Physical Therapy Interventions for Children and Adolescents with Cancer: Collating the Evidence from Research and Clinical Practice

by

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ABSTRACT

Purpose: Children and adolescents with cancer who undergo cancer treatment are at high risk of developing serious late and long-term physical effects, many of which may be amenable to physical therapy (PT). Little is known about the benefits of PT or the services currently provided to address late and long-term effects of cancer and its treatments. This study aims to collate and synthesize the research evidence and current clinical rehabilitation practices to inform a strategy to guide future research in pediatric oncology PT.

Methods: A two-phase study was conducted. Phase I consisted of a scoping review on PT interventions including studies indexed in three relevant databases (MEDLINE, EMBASE, and PEDro) from January 2002 to October 2017. Based on the findings, a protocol was developed for a Cochrane Systematic Review to further examine PT interventions for children and adolescents with cancer. Phase II involved a cross-sectional web-based survey administered to healthcare professionals (HCPs) who provide and/or refer children and adolescents with cancer to physical rehabilitation (PR) services.

Results: Phase I - A total of 12 papers were included in the scoping review, with studies supporting feasibility of PT. Findings demonstrate a (1) lack of high quality research; and (2) wide variability of studies in terms of patient populations, interventions and chosen outcomes, limiting our ability to synthesize the findings and make recommendations for clinical practice. A systematic review protocol was developed to further evaluate research quality and provide direction for future research. Phase II - A total of 54 responses were received including responses from PTs (n= 27), nurses (n= 10), oncologists and oncology residents (n= 9), occupational therapists (n= 6), a speech-language pathologist (n= 1), and

an exercise professional (n= 1). Expertise in pediatric oncology PR exists among PR HCPs working across the country. However, the majority of the PR interventions reported were primarily physical exercise interventions. Limitations in activities, alterations in motor performance, muscle weakness and peripheral neuropathy were reported as top priorities for PR programs. Funding/resources (18.8%), inappropriate space for PR (17.4%), and staffing (16%) were reported as barriers to the provision of PR services.

Conclusions: This thesis work serves as a guide to future research in the field. Given the low numbers of children diagnosed with cancer, collaborative efforts are needed on the part of researchers and clinicians to propose and conduct multicenter trials to further the field of pediatric oncology PT.

PREFACE

This thesis is an original work by Paula Ospina. The research project, of which this thesis is a part, received research ethics approval from the Health Research Ethics Board of Alberta: Cancer Committee (HREBA-CC). The project was proposed under the title "Physical therapy interventions for children and adolescents with cancer: linking patients needs, clinical expertise, and research evidence" No. HREBA.CC-17-0218, June 21, 2017.

Chapters 2, 4, and 5 comprise manuscripts that will be submitted for publication. Manuscript 1 entitled "A scoping review of physical therapy interventions for childhood cancers" was co-authored by Margaret L. McNeely (MM). Manuscripts 2 and 3 entitled "Exploring physical rehabilitation referral patterns and service provision for children and adolescents with cancer across Canada" and "Physical rehabilitation practice patterns and outcome measures in children and adolescents with cancer across Canada" respectively, were co-authored by Margaret McNeely, Lesley Wiart (LW), and David Eisenstat (DE). I was responsible for the manuscript composition. LW, DE, and MM assisted with study concept and design, study conduct, data collection, and manuscript editing. Chapter 3 of this thesis has been published as Ospina PA, McComb A, Wiart LE, Eisenstat DD, McNeely ML. Physical therapy interventions, other than general physical exercise interventions, in children and adolescents before, during and following treatment for cancer (Protocol). Cochrane Database of Systematic Reviews 2018, Issue 1. Art. No.: CD012924. DOI: 10.1002/14651858.CD012924. I was responsible for the manuscript composition. AM, LEW, DDE, and MLM assisted with protocol development, manuscript composition and editing.

DEDICATION

Dedicated to my parents,

Ana Maria López and Juan Ospina

I love you; you are and will always be my inspiration.

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I would like to acknowledge my supervisor, Dr. Margaret McNeely, for her continuous support throughout my program. She believed in my capacities to conquer the goals set forth and encouraged me to expand my knowledge beyond the boundaries of school. I am eternally grateful to her for sharing her expertise, knowledge, passion, and charisma in oncology rehabilitation research and practice. It is an honour to embark on the next journey to continue my Doctoral studies with her as my supervisor.

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Terminology, Abbreviations, Acronyms, and Definitions

1. Oncology related

a. *Cancer* – A group of diseases caused by an uncontrolled division of abnormal cells with the potential to spread into, or invade, nearby tissues.

b. *Cancer survivor* – Any person diagnosed with cancer, from the time of initial diagnosis until the end of life.

c. *Cancer care continuum* – Delivery of healthcare services for and interaction with patients from screening to diagnosis, treatment, follow-up, survivorship, and end-of-life care.

d. *Leukemia* – Type of cancer that begins in the bone marrow featuring an increased number of immature abnormal white blood cells.

e. *Lymphoma* – A group of blood cancers that begins in cells of the immune system

f. *Neuroblastoma* – A type of cancer that forms from immature nerve cells, most commonly in the adrenal gland.

g. *Central-Nervous System (CNS) cancer* – Group of cancers characterized by an uncontrolled growth of abnormal cells in the brain or spinal cord.

h. *Chemotherapy-Induced Peripheral Neuropathy (CIPN)* – A progressive and potentially reversible condition causing symptoms such as pain, numbness, tingling, and hyper-sensitivity to cold in hands and feet of patients who have received neurotoxic chemotherapeutic agents.

i. *Cancer-related fatigue* – A persistent, subjective sense of tiredness related to cancer or cancer treatment that interferes with usual functioning.

2. Physical rehabilitation related

a. *Physical rehabilitation* – Discipline that aims to enhance and restore functional ability and quality of life in those with physical impairments and disabilities.

b. *Physical therapy* – Health-care profession that aims to restore and optimize function, mobility, and quality of life of individuals of all ages.

c. *Physical exercise* – Planned and structured leisure-time physical activity aiming to maintain or enhance physical fitness, overall health, and wellness.

d. *Physical agents* – Techniques applied to produce a therapeutic response and optimize healing of soft tissue through the use of light, water, temperature, sound, or electricity.

3. Outcomes related:

a. *Facilitators* – Existing factors that enhance the implementation of pediatric oncology physical rehabilitation programs.

b. *Barriers* – Existing factors that hamper the implementation of pediatric oncology physical rehabilitation programs.

c. *Clinical practice guidelines* – Evidence-based statements that provide recommendations aiming to guide and optimize patient care, taking into account the benefits and harms of alternative care options.

CHAPTER 1: INTRODUCTION

1.1 Review of childhood cancer

It is estimated that globally over 250,000 children and adolescents between the ages 0 to 19 years will be diagnosed with cancer each year[1,2] and 175,000 of them are younger than 15 years of age.[3] In Canada, cancer in children and adolescents (0-19 year-old) is relatively rare and accounts for only 1% of all new cancer cases.[4] Nevertheless, one in five Canadian children diagnosed with cancer will die of the disease.[2] According to the Canadian statistics of 2012, cancer was the main disease-related cause of death in children under 15 years of age.[5] Cancer of the brain and central nervous system (CNS) and leukemia caused 60% of childhood cancer deaths of children aged 0 to 14 years and 32% of adolescents and young adults aged 15 to 29 years.[6]

Based on the latest publication by Statistics Canada, the annual incidence rate of childhood cancer during 2006-2010 was 161 new cases per 1,000,000 children aged 0-14 years. This accounts for 905 new cases of childhood cancer per year, about 0.5% of the total cancer diagnoses in Canada. The most common childhood cancer diagnoses are: leukemia (32%), followed by CNS cancer (19%), lymphomas (11%), neuroblastomas (8%), and soft tissue sarcomas (6%).[6] Incidence rates are higher (10%) in boys than in girls. Between 1992 and 2010, new childhood cancer diagnoses increased 0.4% every year, whereas childhood cancer deaths decreased by 2.0% per year.[5]

The incidence rate per type of childhood cancer varies depending on age. Among children aged 1 to 4 years, the incidence rates for leukemias and CNS cancers were higher than in children aged 10 to 14 years, while higher incidence rates of lymphoma are seen in older ages. In neuroblastoma, the incidence rates decrease with age, starting from 68 new cases per million in the first year of life, followed by 24 new cases per million in children aged 1 to 4 years, to 1 new case per million in children aged 10 to 14 years.[5]

Progress in cancer treatments has resulted in improved survival rates of children and adolescents with cancer, approaching or exceeding 80% 5-year survival post-diagnosis.[7] In Canada, the 5-year survival rate of children diagnosed with cancer is 83%. Currently there are over 30,000 childhood cancer survivors who are living with the long-term health effects resulting from cancer and its treatments.[2] Thus, there has been increased awareness of the need for improved survivorship care plans including medical follow-up and surveillance for long-term effects of cancer treatment.[6,8,9]

1.2 Cancer treatments

Cancer treatments aim to maximize cure and minimize long-term toxicities.[10] The treatment or combination of cancer treatments prescribed is dependent on the type and location of the tumour, stage of cancer, and likely response to the cancer therapy. The most commonly prescribed childhood cancer treatments include chemotherapy, radiation therapy, surgery, and stem-cell transplantation.[11]

1.2.1 Chemotherapy

Chemotherapy involves the administration of pharmaceutical agents to destroy cancer cells. Unfortunately, chemotherapeutic agents can also negatively impact healthy cells.[10] Consequently, chemotherapy is administered in small doses over extended periods of time, aiming to minimize the damage to healthy cells.[11] While there are different chemotherapy drugs used to treat childhood cancers, some of the more commonly used agents include: vincristine, daunorubicin, doxorubicin, methrotrexate, cyclophosphamide, prednisone, and dexamethasone. Chemotherapy agents are delivered either intravenously or orally[12] and in most cases regimens will include a combination of drugs. Possible side effects of chemotherapy include anemia (decreased red blood cells resulting in fatigue), neutropenia (decreased white blood cell count which increases the risk of acquiring an infection) and thrombocytopenia (decreased platelets resulting in increased risk of bruising and bleeding). Corticosteroids are also used to treat leukemias, lymphomas, and CNS tumours, and may cause muscle atrophy, steroid-induced myopathy, osteopenia/osteoporosis, and possibly osteonecrosis.[13,14] A literature review in 2014 explored the impact of chemotherapy on the musculoskeletal system in children and adolescents with acute lymphoblastic leukemia (ALL).[15] Results indicated that chemotherapy for ALL results in musculoskeletal morbidity with initial manifestations including joint pain, decrease of range of motion, fractures, and deformities.

Vincristine and vinblastine are chemotherapeutic agents used to treat leukemias, lymphomas, as well as brain and solid tumours. These agents may cause motor and

sensory peripheral neuropathy. Vincristine-induced peripheral neuropathy may manifest as hypoesthesia (reduced sensation), or mild paresthesia (abnormal sensation such as tingling) advancing to intense dysesthesia (unpleasant abnormal sensation). Distal muscle weakness manifesting as drop foot, alterations in fine motor skills, reduction of the reflexes, and myalgia are common, and along with the sensory changes that place the child at increased risk of falls and fractures.[15] One major side effect of chemotherapy is cancer-related fatigue, which negatively impacts the quality of life of 70 to 96% childhood cancer patients.[15] Methotrexate, a drug to treat leukemias, lymphomas, and some bone tumours may cause side effects such as osteopenia/osteoporosis[10] and neurotoxicities such as encephalopathy, seizures, and/or aphasia.[16] Moreover, a major chemotherapy long-term side effect includes cardiotoxicity, caused by the administration of anthracyclines such as Daunorubicin and Doxorubicin.[43]

1.2.2 Radiation therapy

Radiation therapy involves the use of high-energy x-rays and other particles to destroy cancer cells and is usually delivered in repeated small doses over time.[11,12] Radiation therapy can be a very effective treatment for some childhood cancers[10] and is commonly used as an adjuvant strategy to improve local control or for metastatic disease.[13] In soft tissue sarcomas, neuroblastomas, advanced nephroblastomas (wimls tumours), and Ewing's sarcomas, radiation therapy may be prescribed along with chemotherapy as an adjuvant treatment. On the other hand, in some brain tumours,

radiation therapy is considered the treatment of choice, due to the poor response and sensitivity of tumours to chemotherapy (except in very young children).[17]

Radiation therapy may be delivered either by external beam radiation or through internal radiation also called brachytherapy.[12] External beam radiation is the most common type of radiation therapy used to treat childhood cancers. Radiation is delivered by a machine outside the body (usually a linear accelerator) that aims the radiation beam at the location of the individual's cancer to destroy the local cancerous cells. Brachytherapy is a sophisticated type of radiation treatment in which radioisotopes are implanted in "seeds" within the body close to the tumour.[12,18] With the administration of brachytherapy, the amount of radiation delivered to the tissue is considerably lower compared to the external beam technique.[18] As a result, the risk of long-term complications after radiation therapy can be minimized. Children diagnosed with soft-tissue sarcomas and vaginal cancers may benefit from brachytherapy, due to the proximate location of the tumours to vital structures.[18] Specialized brachytherapy techniques exist for the management of retinoblastoma such as ocular brachytherapy, aiming to preserve the retina and adjacent structures.[18] Although brachytherapy is administered to minimize the side effects of radiation, it is not commonly used in pediatric cancers due to challenges in treatment planning.[19]

Long term effects of radiation therapy are those that persist three months or more from administration of the treatment.[13] Long-term and late effects occur in most of the body systems and the severity of effect depends on the radiation dosage, area irradiated, and type of radiation therapy.[13] Some of the more significant long-term

effects, depending on the anatomic location receiving therapy, include: demyelination, neurocognitive deficits, brain necrosis, neurotoxicity, chronic renal failure, hypertension, anemia, radiation-induced hypoplasia, radiation pneumonitis, cardiomyopathy, and hypothyroidism. Additional late effects after radiation therapy in cancer include: growth reduction, functional limitations, and secondary cancers.[13]

CNS malignancies and their treatments carry increased risk of developing significant deficits in cognitive and motor function that may potentially affect the child's ability to live independently as an adult. Radiation therapy is known to negatively affect the white matter tracts and myelination process. Endocrine impairments may affect: growth hormone, thyroid hormone, pubertal development, and axial skeletal growth. Risks of late effects are greater in younger children and those with metastasized tumours at diagnosis.[13]

1.2.3 Surgery

Surgery is the process of extraction of a tumour whether cancerous or noncancerous, along with a margin of surrounding healthy tissue.[11,12] The severity of the surgery depends on the tumour size and location, and in some cases radiation therapy and chemotherapy may be administered to reduce the size of the tumour in advance of surgery (neoadjuvant therapy).[12] In recent years, minimally invasive surgical approaches such as laparoscopy and thoracoscopy[20,21] have become more common for childhood cancers involving the lung and abdomen.[22] Laparoscopic surgery involves the insertion of a fiber-optic instrument to visualize the organs and to

perform a surgical procedure with minimal scarring and reduced wound complications. For example, laparoscopic surgery results in a lowered risk (1-2%) of haemorrhage and visceral injury when compared to traditional open surgical techniques.[23] Benefits have been attributed to the use of minimally invasive surgery, including a faster recovery, less pain,[24] and shorter hospital stay.

Osteosarcoma is a primary bone cancer, which may be treated either by limb-salvage surgery or amputation. Limb-salvage surgery involves the removal of the cancerous tissue and surrounding healthy tissue, while aiming to leave the limb intact. Limb-salvage surgery carries potential complications such as: infections, grafts or rod defects, non-union, pathologic fracture, limb-length discrepancy, endoprosthetic fracture, and limited joint range of motion.[25] Limb amputation may be performed if, for example, the tumour is large and extends into the nerve or blood vessels, and where preservation of the limb is not possible. Complications resulting from amputation include issues with fit of the prosthetic limb, chronic pain in the residual limb, phantom limb pain, and bone overgrowth.[25]

1.2.4 Stem cell transplantation

Stem cell transplantation (SCT) is a procedure in which hematopoietic stem cells found in the bloodstream are removed, or harvested, from the individual themselves or a donor prior to chemotherapy, then transplanted into the body after completion of chemotherapy.[12] This procedure is commonly used in cases where the cancer in the child has not or will not have a satisfactory response to conventional chemotherapy,

and the chances of cure are low.[26] SCT allows the administration of higher doses of chemotherapy than a child could normally tolerate.

The three types of SCT are: the allogeneic transplant, syngeneic transplant, and autologous transplant. The type of transplant commonly used in childhood leukemias is the *Allogeneic stem cell transplant (ASCT),* a procedure that uses the stem cells of a donor who is compatible with the tissue type of the child.[26] ASCT is an option when initial treatment for Acute Lymphoblastic Leukemia (ALL) is not successful. ASCT may be considered in children with Acute Myelogenous Leukemia (AML) and in other less common types of leukemias such as Juvenile Myelomonocytic Leukemia (JMML) and Chronic Myelogenous Leukemia (CML).[26] Despite the benefits, ASCT is considered a procedure that may cause other serious and potentially life-threatening effects such as: graft-versus-host disease (GvHD) (patient's own cells are attacked by donor immune system cells), lung damage, thyroid complications, alterations with bone growth, and the development of a secondary cancer.[26] A *Syngeneic transplant* is a special kind of allogeneic transplant that can be used only with an identical twin or triplet having the same genes and tissue type as the patient. *Autologous transplant* is another type of transplant that uses the child's own stem cells and is commonly administered for certain leukemias, lymphomas, and solid tumors such as neuroblastoma. In this type of transplant, the child's own healthy stem cells are harvested before the administration of the chemotherapy treatment (aiming to avoid their destruction) and the healthy stem cells are returned to the body after completion

of chemotherapy.[26] The advantages of the Syngeneic and Autologous transplants are that there is significant reduction of developing GvHD.[26]

1.3 Long-term complications after cancer treatment

Two thirds of children who have been diagnosed with cancer will also develop at least one chronic or long-term adverse effect of cancer treatment.[13] Long-term and late effects are expected health complications resulting from the cancer or cancer therapy[27] (chemotherapy, radiation therapy, surgery and stem cell transplant), that never resolve or begin to emerge months or years following treatment completion, and impact overall health and quality of life.[28] These adverse effects include impairments such as pain, fatigue, weakness,[29] peripheral neuropathy, limitations in strength, range of motion, deficits in balance and gait;[8,13,30] all of which may negatively affect the child's overall function, quality of life and ability to participate in age-appropriate activities including play.[31]

During the active cancer treatment period, children may spend periods of time on bedrest that may lead to general deconditioning including muscle weakness and decreases in cardiovascular fitness. Lack of mobility resulted from prolonged bedrest may induce: muscle contractures (shortening of muscles and connective tissues), osteopenia (minor loss of bone mass), osteoporosis (severe loss of bone mass), or result in pressure sores, cardiovascular system changes (reduced aerobic capacity, lower blood pressure, shortness of breath, and fatigue), blood clots, and lung infections.[13]

Cancer treatments for children and adolescents may lead to several long-term adverse effects amenable to physical therapy. The severity of these adverse effects depends on factors such as: type of cancer, type and dosage of treatment, and age at the time of the treatment.[32] The adverse effects associated with the five most incident types of childhood cancer are:

- ***Leukemia -*** Growth impairments secondary to stem cell transplant and osteoporosis resulting from the administration of certain chemotherapy drugs (prednisone, dexamethasone, and other steroid drugs).[32]
- ***CNS cancer -*** Impaired growth and development, muscle weakness, fatigue, neurological and cognitive deficits, and pituitary and endocrine dysfunction.[14]
- ***Lymphoma*** - Heart and lung problems derived from the administration of certain chemotherapy agents or radiation therapy to the chest area, slowed or reduced growth and development (seen mostly after stem cell transplant treatment), and osteoporosis.[32]
- ***Neuroblastoma*** – Delayed muscle development, slowed growth and development, and osteoporosis.[32]
- ***Bone sarcoma*** – Slowed or decreased growth and development in bones.[32]

According to the National Cancer Institute, cancer treatments can negatively impact the major body systems including musculoskeletal, cardiorespiratory and neurological systems.[25] The risk of long-term effects iss dependent on the tumour type and tumour related factors (e.g., location within the body, extent of the cancer), the type of cancer treatment administered (e.g., type of surgery, chemotherapy type and dosage, radiation

therapy type, location, dosages), as well as patient related factors (e.g., the child's gender, overall health pre-cancer diagnosis, age and developmental stage at time of diagnosis).[25] Many long-term effects are amenable to physical therapy intervention, particularly those involving musculoskeletal and neurological systems.

