of international insights from 10 countries. Experts in this study included: nurses, nursing scientists, oncologists, exercise physiologist, physiotherapists, AYA cancer behavioralist, social workers, rehabilitation physicians, occupational therapists, physical therapists and community providers who specialized in providing physical activity to both YA and adult cancer survivors. The use of a two-tier expert panel allowed for a measurement survey tool to be used on a larger group of experts to test its usefulness. The inductive approach to knowledge generation offered trustworthiness to the data collection by removing bias from the researcher in the measurement tool development. The retention rate of experts was high, exhibiting their commitment to this research. This wide range of experts included exercise physiologists, specially trained exercise oncologists, cancer researchers and clinicians from multiple discipline (nursing, oncology physicians, rehabilitation

physicians, occupational therapists, physical therapists, behavioralists, social workers, epidemiologists, adolescent and YA specialists) and community providers specially trained in physical activity for cancer survivors) offered insights from diverse positionalities on areas where further research and implementation studies should direct efforts. The inclusion of open-text responses in round II and III of the study also provided continuous feedback on areas that needed further clarification. We believe the insights from this study can be utilized by other health researchers considering use of the Delphi method. The statements that exhibited strong consensus can be also used as a starting point by other health care settings to gather consensus as they aim to integrate physical activity in their YA survivorship programs.

Limitations of this study include the inability to fully assess interrater reliability due to limited rounds. Interrater reliability measures the building of consensus over multiple rounds. The aim of this research however was to establish emerging areas of consensus and areas lacking thereof to guide further research and initiate clinical implementation discussions. An *a priori* decision was made to limit the consensus study to four rounds, to minimize participant burden. During these rounds the sample size and demographics changed limiting the ability to fully measure interrater reliability. Therefore we relied on descriptive statistics (% agreement, SD, mean) to measure areas of consensus. Potential bias in the purposeful sampling of experts exists, as pertinent research to identify experts may not have been fully captured. The use of language to create statements for the measurement tool allows for interpretation by the expert, which could be a limitation of this study. Statements were modified as needed when an expert articulated the need for clarification. As we expanded the study with additional experts in round III, there was less control over purposeful sampling which could have resulted in a wide range of expertise weighing in on this consensus. This was further compounded by the lack of ‘do not know’ option in the final rounds. In addition, the cancer roles of the participants in round IV resulted in less

experience in exercise oncology than previous rounds, perhaps skewing the data. The most profound limitation however is the absence of the direct voice of the most pertinent stakeholder in questions of cancer care, the YA cancer survivor themselves. Current research endeavors by others are capturing that voice. This study supports that work by describing consensus opinions among clinical experts who are critical wardens of cancer care. Describing how clinicians and other experts think about physical activity in the context of YA cancer survivorship care, exposes potential opportunities and barriers to further implementation and dissemination.

Conclusions

Physical activity use in cancer survivorship provides functional, cardio-metabolic, and psychosocial benefits as a flexible non-pharmacological intervention that can be controlled by offering them critical independence at this life stage. Experts in this consensus study highlighted the need for physical activity as a flexible non-pharmacological intervention that should be offered YA as part of supportive oncology. Further interventions should be tailored to consider individual facilitators, barriers, preferences, motivation, and stage in the cancer continuum. Guidance and guidelines are needed for YA survivors to acclimatize intervention to YA at all points on the cancer care continuum. In addition, guidance and guidelines are needed for those providing support and healthcare for them. This finding moves beyond individual factors and extends into structural frameworks that are needed to disseminate and implement physical activity guidelines in YA survivorship care. Areas related to cognitive health, pain, nausea/vomiting, chemotherapy induced peripheral neuropathy, mitigation of cellular inflammation, low bone mineral mass, symptoms of fragility, a sense of normalcy, symptoms of distress lacked the threshold for agreement in this study and warrant further investigation. Frailty symptoms go beyond physical manifestations and impact emotional and mental health dimensions of YA survivors (Gee et al., 2019). Given the propensity of unmet needs (Smith et al., 2019),

longitudinal measurement of symptoms that contribute to frailty warrant further research investigation. In addition, comprehensive clinical assessments that capture risk factors for frailty in YA survivors throughout the cancer care continuum are needed. from the clinical team caring for YA survivors. This research adds to the YA cancer survivor literature, by offering further research opportunities to this understudied group of cancer survivors. Areas of consensus and lack thereof offer a blueprint to guide future physical activity symptom management research and clinical endeavors. It supports the use of physical activity to address the unmet needs of information and support on health promotion and lifestyle issues that YA have articulated. Guidance and guidelines that facilitate physical activity implementation at all points on the cancer care continuum are needed to integrate its use as a symptom management strategy. We have a call to action to realize that surviving cancer is not enough, we need to provide precision-health interventions that mitigate the ‘consequences of the cure’ (Kopp, et al., 2016). As we look at the results of this study in the context of the Revised Symptom Management Theory (Dodd et al., 2001), the significance of the YA affected by cancer goes beyond existence in their own environment and expands to the structural framework of survivorship. Symptom management and person-centered care exist in structural systems that ultimately impact translation from expert recommendations to further research, dissemination and implementation efforts. The consensus (91%) that physical activity should be integrated into YA survivorship care call for further exploration into the structural intricacies of survivorship care and clinical considerations that facilitate its efficacy.

CHAPTER FOUR
YOUNG ADULT CANCER SURVIVORSHIP AND PHYSICAL ACTIVITY: EXPERT
CONSENSUS STUDY RESULTS ON CLINICAL RELEVANCE AND
CONSIDERATIONS

Abstract

Significance: Elevated survival rates in YA survivors have led to elevated levels of morbidity that result in unmet needs and limit full life potential. Physical activity has exhibited positive impacts on physical, psychological and social aspects of health following a cancer diagnosis. There are no standardized guidelines tailored to physical activity use in YA cancer care representing a critical need to understand areas of relevance/agreement on its use.

Aim: To identify expert consensus areas on assessing, prescribing and implementing physical activity as a symptom management strategy in YA cancer survivorship; identify areas of clinical relevance and endorsement of physical activity as a symptom management strategy in YA cancer survivorship.

Methods: A four-round modified Delphi study of international multidisciplinary experts (Round I/II $n=18$; Round III $n=57$, Round IV $n=45$) in exercise oncology, symptom management, survivorship care, AYA cancer care was conducted. Qualitative content analysis, descriptive statistics (% agreement, SD, mean) and interrater reliability (Kappa) were calculated.

Results: Consensus ($\geq 70\%$ strong agreement) was established in 16/30 statements related to the “village of experts” needed to assess, refer and provide PA interventions. Consensus ($\geq 70\%$ strong agreement) was established in 18/21 statements regarding the need for guidelines and essential components of care delivery systems in which health promotion activities, including physical activities, should exist.

Conclusions and implications: The results from this expert consensus study add to the existing literature the need for flexible care models that provide clinical support and expertise. Cancer

care models should optimally address the unique preferences, strengths and developmental stage of YA affected by cancer.

Keywords: cancer care delivery systems, YA cancer survivorship, self-management, exercise oncology, multidisciplinary collaborations

YOUNG ADULT CANCER SURVIVORSHIP AND PHYSICAL ACTIVITY: EXPERT CONSENSUS STUDY RESULTS ON CLINICAL RELEVANCE AND CONSIDERATIONS

Introduction

Despite significant increases in survival rates of adolescent and YA cancer survivors (Barr, 2011; Keegan et al., 2016; Roberts, et al., 2017), cancer morbidity has increased over the last two decades at a rate three times higher among those 15-29-years than among children (Bleyer, 2007; Bleyer et al., 2017). This disparity in cancer morbidity limits the full life potential of adolescents and young adults (AYA) affected by cancer (Bradford & Chen 2017; Phillips et al., 2015).

The YA (age 18-39 years) cancer survivors, a subpopulation of AYA, are an especially vulnerable population, due to reports of high unmet needs and an increased risk of chronic disease (Fernandez et al., 2011; Patterson et al., 2015; Zebrack, 2009; Zebrack et al., 2014) which are exacerbated by unhealthy lifestyle behaviors (Nass et al., 2015). Reports indicate during this transformative developmental stage, greater than 50% report unmet needs with most of those needs in physical and emotional health domains (Wong et al., 2017). In addition, less than 2% of YA cancer survivors are involved in clinical trials (Bleyer, 2007; Docherty, et al., 2015; Fernandez et al., 2011; Keegan et al., 2016).

In YA affected by cancer there are long-lasting insults to biological and psychosocial systems that cause distress, disrupt social functioning and result in unmet needs (Nass et al., 2015; Wurz & Brunet, 2016; Wurz & Brunet, 2017). AYA's affected by cancer represent the greatest number of affected life-years by cancer (Bleyer et al., 2017). The longevity of YA symptom burden, upwards of 50-60 years, needs to be considered when considering the impact of cancer on life potential and quality of life. In addition, their survivorship care straddles pediatric and adult

survivorship program often leaving them in fragmented care models further amplifying the multitude of unmet needs (Bleyer et al., 2017; Fernandez et al., 2011; Patterson et al., 2015). Unmet needs are associated with worse health-related quality of life (Bradford & Chan, 2017), in YA survivors, who are less likely to access supportive and preventative services (Coccia et al., 2018; Jones et al., 2020). There are disparities in the availability of clinical trials and tailored survivorship programs for YA, further intensifying health risks (Bleyer et al., 2017; Bradford & Chan 2017; Docherty et al., 2015; Fernandez et al., 2011; Keegan et al., 2016; Nass et al., 2015; Rabin et al., 2013). Disparities in morbidity are further exacerbated by increased financial toxicity experienced by YA cancer survivors (Guy et al., 2014). Results from the adolescent YA health outcomes and patient experiences (HOPE study), a large longitudinal population-based study, indicate the annual healthcare cost of YA survivors is \$920 > than non-cancer peers (Guy et al., 2014). To put that in context we must consider the economic impact of 1million YA survivors for upwards of 50 years of survivorship. A recent report from the Samfund that provides financial support to YA cancer survivors found YA face significant alterations in their net worth of > \$100,000 than that of the general population (Landwehr et al., 2016), further intensifying existing emotional, and psychosocial symptoms from cancer and its treatment.

When assessing risk and protective factors that influence long-term health in cancer survivorship, the consideration of biopsychosocial adaptations is important (Docherty et al., 2015). Physical health and psychological wellbeing are key indicators to healthy transitions/adaptations in adulthood (Scales et al., 2016). Highlights from the HOPE study indicate that YA cancer survivors have worse health-related quality of life compared to their non-cancer peers; most of these deficits are seen in physical and emotional domains, physical and social functioning, and levels of fatigue (Fitch et al., 2020). Physical activity has exhibited positive effects on physical, psychological, social and spiritual dimensions of quality of life in cancer survivorship (Burke et al., 2017).

Physical activity includes any form of movement produced from skeletal muscles that demands energy expenditure, to include non-sedentary leisure time activities to vigorous activity (Caspersen et al., 1985; Rochmis & Blackburn, 1971; World Health Organization, 2020). Its effects can be felt in the microenvironment our cells live in, to the macro environment we interact and function in (Wang & Zhou, 2020) and provides benefit to our heart, body and mind (World Health Organization, 2020). The field of exercise oncology has grown exponentially to develop reliable evidence on the role of physical activity in cancer care to mitigate acute and long-term consequences of their cure (Courneya et al., 2015; Jones & Albano, 2013; National Cancer Institute, 2019). The American College of Sports Medicine has recently published adult physical activity guidelines for cancer survivors (Schmitz et al., 2019). Most of the exercise oncology research, however, is tailored to adult cancer populations.

Physical activity positively affects physical and psychological adaptations to a cancer diagnosis (Burke et al., 2017). Further, YA have expressed a strong interest in receiving information regarding physical activity with (Belanger et al., 2012; Gupta et al., 2013; Rabin, 2011). Greater than 75% of YA surveyed expressing interest and 88% felt capable to participate in activity programs (Belanger et al., 2012) and > 80% ranked information about healthy lifestyle including physical fitness during treatment as high importance (Gupta et al., 2013). YA have articulated programming preferences related to such; 64% preferred information from a brochure with almost 50% preferring input from a cancer care specialized fitness expert (Belanger et al., 2012). Their preferences are essential given the developmental stage of self-autonomy, adaptation and independence inherent to this age (Fernandez et al., 2011; Scales, et al., 2016). Yet, there is no standardized guidance, tailored to YA regarding assessment, prescription or implementation of physical activity into cancer care, and limited insights on clinical considerations to doing such (Brunet et al., 2018; Munsie et al., 2019; Nass et al., 2015; Pugh et al., 2016; Rabin, 2011).

Therefore, there is a critical need to understand the areas of relevance and the extent of agreement

on considerations with the use of physical activity in YA survivorship care. The aim was to identify 1) expert consensus areas on assessing, prescribing and implementing physical activity as a symptom management strategy in YA cancer survivorship; and 2) areas of clinical relevance and endorsement of physical activity as a symptom management strategy in YA cancer survivorship. To achieve this we specifically aimed to:

- a. Identify areas of expert consensus on *assessing* physical activity as a symptom management strategy in YA cancer survivorship.
- b. Identify areas of expert consensus on *prescribing* physical activity as a symptom management strategy in YA cancer survivorship.
- c. Identify areas of expert consensus on *implementing* physical activity as a symptom management strategy in YA cancer survivorship.
- d. Identify areas of expert consensus on clinical relevance and endorsement of physical activity as a symptom management strategy in YA cancer survivorship.

Methods

This dissertation work began with the theoretical underpinnings of the Revised Symptom Management Theory. This model is framed around three main constructs: The symptom experience, symptom outcomes, symptom management strategies, encapsulated by the person, their environment and the influences of health and illness. (Dodd et al., 2001, Larson, UCSF 1994) This Dephi study was embedded in a parent study of cancer experts designed to comprehensively examine all aspects of physical activity in YA survivorship care. Complete study design, data collection and analysis, and methods for the study are reported elsewhere (Moraitis et al., 2021). Our study utilized a 4-round modified Delphi method (Figure 2) to elicit areas of relevance and the extent of agreement on the use of physical activity in YA survivorship care among a panel of multidisciplinary experts with experience in one or more of the following

exercise oncology, survivorship care, symptom science/management, adolescent YA cancer (table 1).

In round I (n = 18) qualitative interviews were transcribed and analyzed using conventional qualitative content analysis (Hseith & Shannon, 2005) for theme extraction with consensus achieved by the research team. Data from Round I interviews was used to inform the creation of a 5-point Likert (Likert, 1932) scale (1-strongly agree, 2-somewhat agree, 3-neither agree nor disagree, 4-somewhat disagree, 5-strongly disagree) of statement and open-response survey clustered around overarching themes, categories, and codes that were articulated by the initial experts to build consensus. There were three iterations (Round II, III, and IV) of the survey based on analysis following each round. Round II (n = 18) consisted of Likert survey development for initial experts' participation to establish agreement on the survey content for use in further iterations with a larger group of experts in round III (n = 56) and round IV (n = 45). Consensus in round II, a developmental round included $\geq 70\%$ of initial experts chose a rank of 1 (strongly agree), 2 (somewhat agree) or 4 (strongly disagree) or 5 (somewhat disagree). Open-text responses was analyzed using the conventional qualitative content analysis approach (Hseith & Shannon, 2005) as described in chapter 3. Consensus in round III and IV, included $\geq 70\%$ of initial experts who chose either a rank of 1 (strongly agree) or 5 (somewhat disagree). Areas with lack of consensus and levels of dispersion were noted for reporting in the study results. Descriptive statistics were used including % agreement, measures of central tendency (mean), level of dispersion (standard deviation) using IBM SPSS Statistics for Mac, version 27 (IBM Corp., Armonk, N.Y., USA).

Results

Delphi Round I (n = 18)

The distribution of initial experts' role in cancer care were as follows: exercise oncology (50.0%), survivorship care (55.6%), symptom science/management (38.9%), adolescent YA

cancer (33.3%). Three emergent overarching themes emerged from round I of the study: the effect of physical activity on symptom management in YA; integration of physical activity into YA survivorship care; clinical consideration of integrating physical activity into YA survivorship care. The results in this paper will specifically address integration of physical activity into YA survivorship care and clinical consideration of integrating physical activity into YA survivorship care. Codes were identified and then sorted into the following themes: village of experts, care delivery systems, guidance/guidelines (Table 2).

Delphi Round II (n =18)

Expert distribution

The distribution of initial experts' role in cancer care were as follows: exercise oncology (50.0%), survivorship care (55.6%), symptom science/management (38.9%), adolescent YA cancer (33.3%).

Analysis of open-text responses. Open text responses included insights on the use of family members, peer mentors, patients and physiotherapists as “village of experts” to provide physical activity referrals, assessments and interventions. It noted that while clinical professionals like nurses, advanced practice nurses, medical doctors, and physician assistants could refer and assess, ‘that may not be the best use of their time’ and therefore should not be relegated to them. It suggested that education endeavors about the use of physical activity in YA cancer survivors, could include exercise professionals, peer coaches and pharmacists. It was noted that while supportive oncology “should be part of supportive oncology”, it is “not regularly included”.

Village of experts

To adequately address the multitude of unmet need in YA survivorship, the initial experts articulated a village of experts were needed to properly implement physical activity in cancer care. The results reported here are areas of consensus from the initial experts on assessing,

prescribing/referring and implementing physical activity as a symptom management strategy in YA cancer survivorship (table 7)

Assessing Physical Activity. There was expert consensus on the following regarding who can assess physical activity patterns in YA cancer survivors: exercise physiologist (100.0%), occupational therapists (88.9%), physical therapists (100.0%), nurses (77.8%), advanced practice nurses (83.3%), medical doctors (77.8%), physician assistants (83.3%), specialty trained community based provider (83.3%). Areas lacking consensus included osteopaths (66.7%) and behavioralists (66.7%). An important caveat was articulated in an open text response “while they can be done by diverse disciplines, that doesn’t mean it’s the best use of their time and shouldn’t be delegated” (nurse scientist, cancer researcher).

Referrals for Physical Activity. There was expert consensus regarding who can conduct physical activity referrals in YA cancer survivors: exercise physiologist (72.2%), occupational therapists (88.8%), physical therapists (100.0%), nurses (83.3%), advanced practice nurses (88.9%), medical doctors (100.0%), physician assistants (94.4%), osteopaths (83.3%); Areas lacking consensus included specialty trained community-based provider (55.6%) and behaviorist (66.7%).

Physical Activity Interventions. There was expert consensus on the following regarding who can assess physical activity patterns in YA cancer survivors: exercise physiologist (100.0%), physical therapists (94.4%), specialty trained community-based provider (72.2%). Areas that lacked consensus include occupational therapist (66.7%), advanced practice nurses (55.6%), medical doctors (44.4%), physician assistants (55.6%), and osteopath (38.9%).

Care Delivery Systems

A collection of statements related to care delivery systems included the need for tailored programs, statements that related to delivery models. Statements in this category showed the greatest lack of consensus throughout the Delphi rounds (table 6b).

Tailored Programs. There was expert consensus that to 'restore balance' that resonates with a particular minoritized population, design input is needed from that minoritized population (94.4%).

Delivery Models: Telehealth. There was expert consensus that advantages of telehealth include: greater access to supportive cancer care in rural dwelling cancer survivors (77.8%); physical activity interventions in the comfort of your own environment (83.3%); removal of the need for another clinical setting visit (77.8%);

Guidance/Guidelines

A collection of statements related to expert opinions on points in the cancer care continuum where physical activity interventions and assessments should be included, and areas related to physical activity endorsement, communication and education.

Cancer Care Continuum. A collection of statements related to points in the cancer continuum where physical activity assessments should be included (table 6a). Results yielded the following expert consensus: assessments should be included in the prehabilitation phase (83.3%), active treatment phase (83.3%), immediate post-treatment phase (94.4%), in long-term survivorship (88.9%). Statements related to at what points in the cancer continuum physical activity interventions should be included yielded the following expert consensus: interventions should be included in the prehabilitation phase (72.2%), active treatment phase (72.2%), immediate post-treatment phase (94.4%), to maximize long-term adaptation, physical activity interventions in survivorship care should be the standard of care (83.3%).

Clinical Relevance and Endorsement; Communication. There was expert consensus on the following statements: there is a need for guidance/guidelines for the healthcare delivery team on the use of physical activity in YA survivorship care (77.8%).

Need for Education. There was expert consensus on the following statements: the education curricula of health care providers [medicine (100.0%); nursing (100.0%); social work

(71.8%); occupational therapy (83.3%); physical therapy (100.0%); specially trained community-based provider (66.7%)] should include information about the use of physical activity in cancer care.