1.4 Systems affected after cancer and its treatment

1.4.1 Musculoskeletal System

Specific long-term effects from cancer treatment on the musculoskeletal system include effects on muscle and soft tissues (myopathies including proximal muscle weakness, soft tissue contracture, and radiation fibrosis syndrome), as well as effects on bone resulting in inhibition or cessation of bone growth, scoliosis or kyphosis, limb length discrepancies, osteoporosis, avascular necrosis (often attributed to corticosteroids, especially in our adolescents and young adult patients), and osteoradionecrosis.[25] The impact of surgery such as amputation and limb-salvage techniques may result in chronic pain, gait and balance dysfunction, and lower levels of overall activity. Effects involving the musculoskeletal system are more likely to occur in cancers such as ALL, osteosarcoma, brain and spinal cord tumours; and in children who have undergone a stem cell transplant.[25]

1.4.2 Neurological System

Specific long-term effects involving the neurological system include impairments in motor function and sensory deficits (loss of fine motor skills, impairments in coordination and balance, movement disorders, and peripheral nerve

damage in the hands and feet).[25] Children with brain tumours or ALL who receive central nervous system prophylaxis with intrathecal chemotherapy (methotrexate) are more likely to develop neurocognitive late effects, especially those who also receive cranial radiotherapy. Neurocognitive deficits in children and adolescents are associated with social withdrawal and reduced social skills; and can impact participation in normal childhood activities. Neurologic late effects in adult survivors of childhood cancer include chronic peripheral neuropathy, a condition that may result from administration of neurotoxic agents such as vincristine and cisplatin.[25]

1.5 Statement of the problem

Focused physical therapy intervention may help children who are experiencing adverse effects resulting from cancer treatment, particularly those effects associated with prolonged cancer treatments.[33] Physical therapy is a health-care profession that aims to restore and optimize function, mobility, and quality of life of individuals of all ages.[34] In oncology rehabilitation, physical therapists work with patients to manage musculoskeletal and neuromuscular impairments.[34] The rehabilitation needs of cancer patients include treatments to address acute, late and long-term effects, as well as those associated with palliative disease.[34]

Physical therapy treatment starts with an evaluation of the child's physical status. The physical therapist will perform an assessment to determine physical function, joint mobility, and muscle strength and flexibility. Findings of the assessment are used to inform an appropriate tailored intervention for the child.[34] Physical therapy can help children with cancer regain function through interventions that aim to reduce

pain in soft tissues (muscles, tendons and ligaments), build muscle strength, improve soft tissue and joint flexibility, range of motion, and function as well as overall mobility. Treatment services can be delivered before (prehabilitation), during and after treatment completion (rehabilitation).[35] Prehabilitation services include interventions that are administered between the time of diagnosis and cancer treatment initiation. Prehabilitation intervention may be prescribed to enhance a child's physical functioning and general health status to enable improved tolerance to cancer treatments, and to optimize overall outcomes and recovery from the upcoming cancer treatment. Rehabilitation services delivered during or following cancer treatment are defined as services that help a child to recover function or relearn skills after a diagnosis of cancer. Importantly, focused and timely physical therapy intervention may help to prevent the development of late effects and attenuate the severity of long-term effects.[35]

To date, the majority of research trials in cancer rehabilitation have been performed with adult cancer survivors. Positive results from physical therapy interventions, primarily in the area of breast cancer, have been reported.[36-40.] Impairment-based cancer rehabilitation for children and adolescents with cancer is a growing area of research and clinical practice. A recent Cochrane Systematic Review examined the effects of physical exercise training interventions for children and adolescents with cancer.[41] The review included 5 studies involving 131 childhood participants, all of which were being treated for ALL. Preliminary findings from the review support the benefit from general physical exercise training for body composition, flexibility and cardiorespiratory fitness. A systematic review in 2016

synthesized the evidence of the effects of non-pharmacologic and non-surgical rehabilitation interventions on physical impairments and functional mobility limitations in children and adolescents undergoing treatment for non-CNS cancers. Twenty-two studies were reviewed, and findings suggested that while research exists evaluating exercise and physical activity programs, a paucity of studies have been performed related to physical therapy interventions, especially in the areas of neuromuscular re-education and functional training.[42]

Thus, to date, little is known about the benefits of physical therapy or the services currently provided to address adverse late and long-term effects of cancer and its treatments. Specifically, (1) no literature reviews have been performed examining the benefits and synthesizing the evidence for physical therapy interventions (that extend beyond exercise training only) for impairments related to childhood cancers and their treatments; and (2) information is lacking on existing physical therapy services and practice patterns across Canada for children and adolescents with cancer.

1.6 Objectives

1.6.1 Primary objective

To collate and synthesize the research evidence and current clinical physical rehabilitation practices to inform a strategy to guide future research in pediatric oncology physical therapy.

1.6.2 Secondary objectives

1). Phase I: To synthesize and evaluate the state of evidence supporting physical therapy interventions for children and adolescents (0-19 years-old) before, during and following the treatment for cancer, to provide a best-evidence synthesis of the research, and to identify areas requiring further research.

2). Phase II: To identify current clinical rehabilitation practice patterns and service provision offered by physical therapists and healthcare practitioners working with children and adolescents with cancer across Canada.

- To collate information on clinical programs and evidence-based guidelines specific to pediatric oncology rehabilitation.
- To identify existing barriers and facilitators that may impact the implementation of pediatric oncology physical rehabilitation programs.

1.7 Hypotheses

Phase I

We hypothesized that, to date, there is limited high quality research evidence supporting the benefit of physical therapy for children and adolescents with cancer.

Phase II

We hypothesized that expertise exists among clinical physical therapists and healthcare providers working in the pediatric oncology field and that specialized interventions are currently being delivered in some clinical settings.

1.8 Delimitations

1. A scoping review was performed examining the literature using three primary databases.

2. A convenience sample of healthcare providers was used for the survey. Participants were contacted through pediatric oncology professional connections and organizations.

3. A secure database at the University of Alberta (REDCap) was used to create and deliver the survey instrument in English and French languages.

4. The survey consisted of three sections gathering information on practice patterns and service provision related to physical rehabilitation in childhood cancer survivors.

1.9 Limitations

1. Findings of the scoping review were limited by the small number of studies included in the review and the variability of the included studies in terms of patient populations, interventions and chosen outcomes, limiting our ability to synthesize the findings and make recommendations for clinical practice.

2. The survey sample consisted of 54 healthcare providers across Canada. Professional designations included: physiotherapists (n= 27), nurse and nurse practitioners (n= 10), oncologists and oncology residents (n= 9), occupational therapists (n= 6), a speech-language pathologist (n= 1), and an exercise professional (n= 1).

3. The sample of survey respondents represents a sample of physical therapists and healthcare professionals who provide and/or refer children and adolescents with cancer to physical rehabilitation services and who were interested and willing to complete the survey.

1.10 Significance of the Survey Study

The results of this study will help identify and characterize pediatric oncology rehabilitation services across Canada and identify clinical programs and protocols in the area. Additionally, a better understanding of the current practices in physical rehabilitation in children and adolescents with cancer will allow health practitioners and researchers to design, implement, and test protocols to improve outcomes before, during, and after cancer treatments. Given the potential benefits of physical therapy and cancer rehabilitation for childhood cancer survivors, it is hoped that this information will encourage collaborative research in the area.

1.11 Thesis Format

Moving forward, this thesis is presented in a combination of the traditional monograph format and in a multiple-manuscript, journal-article format:

Chapter 2 comprises Manuscript #1 entitled: ***"A scoping review of physical therapy interventions for childhood cancers".***

Chapter 3 comprises Manuscript #2, a protocol paper published in the Cochrane Database of Systematic Reviews entitled: "***Physical therapy***

interventions, other than general physical exercise interventions, in children and adolescents before, during and following treatment for cancer".

Chapter 4 comprises Manuscript #3, Paper I of the Survey entitled: ***"Exploring physical rehabilitation referral patterns and service provision for children and adolescents with cancer across Canada".***

Chapter 5 comprises Manuscript #4, Paper II of the Survey entitled: ***"Physical therapy practice patterns and outcome measures in children and adolescents across Canada".***

Chapter 6: Discussion

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CHAPTER 2: PHASE I - LITERATURE REVIEW

Manuscript 1

A scoping review of physical therapy interventions for childhood cancers

(A manuscript submitted to the journal:

Physiotherapy Canada)

2.1 Abstract

Relevance: Children and adolescents with cancer who undergo cancer treatment are at high risk of developing serious long-term physical effects, which may negatively affect the child's overall quality of life and ability to participate in age-appropriate activities including play. Impairment-based cancer rehabilitation for children is a growing area of physical therapy (PT) that requires further development and research. **Objectives:** This scoping review aims to (1) outline the state of the research involving PT for children with cancer to inform clinical practice, and (2) identify gaps in the literature for future research. **Materials and Methods:** Electronic searches were conducted in three major databases (MEDLINE, EMBASE, and PEDro) from January 2002 to October 2017 as well as reference lists, manual searches, theses, and conference proceedings. **Analysis:** We conducted a descriptive analysis of the included studies. **Results:** Of 4,182 articles retrieved using the search strategy, a total of 12 papers were included in the review, including 1 randomized controlled trial, 1 pilot randomized trial, 5 pilot or feasibility studies, 2 prospective studies, 1 case series, 1 case report, and 1 retrospective study. The research examining PT for childhood cancer supports feasibility of interventions; however, current evidence is not at a level yet to inform clinical practice. To better elucidate treatment protocols and assess benefits for tumour-specific impairments, research is needed examining the effects of PT within specific cancer tumour types. **Conclusions:** Collaborative efforts through multicenter trials are needed to further field of pediatric oncology PT.

Keywords: cancer, physical therapy, rehabilitation, pediatrics, children, adolescents

2.2 Introduction

It is estimated that globally over 250,000 children and adolescents between the ages 0 to 19 years will be diagnosed with cancer each year.[1,2] Cancer is the main disease-related cause of death in children under 15 years of age,[2,3] with one in five Canadian children diagnosed succumbing to the disease.[2] Progress in cancer treatments has resulted in survival rates approaching or exceeding 80% five-year survival post-diagnosis, with over 30,000 Canadian children living with the effects of cancer.[2,4-6]

Two thirds of children diagnosed with cancer will develop at least one late or long-term adverse effect.[6,7] These effects include impairments such as pain, fatigue, weakness, peripheral neuropathy, limitations in strength, range of motion, and deficits in balance and gait;[5,6,8,9] all of which may negatively affect the child's overall function, quality of life, and ability to participate in age-appropriate activities, including play.[10] Thus, there is a need for inclusion of rehabilitation in survivorship care plans to monitor for, and address these late and long-term effects of cancer treatment.[5,11]

Focused cancer rehabilitation may help children who are experiencing adverse physical effects resulting from prolonged cancer treatments. Evidence supports the benefits of general physical exercise training regimens and other nonpharmacological interventions in childhood cancer.[12-15] A 2016 Cochrane Systematic Review examined the effects of physical exercise training interventions involving 131 children and adolescents with Acute Lymphoblastic Leukemia (ALL).[16] Preliminary findings support the benefit of exercise for outcomes related to body composition, flexibility and cardiorespiratory fitness. Another systematic review published in 2016 synthesized the

evidence from 22 studies examining conservative rehabilitation interventions on physical impairments and functional mobility limitations in children and adolescents undergoing treatment for non-CNS cancers.[17] The authors concluded that while studies exist supporting general exercise programs, there is a lack of research examining physical therapy (PT) interventions in areas such as neuromuscular re-education and functional retraining.

To date, no reviews have been performed evaluating and synthesizing the evidence specifically for PT interventions for impairments related to cancer and their treatments. This scoping review aims to (1) inform the state of the research evidence on the benefits of PT for children and adolescents with cancer, and (2) identify priorities for future research.

2.3 Methods

A scoping review was conducted to inform the state of the evidence in the field of pediatric oncology PT. This approach for identifying literature provides an overview of an area of research that is still growing, and helps to identify gaps and synthesize information for those working in the field.[21] The methodology used in this scoping review was based on the framework proposed by Arksey and O'Malley (2005)[18] and recommendations made by Levac D, Colquhoun H, & O'Brien KK (2010).[19] The five stages of conducting a scoping review include: 1) identifying the research question; 2) identifying relevant studies; 3) study selection; 4) charting the data; and 5) collating, summarizing and reporting the results.

2.3.1 Identifying the research question

"What is the state of the evidence on PT interventions used to treat impairments and functional limitations related to cancer and cancer treatment in children and adolescents?" For this review, PT interventions were defined as those that aim to address impairments and optimize function, mobility, and quality of life in children and adolescents with cancer.[20] Interventions of interest for this review included: manual therapy techniques, therapeutic exercise, balance and coordination retraining, gait re-education, neuro-motor rehabilitation, and electrophysical modalities for symptom relief.[21]

2.3.2 Identifying relevant studies

A medical librarian at the University of Alberta was consulted to help develop the appropriate search strategies for the three major databases relevant to the area. Our aim was to enhance the quality of the literature search and to capture relevant articles for the scoping review. Articles published from January 2002 to October 2017 were searched in three electronic databases including MEDLINE (high-quality research trials), EMBASE (grey literature), and PEDro (physical therapy specific); as well as reference lists of articles reviewed, theses, and conference proceedings. Language was restricted to English and Spanish only. The search strategies for the three electronic databases (using a combination of controlled vocabulary and text words) are shown in Appendix A.

2.3.3 Study selection

Inclusion/exclusion criteria for article selection

Articles were selected according to the following criteria:

1) studies including children and adolescents from 0 to 19 years of age,
2) full-text article was available,
3) PT intervention (as defined above), and
4) available in English or Spanish.

Studies were excluded if:

1) data were available in abstract form only, and
2) the intervention involved general physical exercise or a physical activity intervention alone.

2.3.4 Article extraction

After applying the search strategy, two authors (Xs and Zs) independently identified potentially relevant articles via abstract review. A full copy of the article was then obtained. Articles were evaluated for inclusion. All discrepancies were solved by consensus between the two authors.

2.3.5 Charting the data

The authors developed a data extraction table and independently collected relevant information on PT interventions in the following areas: type of study, purpose of the intervention, type of cancer, type of intervention, primary outcome, outcome

measures and measurements, and relevant findings. All discrepancies were solved by consensus between the two authors.

2.3.6 Collating, summarizing and reporting the results

A level of evidence was applied to the studies according to the Oxford Centre of Evidence Based Medicine (OCEBM) Levels of Evidence 2011 (Table 1).[22] Findings were summarized with the aim to identify gaps in knowledge and research needs.

Table 1: Oxford Centre for Evidence-Based Medicine 2011 Levels of Evidence

Level 1	Systematic Reviews of randomized trials
Level 2	Randomized trials
Level 3	Non-randomized controlled cohort/follow-up study
Level 4	Case series, Case-control studies
Level 5	Not applicable

Adapted from Howick et al. 2011[22] and Turner et al. 2013[41]

2.4 Results

After searching the three major electronic databases and other sources, a total of 4,182 articles were retrieved. After scanning titles and abstracts, and removing duplicates, 98 abstracts were selected for initial screening. Twenty-five full-text articles were screened and 12 articles were deemed eligible. Figure 1 illustrates the screening process and number of articles selected based on the inclusion and exclusion criteria.

2.4.1 Study design & Methodological quality

Five studies were pilot or feasibility studies,[23-27] two prospective studies,[28,29] one was a randomized trial,[30] one was a pilot randomized trial,[31] one retrospective study,[32] one case series,[33] and one case report.[34] Further information on the included studies is provided in Table 2. One study was classified as Level 2 evidence,[30] 9 studies as Level 3,[23-29,31,32] 1 study as Level 4,[33] and 1 study was not classified as it is a case report.[34] Small sample sizes were common across the included studies with 7 studies having sample sizes less than 30 (Table 2).

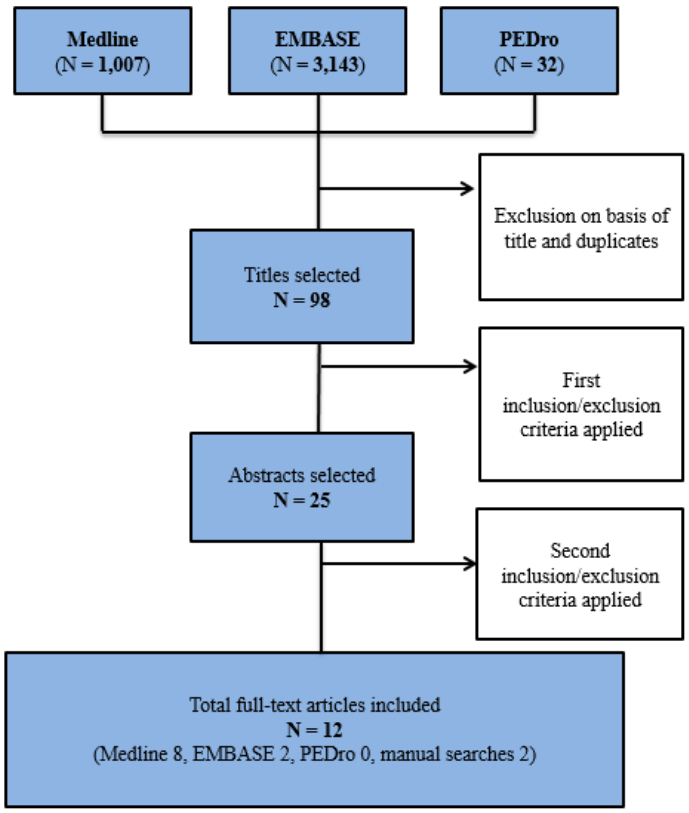

Figure 1. Search strategy for retrieved articles

2.4.2 Type of cancer

The types of cancer identified in the studies include: leukemia, sarcoma, bone tumour, brain tumour, lymphoma, central nervous system (CNS) cancer, neuroblastoma, medulloblastoma, bone and soft tissue sarcoma, and Wilms' tumour. Four studies included children diagnosed with ALL alone,[24,25,30,34] 7 included multiple cancer types,[23,25,27-29,31,32] and 1 included children diagnosed with medulloblastoma (Table 2).[33]

2.4.3 Physical therapy interventions

PT interventions varied among the 12 identified studies (Table 2). Interventions included upper/lower-extremities strengthening exercises,[24,26,27,29,30,34] aerobic exercises,[24,28-30,34] functional exercises;[30,34] transfer skills;[25,27, 34] static/dynamic balance training,[26,29,33,34] upper/lower-extremities stretching exercises;[24,30] mirror therapy;[31,32] gait training;[25-27,29] coordination exercises;[33] manual therapy;[31] neuro-motor/motor/strain rehabilitation;[23] and hippo therapy and aquatic exercises.[28,29] Details on the PT interventions are shown in Table 2.