Delphi Round III (n = 56)

Following analysis from Round II, the survey was modified. Round III consisted of a 107-statement survey for dissemination to initial experts and a larger sample of experts for consensus building.

Expert Distribution

The distribution of initial experts was as follows: exercise oncology (47.4%), survivorship care (71.9%), symptom science/management (24.6%), adolescent YA cancer (33.3%).

Village of Experts

Assessing Physical Activity. There was consensus on the following regarding who can assess physical activity patterns in YA cancer survivors: exercise physiologist (96.5%), occupational therapists (71.9%), physical therapists (94.7%).

Referrals for Physical Activity. There was consensus on the following regarding who can refer physical activity interventions in YA cancer survivors: exercise physiologist (82.5%), occupational therapists (82.5%), physical therapists (89.5%), nurses (80.7%), advanced practice nurses (86.0%), medical doctors (87.7%), physician assistants (82.5%).

Physical Activity Interventions. There was consensus on the following regarding who can provide physical activity interventions in YA cancer survivors: exercise physiologist (98.2%), occupational therapists (73.7%), physical therapists (94.7%).

Based on open responses from the experts in round II of this study the following statements were added and there was expert consensus on: culturally and environmentally tailored programs are facilitators to integration of physical activity integration in YA cancer care (70.2%); formation of

an advisory panels with YA stakeholders from minority groups and communities is essential for program design and implementation (70.2%).

There was expert consensus that advantages of telehealth include: greater access to supportive cancer care in rural dwelling cancer survivors (75.4%); physical activity interventions in the comfort of your own environment (73.7%); removal of the need for another clinical setting visit (70.2%).

Guidance/Guidelines

Cancer Care Continuum. Statements related to at what points in the cancer continuum physical activity assessments should be included yielded the following expert consensus: assessments should be included in the prehabilitation phase (82.5%), active treatment phase (73.7%), immediate post-treatment phase (84.2%) in long-term survivorship (86.9%). Statements related to at what points in the cancer continuum physical activity interventions should be included yielded the following expert consensus: interventions should be included in the prehabilitation phase (73.7%), immediate post-treatment phase (82.5%); to maximize long-term adaptation, physical activity interventions in survivorship care should be the standard of care (87.7%).

Clinical Relevance and Endorsement; Communication. There was expert consensus on the following statements: there is a need for guidance/guidelines for the healthcare delivery team on the use of physical activity in YA survivorship care (78.9%); the healthcare team of YA cancer survivors need to effectively communicate with community-based physical activity providers (71.9%).

Need for Education. There was expert consensus on the following statements: the education curricula of health care providers [medicine (84.2%); nursing (80.7%); occupational therapy (75.4%); physical therapy (86.0%)] should include information about the use of physical activity in cancer care.

Survey Modification

Preliminary Round III survey results were embedded in the Round IV survey to convey consensus from previous iteration to establish rigor as recommended in Delphi studies (Ogbeifun et al, 2016). Thirty-seven statements were removed due to lack of consensus (table 10a, b). Two additional questions were added to collect further data on the role in cancer and years in this role.

Delphi Round IV

Expert distribution

The demographics of the experts in the final consensus (round IV) is provided here. Roles in cancer care were exercise oncologists (20%; n = 9), survivorship care (60%; n = 27); symptom science/management (31.1%; n = 14) and AYA cancer specialist (33.3%; n = 15). In addition, they identified themselves as having diverse positionalities in cancer care were nurses/advanced practice nurses (n = 19), MD (n = 8), PT (n = 5), behavioralists (n = 4), community specialists (n = 2), epidemiologists (n = 2), PA (n = 1).

Village of experts

Assessing Physical Activity. There was consensus on the following statements regarding who can assess physical activity patterns in YA cancer survivors: exercise physiologist (95.6%), occupational therapists (76.1%), physical therapists (95.6%), specialty trained community-based provider (71.1%), osteopaths (75.6%).

Referrals for Physical Activity. There was consensus on the following statements regarding who can assess physical activity patterns in YA cancer survivors: exercise physiologist (84.4%), occupational therapists (80.0%), physical therapists (91.1%), nurses (84.4%), advanced practice nurses (88.9%), medical doctors (84.4%), physician assistants (80.0%), specialty trained community-based provider (75.6%).

Physical Activity Interventions. There was consensus on the following statements regarding who can assess physical activity patterns in YA cancer survivors: exercise physiologist (100.0%), occupational therapists (75.6%), physical therapists (97.8%).

Care Delivery Systems

Tailored Programs. There was expert consensus that culturally and environmentally tailored programs are facilitators to integration of physical activity integration in YA cancer care (82.2%); formation of an advisory panels with YA stakeholders from minority groups and communities is essential for program design and implementation (73.3%);

Delivery Models: Telehealth. There was expert consensus that advantages of telehealth include: greater access to supportive cancer care in rural dwelling cancer survivors (93.3%); physical activity interventions in the comfort of your own environment (86.7%); removal of the need for another clinical setting visit (88.9%); the ability to connect with fellow YA survivors (75.6%).

Guidance/Guidelines

There was expert consensus that there is a need for guidelines/guidance for the healthcare delivery team on the use of physical activity in YA cancer survivorship (91.1%).

Cancer Care Continuum. Statements around at what points in the cancer continuum physical activity assessments should be included yielded the following expert consensus: assessments should be included in the prehabilitation phase (84.4%), active treatment phase (73.3%), immediate post-treatment phase (80.0%), Interventions should be included in the prehabilitation phase (77.8%), active treatment phase (75.6%), immediate post-treatment phase (86.7%), and to maximize long-term adaptation, physical activity interventions in survivorship care should be the standard of care (86.7%).

Clinical Relevance and Endorsement; Communication. There was expert consensus that there is a need for guidance/guidelines for the healthcare delivery team on the use of physical

activity in YA survivorship care (91.1%); effective communication between healthcare provider and YA cancer survivors about physical activity should be the standard of care (91.1%).

Need for Education. There was expert consensus on the following statements: the education curricula of health care providers [medicine (97.8%); nursing (97.8%); social work (71.1%); occupational therapy (93.3%); physical therapy (95.6%)] should include information about the use of physical activity in cancer care.

Areas Lacking Consensus (refer to tables 10a,b)

Discussion

One of the aims of this study was to identify areas of expert consensus on assessing, prescribing and implementing physical activity as a symptom management strategy in YA cancer survivorship and to identify areas of expert consensus on clinical relevance and endorsement of physical activity as a symptom management strategy in YA cancer survivorship. Experts represented multiple roles and positionalities in cancer care with varied representation in each study rounds (table 1).

Experts in this study found consensus that physical activity in YA survivorship should be integrated in YA cancer care plans as part of supportive oncology (91.1%). Previous research has identified, and experts in this study agree, that physical activity is one of the most promising health behavior focus based on its impact on symptoms, physical health and psychosocial wellbeing & quality of life (Burke et al, 2017; Pugh et al., 2016; Rabin, 2011; Schmitz et al., 2019; Signorelli et al., 2018; Wurz & Brunet, 2016). However, in the literature, YA have high levels of physical inactivity are reported in YA survivors compared to non-cancer peers (Patterson et al., 2015; Rabin, 2011; Valle et al., 2021), highlighting the need for research into its use in YA cancer survivors as a health promoting and risk reduction intervention.

The Exercise is Medicine™ *Moving Through Cancer Initiative* seeks to incorporate exercise at all points in the cancer care continuum by encouraging healthcare providers to assess,

advise and refer (Schmitz et al., 2019). This study adds to the literature on where in the cancer continuum assessments, and interventions should be included specific to YA survivors. Experts found consensus that assessments should be included (73.3% to 84.4%) at all points on the cancer care continuum. Further, experts found consensus that interventions should be included (75.6% to 86.7%) at all points on the cancer care continuum. Previous research has called for the measurement of physical activity as the 5th vital sign, highlighting the need for assessing and initiating a discussion about the benefits of exercise as a medicine (Sallis, 2011) There are few contraindications with physical activity use and that physical activity dosages can be individualized (Loellgen, Zupet, Bachl & Debruyne, 2020). Experts in this study found consensus that the dose, duration, intensity and frequency of physical activity in YA survivors should be included in assessments (75.6%; n = 34) and prescribed interventions (88.9%; n = 40). Previous research and reviews of the benefits of physical activity in AYA survivors indicate that outcome measures often include physical performance outcomes, body composition, bone health, quality of life outcomes, symptom burden measures, cognitive function, and social health (Brunet et al., 2017; Burke et al., 2017; Munsie et al., 2019; Treanor et al., 2016; Wurz et al, 2016). Often, physical activity measurement is clustered with other health behaviors (Pugh et al., 2016), making it difficult to exclusively capture its effects. Experts in this study agreed that multiple outcome measures should be included in physical activity research to fully capture its effects (84.4%; n = 38).

Experts in this study showed strong consensus on the need for guidelines for the healthcare delivery team on the use of physical activity in YA survivorship care (91.1%; n = 41). Recommendations from the National Academies of Sciences, Engineering, and Medicine Cancer Control call for an increase in effective and affordable interventions for preventive, screening, and diagnostic cancer care that integrates social and behavior information to develop reliable evidence (National Academies of Sciences, Engineering, and Medicine, 2019). Moreover, there is

a call for interdisciplinary collaboration to provide high quality survivorship care that addresses optimal care for individuals living with cancer as a chronic illness (Jacobs & Shulman, 2018; Patterson et al, 2015; Silver et al., 2018). Supportive cancer care, a pillar in oncology nursing, promotes self-management (Young et al., 2020). Additionally, it restores and promotes function and activity (Schmitz et al., 2019). Physical activity interventions need to take into account personal barriers/facilitators, cultural and environmental preferences, individual motivations, and their trajectory on the cancer care continuum (Nass et al., 2015; Patterson et al., 2015; Rabin 2017). The limited research in YA cancer survivorship and physical activity consists of primarily White and English-speaking individuals (Bradford & Chan, 2017; Kopp et al, 2016; Pugh et al., 2016). Previous research has indicated that tailored programs that are culturally and environmentally adaptive are essential to facilitate integration, especially in communities that face disparities in cancer care access (Schwartz, Dirk de Heer, Bea, 2017). A recent open-ended response questionnaire study of AYA survivors (n= 575), noted 48% of the over 900 challenges listed were physical in nature, and > 24% were psychological (Fitch, Nicoll, Lockwood, Chan, & Grundy, 2020). The statistic of over 900 identified challenges by the AYA community reports the need for tailored interventions. The overarching theme the AYA survivors offered in the study was a need for tailored care that “fits me” (Fitch et al., 2020). The experts in this study showed strong consensus on the importance of culturally tailored physical activity interventions are facilitators to integration of physical activity integration in YA survivorship care (82.2%; n = 37).

YA cancer survivors face a multitude of care needs that change throughout their care journey. To create personalized physical activity interventions a village of experts is needed, as one expert opined in their qualitative interview for round I of this study (Table 9). National initiatives have been started to address the culmination of biological, psychosocial and economic impacts of cancer in YA that significantly impact their quality of life (Bleyer, 2007).

Previous research indicates a lack of clarity exists in who is best suited to assess, prescribe, intervene and advise on the use of physical activity (Schmitz et al., 2019; Schwarz et al., 2017). This study added to the literature by exploring attitudes and beliefs around the village of experts needed to provide physical activity assessments, referrals and interventions to YA survivors. Findings indicate expert consensus that physical activity assessments were best performed by exercise physiologist (95.6%), occupational therapists (76.1%), physical therapists (95.6%), specialty trained community-based provider (71.1%), osteopaths (75.6%). Referrals were best performed by exercise physiologist (84.4%), occupational therapists (80.0%), physical therapists (91.1%), nurses (84.4%), advanced practice nurses (88.9%), medical doctors (84.4%), physician assistants (80.0%), specialty trained community-based provider (75.6%). Interventions were best performed by exercise physiologist (100.0%), occupational therapists (75.6%), physical therapists (97.8%). The unanimous consensus of utilizing exercise physiologist in interventions warrants further exploration to facilitate this in clinical settings. Exercise physiologists are trained in integrative biology, with a subset certified in exercise oncology, yet their services are not reimbursable in most cancer care models. While occupational and physical therapy services are often covered by insurance cancer rehabilitation is not routinely reimbursable (Silver et al., 2018). Insurance reimbursement issues continue to inhibit access to support physical activity as part of supportive oncology (Ijsbrandt, et al., 2019).

YA cancer survivors experience unique biological needs and increased vulnerabilities to psychosocial health, at a developmental time of self-autonomy, building of life skills and adaptations to the world around them. Cancer care models that address physical and psychosocial needs and provide health promoting behaviors that improve biopsychosocial health and health-related quality of life in youth affected by cancer are a top priority in AYA survivorship (Docherty, et al., 2015; Feuz, 2014; Fitz et al., 2020; Signorelli et al., 2018; Zebrack 2009). Previous work has called for collaboration from governing agencies to address the need for

cancer care models to address the specific needs of childhood, adolescent and YA survivors and recommend research on lifestyle behaviors (Children's Oncology Group 2018; Nass et al., 2015; Pugh, Gravestock et al., 2016).

As we look at optimal delivery systems, there is a potential to expand research efforts that resonate with YA resulting in increased clinical trial participation. The research endeavors of the Children's Oncology Group (COG) work within the guiding framework of investigating effective cancer treatments, translational research on treatment efficacy while mitigating side effects, primary prevention, and research that improves quality of life (QOL) and survivorship (COG, nd). However, the focus is most often on addressing tobacco, and alcohol drug use, which is reported in < 25 % of YA survivors (Children's Oncology Group 2018). Previous research indicates the feasibility and acceptability of physical activity interventions along with psychological interventions have been established in the AYA populations, with positive effects reported both during and after treatment (Bradford et al., 2017; Munsie et al., 2019; Pugh, Gravestock et al., 2016; Wurz et al., 2016). Furthermore, over 75% of YA express a high priority for receiving information about physical activity use both during and after cancer treatment with > 85% articulating the capability of partaking in physical activity interventions (Belanger, et al., 2012; Gupta et al., 2013). Recommendations from the National Academies of Sciences, Engineering, and Medicine Cancer Control call for an increase in effective and affordable interventions for preventive, screening, and diagnostic cancer care that integrates social and behavior information to develop reliable evidence for practice (National Academies of Sciences, Engineering, and Medicine, 2019). In 2010, the Canadian Task Force released recommendations tailored to adolescents and YA to establish and support research that optimizes health and quality of life (Fernandez et al., 2011). Healthcare systems, however, continue to be designed on biomedical principles (Wade & Halligan, 2017) exposing inadequacies in current cancer care delivery systems that serve YA.

Insufficiencies of current cancer survivorship care models are well articulated in the literature, most notably by AYA survivors themselves (Dahlke et al., 2017; Docherty et al., 2015; Fitch et al., 2020; Feuz, 2014; Richter, Koehler, Friedrich, Hilgendorf, Mehnert & Weißflog, 2015). A vast amount of unmet needs and chronic disease vulnerabilities appear decades after treatment (Tai et al., 2012; Wang et al., 2021) highlighting the critical need for symptom management and health promotion in long-term survivorship care (Zebrack, Kent et al., 2014). YA exist in cancer care models that straddle pediatric and adult systems often leaving them with fragmented care (Fernandez et al., 2011; Patterson et al., 2015) contributing further to unmet needs and chronic disease vulnerabilities. Experts in this study, showed strong consensus that to maximize long term adaptations, physical activity interventions in survivorship care should be the standard of care for YA (86.7%). Survivorship care models are highly individualized, based on available resources in a given community or care system, limiting the ability of a ‘standard’ in survivorship programs (Halpern et al., 2015). Cancer care delivery systems that are tailored to younger cancer survivors are evolving but are limited and vary dramatically across the United States and internationally (Feuz 2014; Wurz et al., 2019). A recent international environmental scan determined that 46 physical activity programs tailored mostly to children <18 years but included some adolescent and YA existed in 10 countries (Wurz et al., 2019).

Developmentally, young adulthood is a time for adaptation, interaction and the building life skills (Scales et al., 2016) yet over 65% of YA with cancer have not met others with cancer (Gupta et al., 2013), fostering a sense of isolation. Experts in this study opined but did not reach consensus that interventions that engage other YA cancer survivors are a facilitator for physical activity integration in YA cancer care (66.7%). YA, including those from minorized populations need to be involved as stakeholder for survivorship program design and implementation. Expert in this study found that formation of an advisory panel with YA. Stakeholders from minority groups and communities is essential for program design and implementation (73.3%).

Previous research has provided concept mapping of care outcomes after intensive cancer care to understand the trajectory for a propensity of unmet needs in AYA survivorship (Dahlke et al., 2017). In addition, concept mapping has been used as a research strategy to understand physical activity determinants across the life span (Condello et al., 2016). This concept mapping illuminated the need for policy and program enhancements that extend into the community to provide tailored cancer care to support AYA psychosocial health (Dahlke et al. 2017).

Emerging care models that partner with community settings are being coordinated by clinical nurse specialists; these care models offer long-term support and risk reduction opportunities that are adaptive to the changing needs of the AYA cancer survivor exist (Marjerrison & Barr, 2018). Community-based physical activity interventions provide a care delivery model that affords YA an opportunity to connect and interact with fellow YA survivors. There was a lack of consensus in this study that interventions that engage other YA cancer survivors are a facilitator for physical activity integration in YA cancer care (66.7%). Experts in this study did find consensus on the role of specialty trained community-based providers of physical activity to cancer survivors (assessments 71.1%, referrals 75.6%). The majority of community-based physical activity programs for cancer survivors in the United States are provided by programs like LIVESTRONG at the YMCA, yet this program represents only 0.0004% of the cancer population (Faro et al., 2020). Experts in this consensus study noted that advantages of telehealth for physical activity interventions include greater access to supportive cancer care for rural dwelling cancer survivors (93.3%), care in the comfort of your own environment (86.7%), the ability to connect with fellow YA cancer survivors (75.6%), and the removal of another visit to a clinical setting (88.9%) . The experts in this study felt that telehealth offers untapped potential as a delivery intervention mode. In round I of the study, all of the initial experts expressed that the COVID-19 pandemic has removed many logistical and reimbursement barriers telehealth implementation in cancer survivorship (Table 9). Exercise oncologists and

physical therapists have rapidly adopted this practice in light of the pandemic, offering promising and radical shifts to both cancer survivorship care and research (Bland et al., 2020). Experts in this study found consensus that telehealth use could provide greater care access to rural dwelling cancer survivors (93.3%); however, there was less consensus on its advantages in addressing inequities in cancer care in minoritized populations (55.6%). Recent research investigated disparities in telehealth use of cancer survivors during the COVID-19 pandemic and found that while telehealth use increased from 1% in 2019 to 76% in 2020, disparities in use were observed with less utilization noted in Black, Hispanic and Asian persons (Smith & Bhardwaj, 2020). In addition, telehealth (mhealth, Tech based interventions) has been suggested by others as the most promising delivery system for YA survivors and its potential efficacy with increase access was surmised (Kopp et al 201; Pugh et a., 2016; Signorelli et al., 2018). Telehealth and digital interventions that promote shared decision-making and reduce health disparities are a focus area for their current research (NIH, nd). Previous research shows the feasibility and cost effectiveness of online platforms via social media (Pallier et al., 2020; Keaver et al., 2019). More research is needed to understanding determinants that impact disparities in access and what efforts are needed to remedy such.

Education is a powerful predictor of health outcomes (White, 2012). Experts in this study found consensus that effective communication between healthcare providers and YA survivors about physical activity should be the standard of care (91.1%). Healthcare providers need to possess the necessary education to communicate the benefits of physical activity in survivorship care. Previous research has indicated that 80% of oncology providers lack knowledge of the benefits of physical activity and less than 9% of nurses discuss physical activity with cancer survivors (Schmitz et al., 2019; Schwartz et al., 2021). A worldwide collaboration has recently been formed to specifically address long-term effects of cancer on children and YA (Kremer et al., 2013). There is a need for health literacy in AYA survivorship that extends beyond the

survivor to the clinical team and society (Dahlke et al., 2017); failure to address such, creates the additional risk of provider complacency on AYA survivors (Close et al., 2019). To address this critical need, further educational opportunities for the healthcare and community teams that support YA survivorship are needed. Experts in this study showed consensus on the need for information on the use of physical activity in cancer survivorship care to be provided in education curricula of the following health care providers: medicine (97.8%); nursing (97.8%); social work (71.1%); occupational therapy (93.3%); physical therapy (95.6%).

There is abundant literature noting limited trials for YA and limited participation in existing trials (Bradford et al., 2017; Bleyer, 2007; Bleyer et al., 2017; Bradford et al., 2017; Cabilan et al., 2017; Close et al., 2019; Coccia et al., 2018; Fernandez et al., 2011; Patterson et al., 2015; Smith et al., 2016). YA have the lowest participation in clinical trials compared to other ages of survivors (Sandford et al., 2017). Late and long-term effects are often not captured or managed in current YA cancer survivorship models. Previous research has called for cancer care models that provide psychosocial support tailored to the AYA population (Osborne et al., 2019). There is a call for international multi-site collaborations that extend into the community and corresponding public relation support to insure access to physical activity (Nass et al., 2015; Osborne et al., 2019; Schwarz et al., 2017; Wurz et al., 2019). Survivorship care models and clinical trials opportunities may need to be restructured to meet the needs of YA. A new paradigm of long-term survivorship could include risk reduction and clinical trials opportunities alongside health promoting and wellness-based interventions. Community settings offer an opportunity for advocacy for unmet needs and wellness-based interventions, community-based participatory research and resource sharing (Dahlke et al., 2017). Incorporating wellness-based care into a community setting, offers an opportunity for continued engagement with YA cancer survivors to manage this chronic disease.

There is significant economic impact of YA survivors facing chronic disease. Reach from the HOPE study indicates the annual healthcare cost of YA survivors is \$920 > than non-cancer peers (Guy et al., 2014). To put that in context we must consider the economic impact of 700,000 YA survivors for upwards of 50 years of survivorship. Supportive risk reduction care such as cancer rehabilitation centers and community cancer physical activity programs (e.g. LIVESTRONG at the YMCA), are free for participants (Schmitz et al., 2019) usually for a limited time through grants and private funding. Previous findings indicate that cancer rehabilitation is not reimbursed by insurance like other chronic diseases and policy changes are critical to the advancement of survivorship care (Silver et al., 2018). Financial concerns are often cited as a limitation for the creation of AYA specific survivorship programs yet the economic potential from chronic disease other late effects offers potential to offset such financial concerns (Marjerrison & Barr, 2018).

Study Considerations

The strengths of this study includes the use of a graphic interview guide that fostered inductive insights from the initial experts, which broadened the scope to include organizational systems that influence clinical consideration to the use of physical activity in YA survivorship care. The diverse geographical settings of this expert panel that ranged from rural and indigenous settings to large metropolitan settings both in the United States and in other countries, added broad insights on cancer care delivery systems. A more comprehensive, detailed summary of strengths and limitations of this research was outlined in a prior manuscript (Moraitis et al., 2021). Strengths include the use of a multidisciplinary panel of experts from diverse healthcare positionalities, high retention rates of experts in the multiple rounds, and the use of qualitative interviews to create a measurement tool for gathering consensus. Limitations of the work include the use of language to create statements for the measurement tool which allows for interpretation

by the expert, potential bias in the identification of experts and the limited interpretability of the results by using a Delphi method.

Conclusion

This study set out to identify areas of expert consensus on clinical relevance and endorsement of physical activity as a symptom management strategy in YA cancer survivorship. Our results indicate clinical experts in exercise oncology, survivorship care, symptom science and AYA cancer care believe physical activity is an effective strategy for managing the unique symptoms that YA face. YA affected by cancer have reported they need more information and support related to the adoption and maintenance of health promoting behaviors, including physical activity, at all points of their cancer care continuum. Clinical considerations include role allocation for the assessment, prescription, referral, and implementation of physical activity strategies. In addition, considerations include the co-creation of wellness-based survivorship programs that provide physical activity interventions that are flexible and tailored to the individual, align with both their stage in the cancer care continuum and available community resources; The findings in this study support that YA affected by cancer need to be key stakeholders in this design process, identifying needs, individualized motivations, cultural preferences, and personalized facilitators and barriers. Moreover, in order to address care access issues that this YA cohort face, the utilization of telehealth use might be helpful to those in a position to access it. The findings indicate a need for further education to address health literacy issues of the clinical/community team regarding the use of physical activity in YA survivorship. Implementations that embed risk reduction, health literacy and clinical trial opportunities within a wellness-based setting may hold great potential as a platform for engagement that promotes independence and autonomy to YA affected by cancer.

The possibilities of telehealth, especially in this time of the COVID-19 pandemic, where previous administrative and reimbursement barriers to such have rapidly been removed, is an area that the experts in this study felt needed to be harnessed. Most peer support groups are now being offered to YA survivors via a secure online platform (Paul, 2020).

As we consider the propensity for unmet needs in YA cancer survivor population, we must also consider that <2% of YA are involved in clinical trials. This finding reflects a lack of clinical trials specific to YA, as well as low participation rates. Co-design clinical trial endeavors that address the priorities and most pressing challenges articulated by YA holds potential for further engagement of YA. Furthermore, clinical trials should extend into the communities in which they exist and honor their life stage of emerging independence by recognizing them as experts in this space. Early identification and phenotyping of survivors most at risk for inactivity has been proposed to mitigate late/long term effects following research from large population studies (Ness et al., 2009). Yet a decade later standard implementation of physical activity remains elusive, further highlighting the need for guidelines. These guidelines however need to exist in cancer care systems that allow them to be actionable at mitigating symptom burden.

Current care delivery systems are not set up to optimize physical health and psychological wellbeing by incorporating personal preferences, self-autonomy and independence. Current structural systems limit effective wellness-based survivorship care tailored to YA. A paradigm shift is needed. Previous research has called for cancer care models that provide psychosocial support tailored to the AYA population (Osborne et al., 2019). There is a call for international multi-site collaborations that extend into the community and corresponding public relation support to insure access to physical activity (Nass et al., 2015; Osborne et al, 2019; Schwarz et al., 2017; Wurz et al., 2019). Discussion of physical activity use in clinical survivorship practice is lacking despite the consensus of clinical experts regarding on its utility (Schmitz et al., 2019; Schwartz et al, 2017). This disparity represents a missed opportunity on

multiple levels. As we explore supportive oncology policies and care delivery models, a clearer understanding of what model of support is most beneficial to address the propensity of late/long-term needs in YA affected by cancer.

There is a call for international multi-site collaborations that extend into the community and corresponding public relation support to insure access to physical activity (Nass et al., 2015; Osborne et al, 2019; Schwarz et al., 2017; Wurz et al., 2019). This expert study adds to the literature by calling for physical activity to be supported in survivorship care, including extending into non-traditional clinical settings through the use of telehealth and community partnership. This highlights the potential of physical activity implementation as a wellness-oriented survivorship care component that promotes self-autonomy. In addition, it amplifies previous research and policy statements to improve and standardize YA cancer care delivery models by moving beyond acute rehabilitative settings partnering with the community, harnessing telehealth and incorporating YA in research and care delivery design. In order to provide support to YA in health promoting behaviors, like physical activity in long-term survivorship, sustainable funding structures need to be in place. These symptom management and risk reduction interventions offer the opportunity to provide self-managed care to this group of cancer survivors who have been forced to navigate cancer treatment and survivorship at a unique and especially vulnerable life stage.

Implications/Innovation

Nurses make up 80% of the healthcare system; they are symptom scientists who address the holistic and human factors of an individual in both clinical and community settings. The National Institute for Nursing Research, a division of the National Institute of Health is dedicated to the improvement of health with emphasis on self-management, symptom management, personalized health strategies in the promotion of wellness (National Institute of Health, nd).

Interdisciplinary clinical and research collaborations that engage nurses are vital to elevate the role of physical activity as a self-management wellness-based strategy in YA survivorship care.

The results from this expert consensus study add to the existing literature the need for flexible care models that provide clinical support and expertise that match the unique needs of the YA survivor and are adaptive to their survivorship place on the cancer care continuum. This study added to the literature the need for guidance and guidelines on physical activity use in all along the cancer care continuum. It also articulated what clinical and community providers may best be suited to provide physical activity assessments, referrals and interventions to the YA impacted by cancer. Exercise physiologists provided a leading role in assessments, referrals and interventions; however, their clinical services are not individual reimbursed by insurance in current systems. Study results articulated the need for education of the healthcare and community on the role of physical activity as a symptom management technique to address some of the unmet needs and improve the biopsychosocial health of YA cancer survivors.

Structural inadequacies of cancer care delivery systems were explored by the experts with consensus that successful delivery systems needed to incorporate physical activity use in survivorship that is tailored to the unique needs and developmental stage of young adulthood. Physical activity assessments, interventions and support should be provided at all stages of the cancer care continuum. Multi-site collaborations that incorporate the community are needed to insure access to physical activity in survivorship care. In order to minimize the ‘*consequences of the cure*’ (Kopp et al., 2016) in YA: researchers, clinicians, communities, YA survivors and their support persons need to co-create customized, actionable physical activity interventions that function in care delivery systems that are tailored to their unique developmental stage and address their unique needs.

CHAPTER FIVE

Conclusions

The overarching goal of this dissertation was to understand how best to optimize wellbeing, and overall quality of life in YA affected by cancer by physical activity as a symptom management strategy. To do so, we addressed the following aims: to address the critical need to understand the state of the science in how physical activity, a modifiable precision health strategy, contributes to biopsychosocial health, as a symptom management strategy and how it can be feasibly and sustainably incorporated into survivorship care. The study design included international experts with diverse backgrounds in cancer care and expertise in one or more of the following: exercise oncology, symptom science, survivorship care and adolescent YA cancer care. The Revised Symptom Management Theory (Dodd et al., 2001) guided this research. This model incorporates the constructs of an individual's symptom experience (perception of symptoms, evaluation of symptoms, response to symptoms), symptom outcomes (e.g. functional status, quality of life, morbidity/mortality, self-care, cost) and symptom management strategies (e.g. who delivers care, when); further incorporated in this model is the person, their environment, and health and illness status. This model guided all aspects of this dissertation research as we explored the use of physical activity as a symptom management strategy and clinical considerations relevant to implementation of physical activity into YA survivorship care.

Governing and regulatory bodies have defined survivorship care as care that focuses on the overall health, wellbeing, and quality of life of individuals affected by cancer (American Society of Clinical Oncology (ASCO), nd; NCCN, 2020). A critical component of quality survivorship care is the dynamic health promotion interventions to mitigate late/long term impacts of cancer treatments and reduce risk of cancer recurrence that is tailored to the unique and evolving needs of those affected by cancer (Howell, 2018; NCCN survivorship, 2020). The

Survivorship Care Compendium extends further to create a repository of resources to facilitate best practices in implementation and further improve survivorship care (ASCO, nd).

There is a critical need to understand the state of the science of physical activity use in YA survivorship care. Therefore a scoping review of existing research to date, incorporating published clinical guidelines, protocol statements and critical work in the field, was performed to identify: 1) relationships between physical activity and cancer-related symptoms and quality of life among YA cancer survivors; 2) the measurement of physical activity in research involving YA cancer survivors and; 3) guidelines for activity among YA survivors. Results from our scoping review highlighted that the rise in YA cancer survival rates have been met with increasing morbidity (Barr, 2011; Bleyer, 2007; Bleyer et al., 2017; Keegan et al., 2016; Roberts et al., 2017). Late and long-lasting symptoms, termed the ‘consequences of the cure’ (Kopp et al., 2016) cause distress, profound disruptions to normal psychosocial functioning and developmental milestones, elevated health risks and longevity of symptom burden (Barnett, et al., 2016; Bradford & Chen 2017; Zebrack, 2009; Smith et al., 2017; Smith et al., 2019). These impacts result in a staggering 50% of YA cancer survivors report unmet needs (Wong et al., 2017) and are less likely to access supportive and preventative services (Coccia et al., 2018; Jones et al., 2020). Further compounding these findings is a lack of clinical trials tailored to YA affected by cancer that addresses their multitude of unmet needs and biopsychosocial health ((Bleyer, 2007; Docherty, et al., 2015; Fernandez et al., 2011; Keegan et al., 2016). Close et al., 2019; Dahlke et al., 2017; Feuz 2019; Fitch et al., 2020).

In adults, strong evidence exists on the efficacy of physical activity, a modifiable precision health behavior, as a symptom management strategy for anxiety, depressive symptoms, fatigue, and perceived physical function (Schmitz et al., 2019). In addition, it positively impacts the ability to physically manage many effects of cancer and its treatment, the psychological ability to have positive self-perceptions, social aspects of interactions, and creating

purpose/meaning within a cancer diagnosis (Burke et al., 2017). Physical activity in YA cancer survivors has shown improvements in physical function, yet there is a paucity of research. In adults, physical activity has shown positive impacts on emotional stress, quality of life, fatigue levels, prognostic biomarkers, comorbidities and mortality (Schmitz et al., 2019; Schwartz et al., 2017; Wolin et al., 2018). Clinical experts have recognized the urgent need to develop and deliver survivorship care tailored to the specific needs and unique life circumstances of YA, an understudied group of cancer survivors (Rabin, Horowitz, & Marcus, 2013). To fully optimize biopsychosocial health and overall QOL in YA survivorship, guidelines on physical activity integration are needed. A lack of clinical guidelines and limited research specific to YA cancer survivors, hinders its use as a symptom management strategy. Research is needed that addresses development and clinical implementation of physical activity guidelines.

Findings

Key areas of consensus emerged around three overarching themes: 1) the effect of physical activity on symptom management in YA 2) integration of physical activity into YA survivorship care, 3) clinical consideration of integrating physical activity into YA survivorship care. Physical activity in YA survivorship provides biopsychosocial health benefits and can be self-managed, offering them critical independence at this life stage. More specifically, results from this expert consensus study indicate: physical activity should be integrated into YA cancer care as part of supportive oncology to mitigate symptoms of fatigue, cardio-metabolic health, muscle mass loss, altered body composition, and anxiety/depression; physical activity use improves functional capacity and wellbeing; at all points on the care continuum. YA should be asked if they would like guidance on physical activity use; to maximize survivorship adaptations physical activity interventions should be tailored to account for personal facilitators, barriers and motivations. Experts expressed that physical activity interventions should be tailored to consider individuals facilitators, barriers, preferences, motivation, and stage in the cancer continuum.

Guidance and guidelines are needed to acclimatize physical activity intervention to YA at all points on the cancer care continuum.

In addition, the results from this expert consensus study indicate the need for flexible care models that provide clinical support and expertise that match the unique needs of the YA survivor and are adaptive to their survivorship place on the cancer care continuum. Experts articulated how clinical and community providers may best provide physical activity assessments, referrals and interventions to the YA impacted by cancer. Experts found consensus that exercise physiologists should provide a leading role in assessments, referrals and interventions; however, their clinical services are not individual reimbursed by insurance in current systems. Cancer care delivery systems were explored by the experts with consensus that successful delivery systems needed to be tailored to YA and their unique needs and developmental stage. In particular, they needed to allow for the YA to be asked if they would physical activity support at all stages of the cancer care continuum. The possibilities of telehealth, especially in this time of the COVID-19 pandemic, where previous barriers to such have rapidly been removed, was an area that the experts felt needed to be harnessed. The need for guidance and guidelines all along the cancer care continuum was articulated by the experts as was the need for education of the healthcare and community on the role of physical activity as a symptom management technique to address some of the unmet needs and improve the biopsychosocial health of YA cancer survivors.

Areas for Further Exploration

Areas related to cognitive health, pain, nausea/vomiting, chemotherapy induced peripheral neuropathy, mitigation of cellular inflammation, low bone mineral mass, symptoms of fragility, a sense of normalcy, symptoms of distress lacked the threshold for agreement in this study and warrant further investigation. There was expert consensus in this study that YA survivorship care should support health promoting behaviors, such as physical activity, as a symptom management and risk reduction intervention. There is a chasm from other chronic

diseases, where rehabilitation services and long-term health promotion and lifestyle intervention care are provided (e.g. cardiac, pulmonary, diabetes rehabilitation). The least consensus in the study related to who could assess, refer and provide physical activity intervention, therefore this area should be further explored. Further research is needed to explore the care delivery systems that are needed to provide sustainably funded wellness-based interventions and risk reduction opportunities for YA affected by cancer that honors their self-autonomy critical of this life stage.

Implications for Knowledge/Theory Development

The results of this study identified areas of consensus/lack thereof to warrant physical implementation in YA survivorship care to guide future physical activity symptom management research and clinical endeavors. It became clear early on in the qualitative interview of international experts from diverse backgrounds in cancer care that there were multilevel factors to consider in this research. Further research endeavors need to consider individual symptoms, as well as structural symptoms. The structural components of care delivery systems that provide health-promotion activities (e.g. physical activity) in cancer survivorship are not routinely discussed, provided or reimbursed. Creating guidelines and guidance, person-centered interventions need to be supported in structural systems that promote long-term wellness-based care that is tailored to YA cancer survivors. Experts in this study agreed that education related to the use of physical activity in YA cancer care needs to be incorporated in the education curriculum of healthcare professionals and community liaisons to foster health literacy around this wellness-based autonomous intervention. To fully explore physical activity as a symptom management method to mitigate insults to biopsychosocial health, a theoretical model that spans from the micro molecular level to the macro, environmental, and the policy level is needed. The Public Health Action Model for Cancer Survivorship (Moore et al., 2015) incorporate the long-term objectives, we see in *Healthy People 2020-2030* research and expands to include cancer survivors. This model incorporates diverse stakeholders in the cancer survivorship community

who hold diverse positionalities: survivors, advocates, caregivers, public health providers, health care providers and policymakers to identify develop and implement interventions that benefit cancer survivors. If we focus again on YA affected by cancer, and consider their life stage, we see both a challenge and an opportunity, a symptom, both individual and structural, waiting for mitigation. Transdisciplinary models of care go beyond the limitations of one's own discipline to allow full equity to community-level expertise (Heinzmann, Simonson, & Kenyon, 2019). These cancer care delivery models may be better suited for YA survivorship as a shared learning space where YA survivors, clinical providers, researchers, and community-experts can coalesce to provide wellness-based interventions, risk reduction measures, and increase clinical trial enrollment (Osborne et al., 2019).

Practice Implications

Results of this study support the conclusion that physical activity should be recommended as a management strategy to address some of the unmet physical and mental health needs of YA cancer survivors. Such health promoting and risk reduction opportunities provide autonomy and self-management critical to the life stage of young adulthood.

Policy and Care Delivery System Implications

This study established multidisciplinary consensus that physical activity should be integrated into YA cancer care as part of supportive oncology. Previous research and statements by the American College of Sports Medicine has called for the integration of physical activity as part of supportive oncology in adult cancer survivors (Wolin et al., 2012). In addition, experts established consensus on who could provide physical activity assessments, referrals and interventions. The measurement tool, created to establish expert consensus, provides a prototype for assessing consensus within care delivery systems considering physical activity integration into survivorship care.

Directions for Future Research

More research is needed to address YA cancer survivors unique needs which are often unmet in existing care delivery systems. Integrating health promotion strategies like physical activity as a core concept in survivorship care and co-designing risk reduction and clinical trial opportunities from a wellness, community-based survivorship offers a paradigm shift to current cancer care survivorship programs. Future interventions, and research endeavors need to be tailored to them, allowing their voice needs to be heard and impact policy that dictates the care delivery system that will best mitigate the consequences of their cure.