2.4.4 Outcome measures and measurement methods

Outcome domains were classified under 11 categories of measures (Table 3). The most common outcomes evaluated across the studies were measures of function

Table 2 - Summary of Included Studies

Author(s); year; country	Type of study/ Level of evidence	Objectives	Type of cancer/ age range/ sample size (N)	Interventions	Outcome measures and measurements	Main findings
Marchese et al (2004)[30] USA	RCT Level 2	To examine the efficacy of PT on strength, ROM, endurance, and quality of life (QoL)	ALL Ages: 4-15 yrs N= 28 IG: n= 13 CG: n= 15	IG: Play/ enjoyment based: 5 sessions; 20min-1h duration + home exercise program with focus on functional exercises, lower extremity (LE) strengthening, ankle dorsiflexion stretching, daily aerobic fitness x 4 months CG: usual care: no instruction or PT treatment	**Strength:** Hand-held dynamometry **ROM:** Goniometry **Functional mobility:** Timed up and down stairs (TUDS) test **QOL:** PedsQL **Functional capacity:** 9-min run-walk test	**Efficacy:** PT significantly increased ankle dorsiflexion active range of motion ($p < 0.01$) and knee extension strength ($p < 0.01$) in favour of intervention.
Savio et al (2007)[23] Italy	Pilot single group: before/ after Level 3	To determine feasibility of clinical program delivery model: Report on first two years of an integrated home/ hospital PT program	CNS tumours, Leukaemia, Neuroblastoma, Bone tumours, Lymphoma, Sarcoma Ages: 6 months to 21 yrs N= 46	Integrated PT home & hospital-neuro-motor rehabilitation, motor and functional retraining, respiratory care, and symptom management: massage, mobilizations and postural correction	**Feasibility:** # visits, treatments & treatment duration in days **Treatment cost**: euros	**Feasibility:** 46 children received PT treatment; 1,398 treatments provided; 67% of PT sessions provided at child's home; median duration 39 days; PT salary: 15000 Euros; cost of single treatment: 32 Euros.
Gohar et al (2011)[24] USA	Pilot Single group: before/ after Level 3	To determine feasibility of an in-hospital PT- and home exercise program during the first four phases of cancer treatment	ALL Ages: 2-14 yrs N= 9	Individualized home exercise program – age appropriate exercise (Play/ enjoyment-based): stretching, strengthening, aerobic exercise At hospital PT 3/wk	**Functional abilities:** Gross Motor Function Measure **QOL**: PedsQL **Family satisfaction:** Parent satisfaction questionnaire	**Feasibility:** 98% completion rate. **Descriptive:** PedsQL and GMFM scores showed a gradual increase since diagnosis.
Harbourne et al (2014)[33] USA	Case series Level 4	To determine feasibility of neuromodulation devices combined with an intensive PT intervention	Medulloblastoma Ages: 5 months & 14 yrs N= 2	Electrical neuromodulatory device for each child. 3 days of therapy to train the use of the devices and motor learning activities. General exercises - static balance for postural steadiness feedback, dynamic balance, and coordination	**Balance:** Berg Balance Test for Pediatrics (BBT-P); Bruininks-Oseretsky Test of Motor Skill (balance section) **Gait:** Gait-Rite mat and software system	**Feasibility (descriptive findings):** improved Berg Balance Test for Pediatrics scores and ability to stand on a dynamic surface.
Tanner et al (2015)[25] USA	Pilot single group: before/ After	To determine feasibility and preliminary efficacy of PT + Ankle Foot	ALL Ages: 5-11 yrs N= 7	PT training of heel-toe gait pattern, floor to stand transitions, and stair negotiation (45-60 mins) wearing the AFO (23-24 hours/day)	**Gait:** GAITRite Analysis System; **ROM:** Goniometry; **Strength:** Hand-held dynamometry; Manual muscle test	**Feasibility:** no adverse events **Preliminary efficacy:** Increased ankle dorsiflexion strength ($p = .046$); passive ankle dorsiflexion

	Level 3	Orthosis (AFO) for peripheral muscle weakness			**Physical performance:** Six-minute walk test; Actigraphy **Fatigue:** The Childhood Fatigue Scale	ROM (p = .027); step length, stride length, and velocity (p = .028).
Casanova-Garcia (2015)[31] Spain	Pilot RCT (Protocol paper with preliminary results) Level 3	To describe the effect of Graded Motor Imagery (GMI) and Neural Mobilization (NM) on neuropathic pain	Any cancer Ages: 5-18 yrs Preliminary N= 7	IG: receive pharmacological management + Physical therapy: including manual therapy & Graded Motor Imagery (Motor imagery, Laterality recognition, Mirror therapy) CG: receive pharmacological management alone	**Pain:** Neuropathic pain survey; Visual Analog Scale; Algometry **Neurodynamics:** Slump test; Upper-limb Neurodynamic tests	**Descriptive:** preliminary results at 4 weeks demonstrate improvement in pain threshold of the limb and pain perception.
Anghelescu et al (2016)[32] USA	Retro-spective descriptive study Level 3	To describe the benefit of mirror therapy (MT) + standard therapy to standard therapy alone	Sarcoma Ages: 8-24 N = 18 IG: n= 9 CG: n= 9	Mirror Therapy: place residual limb in a mirror box triangle, performing ankle pumps, ankle circles, and quadriceps contractions while viewing intact extremity reflection.	**Phantom limb Pain:** 11-point Numerical Pain Score (0-10)	**Descriptive:** Mirror Therapy group had a lower incidence (11%) and duration of Phantom Limb Pain compared with non-Mirror Therapy group (67%) at 1-year post amputation.
Vercher et al (2016)[34] USA	Case report Not classified	To describe the benefit of a play-based PT intervention during chemotherapy	ALL (relapsed) Age: 3 yrs N = 1	Play-based therapy: 3-5/wk for 5 wks: functional exercises, transfer skills, aerobic activities, LE strengthening, balance	**Pain:** Wong-Baker (Faces) Pain Scale **Functional exercise capacity and endurance:** 6MWT **LE strength:** Observation **Functional mobility:** Functional Independence Measure **QOL:** HUI3	**Feasibility:** play-based inpatient PT protocol is feasible. **Descriptive:** improvement in FIM scores for transfer activities, HUI3, 6MWT, and LE strength
Müller et al (2016)[28] Germany	Single-group: before/ after Level 3	To examine the benefit of a 4-week inpatient rehabilitation program after acute cancer treatment	Leukemia, Lymphoma, Brain tumour, Sarcoma Ages: 4-18 yrs N= 150 (Leukemia/ lymphoma n=86; Brain tumour n= 38; Sarcoma n=26)	Land-based and aquatic exercises, hippo therapy, exercise training, sports games	**Physical activity and cadence:** Activity Monitor **QOL:** KINDL® questionnaire	**Preliminary efficacy:** Significantly higher levels of cadence and gait cycles at 12-month follow-up (p <0.001). Improvements in QOL at 4-week (p < 0.001) and 12-months (p < 0.006)
Tanner et al (2017)[26] USA	Longitudinal, descriptive, study Level 3	To determine the feasibility of "The Spotlight" (SLP) PT program during ALL treatment	ALL Ages: 1-22 yrs N= 135	5-sessions SPL (45-60min), 3 intensity levels: ROM, gait, strength, balance, gross motor function	**ROM:** Goniometer **Functional strength:** Floor to stand **Gait:** Observation **Balance:** SLS **Gross motor:** PDMSII, BOT-2 **Activity level:** Lansky Play and Karnofsky	**Feasibility:** safe intervention, 46% completion rate; 32% meeting discharge goals **Descriptive**: improvements seen in physical outcomes.

					Performance scales	
Muller et al (2017)[29] Germany	Single-group: before/ after Level 3	To examine the effects of a 4-wk inpatient rehabilitation program on postural control	Brain tumour Bone and Soft Tissue Sarcoma Ages: 4-18 yrs N= 88 (brain tumour n =59; Sarcoma n= 29)	Individual and deficit-oriented land-based PT, aquatic PT, hippo therapy, exercise therapy	**Postural Control:** Single leg stance **Gait:** Video Gait analysis	**Preliminary Efficacy:** Moderate to large beneficial effects on Postural Control - reduction in postural sway ($p < 0.009$) and increased single leg stance time ($p < 0.001$). Small beneficial effect on Gait for walk ratio ($p = 0.056$).
Corr et al (2017)[27] USA	Prehabilitation Pilot study – age & gender matched historical control Level 3	To determine feasibility of a strength and mobility training program during chemotherapy and prior to limb-sparing procedure or amputation.	Osteosarcoma, Ewing's sarcoma, undifferentiated sarcoma Ages: 8-20 yrs N = 49 CG n= 35 IG n= 14	Prehabilitation during neo-adjuvant chemotherapy: 10-12wks: endurance, strengthening, stretching, standing, transfer training, gait training, bilateral LE ROM	**Physical function:** Functional Mobility Assessment **ROM:** Goniometer **Strength:** Break test	**Feasibility:** 50% mean attendance at sessions. **Preliminary Efficacy:** IG had a significantly higher Functional Mobility Assessment score compared to CG ($p= 0.0267$)

Abbreviations: PT: physical therapy; RCT: randomized controlled trial; QoL: quality of life; LE: lower extremity; ROM: range of motion, IG: intervention group; CG: control/ usual care group; Mirror Therapy (MT): 6MWT: six minute walk test

(n= 6), strength (n= 5), sensorimotor outcomes (n= 4), gait (n= 4), flexibility/ joint ROM (n=4), and quality of life (n=4).

Table 3. Outcome domains

Study	Outcome domains										
	Gait	**Posture**	**Balance**	**Strength**	**Flexibility/ Joint ROM**	**Motor development**	**Functional abilities**	**Quality of life**	**Pain**	**Sensory-motor function**	**Fatigue**
Marchese et al (2004)[30]				✓	✓		✓	✓		✓	
Savio et al (2007)[23]											
Gohar et al (2011)[24]						✓	✓	✓		✓	
Harbourne et al (2014)[33]	✓		✓								
Tanner et al (2015)[25]	✓			✓	✓		✓			✓	✓
Casanova-Garcia (2015)[31]									✓	✓	
Anghelescu et al (2016)[32]									✓		
Vercher et al (2016)[34]				✓			✓	✓	✓		
Müller et al (2016)[28]								✓			
Tanner et al (2017)[26]	✓		✓	✓	✓	✓	✓				
Muller et al (2017)[29]	✓	✓	✓								
Corr et al (2017)[27]				✓	✓		✓				
Total	**n= 4**	**n= 1**	**n= 3**	**n= 5**	**n= 4**	**n= 2**	**n= 6**	**n= 4**	**n= 3**	**n= 4**	**n= 1**

***n:** number of studies classified in the category

2.4.5 Synthesis of Findings

To better elucidate the extent of the literature in the field, findings were synthesized by type of cancer examined, timing and type of PT intervention, primary objective of the study, focus of the study findings, and level of the evidence. As demonstrated in Table 4, a majority of studies were open to participants with multiple different cancer types (mixed), were performed during cancer treatment, involved multiple/ mixed interventions, did not report a primary objective outcome, reported data related to feasibility, and used non-randomized controlled trial designs.

Table 4. Synthesis of results

Types of cancer				
ALL **(n* = 4)** [24,25,30,34]	CNS cancer **(n = 1)**[33]	Lymphoma **(n = 0)**	Neuroblastoma **(n = 0)**	Mixed cancers **(n = 7)** [23,25,27-29,31,32]
Timing of interventions				
Prehabilitation **(n = 1)**[27]	During cancer treatment **(n = 7)** [23-26,29,30,34]	After cancer treatment **(n = 3)**[28,31,32]	Survivorship **(n = 1)**[33]	Across cancer continuum **(n = 0)**
Types of intervention				
Gait retraining **(n = 1)**[25]	Balance/ coordination **(n = 1)**[33]	Neuro-motor rehabilitation **(n = 3)**[23, 31, 32]	Physical agents **(n = 0)**	Mixed interventions **(n = 7)** [24,26-30,34]
Primary outcomes				
Balance **(n =1)**[33]		Quality of life **(n =0)**	Pain **(n =1)**[32]	Unclear/not reported

	Physical activity **(n =1)**[28]			**(n =9)** [23-27,29-31,34]
Study findings				
Feasibility **(n =6)**[23-27,33]	Effects **(n =3)** [29-31]	Effectiveness **(n =1)**[34]	Difference description **(n =1)**[32]	Results evaluation **(n =1)**[28]
Levels of evidence				
Level 1 **(n = 0)**	Level 2 **(n = 1)**[30]	Level 3 **(n = 9)** [23-29,31,32]	Level 4 **(n = 1)**[33]	Level 5 **(n = 1)**[34]

***n:** number of studies classified in the category

2.5 Discussion

The primary finding of this scoping review is that hospital and home-based PT programs are feasible for children during and following cancer treatment.[23, 24] No adverse events were reported and preliminary results support potential benefit both descriptively, and when analyzed, statistically.

2.5.1 Level of evidence

In assessing the level of research evidence, the majority of the included studies were considered Level 3 evidence, indicating that higher quality research is needed. Marchese et al (2004) performed one of the first studies and highest quality study in the field. The investigators used a randomized trial design to examine the effects of a PT intervention in children with ALL.[30] Although this study was published in 2004 when childhood cancer survivors' treatments may have been more aggressive, findings are

still relevant to practice today as deficits resulting from the chemotherapeutic agent vincristine, such as drop foot, are still commonly seen. A further randomized controlled trial (RCT) examining interventions for neuropathic pain is currently underway; however, only preliminary results are available.[31]

2.5.2 Types of cancer

One-third of the studies included only children with ALL, the most common type of cancer in children.[24, 25, 30, 34] We did not find any studies, however, examining the efficacy of PT programs specific to Lymphoma or CNS cancers alone which are the second and third most common cancers in children.[35] To better elucidate treatment protocols and assess benefits for tumour-specific impairments, research is needed examining the effects of PT within specific cancer tumour types.

2.5.3 Timing of interventions

Most of the studies included were conducted during and after cancer treatments. One pilot study was carried out during the prehabilitation phase during neoadjuvant chemotherapy prior to surgery.[27] This study demonstrated that 85% of children awaiting a limb-salvage procedure or amputation were able to complete the 10 to 12 weeks of prehabilitation. Improvements were seen in walking distance 9-Minute Walk/Run (9MRT) and Functional Mobility Assessment (FMA) scores, suggesting that this program is feasible and has the potential to improve functional mobility that may prove beneficial for post-surgical outcomes.

2.5.4 Types of interventions

The wide range of prescribed PT interventions and different combinations of interventions make it difficult to compare and synthesize results across studies. In general, however, PT interventions comprised play-based activities or individually tailored interventions with most of the studies reporting some adaptation of the PT intervention to meet the needs and interests of children and families. As an example, a case report involving a 3-year old child with ALL demonstrated that a play-based PT intervention can improve quality of life, aerobic capacity, lower extremities strength, transfer skills, and overall activity endurance.[34] Preliminary findings from a pilot study involving graded motor imagery including motor imagery exercises, laterality recognition, and mirror therapy, showed improvements in the pain threshold and pain perception in the limb.[31]

2.5.5 Outcome measures

Only three of the included studies reported a primary objective outcome (Table 3). A wide variability of outcome measures was seen across the studies with the most common focusing on function and impairments of pain and ROM. Of note, outcomes related specifically to chemotherapy-induced peripheral neuropathy (CIPN) and fatigue were generally lacking. CIPN is a major cancer treatment-related impairment that commonly occurs after the administration of neurotoxic chemotherapeutic agents, including vincristine and platinum-based compounds. While four studies examined interventions for drop foot, and others examined neuropathic pain, none of the included studies examined the effects of PT interventions on CIPN as a clinical entity.

Fatigue is one of the most distressing side effects of cancer in children and adolescents.[36, 37] Previous studies have reported positive benefits of physical exercise on symptoms of fatigue.[38-40] While one study included fatigue as an outcome,[25] none of the included studies reported measuring fatigue in terms of its impact on adherence to the PT intervention. Including fatigue as an outcome may prove valuable in better understanding the issues compromising adherence[26] and completion rates[27] that were reported in two of the studies, respectively.

2.5.6 Key findings

The majority of research in the area has focused on documenting aspects related to the feasibility of PT interventions.[23,24,26,27,33] Thus, future research is needed examining the efficacy of PT interventions for children within specific cancer tumour types. Moreover, the findings of this scoping review suggest a need for prioritization of childhood cancer survivors' rehabilitation needs so that future research efforts can ultimately inform clinical practice. Thus, a strategy is needed to facilitate high quality clinical trials and address issues related to small sample sizes - a common concern in pediatric oncology. Collaborative efforts are needed on the part of researchers and clinicians to propose and conduct national and international multicenter trials. Pediatric oncology organizations/associations such as the Canadian Physiotherapy Association - Oncology and Pediatric Divisions, Canadian Association of Nurses in Oncology, C17 Children's Cancers and Blood Disorders Council, Canadian Pediatric Society, Pediatric Oncology Group of Ontario (POGO), and the Kids with Cancer Society may serve as

channels to potentially connect clinicians and researchers. Embracing this type of strategy is likely essential to progress the field of pediatric oncology rehabilitation.

2.5.7 Limitations

A potential limitation of this scoping review is that only three electronic databases were searched (Medline, EMBASE, PEDro). Thus we may have missed some relevant articles. However, to further obtain articles, we searched the references lists, conference proceedings, and dissertations, which may have alerted us to other research in this area. The main limitation of this review is related to the variability of the included studies in terms of patient populations, interventions and chosen outcomes, limiting our ability to synthesize the findings and make recommendations for clinical practice.

2.6 Conclusions

Given the paucity of research examining PT interventions in childhood cancer, it is difficult to draw conclusions to inform clinical practice. At present, strong evidence supporting the benefit of PT interventions is lacking. Evidence to date, from feasibility and pilot study work, however, can serve to inform future researchers in designing, developing and testing PT interventions. Collaborative efforts to design and conduct multicenter trials is strongly recommended to enhance research productivity and quality in the pediatric oncology rehabilitation field.

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Declarations of interest

The authors report no declarations of interest.

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CHAPTER 3: PHASE I - SYSTEMATIC REVIEW PROTOCOL

Manuscript 2

Physical therapy interventions, other than general physical exercise interventions, in children and adolescents before, during and following treatment for cancer (Protocol)

This Protocol of a Cochrane Review was published in the *Cochrane Database of Systematic Reviews* 2018, Issue 1. Cochrane Protocols and Reviews are regularly updated as new evidence emerges and in response to feedback, and the *Cochrane Database of Systematic Reviews* should be consulted for the most recent version of the Protocol

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[Intervention Protocol]

Physical therapy interventions, other than general physical exercise interventions, in children and adolescents before, during and following treatment for cancer

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3.1 Abstract

This is a protocol for a Cochrane Review (Intervention). The objectives are as follows:

3.1.1 Primary objective

To evaluate the efficacy of physical therapy intervention on the quality of life (QoL) outcomes of children and adolescents who have been diagnosed with cancer. Participants must be between the ages of 0 and 19 years at the time of the physical therapy intervention study. The intervention may occur prior to, during or following cancer treatment, or in a range of times of delivery. The intervention must be compared to a control group of children receiving standard care, no physical therapy intervention or a comparison intervention. We will exclude general physical exercise studies where the primary aim is to improve physical fitness through aerobic, anaerobic, resistance exercise, or combined physical exercise training regimens (i.e. combined aerobic and resistance exercise regimens). We will also record any adverse effects resulting from physical therapy interventions.

3.1.2 Secondary objectives

To evaluate the efficacy of physical therapy interventions on fatigue, pain, peripheral neuropathy, balance and gait, as well as the range of motion and strength of a specific joint or impaired body region.

3.2 Background

3.2.1 Description of the condition

It is estimated that globally over 250,000 children and adolescents between the ages 0 to 19 years will be diagnosed with cancer each year (Kids Cancer Care 2016; WHO 2016); and 175,000 (70%) of them will be children under the age of 15 years (Ward 2014). Progress in cancer treatments has resulted in improved survival rates of children and adolescents with cancer, now approaching or exceeding 80% for 5-year post-diagnosis survival (O'Leary 2008; Robison 2009; Skinner 2012); thus, there has been increased awareness of the need for survivorship care plans including medical follow-up and surveillance for long-term effects of cancer treatment (Buckner 2014; CCS 2015; Robison 2009).

Two-thirds of children who have been diagnosed with cancer will also develop at least one chronic or long-term side effect after the cancer treatment (Skinner 2012). Long-term and late effects are expected health complications resulting from the cancer or cancer therapy (chemotherapy, radiation therapy, surgery and stem cell transplant), that never resolve or emerge months or years following treatment completion, and impact overall health and quality of life (Green 2012). These effects include impairments such as pain, fatigue, and weakness (Van Cleve 2012), peripheral neuropathy, limitations in range of motion, and deficits in balance and gait (Robison 2009; Skinner 2012; Baggott 2009); all of which may negatively affect the child's overall function, quality of life and ability to participate in age-appropriate activities including play (Moody 2006; Pruitt 2009).

Cancer treatments can negatively impact the major body systems including musculoskeletal, cardiorespiratory and neurological systems (Pruitt 2009). The risk of

long-term side effects are dependent on the tumour type and tumour-related factors (e.g. location within the body, extent of the cancer), the type of cancer treatment administered (e.g. type of surgery, chemotherapy type and dosage, radiation therapy type, location, dosage), as well as patient-related factors (e.g. the child's gender, age, overall health pre-cancer diagnosis, and developmental stage at time of diagnosis) (Pruitt 2009; NCI 2016). The focus of this review will be on the musculoskeletal and neurological effects of cancer and cancer treatment.

Musculoskeletal System

Specific long-term effects from cancer treatment on the musculoskeletal system include effects on muscle and soft tissues (myopathies including proximal muscle weakness, soft tissue contracture and radiation fibrosis syndrome), as well as effects on bone resulting in scoliosis or kyphosis, limb length discrepancies, and osteoporosis (NCI 2016; Pruitt 2009). The impact of surgery such as amputation and limb-salvage intervention may result in chronic pain, gait and balance dysfunction, and impact overall activity. Effects involving the musculoskeletal system are more likely to occur in cancers such as acute lymphoblastic leukaemia, osteosarcoma, and brain and spinal cord tumours; and in those children who have undergone a stem cell transplant (NCI 2016; Pruitt 2009).

Neurological System

Specific long-term effects involving the neurological system include motor and sensory deficits (loss of fine motor skills, impairments in coordination and balance,

movement disorders, and peripheral nerve damage in the hands and feet) (NCI 2016; Pruitt 2009). A long-term effect seen in adult survivors of childhood cancer includes chronic peripheral neuropathy, a condition that may result from use of a neurotoxic agent such as vincristine and cisplatin (NCI 2016; Pruitt 2009).

3.2.2 Description of the intervention

Focused physical therapy intervention may help children with the late and long-term physical effects resulting from cancer treatment, particularly those effects associated with prolonged cancer treatments (Stubblefield 2013). Physical therapy is a health-care profession that aims to restore and optimise function, mobility and quality of life of individuals of all ages (Punzalan 2009). In oncology rehabilitation, physical therapists work with clients to manage musculoskeletal and neuromuscular impairments (Punzalan 2009). Rehabilitation needs of cancer patients include treatments to address acute, late and long-term effects as well as those associated with palliative care (Punzalan 2009).

The physical therapist will perform an assessment to determine physical function, joint mobility, and muscle strength and flexibility. Findings of the assessment are used to inform an appropriate tailored intervention for the child (Punzalan 2009). Physical therapy can help children with cancer regain function through interventions that aim to reduce pain in soft tissues (muscles, tendons and ligaments), build muscle strength, improve soft tissue and joint flexibility, range of motion, and function as well as overall mobility. Treatment services can be delivered before (prehabilitation), during

and after treatment completion (rehabilitation) (Krivitzky 2015). Prehabilitation services include interventions that are administered between the time of diagnosis and cancer treatment initiation. Prehabilitation intervention may be prescribed to enhance a child's physical functioning and general health status to enable improved tolerance to cancer treatments, overall outcomes and recovery from the upcoming cancer treatment. Rehabilitation services delivered during or following cancer treatment, are defined as services that help a child to recover function or relearn skills after a diagnosis of cancer. Importantly, focused and timely physical therapy intervention may help to prevent the development of late effects and attenuate the severity of long-term effects (Krivitzky 2015).

The interventions considered in this review will include physical therapy techniques such as manual therapy, therapeutic range of motion and strengthening exercises for a joint or muscle region, balance retraining, gait re-education, and electrophysical modalities that are provided with the aim of addressing impairments related to cancer treatment. The physical therapy may be delivered as prehabilitation or rehabilitation intervention; however, the children and adolescents participating in the study must be between 0 and 19 years old at the time of the study physical therapy intervention.

3.2.3 Why it is important to do this review

To date, the majority of research trials in cancer rehabilitation have been performed with adult cancer survivors. Positive results from physical therapy

interventions, primarily in the area of breast cancer, have been reported (Cho 2016; De Groef 2015; McNeely 2010; Nilsen 2015; Pergolotti 2015).

Impairment-based cancer rehabilitation for children and adolescents with cancer is a growing area of research and clinical practice. Studies with childhood cancer patients and survivors including physical therapy have been performed; however, factors such as small sample sizes, varying intervention protocols and differences in cancer types among trials make it difficult to draw conclusions on overall efficacy.

A recent Cochrane Review examined the effects of general exercise training interventions for children and adolescents with cancer (Braam 2016). The review included five studies involving 131 participants, all of whom were being treated for Acute Lymphoblastic Leukaemia. Preliminary findings support benefit from general physical exercise training for body composition, flexibility and cardiorespiratory fitness. To date, however, no systematic reviews have been performed examining the benefits of physical therapy interventions for specific impairments related to cancer treatment. Thus, the main distinctions between this review and that of Braam 2016 will be (1) the type of intervention (physical therapy vs general physical exercise) and (2) the focus of the intervention (impairment-driven vs physical fitness).

3.3 Objectives

3.3.1 Primary objective

To evaluate the efficacy of physical therapy intervention on the quality of life (QoL) outcomes of children and adolescents who have been diagnosed with cancer.

Participants must be between the ages of 0 and 19 years at the time of the physical therapy intervention study. The intervention may occur prior to, during or following cancer treatment, or in a range of times of delivery. The intervention must be compared to a control group of children receiving standard care, no physical therapy intervention or a comparison intervention. We will exclude general physical exercise studies where the primary aim is to improve physical fitness through aerobic, anaerobic, resistance exercise, or combined physical exercise training regimens (i.e. combined aerobic and resistance exercise regimens). We will also record any adverse effects resulting from physical therapy interventions.

3.3.2 Secondary objectives

To evaluate the efficacy of physical therapy interventions on fatigue, pain, peripheral neuropathy, balance and gait, as well as the range of motion and strength of a specific joint or impaired body region.

3.4 Methods

Criteria for considering studies for this review

3.4.1 Types of studies

We will include randomised controlled trials (RCTs), cross-over trials (if data is available prior to the cross-over), and controlled clinical trials (CCTs) comparing the effects of physical therapy interventions for children and adolescents who are between the ages of 0 and 19 years.

3.4.2 Types of participants

Children and adolescents who are aged 0 to 19 years at the time of the physical therapy intervention. All childhood cancer types will be eligible for inclusion in the review. We will include studies involving adults (20 years old or more) with cancer only if the results of the subgroup of children with cancer (0 to 19 years of age) are available or reported separately.

3.4.3 Types of interventions

We will include studies comparing physical therapy interventions (such as manual therapy techniques, therapeutic range of motion and strengthening for a specific joint or impaired body region, balance and gait retraining), and electrophysical modalities to address a specific symptom (e.g. pain), impairment (e.g. gait dysfunction) or body region (e.g. shoulder). The intervention may be delivered before (prehabilitation), during or following cancer treatment, or in a range of times of delivery. The intervention will be compared to a control group receiving standard care, no intervention or a comparison intervention (assuming the effect of the physical therapy intervention can be isolated).

The physical therapy intervention must be delivered or supervised by a physical therapist or healthcare professional (e.g. nurse, occupational therapist). The programme may be offered as an individualised treatment or a group intervention and can be performed in any setting or location (e.g. hospital, outpatient hospital or physical therapy clinic, home, or elsewhere). The duration of the physical therapy intervention

period must be at least four weeks. The time spent per physical therapy session must be reported or sufficiently described such that delivery of the intervention would take at least 15 minutes.

Exclusion criteria

1. Studies where the primary focus is aerobic capacity or general physical fitness alone.

2. Studies where the prescription is consistent with a general exercise or physical activity prescription that is described in terms of frequency, intensity, type and time.

3.4.4 Types of outcome measures

Primary and secondary outcomes listed below will not be used as criteria for including studies, but rather as a list of outcomes of interest within the included studies.

Primary outcomes

- The primary outcomes of this review will be quality of life and adverse events.

- Quality of life will be measured by scales such as the Pediatric Quality of Life Inventory (PedsQL), Pediatric Quality of Life (PedsQL Core), Child Health Questionnaire (CHQ), and DISABKIDS or other validated questionnaire.

- Adverse events related to the physical therapy intervention such as falls, fractures, soft tissue injuries, or any worsening of impairments (e.g. pain) requiring withdrawal from the study.

Secondary outcomes

- Secondary outcomes of the review are as follows.

- Fatigue will be assessed by a validated scale such as the PedsQL Multidimensional Fatigue Scale, Childhood Cancer Fatigue Scale (CCFS), or the Fatigue Scale for a child (FS-C), the same scale for adolescents (FS-A), and for parents (FS-P), or equivalent valid instrument.

- Pain will be measured by Visual Analog Scale (VAS), or other valid instrument.

- Peripheral neuropathy will be measured by a validated scale such as the Pediatric Modified Total Peripheral Neuropathy Score (ped-mTNS), Total Neuropathy Score-Pediatric Vincristine (TNS-PV), Total Neuropathy Score (TNS).

- Balance will be assessed by a validated scale such as the Bruininks Osteretsky Test of Motor Proficiency (BOTMP) Balance Subtest, Bruininks Osteretsky Test of Motor Proficiency Second Edition (BOT-2) Balance Subtest, Berg Balance Scale (BBS), Alberta Infant Motor Scale (AIMS), Romberg test, Pediatric Balance Scale (PBS), Movement Assessment Battery for Children (Movement ABC-2), The Flamingo Balance Test or equivalent.

- Gait will be assessed descriptively or by use of a computerised/electronic gait analysis.

- Range of motion will be measured by goniometry, or another valid instrument.

- Strength will be assessed with a hand-held dynamometer, use of a Biodex/Cybex, spring scale, lateral step-up test, sit-to-stand test, up-and-down stairs test, minimum chair height test, incremental shuttle walking test, or another valid instrument.

3.4.5 Search methods for identification of studies

Cochrane Childhood Cancer will run the searches in CENTRAL, MEDLINE and Embase; all other searches (CINAHL, PEDro, ongoing trial registries and conference proceedings) will be run by the review authors. We will not apply any language restrictions.

3.4.6 Electronic searches

We will search the following electronic databases: the Cochrane Central Register of Controlled Trials (CENTRAL) in the Cochrane Library - we will use the latest issue; MEDLINE Ovid (from 1946 to present); Embase Ovid (from 1947 to present); CINAHL/EBSCO (1937 to present); and Physiotherapy Evidence Database (PEDro; from 1929 to present) (www.pedro.org.au). We will modify electronic searches from the recommended Cochrane Childhood Cancer methods used in reviews (Module CCG).

The search strategies for the different electronic databases (using a combination of controlled vocabulary and textwords) are shown in the appendices (Appendix 1; Appendix 2; Appendix 3; Appendix4; Appendix 5).

3.4.7 Searching other resources

Bibliographic searching

We will search trials not registered in CENTRAL, MEDLINE, Embase, CINAHL, and PEDro, either published or unpublished, by searching the reference lists of relevant articles and review articles. We will search the five latest editions of conference proceedings of the International Society for Paediatric Oncology (SIOP), the American Society of Clinical Oncology (ASCO), the American Society of Pediatric Hematology/Oncology (AS- PHO), and the Multinational Association for Supportive Care in Cancer (MASCC). We will scan the ISRCTN Registry (www.isrctn.com), the National Institutes of Health (NIH) Register (www.clinicaltrials.gov), and the World Health Organization portal (http://apps.who.int./trialsearch) for ongoing trials.

The search strategies for other resources are shown in the appendices (Appendix 6; Appendix 7).

Personal communication

We will contact oncology rehabilitation researchers working in the paediatric area to verify details of any outstanding clinical trials and any relevant unpublished material.

3.4.8 Data collection and analysis

Selection of studies

After performing the search, two authors will independently identify studies meeting the inclusion criteria. We will resolve discrepancies by consensus between authors. In cases where consensus cannot be reached, a third author will act as arbiter. We will obtain a full copy of the publication for any study potentially meeting inclusion criteria based on information provided in the title or abstract. We will provide reasons for exclusion of screened studies. We will note duplicate publications of the same study, but will count the study only once.

We will provide a flow diagram for the selection of studies in our review.

Data extraction and management

At least two review authors will extract the characteristics for each trial using a data extraction form. We will compare the results, resolve disagreements by discussion and consensus, and create a composite table. In the case of disagreements, a third author will be used for final resolution. We will extract information on the trial design (RCT, cross-over or CCT), data on characteristics of participants, sample size, number of participants in each study arm, type of intervention(s), control intervention, duration of intervention in weeks, randomization and blinding, type and duration of cancer treatment, stage of cancer treatment (e.g. during or after treatment), recruitment method and location where study took place, country of study, outcome assessed, inclusion/exclusion criteria, outcomes, follow-up times, adverse events, dropouts and withdrawals, conflicts of interests of primary investigations, funding source, and study findings.

In cases where there is more than one publication for a study, we will use the primary publication and reference the other publications if used for supplementary information.

Assessment of risk of bias in included studies

Two review authors will independently assess risk of bias in the RCTs, cross-over trials and CCTs; rating each risk-of-bias item as 'low', 'unclear' or 'high' risk of bias. We will use the 'risk of bias' criteria as mentioned in the module of Cochrane Childhood Cancer (Module CCG); these are based on recommendations in the Cochrane Handbook for Systematic Reviews of Interventions (Higgins 2011). 'Risk of bias' assessment will be done with the following criteria: random sequence generation (selection bias); allocation concealment (selection bias); blinding of participants (performance bias); blinding of personnel (performance bias); blinding of outcome assessment (detection bias) for each outcome separately; incomplete outcome for each outcome separately (attrition bias); selective reporting (reporting bias); and other sources of bias (other bias). We will resolve disagreements by discussion; but if we cannot reach consensus, a third author will be invited to arbitrate. Statistical methods to identify selective outcome reporting are not well developed yet. However, the Cochrane Handbook for Systematic Reviews of Interventions suggests different ways to assess selective reporting (Higgins 2011). If the protocol is available, we will compare the outcomes in the protocol with the published report. If the protocol is not available, we will compare the outcomes mentioned in the Methods section with the reported results. If non-significant results are mentioned but reported inadequately, we will gather

information directly from the authors of the study. In addition to the pre-specified 'Risk of bias' items, we will add 'Treatment Adherence' as a further potential source of bias. We consider adherence to physical therapy treatment to be a vital component to successful treatment. For the purposes of evaluating risk, adherence is defined as the percentage of sessions attended/ completed by the participant with 'low risk of bias' (i.e. adherence 70% or greater), 'unclear' (not reported) or 'high risk of bias' (i.e. adherence < 70%).

Measures of treatment effect

We will analyze continuous data (QoL, adverse events, fatigue, pain, gait, peripheral neuropathy, balance, range of motion, strength) as mean differences either weighted or standardised using a random-effects model. We will use difference in means (MD) for continuous variables when data are provided using the same units, measurement methods or outcome measure. We will use the standardised mean difference (SMD) for continuous variables when trials report results using different measurement units, measurement methods or outcome measures. We will analyze dichotomous outcomes (e.g. adverse event rates, outcomes reported as dichotomous variables) using risk ratio (RR). All results will be presented with corresponding 95% confidence intervals (CIs).

Unit of analysis issues

The only unit of analysis issue we anticipate is with cross-over designs, in which we will use only first-cycle data (prior to cross- over).

Dealing with missing data

When information relevant to study selection, data extraction or assessment of risk of bias is missing, we will attempt to contact the authors to obtain the missing data. When applicable, we will extract data by allocated intervention, irrespective of compliance with the allocated intervention, to allow an intention-to-treat analysis. We will state if this is not possible and will perform an 'as treated' analysis.