APPENDIX A TABLES

Table 1: Distribution of experts' role in cancer care

Role in Cancer Care	Round I & Round II % (n)	Round III % (n)	Round IV % (n)
Exercise Oncologist	50 (9)	47.4 (27)	20.0 (9)
Survivorship Care	55.6 (10)	71.9 (41)	60 (27)
Symptom Scientist/Management	38.9 (7)	24.6 (14)	31.1 (14)
Adolescent Young Adult Specialist	33.3 (6)	33.3 (19)	33.3 (15)
Countries Represented	USA (<i>n</i> =13), Canada(<i>n</i> =2), Australia(<i>n</i> =3)	USA, Canada, Australia, Brazil, Turkey, United Kingdom, England, Belgium, Ireland, Italy	
Round III & IV ‘Other’ Additional Roles*		21.4% (<i>n</i> =12)	
Years in cancer care role (mean ± SD)		17.4 ± 10.4	
*(additional roles) AYA mental health specialist; behavior change researcher, breast cancer, specialist care models and implementation of care models, medical nutrition therapy/dietetics, physiotherapy rehabilitation (cancer specific), psychologist, supportive care, cancer survivor, AYA survivor			

Table 2: Emergent Themes from Content Analysis of Qualitative Data

Themes	Categories	Codes
The effect of physical activity on symptom management in young adults	Symptom outcomes	Fatigue, pain, cardio-metabolic, loss of muscle mass, anxiety/depression
	Symptom Status	Function, wellbeing, function, symptoms of distress, unmet needs
Person-centered young adult survivorship care	Self-advocacy	Motivation, self-efficacy, control,
	Individualization of physical activity	Tailored, flexible assessments, prescriptions, interventions, culture, minorities
Clinical considerations of integrating physical activity into young adult survivorship care	Village of experts	Exercise oncologist, nurse, MD, nutritionist, physical therapy, (assess refer, intervention, education)
	Guidance/guidelines	Need for policy, education curricula etc., measurement
	Cancer Care Continuum	4 stages of cancer care (prehab, active treatment, immediate post-treatment, long-term); multiple touch points, changes over time
	Care Delivery Systems	Flexible care models, rehabilitation, community setting, telehealth, cost, geographical disparities, minorities

Table 3a: Consensus: Symptom management

Ranking: 1: strongly agree, 2: somewhat agree, 3: neither agree/disagree, 4: somewhat disagree, 5: strongly disagree)

Theme	Statement	Round II Strongly Agree (n=18)		Round III Strongly Agree (n=57)		Round IV Strongly Agree (n=45)	
		% agreement (n)	Mean \pm SD	% agreement (n)	Mean \pm SD	% agreement (n)	Mean \pm SD
Symptom management	Physical activity should be integrated into the young adult cancer care plan as part of supportive oncology. (Q2.2)	72.3 (13)	1.67 \pm 1.328	94.7 (54)	1.05 \pm .225	*91.1 (41)	1.09 \pm .288
	Which of the following indications are reasons you would recommend physical activity in young adult cancer survivors? (Q3.2- 3.5)						
	Fatigue	88.9 (16)	1.11 \pm .323	89.5 (51)	1.11 \pm .310	*91.1 (41)	1.09 \pm .288
	Cardio-metabolic health	94.4 (17)	1.06 \pm .236	91.2 (52)	1.09 \pm .285	*88.9 (40)	1.13 \pm .405
	Loss of muscle mass	100 (18)	1.00 \pm .000	86.0 (49)	1.14 \pm .350	*86.7 (39)	1.13 \pm .344
	Excess body fat	88.9 (16)	1.11 \pm .323	75.4 (43)	1.37 \pm .771	*77.8 (35)	1.33 \pm .739
	Low bone mineral mass	72.2 (13)	1.39 \pm .698	70.2 (40)	1.39 \pm .675	60.0 (27)	1.51 \pm .787
	Anxiety/depression	83.3 (15)	1.17 \pm .383	91.2 (52)	1.11 \pm .363	*77.8 (35)	1.27 \pm .539
	Cognitive health	72.2 (13)	1.33 \pm .594	80.7 (46)	1.32 \pm .760	55.6 (25)	1.60 \pm .863
	Functional capacity is improved by the use of physical activity in young adult (survivorship care) cancer care. (Q3.8)	72.2 (13)	1.28 \pm .461	82.5 (47)	1.18 \pm .490	*86.7 (39)	1.18 \pm .490
	Well-being is improved by the use of physical activity in young adult (survivorship care) cancer care (Q3.9)	72.2 (13)	1.28 \pm .461	78.9 (45)	1.21 \pm .411	*86.7 (39)	1.18 \pm .490

Table 3b: Consensus: Person-centered care

Ranking: 1: strongly agree, 2: somewhat agree, 3: neither agree/disagree, 4: somewhat disagree, 5: strongly disagree.

Theme	Statement	Round II Strongly Agree (n=18)		Round III Strongly Agree (n=57)		Round IV Strongly Agree (n=45)	
		% agreement (n)	Mean \pm SD	% agreement (n)	Mean \pm SD	% agreement (n)	Mean \pm SD
Person-centered cancer care	Young adults with cancer should be asked if they would like guidance on physical activity in the prehabilitation phase. (Q4.3)	83.3 (15)	1.17 \pm .38	80.7 (46)	1.37 \pm 1.01	*88.9 (40)	1.13 \pm .40
	Young adults with cancer should be asked if they would like guidance on physical activity in the active treatment phase (Q5.3)	88.9 (16)	1.11 \pm .32	86.0 (49)	1.25 \pm .78	*86.7 (39)	1.16 \pm .42
	Young adults with cancer should be asked if they would like guidance on physical activity in the immediate post-treatment phase. (Q6.3)	94.4 (17)	1.06 \pm .23	87.7 (50)	1.26 \pm .89	*91.1 (41)	1.09 \pm .28
	Young adults with cancer should be asked if they would like guidance on physical activity in the long-term survivorship (Q7.2)	88.9 (16)	1.11 \pm .32	93.0 (53)	1.19 \pm .81	*97.9 (44)	1.02 \pm .14
	In the immediate post-treatment phase, person-centered physical activity interventions facilitate adaptation to cancer survivorship among young adults. (Q6.2)	83.3 (15)	1.50 \pm 1.33	75.4 (43)	1.35 \pm .89	*73.3 (33)	1.36 \pm .64
	To maximize long-term adaptation, physical activity interventions in survivorship care should be the standard of care (Q7.3)	83.3 (15)	1.22 \pm .54	87.7 (50)	1.14 \pm .39	*86.7 (39)	1.13 \pm .34
	Motivational assessments are beneficial to provide tailored physical activity interventions to young adult cancer survivors. (Q8.2)	77.8 (14)	1.28 \pm .57	64.9 (37)	1.47 \pm .92	*71.1 (32)	1.33 \pm .56
	Personal barriers to physical activity need to be identified in young adult cancer survivors. (Q8.5)	94.4 (17)	1.06 \pm .23	93.0 (53)	1.14 \pm .69	*95.6 (43)	1.04 \pm .20
	Personal facilitators to physical activity need to be identified in young adult cancer survivors. (Q8.6)	94.4 (17)	1.06 \pm .23	86.0 (49)	1.21 \pm .72	*91.1 (41)	1.09 \pm .28
	Tailored physical activity assessments facilitate the integration of physical activity in young adult survivorship care. (Q3.11)	72.2 (13)	1.39 \pm .69	75.4 (43)	1.37 \pm .91	*71.1 (32)	1.33 \pm .56
	Tailored physical activity facilitate the integration of physical activity in young adult survivorship care. (Q3.12)	77.8 (14)	1.33 \pm .68	77.2 (44)	1.35 \pm .91	*80.0 (36)	1.20 \pm .40

Table 4: Interrater reliability Scores : Symptom management & person-centered care

Theme	Statement	Consensus Results (% agreement) (n)			Kappa Value (κ) (95% CI)	
		Round II Strongly Agree (n=18)	Round III Strongly Agree (n=57)	Round IV Strongly Agree (n=45)	Round III/IV Initial Experts (n= 18)	Round III/IV All Experts (n= 45)
Symptom management	Physical activity should be integrated into the young adult cancer care plan as part of supportive oncology.	72.3 (13)	94.7 (54)	91.1 (41)	.440 (-.155, 1.035)	.377(-.155, .910)
	Which of the following indications are reasons you would recommend physical activity in young adult cancer survivors?					
	Fatigue	88.9 (16)	89.5 (51)	91.1 (41)	.632 (-.015, 1.278)	.450(-.003,.903)
	Cardio-metabolic health	94.4 (17)	91.2 (52)	88.9 (40)	.774 (.529, 1.019)	.493(.162,.825)
	Loss of muscle mass	100 (18)	86.0 (49)	86.7 (39)	.000 (.000, .000)	.066 (-.270,.402)
	Excess body fat	88.9 (16)	75.4 (43)	77.8 (35)	.449 (.136, .763)	.353 (.058,.648)
	Low bone mineral mass	72.2 (13)	70.2 (40)	60.0 (27)	.588 (.293, .884)	.614 (.417,.811)
	Anxiety/depression	83.3 (15)	91.2 (52)	77.8 (35)	.759 (.316, 1.201)	.488 (.235,.742)
	Cognitive health	72.2 (13)	80.7 (46)	55.6 (25)	.349 (-.100, .797)	.263 .033, .522
	Functional capacity is improved by the use of physical activity in young adult (survivorship care) cancer care.	72.2 (13)	82.5 (47)	86.7 (39)	.000 (.000, .000)	.000 (.000,.000)
	Well-being is improved by the use of physical activity in young adult (survivorship care) cancer care	72.2 (13)	78.9 (45)	86.7 (39)	.825 (.591, 1.059)	.421 (.151,.691)

Person-centered physical activity young adult cancer care	Young adults with cancer should be asked if they would like guidance on physical activity in the prehabilitation phase.	83.3 (15)	80.7 (46)	88.9 (40)	.160 (-.084, .404)	-.103(-.178, .028)
	Young adults with cancer should be asked if they would like guidance on physical activity in the active treatment phase.	88.9 (16)	86.0 (49)	86.7 (39)	.000 (.000, .000)	-.103(-.171, -.035)
	Young adults with cancer should be asked if they would like guidance on physical activity in the immediate post-treatment phase.	94.4 (17)	87.7 (50)	91.1 (41)	.417 (.032, .802)	.068(-.144, .279)
	Young adults with cancer should be asked if they would like guidance on physical activity in the long-term survivorship.	88.9 (16)	93.0 (53)	97.9 (44)	.000 (.000, .000)	-.015(-.044, .013)
	In the immediate post-treatment phase, person-centered physical activity interventions facilitate adaptation to cancer survivorship among young adults.	83.3 (15)	75.4 (43)	73.3 (33)	.417 (.032, .802)	.305(.105, .500)
	To maximize long-term adaptation, physical activity interventions in survivorship care should be the standard of care	83.3 (15)	87.7 (50)	86.7 (39)	.432 (-.100, .965)	.436 (.045, .826)
	Motivational assessments are beneficial to provide tailored physical activity interventions to young adult cancer survivors.	77.8 (14)	64.9 (37)	71.1 (32)	.604 (.282, .925)	.464 (.265, .664)
	Personal barriers to physical activity need to be identified in young adult cancer survivors.	94.4 (17)	93.0 (53)	95.6 (43)	.192 (-.258, .643)	.233 (-.240, .705)
	Personal facilitators to physical activity need to be identified in young adult cancer survivors.	94.4 (17)	86.0 (49)	91.1 (41)	.140 (-.239, .520)	.090 (-.187, .367)
	Tailored physical activity assessments are a major facilitator to integration in young adult survivorship care.	72.2 (13)	75.4 (43)	71.1 (32)	.488 (.132, .844)	.460 (.267, .654)
	Tailored physical activity interventions are a major facilitator to integration in young adult survivorship care.	77.8 (14)	77.2 (44)	80.0 (36)	.611 (.275, .947)	.454 (.223, .685)

Table 5: Statements that lack agreement: symptom management

Ranking: 1: strongly agree, 2: somewhat agree, 3: neither agree/disagree, 4: somewhat disagree, 5: strongly disagree

Statements	Round II (n=18)		Round III Strongly Agree (n=57)		Round IV Strongly Agree (n=45)	
	% agree (n)	% agree (n)	% agree (n)	% agree (n)	% agree (n)	% agree (n)
	strongly agree	Strongly & somewhat agree	strongly agree	Strongly & somewhat agree	strongly agree	Strongly & somewhat agree
Which of the following indications are reasons you would recommend physical activity in young adult cancer survivors? (Q3.2- 3.5)						
Pain (Q3.2_2)	22.2 (4)	72.2 (12)	31.6 (18)	84.2 (48)	n/a	n/a
Mitigate cellular inflammation (Q3.3_2)	50.0 (9)	72.2 (13)	47.4 (27)	85.2 (47)	n/a	n/a
Low bone mineral mass (Q3.4_3)	72.2 (13)	88.9 (16)	70.2 (40)	93.0 (53)	60.0 (27)	93.3 (42)
Chemotherapy-induced peripheral neuropathy	44.4 (8)	72.2 (13)	35.1 (20)	75.4 (43)	n/a	n/a
Cognitive health (Q3.5_3)	72.2 (13)	94.4 (17)	80.7 (46)	93.0 (53)	55.6 (25)	91.1 (41)
Incorporating physical activity into the cancer care plan for young adults contributes to a sense of normalcy. (Q3.7)	66.7 (12)	88.9 (16)	64.9 (37)	93.0 (53)	n/a	n/a
Symptoms of distress are improved by incorporating physical activity into young adult cancer care. (Q3.10)	66.7 (12)	94.4 (17)	63.2 (36)	87.7 (50)	n/a	n/a
Frailty from bone mineral and muscle mass loss, that often results from cancer treatment, is lessened by physical activity in young adult cancer survivors (Q3.14)	61.1 (11)	100 (18)	52.6 (30)	87.7 (50)	n/a	n/a

Table 6a: Consensus: Cancer care continuum

Ranking: 1: strongly agree, 2: somewhat agree, 3: neither agree/disagree, 4: somewhat disagree, 5: strongly disagree

		Round II Strongly Agree (n= 18)		Round III Strongly Agree (n=57)		Round IV Strongly Agree (n=45)	
Theme	Statement	% agreement (n)	Mean \pm SD	% agreement (n)	Mean \pm SD	% agreement (n)	Mean \pm SD
Measurement	Multiple Outcome Measurements should be included in physical activity research to fully capture its effects. (Q3.15)	77.8 (14)	1.22 \pm .42	82.5 (47)	1.25 \pm .60	*84.4 (38)	1.16 \pm .31
	The nature, dose, duration, intensity and frequency of physical activity in young adult cancer survivors should be included in assessments. Q3.16)	66.7 (12)	1.61 \pm 1.42	77.2 (44)	1.28 \pm .55	*75.6 (34)	1.36 \pm .71
	The nature, dose, duration, intensity and frequency of physical activity in young adult cancer survivors should be included in prescribed interventions. (Q3.17)	83.3 (15)	1.17 \pm .38	73.7 (42)	1.28 \pm .49	*88.9 (40)	1.16 \pm .47
Cancer Care Continuum	In the prehabilitation phase, baseline physical activity assessments should be included. (Q4.10)	83.3 (15)	1.28 \pm .67	82.5 (47)	1.33 \pm .98	*84.4 (38)	1.18 \pm .44
	In the active treatment phase, physical activity assessments should be included. (Q5.1)	83.3 (15)	1.28 \pm .66	73.7 (42)	1.40 \pm .90	*73.3 (33)	1.33 \pm .60
	In the immediate post-treatment phase, physical activity assessments should be included. (Q6.1)	94.4 (17)	1.11 \pm .47	84.2 (48)	1.26 \pm .81	*80.0 (36)	1.22 \pm .47
	In long-term survivorship care of young adults, physical activity assessments should be included. (Q7.1)	88.9 (16)	1.11 \pm .32	86.0 (49)	1.14 \pm .35	*82.2 (37)	1.18 \pm .38
	Physical activity interventions should be included in the prehabilitation phase. (Q4.4)	72.2 (13)	1.44 \pm .78	73.7 (42)	1.42 \pm .96	*77.8 (35)	1.33 \pm .67
	Physical activity interventions should be included in the active treatment phase. (Q5.4)	72.2 (13)	1.44 \pm .78	66.7 (38)	1.44 \pm .73	*75.6 (34)	1.29 \pm .54
	Physical activity interventions should be included in the immediate post-treatment phase. (Q6.4)	94.4 (17)	1.17 \pm .70	82.5 (47)	1.21 \pm .49	*86.7 (39)	1.18 \pm .54

Table 6b: Consensus: Guidance, care delivery systems
(1: strongly agree, 2: somewhat agree, 3: neither agree/disagree, 4: somewhat disagree, 5: strongly disagree)

		Round II Strongly Agree (n= 18)		Round III Strongly Agree (n=57)		Round IV Strongly Agree (n=45)	
Theme	Statement	% agreement (n)	Mean \pm SD	% agreement (n)	Mean \pm SD	% agreement (n)	Mean \pm SD
Care Delivery Systems	Interventions that engage other young adult cancer survivors are a facilitator for physical activity integration in young adult cancer care. (Q9.5)	50.0 (9)	1.67 \pm .76	68.4 (39)	1.51 \pm 1.02	66.7 (30)	1.40 \pm .61
	Physical activity interventions provided in the rehabilitation model adequately address long-term health. (Q9.6)	22.4 (4)	2.62 \pm 1.53	36.8 (21)	2.61 \pm 1.97	44.4 (20)	2.02 \pm 1.17
	Telehealth can be advantageous in addressing inequities in cancer care among minoritized populations. (Q10.5)	50.0 (9)	1.67 \pm .84	57.9 (33)	1.82 \pm 1.41	55.6 (25)	1.56 \pm .69
	Advantages of telehealth physical activity interventions include: (Q10.7 1-4)						
	Greater access to supportive cancer care in rural dwelling cancer survivors	77.8 (14)	1.28 \pm .57	75.4 (43)	1.25 \pm .47	93.3 (42)	1.00 \pm .00
	Comfort of your own environment	83.3 (15)	1.22 \pm .54	73.7 (42)	1.27 \pm .48	86.7 (39)	1.00 \pm .00
	Ability to connect with fellow young adult survivors	61.1 (11)	1.67 \pm .97	56.1 (32)	1.61 \pm .84	75.6 (34)	1.00 \pm .00
	Remove need for another visit to clinical setting	77.8 (14)	1.39 \pm .85	70.2 (40)	1.38 \pm .67	88.9 (40)	1.00 \pm .00
	Culturally and environmentally tailored programs are facilitators to integration of physical activity integration in young adult cancer care. (Q126)	n/a	n/a	70.2 (40)	1.46 \pm 1.02	82.2 (37)	1.22 \pm .51
Guidelines	Formation of an advisory panel with young adult stakeholders from minority groups and communities is essential for program design and implementation. (Q131)	n/a	n/a	70.2 (40)	1.48 \pm 1.04	73.3 (33)	1.40 \pm .80
	Effective communication between healthcare providers and young adult cancer survivors about physical activity should be the standard of care. **(8.7)	44.4(38.9)	4.67 \pm 1.13	87.7 (50)	1.12 \pm .33	91.1 (41)	1.11 \pm .38

	There is a need for guidelines/guidance for the health care delivery team on the use of physical activity in young adult cancer survivorship. (Q11.0)	77.8 (14)	1.22 ± .42	78.9 (45)	1.32 ± .93	91.1 (41)	1.09 ± .28
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**Q8.7 statement reworded based on RII results (original item: 'there is adequate communication about physical activity between healthcare providers and young adult cancer survivors' and strongly disagree / somewhat disagree answers shown) *= final areas of $\geq 70\%$ agreement

Table 7: Consensus: ‘village of experts’ (assessment, referrals and interventions)

	Statement	Round II (<i>n</i> = 18)	Round III (<i>n</i> = 570)	Round IV (<i>n</i> = 45)
Assessments	Physical activity assessments can be conducted by (click all that apply):	% agreement (<i>n</i>)	% agreement (<i>n</i>)	% agreement (<i>n</i>)
	Exercise physiologists	100 (18)	95.5 (55)	95.6 (43)
	Occupational therapists	88.9 (16)	71.9 (41)	76.1 (32)
	Physical therapists	100.0 (18)	94.9 (54)	95.6 (43)
	Nurses	77.8 (14)	61.4 (35)	57.8 (26)
	Advanced practice nurses	83.3 (15)	59.6 (34)	55.6 (25)
	Medical doctor	77.8 (14)	59.6 (34)	44.4 (20)
	Physician assistant	83.3 (15)	61.4 (35)	48.9 (22)
	Specialty trained community-based provider	83.3 (15)	59.6 (34)	71.1 (32)
	Osteopath	66.7 (12)	42.1 (24)	75.6 (34)
	Behaviorist	66.7 (12)	35.1 (20)	n/a
Referrals	Physical activity referrals can be conducted by (click all that apply):			
	Exercise physiologists	72.2 (13)	82.5 (47)	84.4 (38)
	Occupational therapists	88.8 (16)	82.5 (47)	80.0 (36)
	Physical therapists	100.0 (18)	89.5 (51)	91.1 (41)
	Nurses	83.3 (15)	80.7 (46)	84.4 (38)
	Advanced practice nurses	88.9 (16)	86.0 (49)	88.9 (40)
	Medical doctor	100.0 (18)	87.7 (50)	84.4 (38)
	Physician assistant	94.4 (17)	82.5 (47)	80.0 (36)
	Specialty trained community-based provider	55.6 (10)	59.6 (34)	75.6 (34)
	Osteopath	83.3 (15)	68.4 (39)	n/a
	Behaviorist	66.7 (12)	59.6 (34)	n/a

Interventions	Physical activity interventions can be conducted by (click all that apply):			
	Exercise physiologists	100.0 (18)	98.2 (56)	100.0 (45)
	Occupational therapists	66.7 (12)	73.7 (42)	75.6 (34)
	Physical therapists	94.4 (17)	94.7 (54)	97.8 (44)
	Nurses	44.4 (8)	42.1 (24)	n/a
	Advanced practice nurses	55.6 (10)	50.9 (29)	n/a
	Medical doctor	44.4 (8)	47.4 (27)	n/a
	Physician assistant	55.6 (10)	45.6 (26)	n/a
	Specialty trained community-based provider	72.2 (13)	61.4 (35)	n/a
	Osteopath	38.9 (7)	38.6 (22)	n/a
	Behaviorist	44.4 (8)	36.8 (21)	n/a