Assessment of heterogeneity

We will assess heterogeneity by visual inspection of the forest plots and by the use of the statistical test for heterogeneity I^2 statistic (Higgins 2011). I^2 values ranging from 0% (homogeneity) to 100% (heterogeneity) will be calculated to quantify variability in study effect. An I^2 value greater than 50% will be considered the cutpoint for significant heterogeneity (Higgins 2011). Where possible, subgroup analyses will be performed to explore and explain heterogeneity among studies.

Assessment of reporting biases

In addition to the evaluation of reporting bias as described in the Assessment of risk of bias in included studies section, we plan to assess reporting bias by constructing a funnel plot if there are a sufficient number of included studies (at least 10 studies included in a meta-analysis), otherwise the power of the tests is too low to distinguish chance from real asymmetry (Higgins 2011). To minimise the effect of publication bias, we will search the grey literature and contact authors of trials.

Data synthesis

We will enter data of the included studies into Review Manager 5 software (Review Manager 2014) and undertake analyses according to the guidelines of the Cochrane Handbook for Systematic Reviews of Interventions (Higgins 2011).

We will pool the results of studies, (1) if there are at least three studies with the same outcome measure (or measurement) for the given primary or secondary outcome; and (2) if appropriate, after consideration of heterogeneity between the trials. We will pool outcomes when sufficient data are available in the papers or from the trialists' data sets using the random-effects model. We will describe outcomes that we cannot pool in narrative form in the Results section. We will create a 'Summary of findings' table, including post-intervention results as well as short-term follow-up results (3 to 6 months after the intervention completion) and long-term follow-up results (1 year or more after the intervention completion).

In a multi-arm study we will include the intervention groups as separate comparisons if each arm meets the criteria for inclusion, and will split the 'shared' control/comparison group for analyses. We will note all the intervention groups in the table of 'Characteristics of the included studies'. However, we will only describe and analyse the intervention groups relevant to the review (Higgins 2011).

For each comparison we will prepare a 'Summary of findings' table using the GRADE profiler software (Guyatt 2008), in which we will present the following outcomes: QoL, fatigue, pain, balance, range of motion, strength, adverse events. For

each outcome two review authors will independently assess the quality of the evidence by using the five GRADE considerations, i.e. study limitations, inconsistency, indirectness, imprecision and publication bias, as described in the Cochrane Handbook for Systematic Reviews of Interventions (Higgins 2011).

Subgroup analysis and investigation of heterogeneity

A priori subgroup analyses include examining the pooled effect estimate by the type of physical therapy intervention, the timing of the intervention i.e. prior to, during, or following cancer treatment), and cancer type.

Where possible, we will perform subgroup analyses to assess if the observed effect of an intervention is consistent across participants based on subgroups of (1) age of the participant (continuous co- variate) and (2) the location of the physical therapy intervention (inpatient hospital, outpatient clinic or home), and (3) by study design (RCT, CCT, cross-over).

Sensitivity analysis

For any outcomes for which pooling is possible we will perform sensitivity analyses for ’Risk of bias’ criteria separately. We will exclude studies with a high risk of bias and unclear risk of bias in the sensitivity analyses, and compare the results of studies with a low risk of bias with the results of all available studies. Sensitivity analyses will only be done when there remain at least two studies with a low risk of bias in the analyses.

3.5 Acknowledgements

We would like to thank the Editorial Base of Cochrane Childhood Cancer for their advice and support. The Editorial Base of Cochrane Childhood Cancer is funded by KiKA. We would like to acknowledge the assistance of the University of Alberta Health Sciences Librarian Liz Dennett for her assistance in developing the search strategy.

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∗ Indicates the major publication for the study

APPENDICES

Appendix 1. Search strategy for Central Register of Controlled Trials (CENTRAL)

1 For **Children** the following thesaurus terms and text words will be used:

#1. [mh adolescent] or [mh child] or [mh infant] or (infan* or neonat* or newborn or baby or babies or child* or schoolchild* or kid or kids or toddler* or adoles* or teen* or boy* or girl* or minor* or underag* or "under ag*" or juvenil* or youth* or kindergar* or puber* or pubescen* or prepubescen* or prepuberty* or pediatric* or paediatric* or peadiatric* or school* or preschool* or highschool* or "high school*") .tw or (pediatric* or paediatric* or child* or adolesc*).so

2 For **Cancer** the following thesaurus terms and text words will be used:

#2. ([mh Neoplasms] or (oncolog* or neoplas* or carcinom* or tumour* or tumour* or cancer* or malignan* or "hemato-oncologic*" or hematolo* or "haemato-oncologic*" or haematolo or bone marrow transplant* or leukemi* or leukaemi* or AML or lymphom* or hodgkin* or "T-cell" or "B-cell" or "non-hodgkin" or sarcom* or Ewing* or osteosarcom* or wilms* or nephroblastom* or neuroblastom* or rhabdomyosarcom* or teratom* or hepatom* or hepatoblastom* or medulloblastom* or PNET* or retinoblastom* or meningiom* or gliom*) .tw) not (breast*.ti or [mh "breast neoplasms"])

3 For **Physical therapy** the following thesaurus terms and text words will be used:

#3. [mh "Physical Therapy Modalities"] or [mh ^"physical therapy specialty"] or [mh ^"physical and rehabilitation medicine"] or [mh^"range of motion, articular"] or [mh ^gait] or [mh ^proprioception] or [mh ^"postural balance"] or [mh ^"muscle stretching exercises"] or [mh ^"short-wave therapy"] or [mh "ultrasonic therapy"] or [mh

ˆCryotherapy] or ((exercis* near/4 (therap* or strength or balance or gait or stretch*)) or “manual therap*” or “physical therap*” or physiotherap* or “stability training” or “muscle training” or “strength training” or “resistance training” or locomotion* or “functional therap*” or “weight lifting” or kinesiotherap* or manipulation* or “short-wave-therap*” or cryotherap* or electrotherap* or “ultraso* therap*” or (rehab* near/6 physical)).tw

Final search 1 and 2 and 3

ˆ: denotes a non-exploded subject heading

mh: subject heading

[so]: Word in journal title

[tw]: text word (title and abstract)

near/6: up to 6 words can intervene between the word(s) to the left of the operator and the word(s) to the right.

*=zero or more characters

Appendix 2. Search strategy for MEDLINE Ovid

1 For **Children** the following MeSH headings and text words will be used:

1. adolescent/ or exp child/ or exp infant/

2. (infan* or neonat* or newborn or baby or babies or child* or schoolchild* or kid or kids or toddler* or adoles* or teen* or boy* or girl* or minor* or underag* or under ag* or juvenil* or youth* or kindergar* or puber* or pubescen* or prepubescen* or prepuberty* or pediatrics or pediatric* or paediatric* or peadiatric* or school* or preschool* or highschool*).mp.

3. (pediatric* or paediatric* or child* or adolesc*).jw.

4. 4 or/1-3

2 For **Cancer** the following MeSH headings and text words will be used:

1. exp Neoplasms/

2. (oncolog* or neoplas* or carcinom* or tumour* or tumour* or cancer* or malignan* or hemato-oncological or hematolo* or bone marrow transplant* or leukemi* or leukaemi* or AML or lymphom* or hodgkin* or T-cell or B-cell or non-hodgkin or sarcom* or Ewing* or osteosarcom* or wilms* or nephroblastom* or neuroblastom* or rhabdomyosarcom* or teratom* or hepatom* or hepatoblastom* or medulloblastom* or PNET* or retinoblastom* or meningiom* or gliom*).mp.

3. 1 or 2

4. breast*.ti. or exp breast neoplasms/

5. 3 not 4

3 For **Physical therapy** the following MeSH headings and text words will be used:

1. exp Physical Therapy Modalities/

2. physical therapy specialty/

3. “physical and rehabilitation medicine”/

4. “range of motion, articular”/

5. gait/

6. proprioception/ or postural balance/

7. muscle stretching exercises/

8. short-wave therapy/ or exp ultrasonic therapy/

9. Cryotherapy/

10. ((exercis* adj4 (therapeutic or strength or balance or gait or stretch*)) or manual therap* or physical therap* or physiotherap* or stability training or muscle training or strength training or locomotion* or functional therap* or weight lifting or kinesiotherap* or manipulation* or short-wave-therap* or cryotherap* or electrotherap* or ultraso* therap* or (rehab* adj6 physical)).tw,kf.

11. or/1-10

4 For **RCTs and CCTs** the following MeSH headings and text words will be used:

1. exp clinical trial/

2. control groups/

3. double-blind method/

4. random allocation/

5. cross-over studies/

6. (random* or quasi-random* or quasi-experiment* or cross-over or placebo or trial or groups or double blind).mp.

7. randomized controlled trial/

8. 8 or/1-7

Final search: 1 and 2 and 3 and 4

/=MeSH term, *=zero or more characters

adj4, adj6, adj#= up to # words can intervene between the word(s) to the left of the operator and the word(s) to the right

[mp]= multiple places (title, abstract, subject headings, author keywords)

[tw]= text word (title and abstract)

[kf]= author keyword

[jw]= Word in journal title

Appendix 3. Search strategy for Embase Ovid

1 For **Children** the following Emtree terms and text words will be used:

1. adolescent/ or exp child/ or exp infant/

2. (infan* or neonat* or newborn or baby or babies or child* or schoolchild* or kid or kids or toddler* or adoles* or teen* or boy* or girl* or underag* or under ag* or juvenil* or youth* or kindergar* or puber* or pubescen* or prepubescen* or prepuberty* or pediatrics or pediatric* or paediatric* or peadiatric* or school* or preschool* or highschool*).mp.

3. (pediatric* or paediatric* or child* or adolesc*).jx. 4. or/1-13

2 For **Cancer** the following Emtree terms and text words will be used:

1. exp neoplasm/

2. (oncolog* or neoplas* or carcinom* or tumour* or tumour* or cancer* or malignan* or hemato-oncological or hematolo* or bone marrow transplant* or leukemi* or leukaemi* or AML or lymphom* or hodgkin* or T-cell or B-cell or non-hodgkin or sarcom* or Ewing* or osteosarcom* or wilms* or nephroblastom* or

neuroblastom* or rhabdomyosarcom* or teratom* or hepatom* or hepatoblastom* or medulloblastom* or PNET* or retinoblastom* or meningiom* or gliom*).mp.

3. 1 or 2

4. breast*.ti. or exp breast tumour/

5. 3 not 4

3 For **Physical therapy** the following Emtree terms and text words will be used:

1. exp physiotherapy/

2. physical medicine/ or electrostimulation therapy/ or exp kinesiotherapy/ or exp manipulative medicine/ or exp ultrasound therapy/

3. "range of motion"/

4. gait/

5. proprioception/

6. exp body equilibrium/

7. stretching exercise/

8. exp diathermy/

9. cryotherapy/

10. ((exercis* adj4 (therapeutic or strength or balance or gait or stretch*)) or manual therap* or physical therap* or physiotherap* or stability training or muscle training or strength training or locomotion* or functional therap* or weight lifting or kinesiotherap* or manipulation* or short-wave-therap* or cryotherap* or electrotherap* or ultraso* therap* or (rehab* adj6 physical)).tw,kw.

11. or/6-15

12. adolescent/ or exp child/ or exp infant/

13. (infan* or neonat* or newborn or baby or babies or child* or schoolchild* or kid or kids or toddler* or adoles* or teen* or boy* or girl* or underag* or under ag* or juvenil* or youth* or kindergar* or puber* or pubescen* or prepubescen* or prepuberty* or pediatrics or pediatric* or paediatric* or peadiatric* or school* or preschool* or highschool*).mp.

14. (pediatric* or paediatric* or child* or adolesc*).jx.

15. or/1-14

4 For **RCTs and CCTs** the following Emtree terms and text words will be used:

1. exp clinical trial/

2. control groups/

3. double blind procedure/

4. randomization/

5. crossover procedure/

6. (random* or quasi-random* or quasi-experiment* or cross-over or placebo or trial or groups or double blind).mp.

7. randomized controlled trial/

8. 8 or/1-7

Final search 1 and 2 and 3 and 4

/=Emtree term; *=zero or more characters

adj4, adj6, adj#= up to # words can intervene between the word(s) to the left of the operator and the word(s) to the right [mp]= multiple places (title, abstract, subject headings, author keywords)

[tw]= text word (title and abstract) [kw]= author keyword

[jx]= Word in journal title

Appendix 4. Search strategy for CINAHL/EBSCO

1 For **Children** the following Subject headings and text words will be used:

S1. ((MH "Child+") OR (MH "Adolescence+")) OR (infan* or neonat* or newborn or baby or babies or child* or schoolchild* or kid or kids or toddler* or adoles* or teen* or boy* or girl* or minor* or underag* or under ag* or juvenil* or youth* or kindergar* or puber* or pubescen* or prepubescen* or prepuberty* or pediatrics or pediatric* or paediatric* or peadiatric* or school* or preschool* or highschool*) OR SO (pediatric* or paediatric* or child* or adolesc*)

2 For **Cancer** the following Subject headings and text words will be used:

S1. (MH "Neoplasms+") OR (oncolog* or neoplas* or carcinom* or tumour* or tumour* or cancer* or malignan* or hemato-oncological or hematolo* or bone marrow transplant* or leukemi* or leukaemi* or AML or lymphom* or hodgkin* or T-cell or B-cell or non- hodgkin or sarcom* or Ewing* or osteosarcom* or wilms* or nephroblastom* or neuroblastom* or rhabdomyosarcom* or teratom* or hepatom* or hepatoblastom* or medulloblastom* or PNET* or retinoblastom* or meningiom* or gliom*)

S2. (MH "Breast Neoplasms+") OR TI breast*

S3. S1 NOT S2

3 For **Physical therapy** the following Subject headings and text words will be used:

S1. (MH "Physical Therapy+")

S2. (MH "Research, Physical Therapy")

S3. (MH "Proprioception+")

S4. (MH "Balance, Postural")

S5. (MH "Range of Motion")

S6. (exercis* n4 (therapeutic or strength or balance or gait or stretch*)) or manual therap* or physical therap* or physiotherap* or stability training or muscle training or strength training or locomotion* or functional therap* or weight lifting or kinesiotherap* or manipulation* or short-wave-therap* or cryotherap* or electrotherap* or ultraso* therap* or (rehab* n6 physical)

S7. S1 OR S2 OR S3 OR S4 OR S5 OR S6

4 For **RCTs and CCTs** the following MeSH headings and text words will be used:

S1. ((MH "Random Sample+") OR (MH "Control Group") OR (MH "Clinical Trials+") OR (MH "Randomized Controlled Trials") OR (MH "Crossover Design") OR (MH "Quasi-Experimental Studies+")) OR (random* or quasi-random* or quasi-experiment* or cross-over or placebo or trial or groups or double blind)

Final search: 1 and 2 and 3 and 4

MH= subject heading TI= title SO= journal title/source

+= denotes that the subject heading was exploded

*= zero or more characters

n4, n6 (n#) = adjacency operator where # is the maximum number of words that two terms can be separated by

Appendix 5. Search strategy for PEDro

We will search this database with three different search strategies as follows, and combine the results with OR.

Search A

1. paediatric* <Abstract & Title> field
2. oncology <Subdiscipline> field
3. stretching, mobilisation, manipulation, massage <Therapy> field.
4. clinical trial <Method> field

Search B

1. child* <Abstract & Title> field
2. oncology <Subdiscipline> field
3. stretching, mobilisation, manipulation, massage <Therapy> field.
4. clinical trial <Method> field

Search C

1. adolescent* <Abstract & Title> field
2. oncology <Subdiscipline> field
3. stretching, mobilisation, manipulation, massage <Therapy> field.
4. clinical trial <Method> field

Appendix 6. Key terms for ongoing trials registries

1. www.isctrn.org (ISCTRN register)

We will browse by "Cancer" studies, limit by "Child", and scan results with the search terms: "physical therapy"; physiotherapy; rehabilitation.

2. www.clinicaltrials.gov (National Institutes of Health (NIH) Register for ongoing trials)

We will search at the Advanced search page:

Study type: Interventional studies

Group: Child (birth-17yrs) will be checked

Condition: cancer OR neoplasm OR oncology

Interventions: "physical therapy" OR physiotherapy OR rehab*

3. http://apps.who.int./trialsearch (WHO portal)

We will search at the Advanced search page:

(cancer OR oncology OR neoplasm) AND (physical therapy OR physiotherapy OR rehabilitation) Check box for clinical trials in Children

Appendix 7. Key terms for conference proceedings

ASCO (American Society of Clinical Oncology) website

We will search the meeting library (meetinglibrary.asco.org) with different search strategies combining key words. Searches separated by semicolons:

"physical therapy" child; "physical therapy" children; "physical therapy" childhood; "physiotherapy" child; "physiotherapy" children; "physiotherapy" childhood; "rehabilitation" child; "rehabilitation" children; "rehabilitation" childhood.

MASCC (Multinational Association for Supportive Care in Cancer) website

We will search the meeting abstracts (http://www.mascc.org/past-annual-meetings) with different key words: "physical therapy"; physiotherapy; rehabilitation; child; infant.

The SIOP (International Society for Paediatric Oncology) and ASPHO (American Society of Pediatric Hematology/Oncology) abstracts can be searched by using the "Find text" in pdf documents with the keywords: physical therapy; physiotherapy; rehabilitation.

DECLARATIONS OF INTEREST

None known

SOURCES OF SUPPORT

Internal sources

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Dr. McNeely), Stollery Children's Foundation (Dr. Wiart), Alberta Policy Wise for Children and Families (Dr. Wiart), Canada.

Research project support for Dr. Wiart's research projects

External sources

- No sources of support supplied

CHAPTER 4: RESULTS PHASE II – SERVICE PROVISION AND REFERRAL PATTERNS

Manuscript 3

Exploring physical rehabilitation referral and service provision for children and adolescents with cancer across Canada

(A manuscript in preparation for submission to the journal: Supportive Care in Cancer)

4.1 Abstract

Relevance: Children and adolescents with cancer who undergo cancer treatment are at high risk of developing serious late and long-term physical effects, many of which may be amenable to physical rehabilitation (PR). PR may help reduce the burden of cancer side effects; however, few childhood cancer survivors report accessing PR services. **Objectives:** This study aims to (1) explore the frequency and reasons for referrals to PR services in pediatric oncology, and (2) identify existing barriers and facilitators to pediatric oncology PR programs. **Materials and Methods:** A cross-sectional web-based survey in English and French languages was conducted. Participants identified were Canadian healthcare professionals (HCPs) who provide and/or refer children and adolescents with cancer to physical rehabilitation services. The survey included questions on practice patterns including use of protocols/ guidelines as well as the barriers and facilitators to PR programs for children and adolescents with cancer. **Results:** A total of 54 responses were received including physical therapists (n= 27), nurse and nurse practitioners (n= 10), pediatric oncologists and oncology residents (n= 9), occupational therapists (n= 6), a speech-language pathologist (n= 1), and an exercise professional (n= 1). Findings suggest low referral rates of children and adolescents with cancer to PR services. Few HCPs reported using protocols or guidelines in practice. Barriers to service provision included a lack of funding/ resources and HCPs with expertise in pediatric oncology PR. **Conclusions:** Main findings of the survey suggest (1) low rates of referral to PR services, (2) lack of funding and resources for PR services, and (3) the need for HCPs with expertise specific to pediatric oncology PR within hospital and community settings. There is high interest from oncology HCPs to develop and support the implementation of clinical practice guidelines in PR for childhood cancer survivors.