Table 8a: Interrater reliability scores: Cancer care continuum

		Consensus Results (% agreement) (n)			Kappa Value (κ) (95% CI)	
Theme	Statement	Round II Strongly Agree (n= 18)	Round III Strongly Agree (n=57)	Round IV Strongly Agree (n=45)	Round III/IV Initial Experts (n=18)	Round III/IV All Experts (n= 45)
Measurement	Multiple Outcome Measurements should be included in physical activity research to fully capture its effects.	77.8 (14)	82.5 (47)	84.4 (38)	.611 (.275, .947)	.290 (-.025, .605)
	The nature, dose, duration, intensity and frequency of physical activity in young adult cancer survivors should be included in assessments.	66.7 (12)	77.2 (44)	75.6 (34)	.375 (-.034, .784)	.232 (-.052, .516)
	The nature, dose, duration, intensity and frequency of physical activity in young adult cancer survivors should be included in prescribed interventions.	83.3 (15)	73.7 (42)	88.9 (40)	.611 (.275, .947)	.427 (.167, .687)
Cancer Care Continuum	In the prehabilitation phase, baseline physical activity assessments should be included.	83.3 (15)	82.5 (47)	84.4 (38)	.233 (-.001, .467)	.284 (.042, .527)
	In the active treatment phase, physical activity assessments should be included.	83.3 (15)	73.7 (42)	73.3 (33)	.386 (.092, .680)	.414 (.208, .621)
	In the immediate post-treatment phase, physical activity assessments should be included.	94.4 (17)	84.2 (48)	80.0 (36)	.255 (.142, .368)	.343 (.081, .605)
	In long-term survivorship care of young adults, physical activity assessments should be included.	88.9 (16)	86.0 (49)	82.2 (37)	.588 (.107, 1.070)	.241 (-.121, .604)
	Physical activity interventions should be included in the prehabilitation phase.	72.2 (13)	73.7 (42)	77.8 (35)	.604 (.138, 1.069)	.455 (.237, .674)
	Physical activity interventions should be included in the active treatment phase.	72.2 (13)	66.7 (38)	75.6 (34)	.708 (.364, 1.053)	.604 (.382, .826)
	Physical activity interventions should be included in the immediate post-treatment phase	94.4 (17)	82.5 (47)	86.7 (39)	.323 (-.276, .932)	.370 (-.070, .810)
	Effective communication between healthcare providers and young adult cancer survivors about physical activity should be the standard of care. *	44.4(38.9)	87.7 (50)	91.1 (41)	.488 (.132, .844)	.463 (.101, .825)

Table 8b: Interrater reliability scores: Care delivery systems, guidance

Theme	Statement	Consensus Results (% agreement) (n)			Kappa Value (κ) (95% CI)	
		Round II Strongly Agree (n= 18)	Round III Strongly Agree (n=57)	Round IV Strongly Agree (n=45)	Round III/IV Initial Experts (n= 18)	Round III/IV All Experts (n= 45)
Care Delivery Systems	Interventions that engage other young adult cancer survivors are a facilitator for physical activity integration in young adult cancer care.	50.0 (9)	68.4 (39)	66.7 (30)	.576 (.271, .881)	.413
	Physical activity interventions provided in the rehabilitation model adequately address long-term health	22.4 (4)	36.8 (21)	44.4 (20)	.197 (-.222, .616)	.262
	Telehealth can be advantageous in addressing inequities in cancer care among minoritized populations.	50.0 (9)	57.9 (33)	55.6 (25)	.588 (.249, .928)	.378
	Advantages of telehealth physical activity interventions include:					
	Greater access to supportive cancer care in rural dwelling cancer survivors	77.8 (14)	75.4 (43)	93.3 (42)	.000 (.000, .000)	.000 (.000, .000)
	Comfort of your own environment	83.3 (15)	73.7 (42)	86.7 (39)	.000 (.000, .000)	.000 (.000, .000)
	Ability to connect with fellow young adult survivors	61.1 (11)	56.1 (32)	75.6 (34)	.000 (.000, .000)	.000 (.000, .000)
	Remove need for another visit to clinical setting	77.8 (14)	70.2 (40)	88.9 (40)	.000 (.000, .000)	.000 (.000, .000)
Guidance/Guidelines	Culturally and environmentally tailored programs are facilitators to integration of physical activity integration in young adult cancer care.	n/a	70.2 (40)	82.2 (37)	.323 (-.016, .661)	.230
	Formation of an advisory panel with young adult stakeholders from minority groups and communities is essential for program design and implementation.	n/a	70.2 (40)	73.3 (33)	.632 (.442, .821)	.426
	There is a need for guidelines/guidance for the health care delivery team on the use of physical activity in young adult cancer survivorship.	77.8 (14)	78.9 (45)	91.1 (41)	.440 (-.155, 1.035)	.362

Table 9: Sampling of results of conventional qualitative content analysis (*codes are not exclusive to one category or theme)

Codes	Quotation
Supportive oncology	<i>“Really that should be part of the conversation at diagnosis- when your starting to tell them about what their treatment plan includes and saying this a supportive aspect that will help you get through this...and likely be stronger”</i> (Initial expert 16, Oncology Nurse Scientist).
Fatigue	<i>“You know it can help with fatigue. It can, you know there's good reasons to suggest that we should be encouraging activity. But that's not what happens in the practice. I'm trying to change that I'm trying to get our symptom management guidelines changed because our advice our current advice that we give families, you know... is if you've got fatigue, take frequent rests. And we know that's wrong”</i> (Initial expert 09, Oncology Nurse, MPH, Epidemiologist)
Body Composition	<i>“When I think about physical activity, I think of it as a method to prevent some of that loss of function or loss of muscle mass. Both prevent and then also to treat “(Pediatric Researcher, Cancer Biologist). “...get them to be more active, they'll change their body composition, lose fat mass, gain muscle mass, gain bone mineral, they'll be healthier, they'll be less likely to be frail and so less likely to have the burden of morbidity that comes with that. (Initial expert 15, AYA Oncologist, Oncology Researcher).</i>
Anxiety/Depression	<i>“It's definitely clear that any amount of non-sedentary time is best in terms of preventing recurrence. But also optimizing health... quality of life. And specifically, mental health outcomes- so minimizing depression, anxiety”</i> (Initial expert_13, Cancer Researcher, Occupational Therapist).
	<i>“So how do we counsel them about, you know, safe activities to engage in that's going to really help them with their fatigue and help them with, you know, any mental health, you know concerns that they may have anxiety, depressive symptoms, and so forth”</i> (Initial expert 08, Oncology Nurse Scientist).
	<i>“cognitive function...the short answer is I don't believe it's well managed I don't believe it's well assessed. And so, I think that the issue in cancer care right now is that we are using objective measures that may have little generalizable to actual functional cognition”</i> (Initial expert 10, Oncology Nurse Scientist).
Functional Capacity	<i>“from an endpoint perspective, really, the things that we should be doing is trying to deliver interventions that impact how patients feel, function, and survive. And I would argue, those are really the only three things that matter. People want to live long. They want to live well, and they want to live independently (Initial expert 03, Exercise Oncologist, Cancer Epidemiologist).</i>
Wellbeing	<i>“symptom burden, psychological well-being and function- I think those is kind of the core pillars of supportive care”</i> (Initial expert 04, Cancer Rehabilitation Specialist, Physician Scientist)
	<i>We look at yoga as well as I guess more traditional exercise. And the key outcomes that I'm most interested in are things like psychosocial well-being, quality of life, physical capacity...”</i> (Initial expert 17, Exercise Oncology, Cancer Exercise Psychology)
Control/Self-Advocacy	<i>“You know they lose this kind of sense of independence and autonomy...this is some way of you taking control back on your life You can choose to do exercise...this is giving you some kind of control back and that tends to help”</i> (Initial expert 12)
Motivation	<i>“...it is all about a survivor's individual motivation, at the time they decide to engage, or not engage in a behavior...if there is a motivational state that facilitates behavior, it is more likely to happen. (Initial expert 05_Biobehavioralist, Exercise Physiologist, Cancer Researcher)</i>

Self-Esteem	<i>"I think is body image. I think that's negatively impacted during cancer and its treatment and kind of neglected but it has a pretty big impact on how people feel about themselves...in terms of like self-esteem or feeling about themselves. And we actually know from like the general population that self-esteem is such a key predictor and so many really important physical and psychological outcomes"</i> (Initial expert 17, Exercise Oncology, Cancer Exercise Psychology)
Barriers	<i>"... personal (barriers)...what was their treatment? What are their side effects? Do they have people around them supporting them? Do they have the money or the transportation to get to programs in their community?"</i> (Initial expert_17, Exercise Oncology, Cancer Exercise Psychology).
Facilitators	<i>I do emphasize the utility of using exercise and physical activity to help manage symptoms and stress management...Exercise maybe ...a central aspect of this person's identity and resuming that was quite difficult and impaired. So, it impacted sort of their sense of sort of fulfillment, their ability to regulate their emotions, their ability to manage their stressors, and they can easily pinpoint because they were identifying exercises as being an outlet. So, there's a desire, but a lack of knowledge about how to resume. So, it's, it's harder for them to reenter physical activity [or exercise. We know that ... is so important to manage all the physical symptoms and ailments that they feel, and in addition to managing the emotion and the stressors. (Initial expert 01 AYA Cancer Behaviorist, Cancer Researcher)</i>
Assessments	<i>"If you're going to assess something, and then something comes up it's a problem, then you have to do something about it."</i> (Initial expert 10, Oncology Nurse Scientist)
Call for more research	<i>"we've asked a whole range of questions around cancer late-effects, quality of life, self-efficacy in managing symptoms, efficacy in managing health, and then we tracked people's activities...I suppose a starting place for us to just see... how do those things relate to each other and what are the associations"</i> (Initial expert 09, Oncology Nurse, MPH, Epidemiologist)
Guidance/Guidelines	<i>"Support for the population hasn't caught up with our great technology to save their lives".</i> (Initial expert 16_ Cancer Epidemiologist, Physical Therapist).

Table 10a: Delphi Round II survey modifications

<i>Statement removed</i>
Q3.2_3: Which of the following are reasons you would recommend physical activity to young adult cancer survivors: nausea/vomiting. (11% strongly agree)
Q10.9: Cancer care delivery systems, like the 'Spoke & Hub' care delivery design foster the integration of physical activity throughout the cancer care continuum. (27.7% strongly agree)
Q10.10: Cancer care delivery systems, like the 'Spoke & Hub' care delivery design provide the flexibility needed for tailored, person-driven interventions in young adult cancer survivors. (16.7% strongly agree)
12.3: What are your insights on how to make meaningful change in providing physical activity interventions for young adult cancer survivors from minoritized groups/communities.
Q12.4: Is there anything that you additional would like included in this survey prior to sending out Round 3 to a larger group of experts?
Q12.5: What is the nature of the population you primarily care/conduct research with?
<i>Statements added</i>
Q123: Assessment of an individual's motivation can facilitate successful physical activity interventions.
Q124. (consent, demographic questions)
Q126: Culturally and environmentally tailored programs are facilitators to integration of physical activity integration in young adult cancer care.
Q127: Integrated knowledge translation projects are required wherein we speak with black indigenous people of color (BIPOC) and actively and meaningfully engage them in the process to develop sensitive and appropriate recruitment, interventions
Q128: Integrated knowledge translation projects are required wherein we speak with and actively engage them in the process to develop sensitive and appropriate intervention strategies
Q129: Design and integration of clinical guidelines/guidance for physical activity in young adult survivorship care should include community health workers.
Q130: Design of physical activity research in young adult survivorship care should include community health workers
Q131: Formation of advisory panel with young adult stakeholders from minority groups and communities is essential for program design and implementation.
Q132: The use of peer coaches within a tailored program is a facilitator to physical activity integration in young adult survivorship.

Table 10b: Delphi Round III survey modifications

<i>Statements removed</i>
Q3.1 Symptoms of distress are improved by incorporating physical activity into young adult cancer care.
Q3.2 Which of the following indications are reasons you would recommend physical activity to young adult cancer survivors: Pain Mitigate inflammatory processes Chemotherapy-induced peripheral neuropathy
Q3.7 Incorporating physical activity into the cancer care plan for young adults contributes to a sense of normalcy
Q3.13 Early interventions to reduce inactivity are essential to mitigate late and long-term effects in young adult cancer survivors.
Q3.14 Frailty from bone mineral and muscle mass loss, that often results from cancer treatment, is lessened by physical activity in young adult cancer survivors
Q4.2 In the prehabilitation phase, person-centered physical activity interventions facilitate adaptation to cancer survivorship, among young adults.
Q5.2 In the active treatment phase, person-centered physical activity interventions facilitate adaptation to cancer survivorship, among young adults.
Q8.3 Patient reported physical activity measurements should be shared by the young adult cancer survivor with the health care team.
Q8.4 Objective physical activity measurements (e.g. accelerometers) should be shared with the health care team of the young adult cancer survivors.
Q9.2 Physical activity assessments can be conducted by (click all that apply): Osteopaths Behaviorists
Q9.3 Physical activity referrals can be conducted by (click all that apply): Behaviorists Specialty Trained Community Settings
Q 9.4 Physical activity interventions can be conducted by (click all that apply): Osteopaths Nurses Advanced Care Practitioners (NP) Medical Doctor Physician Assistant Specialty Trained Community Providers Behaviorists
Q9.7 A general lack of knowledge on the use of physical activity in young adult cancer survivors is a significant barrier to initiating physical activity in young adult survivorship care.

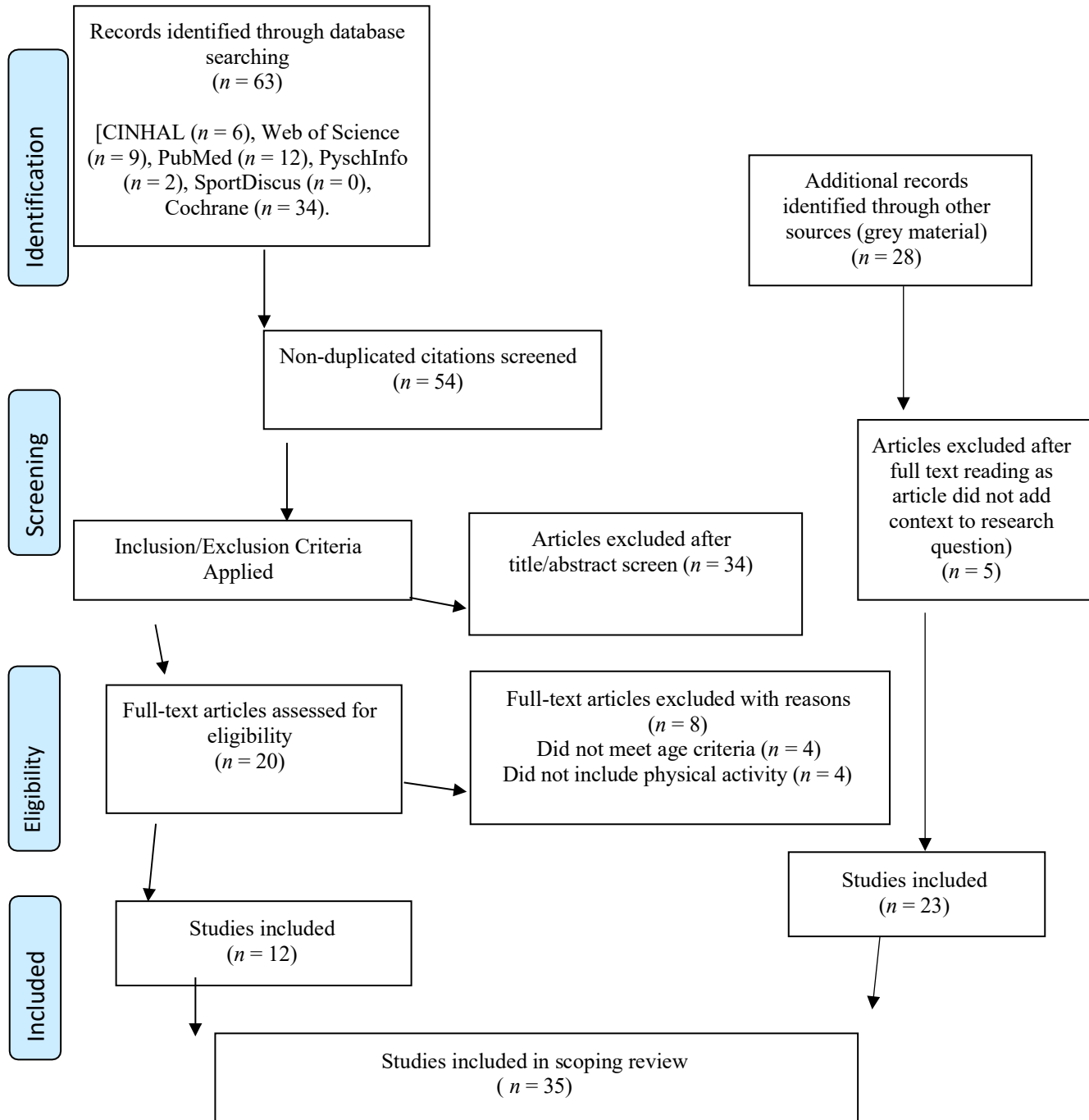
Q10.3 The healthcare team of young adult cancer survivors need to effectively communicate with community-based physical activity providers
Q10.4 Physical activity interventions via telehealth should be provided to young adult cancer survivors.
Q10.6 In order to address access issues, telehealth is a viable option, as long as internet access and technology is provided to that community.
Q10.7_3 Advantages of telehealth physical activity interventions include: Ability to connect with fellow young adult survivors
Q11.3 There is a lack of reimbursement by insurance companies for appropriate supportive care or interventions specifically supporting physical activity interventions during young adult cancer survivorship.
Q11.4 Guidelines/guidance on the use of physical activity in young adult cancer survivorship should include 'opt out' (situations where physical activity is contraindicated) vs. opt in (waiting for approval from the healthcare team).
Q11.5_6 The educational curricula of healthcare providers should include information about the use of physical activity in cancer care: Community Health Workers
Q123 Assessment of an individual's motivation can facilitate successful physical activity interventions.
Q127 Integrated knowledge translation projects are required wherein we speak with black indigenous people of color (BIPOC) and actively and meaningfully engage them in the process to develop sensitive and appropriate recruitment, interventions
Q128 Integrated knowledge translation projects are required wherein we speak with and actively engage them in the process to develop sensitive and appropriate intervention strategies
Q129 Design and integration of clinical guidelines/guidance for physical activity in young adult survivorship care should include community health workers.
Q130 Design of physical activity research in young adult survivorship care should include community health workers
Q132: The use of peer coaches within a tailored program is a facilitator to physical activity integration in young adult survivorship.