Keywords: cancer, physical therapy, rehabilitation, pediatrics, service provision, barriers

4.2 Introduction

Children and adolescents with cancer who undergo cancer treatment are at high risk of developing serious late and long-term adverse effects, many of which may be amenable to physical rehabilitation (PR).[1] These effects include pain, fatigue, weakness,[2] peripheral neuropathy, as well as limitations in strength, range of motion, function, and deficits in balance and gait.[1,3,4] These complications may negatively affect the child's overall quality of life[5] and ability to participate in age-appropriate activities including play.[6]

Although, PR may help reduce the burden of cancer side effects, few childhood cancer survivors report accessing PR services.[7] Montgomery et al[7] conducted an epidemiologic study using a follow-up questionnaire to evaluate the use of rehabilitation services to address late effects on 5+ year survivors from childhood cancer. A total of 9,289 survivors were included in the analysis and overall results demonstrated that only 9.3% survivors reported using PR services.[7] A study conducted by Gohar et al[8], included a retrospective chart review and a prospective questionnaire of frequency and rationale behind physicians' referral of children with Acute Lymphoblastic Leukemia (ALL) to PR services. A total of six physicians completed the questionnaire, and results suggested that physicians referred a minority of patients to PR services. Kumar et al[11] conducted a cross-sectional survey of 313 adult cancer survivors to determine the rates of utilization and barriers to access of supportive and palliative services. Findings suggested that only 15% of patients used PR services and 29% reported "lack of physician referral" as the biggest barrier to access. A cross-sectional online survey conducted by Canestraro et al[9] explored the extent of oncology rehabilitation service provision, practice patterns, and perceived

barriers and facilitators to service for adults with cancer in Canada. Sixty-two out of 116 Canadian facilities responded to the survey. Lack of funding and availability of resources were the main barriers reported that impacted existing oncology rehabilitation programs.

To the best of our knowledge, no published research to date has explored the current service provision and referral patterns specific to pediatric oncology PR in Canada. The purposes of this study were to (1) explore the frequency and reasons for referrals to PR services in pediatric oncology, and (2) identify existing barriers and facilitators to pediatric oncology PR programs.

4.3 Methods

4.3.1. Participants

The study was approved by the Health Research Ethics Board of Alberta: Cancer Committee. Electronic informed consent was obtained from participants (Appendices B, C, and D). We conducted a cross-sectional web-based survey in a secure "REDCap" database at the University of Alberta in Edmonton, Canada. HCPs across Canada were identified using a multi-pronged approach. We identified physical therapists and other HCPs who provide and/or refer children and adolescents with cancer to physical rehabilitation services across Canada through professional networking and organizations such as: the Canadian Physiotherapy Association Oncology and Pediatric Divisions, the C17 Children's Cancers and Blood Disorders Council network, Pediatric Oncology Group of Ontario, Stollery Children's Hospital (Oncology professionals), Cross Cancer Institute (Rehabilitation Medicine Department), CancerControl Alberta, Northern Alberta Childhood Cancer Program, and Alberta Health Services. Furthermore, we conducted an online search of additional organizations, institutions, and facilities that provide cancer care

using the keywords: *cancer rehabilitation* OR *physical rehabilitation* OR *children* OR *adolescents* OR *pediatric* OR *cancer care.* To identify potential participants, we contacted each site via email, and distributed the survey communication to healthcare professionals who were working with the pediatric oncology population (Appendix E). The survey was available for a period of three months from July to October 2017. We sent electronic reminders every three weeks to facilitate a higher response rate (Appendix F). Given the low number of pediatric cancer cases in the country, we anticipated that there would be fewer HCPs working in this field. Thus, we expected approximately 30 respondents would complete this survey over the course of the three-month study period.

4.3.2 Instrument

The survey was available in both official languages of English and French to allow for the inclusion of HCPs across Canada (Appendices G and H). Questions were designed based on previous studies conducted in cancer rehabilitation.[8,9] The survey included 30 questions, subdivided into three sections. The first section of the survey gathered data on practice patterns including demographic information related to the professional designation of the HCP, the location of practice, type of service, length of experience in the field, cancer continuum phase they worked in, as well data on numbers of childhood cancers either seen or referred in the respective facility per year.

The second section included questions to inform service provision within the following domains: average number of children and adolescents with cancer seen for PR interventions per year, the most common cancer effects addressed in PR treatment, the type of PR interventions applied, the type of physical agents applied, the perceived effectiveness

of treatment, and the outcome measures/tests utilized for assessment and follow-up. Data on section two is reported elsewhere (Chapter 5, p. 89).

The final section asked health professionals if their work setting provided a pediatric oncology PR program, the use of any evidence-based guidelines and protocols in their practice setting, and if any barriers and facilitators exist that may impact provision of care or the adoption of guidelines and protocols in their work setting.

4.3.3. Data analysis

The data collected consisted of continuous and categorical data that were reported as the total number of respondents per question/section (n), frequency (f) and percentage (%). Basic descriptive statistics in determining the frequency of responses to all questions were generated by REDCap. Due to the complexity of the survey design, the data were imported into Microsoft Excel for calculating percentages, frequencies, and proportions for further data description. Two study investigators tabulated open-ended questions into frequency distributions, categorized into themes or patterns, and coded responses as a means for organizing and presenting findings. The two investigators shared the findings and a consensus was reached for coding the responses.

4.4 Results

For analysis purposes, this publication only reports results related to service provision and referral patterns gathered from sections 1 and 3 of the web-based survey. Results are categorized in Group 1 – Providers (PRO), Group 2 - Referrers (REF), and Group 3 - Providers who also refer (PWAR) to PR services. Professional designations were allocated in three groups. Group 1 - (PRO) include physical therapists, occupational

therapists, and exercise professionals. Group 2 - (REF) include oncologists, nurses, nurse practitioners, and oncology residents. Group 3 - (PWAR) include physical therapists, occupational therapists, speech-language pathologists, and exercise professionals.

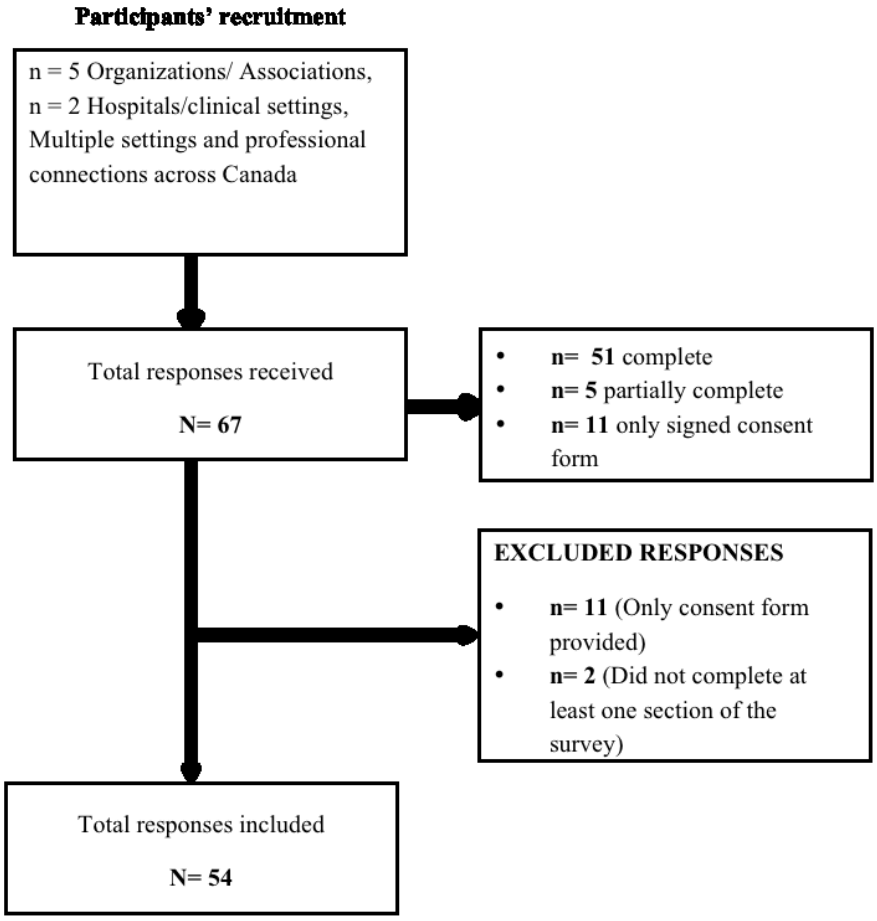

Figure 1. Inclusion and exclusion process of survey responses

4.4.1 Demographics

A total of 67 healthcare providers took part in the study. Fifty-one (76%) responders completed the full survey, 5 (7%) partially completed the survey, and 11 (16%) only signed the consent form. Thirteen responses were excluded, including the 11 that only signed the consent form, and two that had not completed at least one section of the survey. Survey

results from three responders who had completed at least one full section were included. A total of 54 responses were included in the study. Figure 1 illustrates the detailed selection process of included and excluded survey responses. The majority of respondents were located in the province of Alberta (n= 24, 44%) and Ontario (n= 14, 26%), followed by British Columbia (n= 8, 15%), Quebec (n= 5, 9%), Nova Scotia (n= 2, 4%), and Newfoundland (n= 1, 2%). Survey responses were provided primarily by physical therapists (n= 27, 50%), followed by nurse and nurse practitioners (n= 10, 19%), oncologists and oncology residents (n= 9, 17%), occupational therapists (n= 6, 11%), a speech-language pathologist (n= 1, 2%), and an exercise professional (n= 1, 2%).

The majority of the HCP worked in Acute Care Hospitals (n= 34, 63%), followed by rehabilitation hospitals (n= 9, 17%), cancer hospitals (n= 9, 17%), private practice (n= 1, 2%), and community/primary care (n= 1, 2%). Length of experience in the field, in terms of time, ranged between 0.6 to 38 years, with 25% (n= 13) reporting between 10.1 to 15 years of experience, followed by 23% (n= 12) reporting between with 0.1 to 5 years of experience. Of the 54 participants included in the study, 37% (n= 20) classified their primary role as PRO, 35% (n= 19) were REF, and 28% (n= 15) were PWAR. Detailed demographic information is available in Table 1.

Table 1. Demographics

	Overall ***n = 54, 100%***
Province *(n, %)*	
Alberta	24 (44.4%)
Ontario	14 (25.9%)
British Columbia	8 (14.8%)
Quebec	5 (9.3%)
Nova Scotia	2 (3.7%)
Newfoundland	1 (1.9%)
Professional designation *(n, %)*	
Physiotherapist	27 (50%)
Nurse	10 (18.5%)
Oncologist	9 (16.7%)
Occupational therapist	6 (11.1%)
Exercise professional	1 (1.9%)
Speech-Language Pathologist	1 (1.9%)
Work setting *(n, %)*	
Acute care hospital	34 (63%)
Rehabilitation hospital	9 (16.7%)
Cancer hospital	9 (16.7%)
Private practice	1 (1.9%)
Community/Primary care	1 (1.9%)
Length of experience *(n, %)*	***n =52, 100%***
0.1 - 5	12 (23.1%)
5.1 - 10	7 (13.5%)
10.1 - 15	13 (25%)
15.1 - 20	8 (15.4%)
20.1 - 30	9 (17.3%)
30.1 - 40	3 (5.8%)
Role *(n, %)*	
Providers	20 (37%)
Referrers	19 (35.2%)
Providers who also refer	15 (27.8%)

4.4.2. Referral Patterns to Physical Rehabilitation Services

A total of 34 participants (n= 19 REF and n=15 PWAR) were included in the analysis. In brief, the majority of REF indicated that the average number of children and/or adolescents with cancer seen per year ranged between 50 -100 (n = 8, 42.2%), and the majority of PWAR reported seeing between 1 -10 (n = 4, 26.7%) and 21- 49 (n = 4, 26.7%) childhood cancer survivors per year. When asked how often childhood cancer survivors were referred to PR services, 55% (n= 10) of REF indicated that they referred "Often", and 53% (n= 8) of PWAR reported 'Sometimes'. When asked how many childhood cancer survivors they referred to PR services, the majority of REF (n= 7, 37%) reported referring an average of 11 to 20 children, and the majority of PWAR (n= 6, 40%) reported referring 6 to 10 children. The location of referral most reported by REF (n= 16, 52%) was 'Acute Care Hospital Rehabilitation Services', and by PWAR was 'Community/Primary Care Rehabilitation Services' (n= 11, 38%). The percentage of childhood cancer survivors receiving PR services was reported between 75 to 100% for both groups. When asked about the reasons why childhood cancer survivors did not receive PR services, both groups reported 'Parents/Patients choice' as the main reason (f = 5/19, 26% REF and f = 5/15, 33% for PWAR). Detailed information on referral patterns is available in Table 2.

Table 2. Referral patterns

	Overall *n=34, 100%*	
	REF *n=19, 55.8%*	**PWAR** *n=15, 44.1%*
Number of C&A seen per year (*n, %)*		
1-10	0 (0.0%)	4 (26.7%)
11-20	1 (5.3%)	3 (20%)
21-49	6 (31.6%)	4 (26.7%)

50-100	8 (42.2%)	2 (13.3%)
>100	4 (21.1%)	2 (13.3%)
How often refer C&A to PR *(n, %)*		
Often	10 (52.6%)	4 (26.7%)
Sometimes	5 (26.3%)	8 (53.3%)
Rarely	4 (21.1%)	2 (13.3%)
Never	0 (0%)	0 (0%)
Don't know	0 (0%)	1 (6.7%)
Number of C&A referred to PR (*n, %)*		
1-5	4 (21.1%)	4 (26.7%)
6-10	4 (21.1%)	6 (40%)
11-20	7 (36.8%)	4 (26.7%)
21-40	4 (21.1%)	1 (6.7%)
Percentage of C&A that received PR (*n, %)*		
75-100%	14 (73.7%)	8 (53.3%)
50-75%	3 (15.8%)	3 (20%)
25-50%	0 (0%)	1 (6.7%)
< 25%	1 (5.3%)	0 (0%)
Don't know	1 (5.3%)	3 (20%)
Location/type of service referred *(f, %)*		
Acute care hospital	16 (51.6%)	2 (6.9%)
Rehabilitation hospital	7 (22.6%)	10 (34.5%)
Community/Primary Care	6 (19.4%)	11 (37.9%)
Cancer hospital	2 (6.5%)	0 (0%)
Private practice	0 (0%)	4 (13.8%)
Other	0 (0%)	2 (6.9%)
Reasons why C&A referred did not receive PR *(n, %)*		
Parents/patients choice	5 (26.3%)	5 (33.3%)
Don't know	4 (21.1%)	5 (33.3%)
Physiotherapist did not deem necessary	3 (15.8%)	1 (6.7%)
Financial resources	2 (10.5%)	2 (13.3%)
N/A - 100% received	1 (5.3%)	1 (6.7%)
Other	4 (21.1%)	1 (6.7%)
-"Lack of experience in the community" -"Discharge before assessment complete" -"Conflict with chemotherapy regimen" -"Patients do not live in the city to access the program"		-"Basic diagnosis is not admissible or parents' needs answered"

Abbreviations: C&A, children and adolescents; PR, physical rehabilitation

The three main reasons that prompted referral to PR services reported by REF were 'Surgery and/or amputation' (f = 13/72), 'peripheral neuropathy' (f = 12/72); and 'alterations in mobility' (f = 11/72); and by PWAR were 'deconditioning' (f = 6/25), 'peripheral neuropathy' (f = 4/25), and 'weakness' (f = 3/25). Further details on reasons that prompted referral are available in Table 3.

Table 3. Reasons that prompt referral to PR services

	Overall ***n= 34, 100%***	
	REF ***n = 19, 55.9%***	**PWAR** ***n = 15, 44.1%***
De-conditioning	8	6
Peripheral neuropathy	12	4
Weakness	7	3
Surgery and/or amputation	13	2
Altered mobility	11	2
Spinal cord injury	3	2
Abnormal gross and fine motor skills	1	2
Neurological deficits	1	2
Impaired balance	-	2
Bone tumour	3	-
Brain tumour	3	-
CNS tumour	3	-
Tumour	1	-
Graft versus host disease of the joints	1	-
Extended hospital stays	1	-
Pain	1	-
Respiratory issues	1	-
Leukemia	1	-
Bone marrow transplant	1	-
Total frequencies (*f*)	**72**	**25**

Abbreviations: PR, physical rehabilitation; CNS, central nervous system

4.4.3. Availability of Physical Rehabilitation Programs and Clinical Practice Guidelines

A total of 47 survey respondents (n= 19 REF and n= 28 PRO+PWAR) were included in the analysis. When asked about availability of a PR program in their work setting, 79% (n= 15/19) of REF reported having a PR program in their setting, compared to 50% (n= 14/28) of PRO+PWAR. The main reasons for not having a PR program reported by REF was 'Availability of resources/space' (f = 1/6, 17%) and by PRO+PWAR was 'Funding' (f = 4/19, 21%). Of the 47 survey respondents, 84% (n= 16) REF and 61% (n= 17) PRO+PWAR reported they do not follow any PR clinical practice guidelines. Detailed information on availability of PR programs and clinical practice guidelines is available in Table 4.

Table 4. Availability of PR programs and clinical practice guidelines

	Overall *n=47, 100%*	
	REF *n = 19, 40.4%*	**PRO+PWAR** *n=28, 59.6%*
Work settings with a PR program *(n, %)*		
Yes	15 (78.9%)	14 (50%)
No	3 (15.8%)	12 (42.9%)
Don't know	1 (5.3%)	2 (7.1%)
Reasons for not having a PR program *(f, %)*		
Funding	2 (33.3%)	4 (21.1%)
Availability of resources/space	1 (16.7%)	5 (26.3%)
Lack of PR professionals with experience in paediatric oncology	1 (16.7%)	1 (5.3%)
Other - Few admissions of children with cancer	1 (16.7%)	3 (15.8%)
Patients referred to PR programs that are not oncology specific	1 (16.7%)	3 (15.8%)
Lack of evidence to support PR interventions	0 (0%)	0 (0%)
Small paediatric oncology population	0 (0%)	3 (15.8%)
HCP who follow oncology PR CPG *(n, %)*		

No	16 (84.2%)	17 (60.7%)
Yes	3 (15.8%)	9 (32.1%)
Don't know	0 (0%)	2 (7.1%)

Abbreviations: PR, physical rehabilitation; HCP, healthcare professional; CPG, clinical practice guidelines

4.4.4. Facilitators and Barriers to Oncology PR programs

When asked about existing facilitators in their settings to offer PR services, 'Team/Staffing' (f = 11/21, 52.4%) and 'Space/Facilities' (f = 7/21, 33.3%) were the most common existing facilitators reported by REF, and 'Space/Equipment' (f = 13/36, 36.1%) and 'Multidisciplinary team/Staffing' (f = 8/36, 22.2%) were the most common reported by PRO+PWAR. The most common barriers identified by REF were 'Lack of staffing' (f = 7/29, 24.1%) and 'Lack of specialized service' (f = 5/29, 17.2%). On the other hand, 'Inappropriate space for rehabilitation' (f = 10/40, 25%) and 'Lack of funding/resources' (f = 9/40, 22.5%) were the most common barriers reported by PRO+PWAR. Detailed information on barriers and facilitators is available in Table 5.