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APPENDIX B FIGURES

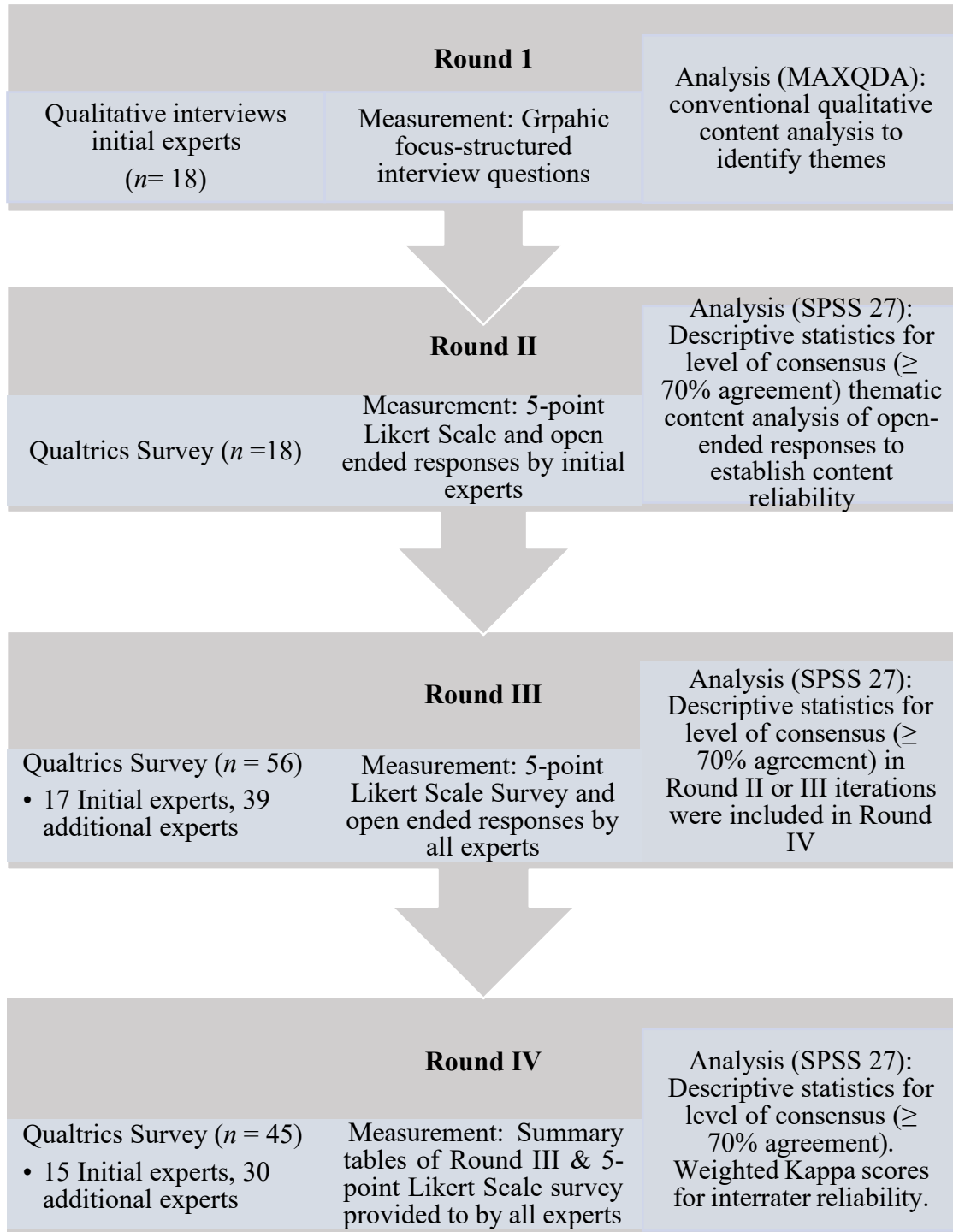
Figure 1: Scoping Review PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analysis)

Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). *Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement*. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097



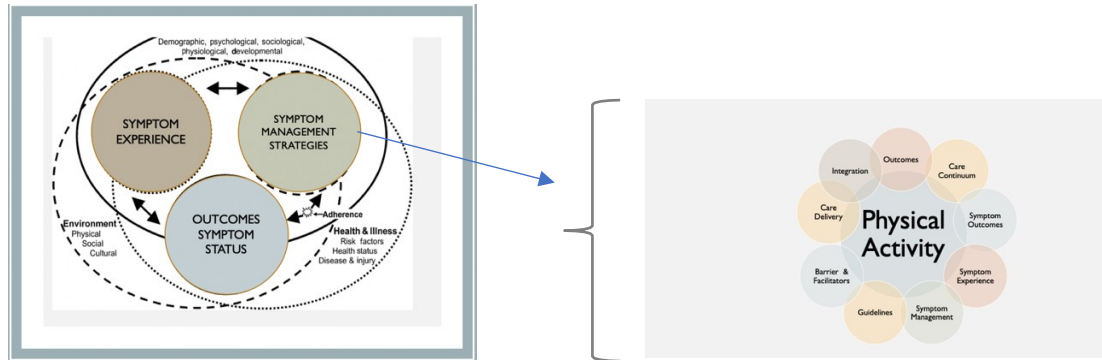
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Figure 2: Four Round Modified Delphi Process



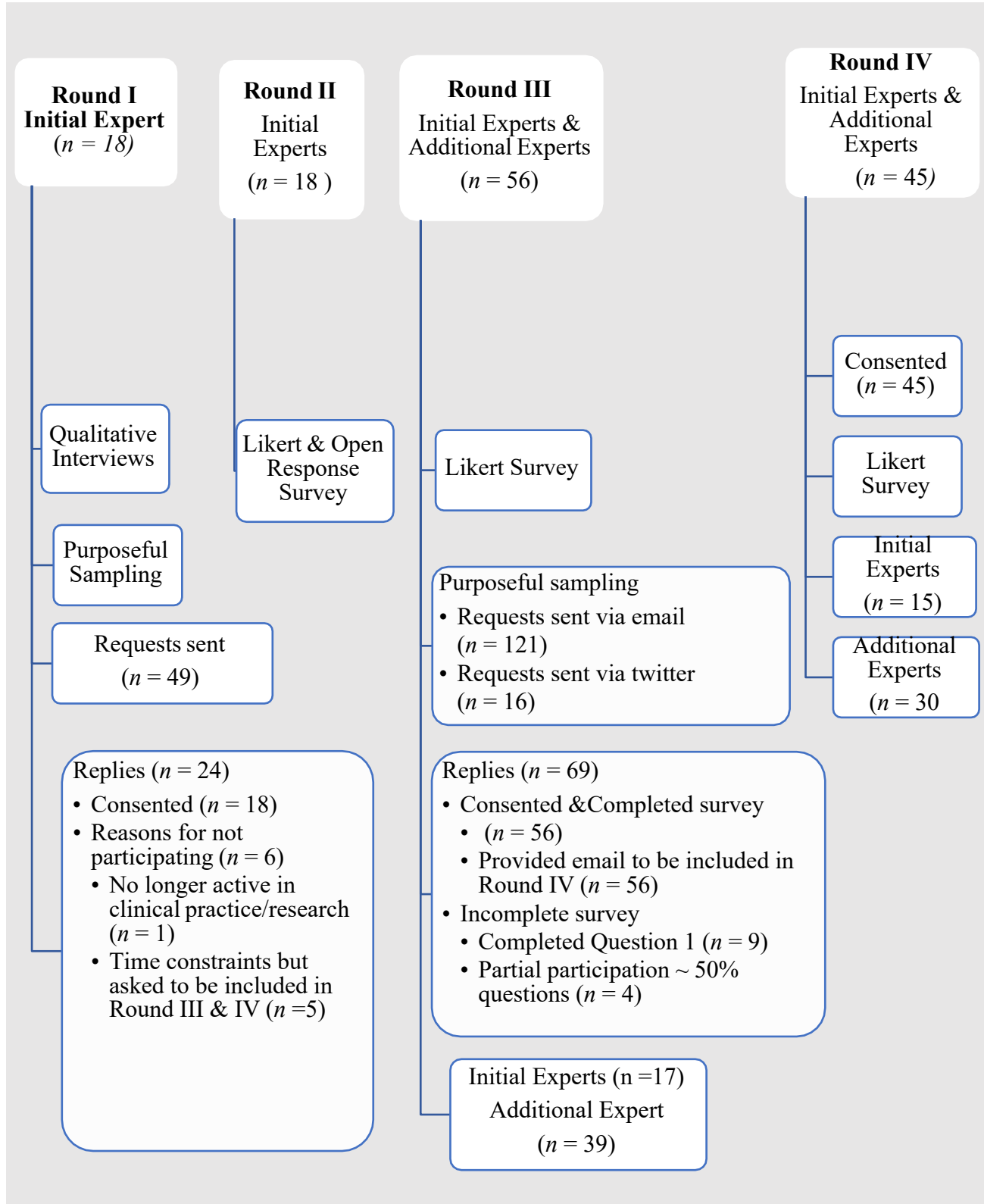
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Figure 3: Graphic Focus Interview Guide: Adapted from the Revised Symptom Management Theory (Dodd et al., 2001; Larson et al., 1999; UCSF 1994)



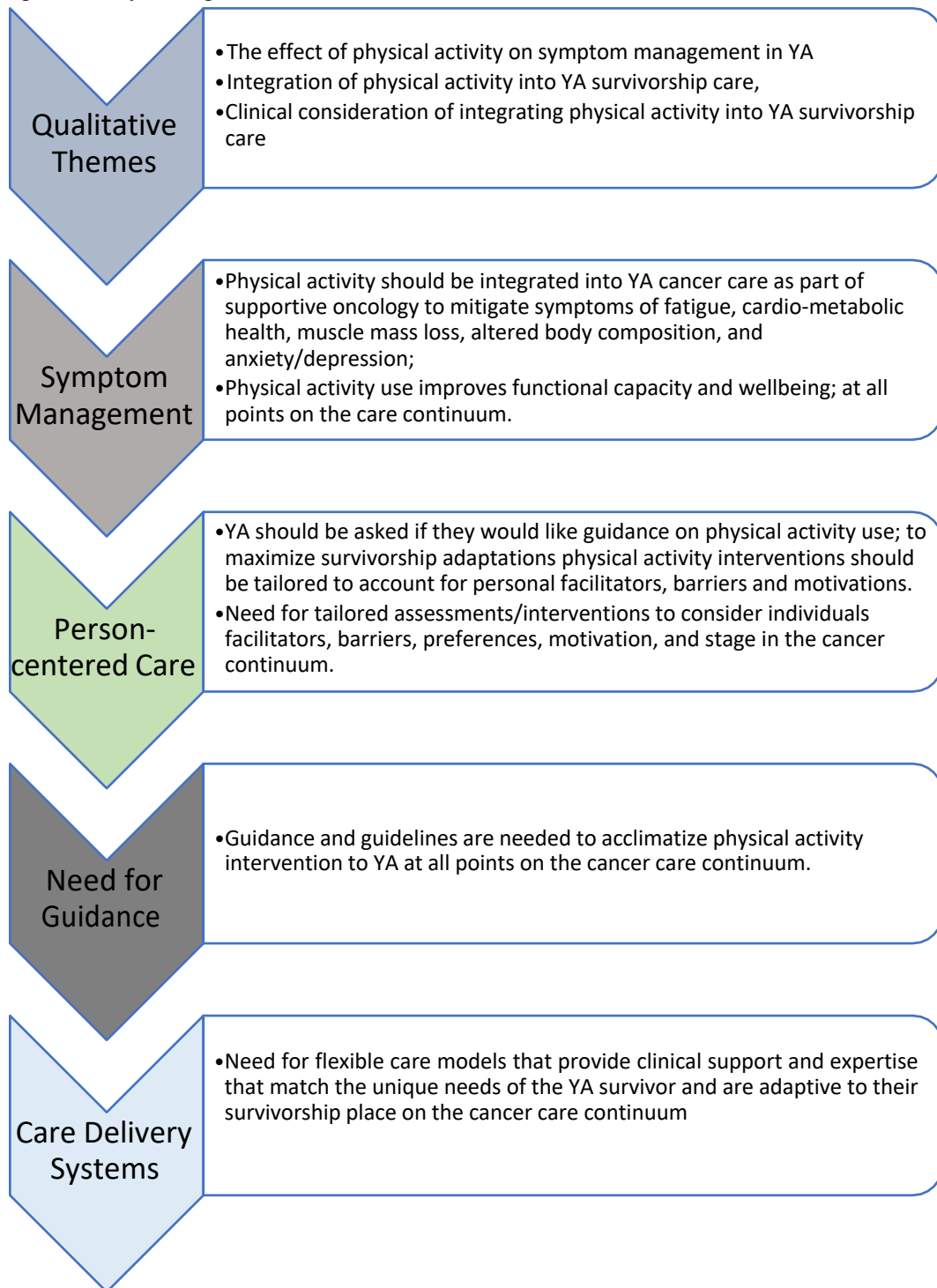
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Figure 4: Expert Recruitment and Study Process



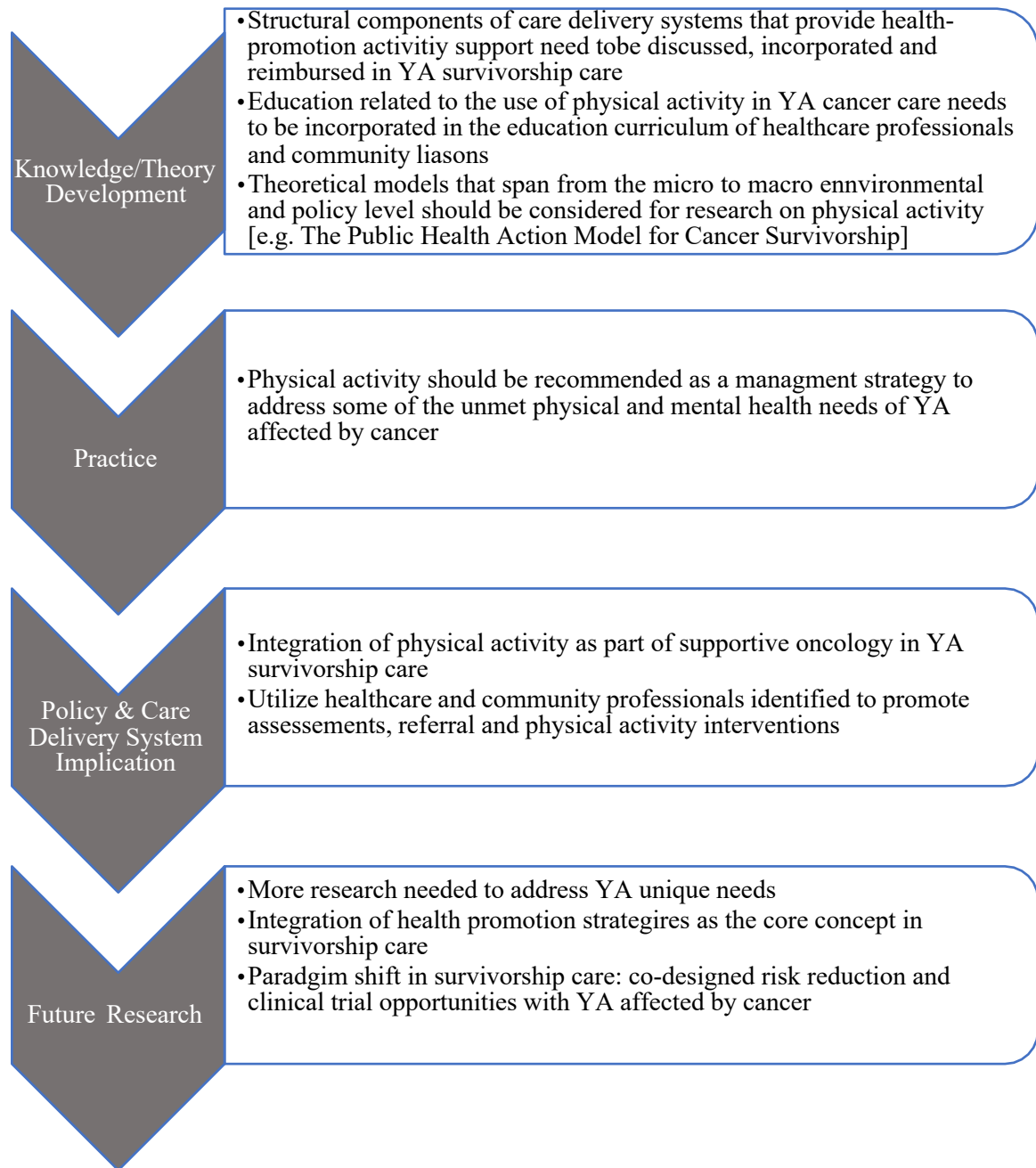
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Figure 5a: Key findings



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Figure 5b: Innovations/Implications



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APPENDIX C: MATRIX OF ARTICLES IN SCOPING REVIEW

Reference	Study Type	Samples included in review	Aim	Main outcome measures	Result	Conclusion	Critique
Braam et al., 2016	Systematic Review with 6 studies	Children & YA during & after childhood cancer (≤ 5 years from dx.)	Effect of exercise on physical fitness on HRQOL, symptoms (fatigue, anxiety, depression) & self-efficacy	Cardio-respiratory fitness (e.g. time run-walk test); Bone health (BMD); Flexibility (e.g. sit and reach); muscle strength, HRQOL	Positive effects on fitness, body composition, cardio-respiratory fitness, muscle strength and some HRQOL. No significance in fatigue, level of daily activity, adverse events.	Effects of exercise on childhood cancer survivors are not clear.	All studies had operational and methodological limitations.
Bradford et al., 2017	Systematic Review with 17 studies	13-39 years; individuals after cancer treatment.; $\frac{3}{4}$ were childhood cancer survivors, with only 2 studies specific to individuals diagnosed as	Identify, appraise & synthesize effects of health promotion, psychological interventions; feasibility and efficacy	Health-related outcomes: symptoms of anxiety, depression, fatigue; Perceived vulnerability & motivation; process outcomes:	5 studies included physical activity as a health promotion intervention, and all reported positive effects on the measured outcomes	There is a need for research studies for survivors diagnosed during AYA. Recommendations for future studies; includes face-to-face interventions,	There is a lack of high-quality studies, especially specifically for individuals diagnosed with cancer as YA. Deficits include a risk of bias, heterogeneity of outcome measures. Further research is warranted.

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		YA. ⅔ were RCT		behavioral change with physical activity, health practices; satisfaction, feasibility		peer-to-peer facilitated support interventions, incorporating the use of social media and technology	
Brunet et al. 2017	Scoping Review with 32 studies	>50% were AYA 15-39 years	Explore the extend, range & nature of published studies on PA in AYA's with cancer and identify gaps for future research	PA intensity, classification of total PA (self-report and accelerometer data), body composition. QOL, symptoms (fatigue, sexual function, sleep, physical functioning, neurotoxicity, stress, depression, distress); aerobic fitness, functional fitness, physiological health, social health, pulmonary function	Almost ½ of studies explored the relationship with PA and descriptive data, physical, personal/psychological, social, and other health behaviors. Mixed-method studies: barriers and facilitators to activity participation were explored. Quantitative experimental studies: targeted print material had a significant effect on those with high levels of sedentary behavior. Interventions involving social support showed significant effect in light activity. There was no relationship between self-efficacy and PA. PA during treatment has a positive effect on physical and appearance changes.	Despite an increase in research on PA in AYA cancer survivors, still limited studies with few outcome measures explored within and across studies. More research is needed to establish benefits of PA.	The most effective and beneficial study designs are not yet articulated. Study limitations exist due to the heterogeneity of study designs and how physical activity is defined and measured. Further interdisciplinary research is needed.

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Cabilan et al., 2017	Systematic review & meta-analysis with 23 studies	Adult colorectal cancer survivors age 29-89 years, post treatment, mostly outpatient hospital setting	To determine the impact of colorectal cancer treatment on 1) PA, 2) functional status, 3) QOL with-in 1 year of treatment or diagnosis.	QOL scales, PA self-report scales, Functional status scales	Colorectal cancer treatments had a negative effect on PA levels (decline from 53% to 32%) and large functional status decline during the first 6 months of treatment then regaining QOL and functional status within 1-year post treatment. Adverse effects of treatment included: pain, sleep disruption, fatigue, nausea/vomiting, inactivity and surgical complications.	Physical and functional QOL status were negatively impacted for those within 3 months of treatment with the likelihood of return to baseline measure at 1-year post treatment.	Limitations include a lack of studies, heterogeneity of studies and methodological limitations.
Kopp et al., 2016	Systematic Review with 6 studies	Cancer survivors age 9-25 years at time of diagnosis, ≥ 2 years off therapy.	To review lifestyle behavioral interventions (including \uparrow PA and \downarrow sedentary behavior & weight-related outcomes) for children & AYA using technology related to chronic disease prevention.	Digital delivery tools (video games, text messaging, social media, mobile phones, pedometers)	4 of the studies were RCT; 2 were single arm pre/post. Sample size 13-86 participants, majority were white, female with acute lymphocytic lymphoma or brain tumors. A major barrier to participation is proximity to programs therefore the use of technology increases reach and decreases cost. AYA preferences, although limited, indicate remote delivery preferred over in-person.	Studies that address chronic disease prevention through behavioral interventions are limited. In addition, there are limited studies related to behavioral interventions that incorporate technology.	Despite limited studies using technology to deliver behavioral interventions including increasing PA in cancer survivors, high retention rates indicate this a feasible and acceptable approach.
Munsie et al., 2019	Systematic review with 6 studies	Studies that included 1) AYA patients (> 50% sample	To investigate current evidence related to exercise intervention in	Physical performance outcomes (e.g. 9 mi. walk test,	Inpatient stem cell transplant patients spent on average 36.5 min exercising/day, with most of that time spent walking.	There was a lack of controls in most studies. In addition, the	Heterogeneity of studies limited the ability to compare across studies and generalizability. All of the

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		AYA) diagnosed with cancer between age 15-25 years, 2) intervention to improve physical performance, physical activity participation, fatigue and/or psychosocial HRQOL	AYA cancer specific populations both during and after treatment.	get up and go, step count, range of motion); Body Composition outcomes (e.g. bone mineral density); Feasibility and acceptability; Self report measures: PA levels, fatigue, HRQOL.	ROM in one study indicated a decline from baseline that was not recouped following post-op rehabilitation. Fatigue was measured in 2 studies, one with no intervention to mitigate and the other not as a primary outcome. Fatigue was lessened following a 16-week intervention and QOL improved.	definition of the AYA age cohort varied in studies. Drop out characteristics were not included limiting full interpretation of feasibility.	studies lacked adequate power to detect clinical significance.
Pugh, Gravestock et al., 2016	Systematic review with 12 studies	Majority were randomized control trials with a few one-armed feasibility or repeated-measure longitudinal studies. Teen and YA cancer survivors age 13-18 years (3 studies were >18 years). Majority were white/caucasian and had	Synthesis of the current research on health behavior change interventions	Moderate to vigorous PA (minutes, calories/day), Total PA (min/week; mets/week); classify by light, moderate, vigorous, strength training), days of drinking, binge drinking, smoking). Diet, vitamin	Feasibility & acceptability established. Small mean change of behavior (pre/post) with mixed results on significance. Studies included remote delivery intervention, in-person workshops, printed materials. The majority facilitated psychosocial support (nurse, group session, interaction with other YA cancer survivors. Only 1 study incorporated family support. ½ were individually tailored support. Approximately 1/2 incorporated input from survivors. 1/3 of studies provided education and risk	There are a range of novel and diverse health promotion modes both in intervention design and delivery for teen and YA cancer survivors. There is a need for more research to articulate most effective means to promote health behavior change	Future studies need to 1) delineate between health promotion and risk promotion behaviors, 2) clearly operationalize the age range in teen and YA.

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		hematological malignancies.		supplementation . Other: decision-making, knowledge, perceived vulnerability. <i>Measurement tools not specified</i>	counseling on late term effects of cancer/cancer treatment. Intervention duration: ranges from 1/2 day to 12 months.	in teen and YA cancer populations. Future research needed to provide evidence on efficacy and feasibility of online interventions and peer support, with social support/networks taken into account. Personalized risk assessment and intervention counseling regarding late effects of cancer and its treatment are emerging in some studies and is an alternative health promotion strategy. PA most widely studied in this review. Timing considerations for	
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						greatest efficacy to initiate behavior change need to be considered.	
Rabin 2011	Systematic Review with 20 studies	YA cancer survivors age 18-45 years	To determine: 1) which lifestyle behavior (physical activity, smoking, alcohol) is most in need of intervention; 2) where the greatest vulnerability is in subset of YA cancer survivors; 3) health behavior theoretical frameworks that may guide interventions	n/a	YA survivors are < physically active than non- cancer peers. Most expressed interest in receiving information on exercise, a modifiable risk factor. Fatigue, lack of time and access are contributory factors. Older YA survivors, racial/ethnic minorities are more likely to be < active than white/non-Hispanic. ↑ Levels of depression correlated with ↓ PA levels. Patterns of sedentary behavior and protective variables (e.g. age at diagnosis) were noted. There is a linear relationship with self-efficacy for PA and adoption of active lifestyle. Social cognitive variables were linked with PA. Constructs of self-efficacy, social support and decisional balance has a linear relationship with PA.	There is a need for ↑ PA in YA survivors in literature, and most expressed an interest in receiving information, despite motivating factors not articulated. Theories of behavior change should drive the interventions.	Small samples of ethnic minorities make interpretation of results difficult. Investigating theoretical underpinnings in research is novel. The inclusion of PA and sedentary patterns as separate risk factors is essential.
Roberts et	Systematic	Review health	Review and	Self-report PA	Digital behavioral intervention	First analysis to	Meta-analysis reported

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al., 2017	Review & Meta-analysis with 15 studies	behaviors using digital technology in cancer survivor to assess use in promotion of physical activity, non-sedentary time and improved dietary quality	analysis of health behavior interventions to ↑ PA, ↓ sedentary behavior and improve diet quality, using digital technologies in cancer survivors. Secondary aims include effect of digital intervention on BMI, weight, and cancer-related outcomes. Theoretical underpinnings explored.	levels (7-day recall, min/days, steps/day), mobile app min/day, calories logged. Fatigue/QOL levels: self-report measures.	exhibited statistically significant ↑ in moderate to vigorous PA. RCT alone showed significance. Interventions showed significant pooled reduction in BMI. Fatigue was ↓ with intervention but with no statistical significance in meta-analysis, 1 fatigue study not included in meta-analysis did find significance. QOL: most studies found no significant change. 1 study found significance with role functioning, emotional and mental health domains <i>after</i> treatment. 1 study, using a non-validated scale, found ↑ in self-rated health, fatigue, pain, SOB, stress, sleep quality and overall QOL. 12 studies reported theoretical underpinnings with the <i>social cognitive theory</i> being the most cited.	assess digital behavior intervention change in cancer survivors, which holds potential to improve both PA & BMI. ↑ studies recently related to PA and/or diet in cancer survivors.	high heterogeneity scores (> 70%), with retention rates varying. Future research needed with sustained engagement in digital behavior efficacy on PA and diet in cancer survivors. Poor reporting of theoretical underpinnings. Large heterogeneity in interventions and reporting of such making it difficult to interpret results.
Spathis et al., 2015	Systematic review and narrative analysis with 60 articles.	Age 13-24 years, with cancer diagnosis in experimental group. Time from diagnosis	To gather a comprehensive review of fatigue studies in teen/YA cancer survivor population.	Self-report subjective fatigue scales.	In 6 of the studies, fatigue was a barrier to physical activity, which further translated into frustration and a lack of confidence. 5 studies used PA as an intervention to manage fatigue with 2 of those studies	In YA cancer survivors, cancer-related fatigue is a major problem that has received limited research on prevention	The limited studies on fatigue and interventions to mitigate such have methodological issues including a lack of control groups, diverse age range of the sample and

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		2 months - 20 year range. Exclusive to lymphoma and or/leukemia diagnosis.			showing significance. Limited studies in adult populations indicate that PA is the only intervention that has shown efficacy, yet despite this, rest is often perceived by families and providers as the best approach.	and/or treatment. Fatigue needs to be addressed to mitigate limited PA levels, social isolation, body image and dependency at a critical age junction of emerging independence. Future research should focus on the efficacy of PA promotion and concurrent symptom management.	heterogeneity of how fatigue is defined and measured.
Treanor et al., 2016	Systematic review with 6 studies	Randomized control trials that assessed cognitive function in women with breast cancer	To evaluate the effects of non-pharmacological interventions on cognitive functioning in cancer patients.	Cognitive function domains: processing speed, executive function, cognitive flexibility, language, delayed and immediate memory.	PA intervention resulted in significant ↑ in processing speed/executive function, compared to control but significance did not remain when controlled for baseline scores.	The evidence of PA interventions on cognitive functioning is limited	Study design issues including lack of power, lack of blinding and use of subjective measures limit firm conclusions.
Wurz et al.,	Systematic	Adolescent	To synthesize the	Health & QOL:	Health and QOL declines	PA is safe and	Studies involving larger

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2016	review with 2 studies	cancer survivors in the isolation phase of stem cell transplant, age range 13-19 years receiving PA intervention	findings from randomized control and controlled clinical trials in that evaluate the effects of PA on <i>health</i> (bone mass, fatigue, grip strength), QOL	bone mass (DEXA), grip strength, QOL, objective and subjective measures (e.g. perceived exertion scale), accelerometers, qualitative interviews, fatigue scales	were attenuated with PA intervention. Fatigue was improved in the intervention group. All results, however, were not significant. QOL exhibited a U-shape trend. Accelerometers indicate intervention group had > min/day of PA (16.9 vs. 1.7) than control. A follow-up visit intervention group continued with > min/day of PA (25.2 vs. 8.0) than control, with a large effect size. Reports included exercise session duration, location, equipment used, facilitator, with length 5weeks- 6 months.	feasible for adolescent cancer survivors.	samples, specific to the adolescent cancer population that assess many outcomes measures are needed to determine effects of PA on health and QOL.
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GREY MATERIAL

Reference	Publication Type	Purpose/Aim	Results	Conclusion/Significance
Barbaric et al., 2010	Systematic Review	Evaluating & summarize evidence on effect of PA on survival in cancer survivors	10 prospective cohort studies. ↑ Physical activity levels (of ≥ 9 MET hr./week) may ↑ survival rates. Results indicate non-significant <i>trends</i> that indicate ↑ PA levels have ↓ levels of cancer mortality (trend found specifically for breast, colon & colorectal cancers). On average, dose response noted (↑ METS/week <i>may</i> ↑ survival rates).	There are limited studies related to PA and cancer survivorship. More research is needed to answer the optimal level of PA for cancer survivors, including the upper threshold level where > PA offers no > benefit. In addition, more randomized control trials with diverse ethnic populations, including non-exercise physical activities and using rigorous psychometric measures are needed. In addition, repeated assessments are various points of cancer continuum needed. More research with rigorous methodology and diverse populations needed.
Bleyer 2007	Summary/ Review	Review of relevant issues (medical, psychosocial, and economical) specific to YA (15-29 years) and their caregivers.	Cancer incidence in 15-29 y.o. is 3x that of younger ages (0-15 years), yet those < 15 years receive far more research. YA cancers are frequently under-recognized by primary care practitioners. There is great benefit to improved survival and QOL of YA survival, in terms of long-term economic and societal	Incidence of invasive cancer dx. Between 15- 30 years is 1 out of 168 Americans. There is a unique distribution of types of cancer in this age group, usually not related to environmental carcinogens, family history or inherited risk. This age cohort has the lowest aggregation of clinical trials, often encounter delayed diagnosis and have the lowest rate of health insurance coverage. In addition,

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			<p>impacts that stress the importance of health and healthy behaviors. The NCI's Adolescent and YA Oncology Program Review Group resulted in 5 recommendations: 1) identification of characteristics that distinguish the unique cancer burden in the older adolescent and YA cancer oncology patient; 2) education, training and communication to improve awareness, prevention, access & quality cancer care to older adolescents and YA; 3) creation of tools to study the older adolescent and YA cancer problem; 4) ensuring excellence in service delivery across the cancer control continuum; 5); strengthening and promoting advocacy and support of the older adolescent and YA cancer patient.</p>	<p>their psychosocial needs, unique from other age cohorts, are often not attended to. Survival rates are lower than children and prognosis is often worse than older adults.</p> <p>There is a lack of awareness of the YA cancer cohort, a lack of health insurance, a lack of access, and a lack of attention to unmet psychosocial needs. These deficits call for translational research and healthcare facilities that are specific to the YA cancer cohort.</p>
Bleyer et al., 2017	Summary/ Review	Assess global status of	Increasing incidence globally of AYA cancer with > 1million	There has been a dramatic increase in AYA in the past 2 decades. Diagnostic

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		emerging discipline of AYA oncology, including changing incidence and survival rates.	new diagnoses of cancer worldwide annually, greatest number of affected life-years by cancer than all other ages. Unique age specific psychosocial challenges are greatest in AYA cancer cohort and demand attention.	and treatment progress lags behind other age groups. There are unique challenges to survival and QOL for this age group including delayed diagnosis, lack of insurance, limited access to care, care that straddles both the pediatric and adult population, poor treatment adherence, unmet psychosocial needs and a lack of access and accrual of clinical trials.
Burke et al., 2017	Meta-synthesis	Identify and critique qualitative research on cancer survivors' perspective on the impact of PA on QOL to understand future research and practice implications.	40 studies were included. PA has a positive impact on 4 QOL dimensions 1) physical 2) psychological (evoking positive self-perceptions), 3) social (feeling understood by others), 4) spiritual (redefining life purpose). This adds to previous reviews indicating PA can be a strategy to improve QOL in adult cancer survivors, irrespective of diagnosis or treatment regimen. Dosage (intensity, frequency, and duration), & type of PA as well as personal preferences need to be considered.	Qualitative interviews offer a person-centered perspective of the meaning and utility of PA for each cancer survivor. Further research is needed to articulate <i>how</i> PA impacts QOL. In addition, research from diverse ages groups (e.g. YA), diagnoses, and at different points on the cancer continuum is needed. Further work is also needed to develop theoretical underpinnings of PA and QOL for cancer survivors as well as qualitative work to understand the multiple conceptual dimensions of QOL.
Chida et	Summary/	Evaluation of	165 studies were included.	Psychosocial factors that are associated

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al., 2008	Review (meta-analysis)	longitudinal stress on cancer incidence and survival.	Stress-related psychosocial factors are associated with statistically significant cancer incidence in initially healthy populations, worse survival rates and morbidity in cancer populations. Subgroup meta-analysis indicates stressful experiences correlated with worse survival and mortality (but not incidence). Individuals more prone to stress, unhealthy coping styles, negative emotional responses, ↓QOL had ↑cancer incidence, poorer survival and ↑ cancer mortality.	with stress impact cancer incidence and survival. These factors may be mediated through behavior and/or biological/physiological pathways. Further rigorous research is needed as other covariates and confounding factors may exist.
Coccia et al., 2018	Clinical Practice Guidelines	National Comprehensive Cancer Network (NCCN) 2018 AYA oncology clinical practice guidelines	The NCCN are a statement of consensus from authors regarding currently accepted treatment approaches. AYA patients have unique needs compared to older adults with cancer (treatment, fertility counseling, psychosocial and behavioral issues and supportive care services). There are < evidence-based data to guide	NCCN recommendations for supportive care/services/interventions for psychosocial and behavioral issues includes the <i>prescription of nutrition and exercise recommendations</i> for all AYA patients. One part of the conclusion section indicates that services (e.g. summer camp) where individuals are <i>physically challenged</i> translate into improved self-confidence, independence and social interactions. The use of

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			treatment regimes in the AYA cancer cohort. The following domains are covered: Fertility, Psychosocial, & Behavioral (for both the individual and for relationships). Behavioral Considerations (AYAO-8) list <i>exercise needs, hobbies, and recreational activities</i> under individual evaluation (however no supportive care services/interventions are listed).	technology as a conduit for communication with healthcare providers is discussed.
Courneya et al., 2015	Recommendation	Identify the most pressing research questions in the emerging field of exercise oncology (physical activity and cancer survivorship)	Multimodal therapies, while improving survival, come with consequences both acute and late term that impact QOL. Exercise oncology is a rapidly evolving field; leading exercise oncologists pose the 10 most pressing questions related to PA and cancer survivorship research.	As the number of cancer survivors increase worldwide, research focused on mitigating both acute and long-term consequences of treatment is needed to ultimately improve the lives of cancer survivors at all points on the cancer care continuum.
Docherty et al., 2015	Summary/ Review	Summary of the impact of cancer/cancer treatment on biopsychosocial	70,000 AYA are diagnosed annually (8 times that of those diagnosed from 0-15 years), with limited improvements in survival noted. AYA are	In AYA cancer survivors, there is a great deal of variability in both risk and protective factors that influence health trajectories. The <i>Life Course Health Development Framework</i> redirects the

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		aspects of AYA with cancer using the <i>Life Course Health Development Framework</i> .	emerging as a distinct cancer cohort, demanding specialized care. The <i>Life Course Health Development Framework</i> considers the influences of longitudinal biopsychosocial factors on health trajectories.	focus from technical and symptom management to biopsychosocial adaptations.
Dodd et al., 2001	Summary/ Review (Theory)	To describe evidence-based revised theoretical model for the science of symptom management: The Revised Symptom Management Theory and areas where further research is needed	The Revised Symptom Management Theory incorporates the experience of a plurality of symptoms and is a generic symptom management model that provides direction for the selection of interventions, informs research, and allows for interdisciplinary integration. There are 3 domains: the symptom experience, symptom management strategies and symptom status (outcomes) that are encompassed by 1) person (demographic, psychological, sociological, physiologic, developmental); 2) environment (physical, social, cultural); 3) health & illness (risk factors, health status, disease, & injury).	The Revised Symptom Management Theory domains are encompassed by social determinants of health (person, environment, health & illness). This conceptual model offers a guide to select symptom management strategies versus description of the symptom found in other symptom models. The model is dynamic and highly generalizable in nature.

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			The model does not articulate between acute or chronic symptoms and is evolving to address symptom clusters.	
Fernandez et al., 2011	Recommendation	The 2010 Canadian Task Force Recommendations on Adolescents and YA with Cancer (mission: to establish and support research to identify how to optimize health and QOL)	Identify and prioritize principles of care for research, identify outcome metrics, strategize ways to implement change to improve outcomes and QOL of AYA survivors, with unique developmental needs. 6 broad categories were identified 1) services that address unique needs of AYA are needed to address inequalities in care; 2) unique psychosocial needs must be addressed to allow for full potential as productive, functioning members of society; 3) Palliative care tailored to their unique needs/developmental stage must be addressed; 4) implementation of lifelong follow-up will secure economic and societal benefits as well as mitigate late-term effects of treatment; 5) research and	The expert opinion recommendations centered around: active therapy & supportive care, psychosocial needs, palliation & symptom management, survivorship, research & metrics, awareness & advocacy were deemed essential. Addressing these deficiencies and gaps will lead to improved care and enhanced survival ultimately to better QOL.

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			outcome measure to examine critical issues specific to AYA cancer survivors are needed for effective interventions and policies aimed to improve all phases of cancer continuum; 6) Awareness and advocacy for unique needs (with stakeholder input) of AYA cancer survivors are paramount,	
Keegan et al., 2016	Summary/ Review	Summary of cancer survival trends of AYA, children & older adults	The 2002-2006 AYA 5-year cancer relative survival rates increased with an 82.5% survival rate . Trends in 34 cancers for the AYA cohort were reviewed with 14 exhibiting statistically significant 5-year survival rates since 1992, however they lagged behind compared with older adults (e.g. ALL, AML, CML, and others). The remaining 20 did not show significant survival rates since 1992. In addition, AYA had a significantly lower survival rates in certain cancers than children (e.g. Ewing	Improvements in therapy have led to improved survival rates for AYA. However, cancer survival improvement rates and prognosis among AYA lag compared to children and older adults in certain cancers and therefore need to be research priority.

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			sarcoma, ALL, AML and others) .	
Mishra et al., 2015	Systematic Review	Evaluate the efficacy of exercise interventions on HRQOL in those preparing or undergoing cancer treatment	56 trials (included up until November 2011). Overall HRQOL, fatigue, physical, role and social functioning improved with 12 weeks moderate to vigorous exercise intervention.	Exercise is a useful strategy to manage HRQOL for those preparing or undergoing cancer treatment. Trials with rigorous methodologies are needed to understand the most effective exercise regime attributes that translate to improved HRQOL.
Nass et al., 2015	Summary/ Review	IOM National Cancer Policy Forum roundtable: To identify gaps in care and challenges specific to the AYA cancer population.	Cancer is the leading cause of death in the AYA age group (15-39 years). 70,000 AYA are diagnosed with cancer annually. Despite unique risks and needs that include both short and long-term health and psychosocial health impacts from cancer and cancer treatment, AYA cancer survivors lack age specific tailored care. There are multiple life disruptions for AYA's with cancer. <u>Summary of key information:</u> Oncofertility is a key area of need. 41% have unmet needs for psychosocial support. >50% report unmet	The IOM workshop captured both research and clinical insights on the challenges that disproportionately affect AYA cancer survivors. The majority of AYA with cancer report unmet needs. Some of the most pressing concerns include attenuating both short- and long-term effects from cancer and cancer treatment with special attention to fertility, psychosocial and QOL issues. There is an increased risk for chronic disease which can be exacerbated by unhealthy lifestyle behaviors.