Table 5. Barriers and facilitators to implement oncology PR programs

	Overall ***n = 46, 100%***	
Facilitators *(f, %)*	**REF** ***n = 19, 41.3%***	**PRO+PWAR** ***n = 27, 58.7%***
Multidisciplinary team/Staffing	11 (52.4%)	8 (22.2%)
Space/Equipment/Facilities	7 (33.3%)	13 (36.1%)
Specialized service/Teleconferences	1 (4.8%)	3 (8.3%)
No facilitators identified	1 (4.8%)	8 (22.2%)
Funding	1 (4.8%)	0 (0%)
Oncology Rehabilitation program	0 (0%)	3 (8.3%)
Guidelines	0 (0%)	1 (2.5%)
Total frequencies, *(f)*	**21**	**36**

Barriers *(f, %)*		
Lack of staffing	7 (24.1%)	4 (10%)
Lack of Specialized service	5 (17.2%)	0 (0%)
Lack of funding/resources	4 (13.8%)	9 (22.5%)
Continuity of care in the community/access to the service	4 (13.8%)	2 (5%)
Lack of time	3 (10.3%)	6 (15%)
Knowledge specific to oncology PR	3 (10.3%)	4 (10%)
Inappropriate space for rehabilitation	2 (6.9%)	10 (25%)
No barriers identified	1 (3.49%)	2 (5%)
Patients' health status	0 (0%)	1 (2.5%)
Lack of communication between professionals	0 (0%)	2 (5%)
Gaps in delivery of service	0 (0%)	2 (5%)
Total frequencies, *(f)*	**29**	**40**

Abbreviations: PR, physical rehabilitation

4.4.5 Importance of Oncology-specific Physical Rehabilitation Clinical Practice Guidelines

A total of 46 survey respondents (n= 19 REF and n= 27 PRO+PWAR) were included in the analysis. The majority of healthcare professionals considered it 'Very important' to implement pediatric oncology-specific clinical practice guidelines in PR (n= 13/19, 68% REF and n= 14/27, 52% PWAR), and would 'Very likely' adopt/support the implementation of the guidelines in the future (n= 12/19, 63% REF and n= 20/27, 74% PWAR). Detailed information on importance of oncology-specific PR guidelines is available in Table 6.

Table 6. Importance of oncology-specific PR clinical practice guidelines

	Overall ***n=46, 100%***	
	REF ***n = 19, 41.3%***	**PRO+PWAR** ***n =27, 58.7%***
Importance of implementing CPG *(n, %)*		

Very important	13 (68.4%)	14 (51.9%)
Moderately important	5 (26.3%)	10 (37%)
Slightly important	0 (0%)	3 (11.1%)
Not at all important	1 (5.3%)	0 (0%)
Likelihood to adopt/support the implementation of CPG *(n, %)*		
Very likely	12 (63.2%)	20 (74.1%)
I don't know	7 (36.8%)	6 (22.2%)
Not likely	0 (0%)	1 (3.7%)

Abbreviations: CPG, clinical practice guidelines

4.5 Discussion

4.5.1 Referral patterns

To our knowledge, this is the first survey across Canada that aimed to explore the PR service provision and referral patterns for children and adolescents with cancer. Our results showed that the majority of REF reported referring childhood cancer survivors "often" (n = 10, 52.6%) to PR services. Nonetheless, the actual frequency of referral was only 25% when we calculated the average percent of referrals based on the total number of survivors seen per year with the total number of survivors referred to PR services (Table 7). Our results are consistent with the findings from a prospective questionnaire conducted by Gohar et al (2010), which demonstrated that the majority of pediatric oncologists "sometimes" referred patients to PR services.[8] Furthermore, when findings were correlated with reasons that prompted REF to refer to PR, the main reason reported was "Surgery and/or amputation" (f = 13/72). Results suggested that childhood cancer survivors are referred to PR services mostly in the presence of, or with the potential for development of serious functional disabilities. Additionally, our findings are supported by those of Cheville and colleagues[18] who found that while rehabilitation is part of the standard care of patients

with pulmonary and coronary disease, it is not commonly offered to childhood cancer survivors.

Table 7. Percentage of C&A referred to PR summary

	Overall *n= 34, 100%*	
Percentage of C&A referred (n)	**REF** ***n = 19, 55.9%***	**PWAR** ***n = 15, 44.1%***
5%	4	0
10%	4	3
25%	5	5
50%	3	3
100%	3	4

Abbreviations: C&A, children and adolescents; PR, physical rehabilitation

It is estimated that two-thirds of childhood cancer survivors will develop at least one long-term side effect after cancer treatment[1], with common cancer side-effects such as limitations in range of motion and gait deficits across multiple childhood cancers, not just sarcoma and brain tumours.[10] Chemotherapeutic agents are associated with neuropathies, resulting in muscle weakness[10] and impaired dorsi-flexion range of motion,[10] and along with treatment-related immobility, has also been associated with other physical limitations in childhood cancer survivors.[12] While the majority of childhood cancer survivors may benefit from a PR program, our results demonstrate that the majority of children are not being referred to PR services. As suggested in this survey, numerous reasons for lack of referrals may exist. Survey respondents indicated that the main reason children and adolescents with cancer did not receive PR services was 'Parents/patients' choice'. This finding may be attributed to the time burden experienced by parents in attending medical

appointments and cancer treatments.[14,15] As such, PR may be seen as less of a priority to medical care. Gohar et al.[8] also found 'parents' choice' in addition to 'financial resources', as the main reasons childhood cancer survivors did not receive necessary PR. Patchell et al[19] also identified poor compliance and attendance as the main challenges of treatment when working with adolescents and young adults (AYAs) with cancer. Other reasons may be (1) a lack of understanding on the part of parents on the importance and benefits of PR programs in cancer, and/or (2) limitations related to access of rehabilitation services close to home. Addressing the needs and wellbeing of families of childhood cancer survivors may facilitate uptake of PR programs. Prior research engaging childhood cancer survivors' parents in exercise[16,17] and diet[17] interventions has shown benefit for parents as well as positive outcomes in promoting long-term lifestyle changes in childhood cancer survivors.[17]

The majority of PWAR (n= 11, 38%) reported referring children and adolescents with cancer to 'Community/Primary Care Rehabilitation Services'. This finding could be interpreted either positively or negatively. PWAR may refer childhood cancer survivors to community services to promote and facilitate continuity of PR care; however, it may also be due to a lack of specialized outpatient hospital-based services at the respective institution. Thus, the PWAR may refer children and adolescents to community outpatient services that may or may not offer specialized services. A survey conducted in Australia[19] compared confidence levels of PTs (n = 104) and exercise professionals (n = 32) treating adults versus AYAs with cancer; and determined clinician interest in specialized oncology education. Results showed that only 36% of PTs (n = 104) and exercise professionals (n = 32) reported confidence treating AYAs undergoing cancer treatment, and 57% reported

feeling confident for AYAs in remission post-treatment. In contrast, 67% reported confidence treating adults undergoing cancer treatment and 87% feeling confident for adults in remission post-treatment. Furthermore, only 5% of survey respondents reported they had received some form of education specific to AYA oncology, with 64% indicating interest in obtaining further education specific to AYA oncology. Thus, further exploration of the educational needs of HCPs working with children and adolescents, especially those working in community sites, may be required.

4.5.2 Barriers and facilitators

Results show that HCPs reported a greater number of barriers (f = 69) than facilitators (f = 57) to pediatric oncology PR programs in their work settings. According to PRO+PWAR, 'inappropriate space for rehabilitation' (f = 10/40, 25%) and 'lack of funding/resources' (f = 9/40, 22.5%) were identified as the main barriers. Results are consistent with findings from a Canadian survey of adult oncology rehabilitation services conducted by Canestraro et al.,[9] which also identified lack of funding and resources as the major barriers. Additional comments on barriers from PRO+PWAR suggested that their work settings lacked funding for appropriate equipment and availability of appropriate space to carry out rehabilitation interventions for childhood cancer survivors. Although, PRO+PWAR also identified 'space/equipment' (f = 13/36, 36.1%) and 'multidisciplinary team/staffing' (f = 8/36, 22.2%) as facilitators, their comments suggested that HCPs are working with the minimal resources available (e.g. no PT available, adult gymnasium, inadequate time for interventions), and that childhood cancer survivors would benefit from age-appropriate spaces and equipment, and dedicated time for PT interventions. In settings where no PR programs were available, HCPs reported 'availability of resources/space' (f

= 1/6, 17% REF and f = 5/19, 26% PRO+PWAR) and 'funding' (f = 2/6, 33% REF and f = 4/19, 21% PRO+PWAR) as the reasons for the lack of PR services.

Contrary to PRO+PWAR, REF identified 'lack of staffing' (f = 7/29, 24.1%) and 'lack of specialized service' (f = 5/29, 17.2%) as the main barriers. Additional comments suggested that their work settings did not have oncology-specific PR services or outpatient PR services to provide continuity of care, or that there was a lack of sufficient staff to meet the needs of childhood cancer survivors. Lack of staffing in clinical settings was attributed primarily to a lack of PTs specialized in pediatric oncology rehabilitation.[9] This finding could be associated with the lack of referrals of childhood cancer survivors to PR services identified in the study. Respondents also identified barriers related to the health system, namely the unrecognized need for (n= 14/27, 52% PWAR and n= 13/19, 68% REF), and support (n= 20/27, 74% PWAR and n= 12/19, 63% REF) to develop and implement pediatric oncology-specific clinical practice guidelines in PR. This highlights a role for PTs to advocate for (1) education specific to pediatric oncology rehabilitation; (2) the development of PR services[9] specific to childhood cancer survivors; and (3) collaboration among HCPs, researchers and leaders in the field to create PR guidelines specific to pediatric oncology services.

Several limitations were identified in this study. First, 'physical rehabilitation' was not defined. While this term was chosen over the discipline-specific term "physical therapy" to better explore service provision across HCP disciplines, there is a possibility that responses differed based on individual HCP's interpretation and professional role. Second, although the survey was pilot-tested prior distribution, the question on facilitators to provision of pediatric oncology PR programs was unclear for some survey respondents.

Third, to protect the right of privacy and confidentiality, we did not ask personal information that identified participants. Therefore, we were not able to follow-up with respondents when survey responses were unclear or incomplete. Fourth, the survey did not encompass respondents from all provinces, which suggests that our results may not be representative of all pediatric oncology PR programs across Canada. A strength of the study involved the higher than anticipated response rate that exceeded our estimated sample size. Second, our results are similar to previous surveys of HCPs conducted to evaluate both adult and pediatric oncology PR service provision.[9]

4.6 Future directions

Our study provides an overview of the practice patterns, and potential barriers and facilitators to pediatric oncology PR services. Future research is needed specific to pediatric oncology PR to inform the development of clinical practice guidelines. Despite the lack of research, educational efforts specific to pediatric oncology PR are needed to build capacity for services across acute care and community/ primary care locations.

4.7 Conclusions

This survey demonstrated that several gaps in the health system exist that impact the implementation of PR programs. The main findings of the survey suggest that (1) the number of children and adolescents with cancer referred to PR services is low, (2) there is a lack of funding and resources for PR services in the clinical setting, and (3) there is a need for HCPs with expertise specific to pediatric oncology PR within hospital and community settings. Although, several barriers were reported, there is high interest from oncology HCPs to develop and support the implementation of clinical practice guidelines in PR for childhood cancer survivors.

Declarations of interest

The authors report no declarations of interest.

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CHAPTER 5: RESULTS PHASE II – PRACTICE PATTERNS

Manuscript 4

Physical rehabilitation practice patterns and outcome measures in children and adolescents with cancer across Canada

(A manuscript in preparation for submission to the journal: Physiotherapy Canada)

5.1 Abstract

Relevance: Children and adolescents with cancer who undergo cancer treatment are at high risk of developing serious late and long-term physical effects, many of which may be amenable to physical rehabilitation (PR). **Objectives:** This study aims to (1) identify the current clinical PR practice patterns of healthcare practitioners (HCPs) working with children and adolescents with cancer across Canada, and (2) collate information on clinical programs and outcome measures specific to pediatric oncology PR. **Materials and Methods:** A cross-sectional web-based survey in English and French languages was conducted. Participants identified were HCPs who provided PR services to children and adolescents with cancer across Canada. The survey included questions on practice patterns and service provision related to existing pediatric oncology PR programs. **Results:** A total of 35 survey respondents were included in the study, including physical therapists (n= 27, 77%), followed by occupational therapists (n= 6, 17%), an exercise professional (n= 1, 3%), and a speech-language pathologists (n= 1, 3%). Survey respondents reported 'limitations in activities', 'alterations in motor performance', 'muscle weakness' and 'peripheral neuropathy' as top priorities for PR services. While providers perceive interventions valuable in reducing the burden of cancer effects, issues such as space and resources were seen as barriers to service provision. A guideline for physical exercise prescription was the only guideline reported in use clinically. **Conclusions:** Expertise exists among HCPs working in pediatric oncology PR within some regions in Canada. Strong support exists among HCPs for the development of pediatric oncology PR clinical practice guidelines.

Keywords: cancer, physical therapy, rehabilitation, pediatrics, practice patterns, outcome measures

5.2 Introduction

Children and adolescents with cancer who undergo cancer treatment are at high risk of developing serious late and long-term physical effects, many of which may be amenable to physical therapy (PT).[1] These effects include pain, fatigue, weakness,[2] peripheral neuropathy; as well as limitations in strength, range of motion, function, and deficits in balance and gait.[1,3,4] These complications may negatively affect the child's overall quality of life[5] and ability to participate in age-appropriate activities including play.[6] Impairment-based cancer rehabilitation for children and adolescents is a growing area of PT that requires further development and research.

To date, little is known about the extent of oncology physical rehabilitation (PR) practices in the clinical setting. Only one study has explored practice patterns in oncology PR in Canada. A cross-sectional online survey conducted by Canestraro et al[9] explored the extent of oncology PR service provision, practice patterns, and perceived barriers and facilitators to service for adults with cancer in Canada. Sixty-two out of 116 Canadian facilities responded the survey. Education and aerobic exercise interventions were reported as the primary interventions offered in the majority of the oncology rehabilitation programs across the country.

To the best of our knowledge, no published study to date has explored the practice patterns specific to pediatric oncology PR in Canada. The purposes of this study were to (1) identify the current clinical PR practice patterns offered by physical therapists (PTs) and healthcare practitioners (HCPs) working with children and adolescents with cancer

across Canada, and (2) collate information on clinical programs and evidence-based guidelines specific to pediatric oncology PR.

We hypothesized that expertise exists among PTs and other HCPs working in the pediatric oncology PR field and that specialized interventions are currently being delivered in some clinical settings.

5.3 Methods

The present study aimed to (1) explore PR practice patterns including use of protocols/ guidelines for clinical practice; (2) characterize the priorities for PR programs; and (3) identify existing barriers and facilitators that may impact the implementation of pediatric oncology PR programs.

5.3.1 Participants

The study was approved by the Health Research Ethics Board of Alberta: Cancer Committee. Electronic informed consent was obtained from participants (Appendices B, C, and D). We conducted a cross-sectional web-based survey in a secure "REDCap" database at the University of Alberta in Edmonton, Canada. Eligible participants across Canada were identified using a multi-pronged approach. We identified PTs and other HCPs who provide and/or refer children and adolescents with cancer to PR services across Canada through professional networks and organizations such as: the Canadian Physiotherapy Association Oncology and Pediatric Divisions, the C17 Children's Cancers and Blood Disorders Council network, Pediatric Oncology Group of Ontario, Stollery Children's Hospital (Oncology professionals), Cross Cancer Institute (Rehabilitation Medicine Department), CancerControl Alberta, the Northern Alberta Childhood Cancer Program, and the Alberta Health Services. Furthermore, we conducted an online search of

additional organizations, institutions, and facilities that provide cancer care using the keywords: *cancer rehabilitation* OR *physical rehabilitation* OR *children* OR *adolescents* OR *pediatric* OR *cancer care.* To identify potential participants, we contacted each site via email, and distributed the survey communication to HCPs who were working with a pediatric oncology population (Appendix E). The survey was available for a period of three months from July to October 2017. We sent electronic reminders every three weeks to facilitate a higher response rate (Appendix F). Given the low number of pediatric cancer cases in the country, we anticipated that there would be fewer HCPs working in this field. Thus, we expected approximately 30 respondents would complete this survey over the course of three-month study period.

5.3.2 Instrument

The survey was available in English and French to allow for the inclusion of HCPs from the two official languages in Canada (Appendices G and H). Questions were designed based on previous studies conducted in cancer rehabilitation.[8,9] The survey included 30 questions, subdivided into sections. The first section included questions to inform service provision within the following domains: average number of children and adolescents with cancer seen for PR per year, the most common cancer effects addressed in PR, the type of PR interventions applied, the type of physical agents applied, the perceived effectiveness of treatment, and the outcome measures/tests utilized for assessment and follow-up.

The next section asked HCPs if their work setting had adopted a pediatric oncology PR intervention program, their views on any evidence-based guidelines and protocols used for this population, and if any barriers and facilitators exist that may impact provision of care or the adoption of guidelines and protocols in their work setting.

5.3.3. Data analysis

The data collected consisted of continuous and categorical data that were reported as the total number of respondents per question/section (n), and frequency (f)/ percentage (%), respectively. Basic descriptive statistics in determining the frequency of responses to all questions were generated by REDCap. Due to the complexity of the survey design, the data were imported into Microsoft Excel for calculating percentages, frequencies, and proportions for further data description. Two study investigators tabulated open-ended questions into frequency distributions, categorized into themes or patterns, and coded responses as a means for organizing and presenting findings. The two investigators shared the findings and a consensus was reached for coding the responses.

5.4 Results

5.4.1 Demographics

A total of 67 HCPs took part in the study. Fifty-one (76%) responders completed the survey, 5 (7%) partially completed the survey, and 11 (16%) only signed the consent form document. Thirty-two responses were excluded, 11 where only the consent form was completed, 19 who were not PR providers, and 2 without at least one completed section of the survey. Survey results from three responders who had partially completed the survey (including one full section) were included. A total of 35 HCPs reported providing PR intervention and their responses were included in the analyses. Figure 1 illustrates a detailed selection process of included and excluded survey responses.