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			<p>needs regarding information; in addition, there are many unmet practical needs regarding support for health insurance, financial issues, transportation, childcare, peer support and health needs (e.g. PT, mental health support). Palliative care and end-of-life care should be addressed. Long-term mortality is elevated, mostly due to secondary cancer and cardiovascular disease. There is an elevated chronic disease risk that is exacerbated by unhealthy lifestyle behaviors. Lifelong Survivorship care that advocates for risk reduction should be incorporated for AYA cancer survivors. There is a great demand for survivorship programs that focus on modifiable risk factors (e.g. diet, exercise) but most are not tailored to AYA age groups; remote delivery methods may be options to explore. <u>Future suggestions:</u> Programs that both</p>	
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			<p>access and standardized comprehensive care that are AYA specific care need to be a priority perhaps through a clearinghouse for information dissemination of existing programs to facilitate continued development and expansion of programs. Care delivery systems should incorporate community-based organizations. It is essential that care providers focus on addressing and advising on access issues to facilitate early diagnosis, cancer care support and adequate surveillance for AYA. There is low AYA participation in clinical trials (14% of those 15-39 vs. 60% in pediatric population). Enhanced research endeavors need to be specific to AYA unique needs and address the wide variability in biological and developmental areas. Further exploration of online tools to address geographic access need to be explored.</p>	
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Neufer et al., 2015	Summary/ Review	NIH 2014 workshop summary re: Understanding the cellular and molecular mechanisms of PA-induced health benefits	PA promotes physiological & clinical outcomes yet the reasons for ~50% of this protection is not yet understood. A two-tier <i>Model of System Controls in Response to Physical Activity</i> has been proposed with the first tier defining physiological regulation & the second-tier accounting form both inherent & acquired characteristics. There is a coordinated response to exercise that is communicated among tissues. Acute responses to exercise are translated into adaptations and health benefits over time. Biological and environmental factors affect these adaptations. Exercise physiologists are trained in integrative biology and physiology and bring unique skills and insights to understanding the mechanisms behind the benefits of PA.	Understanding the underlying mechanisms of the benefits of PA holds great potential for human health. Future research needs to be directed toward the molecular underpinnings of both acute and adaptive responses of PA on health maintenance and prevention/mitigation of disease states. This type of research will allow for tailored exercise prescriptions as a therapeutic strategy.
Patterson et al.,	Summary/ Review	To review medical,	AYA oncology is an emerging specialty with poorly articulated	AYA cancer survivors face unique medical, psychosocial and behavioral late

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2015		<p>psychosocial & behavioral late effects of cancer treatment, survivorship planning, research priorities & clinical implications for AYA cancer survivors.</p>	<p>age-parameters. This group of cancer survivors have unique psychosocial needs based on emerging autonomy, independence and identity (e.g. cognitive and emotional capacities, relationships, careers, finances, emotion/sexual intimacy). In addition, emerging research indicates biological cancer presentations that are unique from other age groups. AYA's who are survivors of childhood cancer differ from those diagnosed with cancer as an AYA yet are often grouped together in clinical trials therefore complicating analysis. Late effects of cancer treatment include an elevated risk of; secondary cancer compared to those ≥ 40 years, cardiotoxicity, chronic disease (vs. those with no cancer history), elevated mortality, fertility issues (>80%). In addition, there is an \uparrow risk of psychological late effects (e.g. post-traumatic</p>	<p>effects from cancer. They face care transition issues post-treatment as they transition from cancer patient to cancer survivor. This is compounded by their unique developmental needs as they transition towards independence. International research priorities for AYA cancer survivors include attention to 1) unique medical, psychosocial, and healthcare delivery needs, 2) lack of survival improvement for this age group compared to other age groups, 3) diagnosis and referral delays, 4) low participation in clinical trials, 5) measurement tool development specific to AYA, 6) knowledge gaps related to late effects, surveillance and treatment, 7) advocacy to create public and healthcare awareness of AYA cancer, 8) issues pertinent to gaps in care transitions, 9) support at all stages of diagnosis, 10) cost analysis of AYA specific services vs. traditional modes of care delivery.</p>
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			<p>stress, depression, anxiety), cognitive abilities, ability to regain ‘normalcy’. Compared with the general population, there were reports of higher levels of unemployment, engagement in health-risk behaviors, including higher levels of obesity (31% vs. 27%) and no leisure time PA (31% vs. 24%). Survivorship care plans need to focus on lifelong surveillance and health behavior risk reduction, proper transition from post-treatment phase to primary care settings, and attention to ‘normalcy’ and financial concerns. Multidisciplinary teams including nurses are needed to offer information and guidance as care is transitioned to place greater autonomy on the AYA cancer survivor.</p>	
Phillips et al., 2015	Summary/ Review	To update the prevalence and burden or	The estimated childhood cancer survivors in the US as of January 2011 was 388,501	As survivorship increases in childhood cancer survivors, so does the prevalence of morbidity. Future research needs to

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		morbidity of childhood cancer survivors using the Surveillance, Epidemiology and End Results (SEER) database and the Childhood Cancer Survivorship Study to estimate morbidity burden indicators as of 2011.	(83.5% \geq 5 years since diagnosis). Chronic disease prevalence ranged from 66% (age 5-19 years) to 88% (age 40-49 years). Pain prevalence was 12% and neurocognitive dysfunction was 35%, with increases noted with age. $\frac{2}{3}$ of 5-19-year old were projected to have chronic conditions (70% had mild/moderate grade chronic conditions, with 32% having severe, disabling or life-threatening chronic conditions). There was a significant increase in survivors with severe, disabling or life-threatening chronic conditions over time. Chronic conditions were prevalent in $\frac{2}{3}$ of cancer survivors 5-14 years post diagnosis, increasing to 77% 15-24 years post diagnosis, 85% 25-36 years post diagnosis. 88% of 40-49-year old had at least 1 chronic condition. 35% of those ages 20-49 had neurocognitive dysfunction. Altered physical	focus on \downarrow morbidity <i>and</i> \uparrow clinical care models to \downarrow morbidity burden and \uparrow health related quality of life, function and well-being.
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			and mental health related quality of life scores for survivors age 20-49 was 16% and 18% respectively. In addition, self-report markers of health status were noted: functional impairment (14%), activity limitations (14%), altered mental health (17%), pain (12%), anxiety/fear (13%). These self-report markers increased with age.	
Rabin 2017	Summary/ Review	To identify barriers to increasing PA by YA cancer survivors	The RENEW study was a randomized control 12-week pilot study with home-based PA and meditation interventions for YA cancer survivors (age 18-39 years). The PA intervention to set-up and gradually increase both duration and frequency of moderate intensity PA with the end goal to reach 30 minutes of exercise/day 5 days/week and mindfulness meditation 4 days/week ($n = 35$). The intervention, based on the social cognitive theory and	There are multiple barriers to increasing PA in YA cancer survivors, with limited time being a key obstacle. In addition, the dropout rate in PA interventional studies is often attributed to limited time. Lack of motivation and psychological stress also contribute to the inability to meet PA goals. YA barriers have unique barriers than older survivors due to their live stage (e.g. careers, caregiving for young children or aging parents). Limitations include: a lack of power to detect significant effects size, lack of generalizability to include those who initiate their own PA program. Future

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			<p>transtheoretical model, involved a weekly phone call with an experienced behavior coach. The following barriers to PA were reported: 62.5% family/work time; 50% identified a general lack of time ; 43.8% identified health issues; 28.1% identified pain. An exploratory analysis explained 27% of the barrier was due to schedule-related, health-related, psychological & weather-related barriers. This is the first study to examine barriers to PA in YA survivors.</p>	<p>research should include better power and exploration of additional demographic influences on barriers to PA.</p>
<p>Schmitz et al., 2019</p>	<p>Recommendation</p>	<p>To address the lack of clarity of healthcare providers role in assessing, advising and referring cancer patients to exercise using The American College of Sports</p>	<p>Several roundtables were convened to address review & update Exercise and Cancer prevention and Control and produced 3 articles. The first article summarizes a roundtable in 2018 presented evidence regarding exercise and its association of lower risk of developing cancer and improved survival rates. There was <i>strong</i></p>	<p>The preservation of function and activity is essential in cancer care. PA levels should be assessed at regular intervals. Patients should be advised on desired levels of PA and stress the importance of PA. Referrals to exercise programs or appropriate health care professionals is needed. Cancer rehabilitation and exercise oncologists needed to be added to the workforce and then further recommendations should be implemented.</p>

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		Medicine (ACSM) guidelines	<p>evidence of PA and lower rate of developing the following cancers: colon, breast, endometrial, kidney, bladder, esophageal and stomach; <i>moderate</i> evidence for lung; <i>limited</i> for myeloma & hematologic, head & neck, pancreas, ovary, & prostate cancer. Sedentary time was associated with <i>moderate</i> evidence of developing endometrial, colon & lung cancers and <i>limited</i> for liver cancer. Prediagnosis PA was associated with <i>moderate</i> lower risk of cancer-specific survival in breast & colon survival. Post diagnosis PA was associated with <i>moderate</i> lower risk of cancer-specific survival in breast, colon and prostate cancers.</p> <p>A second article provides <i>strong</i> evidence based support for the use of exercise on cancer-related health outcomes including physical function, fatigue,</p>	<p>Currently, implementation (assessment, advice, referral, and engagement) of PA a standard of care is lacking and represents a failure in cancer care delivery. This call to action to stakeholders holds promise to transform health and well-being for cancer survivors at all points on the cancer continuum.</p>
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			<p>quality of life, physical function, anxiety & depressive symptoms by doing aerobic activity 3x/week and the same outcome for resistance training 2x/week for all major muscle groups (8-15 reps/set x 2 sets with small increment progressions). This third article proposes the use of elements of the <i>Exercise is Medicine</i> Initiative to overcome referral barriers. A recent study of 971 oncology clinicians by the American Society of Clinical Oncology indicates that 78.9% agree that PA should be recommended to patients. However, translation from the agreed benefit of exercise toward implementation (assessment, advice, referral, and engagement) of PA as a standard of care is needed. In order to be sustainable, awareness of benefits, referral systems, programming, workforce and triaging systems need to be put in place. This</p>	
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			article is a <i>call to action</i> to the various stakeholders (oncology clinicians, policy makers, researchers, clinical educators, health care providers, health and fitness industries, oncology patients/survivors) to initiate multisystem changes to achieve such.	
Schwartz et al., 2017	Summary/ Review	To review ACSM exercise recommendations for survivors at various points on the cancer continuum	The effects of cancer treatment occur both during and after treatment, can be debilitating, and lead to ↓ physical function & altered QOL. Growing evidence indicates exercise is beneficial for ↓ treatment symptoms (e.g. fatigue, muscle weakness, cardiovascular function, neuropathy, QOL, functional ability) as noted by self-reported objective & subjective outcome measures and is associated with ↓ recurrence and mortality across many cancer diseases states. 80% of oncology care providers lack adequate knowledge of the	Oncology care providers need to be prescribed to avoid inactivity and educate on the benefits and safety of exercise at all stages on the cancer continuum. Exercise program progression including volume and intensity should also be discussed. Handouts of ACSM recommendations are a simple efficient way to facilitate an exercise discussion. Exercise can be initiated at any point of the cancer continuum to foster preservation and/or improve functional ability, body composition and QOL; however restorative exercise should be initiated as soon after diagnosis as possible to maximize benefits, improve treatment tolerance as well as provide both physical and emotional benefits.

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			<p>benefits of exercise and as a result are ill-equipped to provide a referral. It was noted that oncology care providers who met guidelines themselves were significantly more likely to discuss and provide an exercise referral. Referrals should be based on level of function and previous exercise experience to either rehabilitation providers (e.g. physical therapy) or community-based programs (e.g. LIVESTRONG at the YMCA). Acute treatment side effects that negatively impact QOL include nausea, vomiting, fatigue, skin rashes, peripheral neuropathy, hair loss, pain, anxiety, depression, self-esteem & body image changes. Multiple studies include that exercise during active treatment improves some of these treatment side effects. Long term treatment side effects can include lymphedema, fatigue, peripheral neuropathy, infertility, hormonal & body</p>	
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			<p>composition changes and cardiopulmonary complications. Many long-term effects cluster with other symptoms (e.g. fatigue levels ↑ with neuropathy, sedentary behaviors ↑ fatigue). Exercise has been shown to mitigate fatigue, improve balance in those with neuropathies, and reverse cardiovascular declines. Exercise oncology research and community-based cancer exercise programs are growing. Insurance offers reimbursement for restorative cancer programs to improve overall function, weakness and range of motion. Community-based programs are led by those with some formal cancer exercise training, while others are more loosely structured. Online programs are also available (e.g. Restwise) and assist in symptom assessment and ways to maximize exercise benefit. Culturally adapted exercise</p>	
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			interventions that focus on vulnerable populations (e.g. African Americans and Native Americans) with poor access to care, poor screening and lower survival rates is imperative.	
Smith et al., 2016	Recommendation	Update 2013 NCI working group on AYA oncology gaps and future research: regarding exercise recommendations at different stages of survivorship	The 2013 AYA workshop presented current evidence and gaps in the literature. Next steps from 5 working groups were as follows; 1) <i>Epidemiology</i> : investigate survival trends overall and by cancer type, sex, age, race/ethnicity and other subgroups when sample size allows, develop data resources to examine population and treatment pattern trends 2) <i>Basic biology</i> : Basic & translational research is needed to facilitate the unique character of AYA cancers compared to other age groups that will aid novel therapeutic intervention, tissue banks specific to AYA cancers is needed to aid research, data sharing and	Despite an explosion of AYA oncology research since the 2006 Progress Review Group, all of the 2013 working groups called for more research. Pooling of data and biological samples specific to AYA are needed. Research on non-modifiable (e.g. biological, genomic differences) and modifiable (trial access, optimal therapy access) and research on understanding and addressing symptoms and HRQOL are needed.

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			<p>collaborations for biobanks and genomic studies need to be fostered.</p> <p>3) <i>Clinical trials</i>: National level tracking for AYA both diagnosis and those engaged in clinical trials is needed. Efforts to ↑ enrollment in community practice settings, maximize scientific collaborations and raise awareness of clinical trials is needed by educating providers about age disparities and using social media for dissemination when possible.</p> <p>4) <i>Health services & medical care</i>: Tracking of where/by whom AYA cancer individuals are treated is needed (e.g. pediatric hospital, comprehensive care center, community hospital). Exam reasons for delayed diagnosis. Examine data sources to identify financial costs and burdens. Examine components and delivery of optimal treatment, AYA adherence and access to</p>	
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			care 5) <i>Health-related quality of life</i> : Conduct well powered, methodologically sound studies of HRQOL specific to AYA population across the continuum of cancer care, including end-of-life care. There is a need for comparative research of AYA to other age groups to articulate the unique needs of the AYA population. Development of psychometric measurement tools & research related to physical psychological & social needs of AYA cancer populations is needed as well as ways to improve transitions back to school/work are needed.	
Speck et al., 2010	Systematic Review/Meta-analysis	To evaluate the appropriateness & effectiveness of PA both during and post treatment in cancer survivors	Review of published literature from Medline (2005-2009) yielding $n = 82$ studies. Studies were evaluated for quality and effect size was determined from high quality studies ($n = 66$). Interventions occurred during treatment in 40% of studies.	The impact of PA on health outcome studies in cancer survivors is growing. Current literature indicated a large effect on upper and lower body strength in breast cancer survivors. A small to moderate effect was noted in PA levels, aerobic fitness, overall QOL, fatigue, biomarkers (IGF-1), body strength, body

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			<p>Some interventions occurred over multiple stages on the cancer continuum, but none occurred during palliation. Most studies lasted > 5 weeks with 40% being > 3 months. Over 50% of interventions were post treatment and the primary aim was behavioral intervention to ↑ PA. Retention rates were high. Only 24% of studies adequately described the sample (race/ethnicity, gender, sociodemographic variables). Failure to describe race was the most consistently overlooked variable. 57% describe PA intervention length, modality, intensity, frequency, duration/session, & progression in a way that allows for study replication. Methodological issues were present in many studies (e.g. reporting on only post values in pre/post intervention, improper analysis techniques, bias). Statistical significance was found in</p>	<p>weight, functional QOL, anxiety, and self-esteem, treatment symptoms and side effects. Intervention timing needs to be considered when determining effectiveness of a PA intervention. The majority of studies focused on coping during active treatment, or rehabilitation or in combination with health promotion, with no studies during palliative care stage or limited studies prior to active treatment, at end of life or during survival stage following eradication of cancer. Pre/post PA interventions with breast cancer was the most widely studied population, highlighting the need for PA intervention studies in other cancers to determine its efficacy. There is heterogeneity in outcome measures for PA intervention studies, limiting the ability to generalize the findings. The establishment of a model or standardization process of methods, measures, documentation and reporting of PA in cancer survivors is needed to advance the science.</p>
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			multiple outcome measures (e.g. PA level, strength/flexibility, functional QOL, positive mood, anxiety, self-esteem). In addition, large effect sizes ($I^2 > 0.70$) were noted in many outcome measures (aerobic fitness, body weight, lean body mass, fatigue, depression, pain). Many other outcome measures lacked sufficient quality of evidence to measure the effect size.	
Tai et al., 2012	Summary/ Review	To describe self-reported health status of AYA cancer survivors	AYA cancer survivors (age 15-29 years) face long term effects from their cancer diagnosis and treatment that affect their morbidity & mortality. Data from the 2009 Behavioral Risk Factor Surveillance System AYA cancer survivors was compared to respondents with no cancer history. Data included demographics, risk behaviors, chronic conditions, health status, health care access of AYA cancer survivors ($n = 4054$) and	AYA cancer survivors experience adverse behavioral, medical and health care effects resulting from cancer diagnosis and cancer treatment disproportionately than those without a cancer diagnosis. These effects impact long term medical and psychosocial health outcomes. Improved outcomes from increased adherence to established guidelines is called for.

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			<p>controls ($n = 345, 592$). The most common cancer included cervical cancer (38%), other female reproductive cancer (1%) and melanoma (9%).</p> <p>Racial/ethnic AYA minorities with cancer were underrepresented (non-Hispanic blacks 6%, Hispanics 8%) vs. controls (non-Hispanic blacks 10%, Hispanics 15%). AYA with cancer were more likely to be out of/unable to work (24%) vs. controls (14%). AYA with cancer were more likely to be smokers (26%) vs. controls (18%). There was no difference in binge drinking habits. AYA with cancer reported ↑ no-leisure time activity (31%) vs controls (24%). AYA with cancer also had an ↑ risk of chronic diseases vs. controls: cardiovascular (14% vs. 7%), hypertension (35% vs. 29%), asthma (15% vs. 8%), diabetes (12% vs. 9%). Disability was > in AYA cancer survivors also had ↑ levels of</p>	
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			disability vs controls (36% vs. 18%). Greater levels of; poor mental health days were reported (20% vs. 10%), poor physical health (24% vs. 10%). Data on health insurance or provider access showed no statistical difference between AYA cancer survivors and controls. However, AYA cancer survivors did report a > inability to visit a physician due to cost than controls (24% vs. 15%).	
Wolin et al., 2012	Recommendations	To outline implementation processes for the 2009 ACSM cancer survivor exercise guidelines for the interface of oncology care providers and exercise/physical therapy professionals	The National Comprehensive Cancer Network produces evidence-based cancer care guidelines as a standard of care. In 2009 the ACSM, Oncology Nursing Society & Siteman Cancer Center conducted a roundtable to review existing literature and establish guidelines for activity. These guidelines were aimed to guide those developing exercise programs for cancer survivors. Individual survivor	Exercise is safe and feasible in cancer survivors, despite a limited amount of evidence on exercise contraindications and precautions. In addition, there are multiple benefits to exercise including: improved physical function, strength, fatigue, QOL and possible improvements in recurrence and survival. A symptom-based approach to individual exercise guidelines is recommended. Exercise guidelines have focused on prescriptions that yield the greatest benefits; however, some benefits may exist at other levels. At a minimum, clinical oncology provider

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			<p>considerations included: stage on care continuum & current health status. ACSM guidelines were founded from 2008 PA Guidelines for Americans (PAGA) & ACSM Guidelines for Exercise Testing & Prescription. PAGA suggests avoiding inactivity, ≥ 150 min/wk of moderate-intensity activity or 75min/week of vigorous activity with dose response effects of benefits to activity amount. The ACSM guidelines were the same as the PAGA with emphasis on returning to normal daily activities as soon as possible during treatment, noting that certain modifications may be needed based on the cancer survivor's health status/risk factors (e.g. type of surgery, immune status). The benefits of exercise include; maintenance of healthy body composition and image, \uparrow QOL, \downarrow fatigue; and the potential to \uparrow physical function,</p>	<p>should recommend inactivity and refer to an exercise specialist when possible. Communication between the cancer care team and exercise specialist is most beneficial.</p>
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			<p>aerobic capacity, strength, flexibility, ↑ disease-free survival, ↓ risk of recurrence & death, ↑ physical and psychological ability to complete treatment, ↓ long-term & late effects of treatment. The guidelines serve to inform both exercise professionals in cancer settings & community settings. The ideal setting would be with an ACSM certified Cancer Exercise Trainer but to eliminate physical location or financial barriers, the clinical care team should be able to provide information on avoiding inactivity. In cancer exercise research, there is a lack of evidence-based threshold so clinical experiences must be drawn upon where research is limited or nonexistent. Large randomized clinical trials are needed. Pre-exercise evaluations may be needed for more vigorous levels of exercise, but not for moderate intensity</p>	
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			<p>activities such as walking stretching, or resistance training. Balancing the risk of sedentary lifestyle vs. the risk of disease need to be considered. A symptom-based approach and consultation with the clinical providers is encouraged when making exercise recommendations. These should take into consideration cancer-related issues (e.g. neuropathies, fracture risk, lymphedema, anemia, cardiorespiratory issues, mobility issues, ostomies). Based on the symptom-based approach, survivors may benefit from one of three settings: community-based program, clinical exercise-specialist training, or PT/clinical rehabilitation expert.</p>	
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