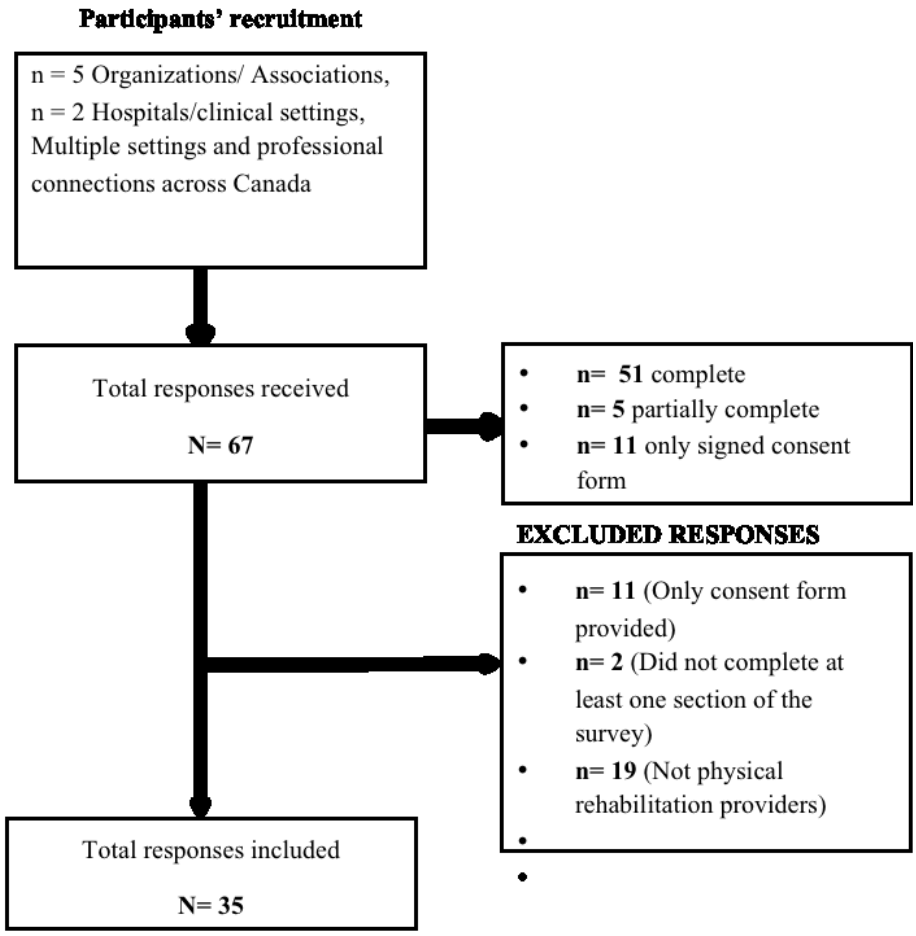


Figure 1. Inclusion and exclusion process of survey responses

The majority of respondents were located in the province of Alberta (n= 17, 49%) and Ontario (n= 8, 23%), followed by Quebec (n= 5, 14%), British Columbia (n= 4, 11%), and Newfoundland (n= 1, 3%). Survey responses were provided primarily by PTs (n= 27, 77%), followed by occupational therapists (n= 6, 17%), an exercise professional (n= 1, 3%), and a speech-language pathologist (n= 1, 3%).

The majority of the HCPs worked in Acute Care Hospitals (n= 17, 49%), followed by rehabilitation hospitals (n= 9, 26%), cancer hospitals (n= 7, 20%), private practice (n=

1, 3%), and community/primary care (n= 1, 3%). Length of experience in the pediatric oncology field, in terms of time, ranged between 0.6 to 37 years. The two major groups were 41% (n= 14) with 10.1 to 20 years and 29% (n= 10) with 0.1 to 5 years. The average number of children and adolescents with cancer seen per year was classified in three groups. A total of 43% (n = 15) reported seeing *few* pediatric oncology patients per year ["1 to 5" (n = 8) and "6 to 10" (n = 7)]; 43% (n = 15) reported seeing *some* pediatric oncology patients ["11 to 19" (n = 7) and "20 to 40" (n = 8)] per year; and 15% (n = 5) reported seeing *many* pediatric oncology patients ["50 to 100" (n = 3) and "more than 100" (n = 2)] per year. Detailed demographic information is available in Table 1.

Table 1. Demographics

	Overall ***n = 35 , 100%***
Province *n* (%)	
Alberta	17 (48.6%)
British Columbia	4 (11.4%)
Newfoundland	1 (2.9%)
Ontario	8 (22.9%)
Quebec	5 (14.3%)
Professional designation *n* (%)	
Physical therapist	27 (77.1%)
Occupational therapist	6 (17.1%)
Physical education	1 (2.9%)
Speech-Language Pathologist	1 (2.9%)
Work setting *n* (%)	
Acute Care Hospital	17 (48.6%)
Rehabilitation hospital	9 (25.7%)
Cancer hospital	7 (20%)
Private practice	1 (2.9%)
Community/Primary Care	1 (2.9%)
Length of experience (years) *n* (%)	***n = 34, 100%***
0.1 - 5	10 (29.4%)
5.1 - 10	6 (17.6%)
10.1 - 20	14 (41.2%)
20.1 - 40	4 (11.8%)

5.4.2 Priorities for physical rehabilitation

When HCPs were asked to rate the top priorities for PR interventions, survey respondents reported the highest priority as 'limitations in activities of daily living' (n = 18, 17.3%), followed by 'alterations in motor performance' (n = 17, 16.3%), 'muscle weakness' (n = 15, 14.4%), 'peripheral neuropathy' (n = 13, 12.5%), and 'cancer-related fatigue' (n = 10, 9.6%). Detailed information of priorities for PR is available in Table 2.

Table 2. Top priorities for physical rehabilitation

	Total
Priorities *f* (%)	
Limitation in Activities of Daily Living	18 (17.3%)
Alteration in motor performance	17 (16.3%)
Muscle weakness	15 (14.4%)
Peripheral neuropathy	13 (12.5%)
Cancer-related fatigue	10 (9.6%)
Motor development alterations	9 (8.6%)
Balance alterations	8 (7.7%)
Pain	7 (6.7%)
Gait alterations	6 (5.8%)
Decrease in flexibility	1 (1%)
Total frequencies (*f*)	**104**

5.4.3 Physical rehabilitation interventions across the cancer continuum of care

A total of 34 PR providers were included in the analysis. The majority of PR providers reported working on hospital inpatient units only (50%, n = 17), followed by outpatients only (26%, n = 9), and both inpatients and outpatients (24%, n = 8).

Inpatient services

PR Interventions: When asked the types of PR interventions provided to childhood cancer survivors before, during, and after cancer treatment, a higher frequency of PR interventions were delivered 'during cancer treatment' (f = 190), followed by 'after cancer treatment' (f = 150), and 'before cancer treatment' (f = 60). The most common PR intervention before, during, and after cancer treatment was 'range of motion (passive/active/active-assisted)' (f = 40), followed by 'functional strengthening' (f = 38), 'balance training' (f = 35), 'flexibility exercises' (f = 34), and 'gait training/re-education' (f = 33). Detailed information on inpatients PR interventions is available in Figure 2.

Physical agents: The majority of PR professionals reported not using any physical agents in childhood cancer survivors (n = 12). Nonetheless, of those using physical agents, the most common agent used in pediatric oncology PR was 'cryotherapy' (f = 6), followed by 'thermotherapy' (f = 4), 'electrical stimulation' (f = 3), 'Transcutaneous Electrical Nerve Stimulation (TENS)' (f = 3), 'ultrasound' (f = 2), and 'paraffin wax bath' (f = 2). The rationale for using 'cryotherapy' and 'thermotherapy' was mainly for pain relief and to increase comfort prior to exercise. Electrical stimulation was used for the recovery of peripheral neuropathy including foot drop, and for postoperative nerve damage. TENS was used for pain relief in a palliative care setting. Ultrasound was used to treat Hand and Foot Syndrome secondary to chemotherapy, for scar healing and prior to manual therapy. Paraffin wax bath was used to treat neuropathic pain in hands, joint stiffness, and chronic graft versus host disease involving the hands.

Figure 2 Inpatients physical rehabilitation interventions

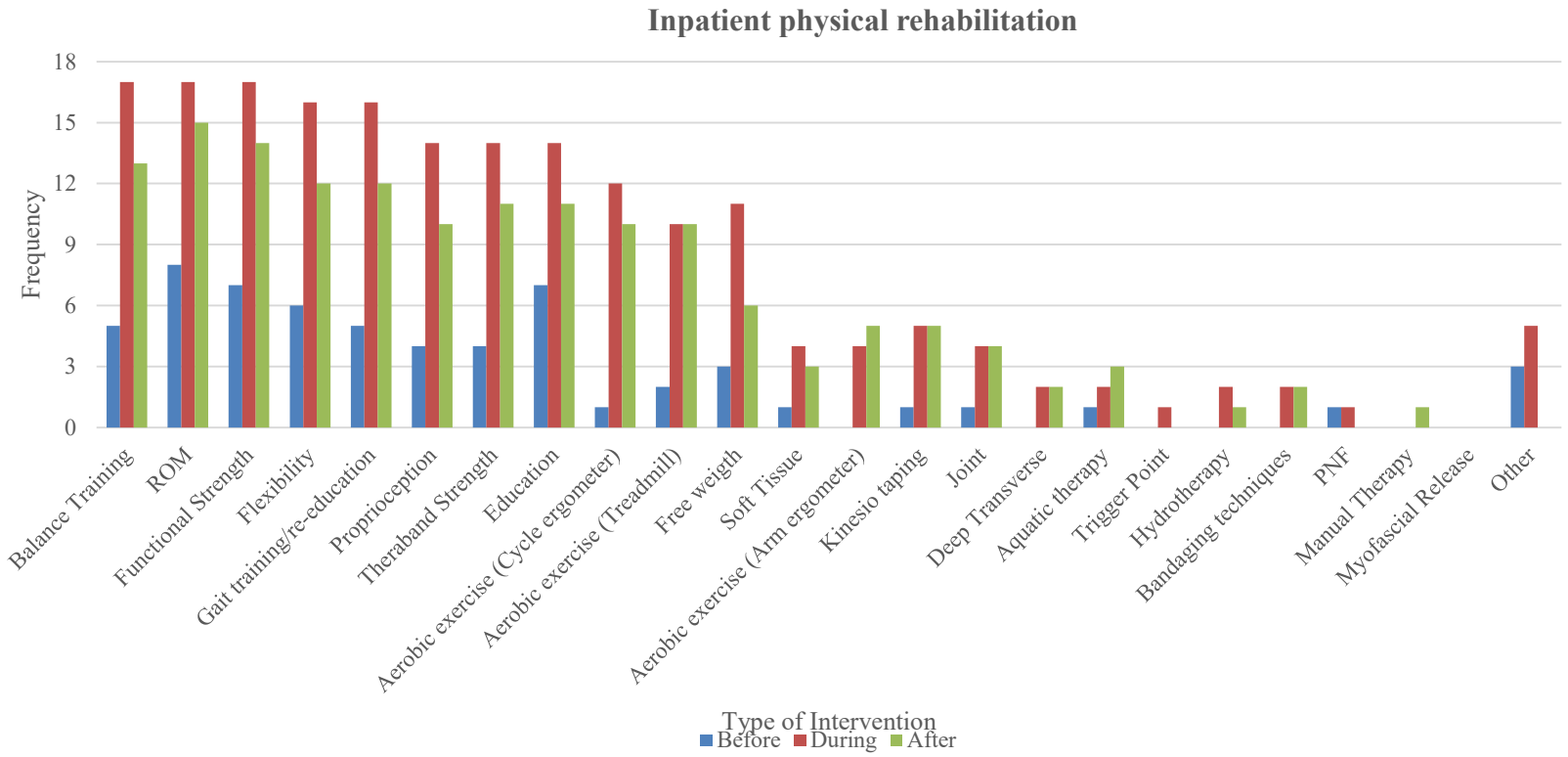
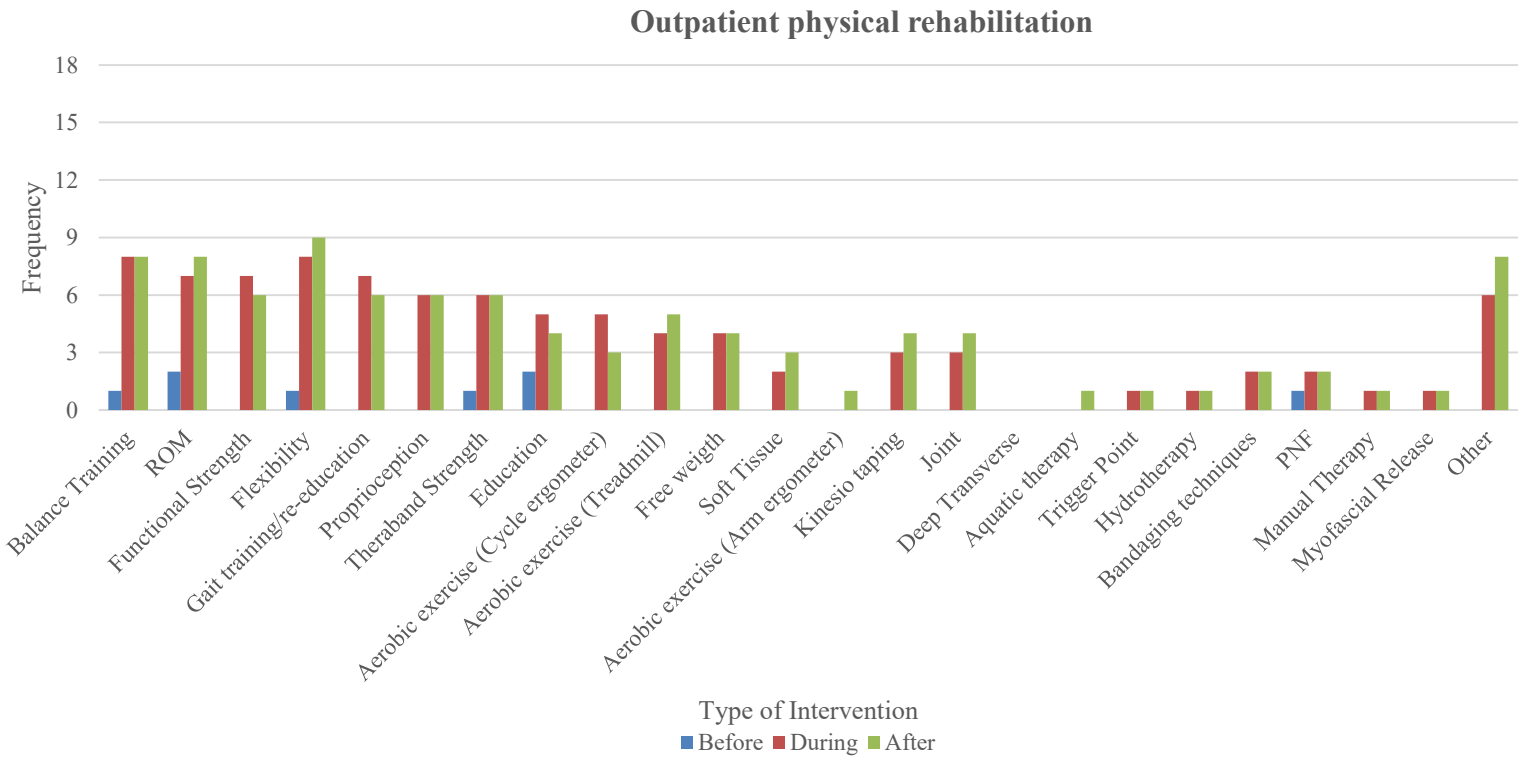


Figure 3 Outpatients physical rehabilitation interventions



Outpatient services

PR Interventions: When asked the types of PR interventions provided to childhood cancer survivors before, during, and after cancer treatment, a higher frequency of PR interventions were delivered 'after cancer treatment' (f = 94), followed by "during cancer treatment" (f = 89), and 'before cancer treatment' (f = 8). The most common PR intervention before, during, and after cancer treatment was 'flexibility exercises' (f = 18), followed by 'balance training' (f = 17), 'range of motion (passive/active/active-assisted)' (f = 17), 'functional strengthening' (f = 13), 'gait training/re-education' (f = 13), 'elastic band exercises' (f = 13), and 'proprioception exercises' (f = 12). Detailed information on outpatients PR interventions is available in Table 3 and Figure 3.

Table 3. Outpatient physical rehabilitation interventions before, during, and after cancer treatment

Intervention	Before	During	After	Total
Balance Training	1	8	8	17
ROM (passive/active/active-assisted)	2	7	8	17
Functional Strengthening		7	6	13
Flexibility exercises	1	8	9	18
Gait training/re-education		7	6	13
Proprioception exercises		6	6	12
Theraband/theratubing strengthening exercises	1	6	6	13
Education	2	5	4	11
Aerobic exercise (Cycle ergometer)		5	3	8
Aerobic exercise (Treadmill)		4	5	9
Free weights strengthening exercises		4	4	8
Soft Tissue massage		2	3	5
Aerobic exercise (Arm ergometer)			1	1
Kinesio taping		3	4	7
Joint mobilizations and manipulations		3	4	7
Deep Transverse friction				0
Aquatic therapy			1	1
Trigger Point therapy		1	1	2
Hydrotherapy		1	1	2

Bandaging techniques		2	2	4
Proprioceptive Neuromuscular Facilitation (PNF)	1	2	2	5
Manual Therapy/distraction techniques		1	1	2
Myofascial Release		1	1	2
Other- Pain management		1	1	2
Other- Return to school		1	1	2
Other- Cardiorespiratory		1	1	2
Other- Prosthesis management for amputees		1	1	2
Other- Equipment prescription		1	1	2
Other- Fatigue management		1		1
Other- General mobility			1	1
Other- Brace fit			1	1
Other- Prosthesis training			1	1
Total - Frequency, *f*	**8**	**89**	**94**	**191**

Physical agents: The majority of PR professionals reported not using any physical agents in childhood cancer survivors (n = 13). For those using physical agents, HCPs reported using 'thermotherapy' (f = 1), 'electrical stimulation' (f = 3), and a 'paraffin wax bath' (f = 1). The rationales for using thermotherapy and electrical stimulation were not reported. Paraffin wax bath was used to treat neuropathic pain in hands and for joint stiffness.

5.4.4 Physical rehabilitation delivery

A total of 28 survey respondents (27 PT + 1 exercise professional) were included in the analysis. The majority of PR providers (96.4%, n = 27) reported that 'each patient receives an individualized intervention according to their needs', and only 1 respondent stated, 'all patients presenting different symptoms receive a similar intervention'. Twenty-four survey respondents (86%) provide PR to childhood cancer survivors individually, 3 (11%) in groups and individually, and only 1 (4%) reported group therapy alone.

5.4.5 Perception of physical rehabilitation programs

A total of 28 survey respondents (27 PT + 1 exercise professional) were included in the analysis. A total of 25 survey respondents (82.2%) believed that their PR interventions helped to reduce the burden of cancer side effects in children and adolescents. Three PR providers (10.7%) provided context to their perceptions:

1) “Yes, but I feel there is a wide range of conditions we do not treat directly that is within our scope due to our lack of resources. The interventions provided benefit the children and reduce the burden”.

2) “Sometimes yes, at other times the child is too unwell to participate and does not seem to benefit from active intervention”.

3) “I don’t see them long term so I wouldn’t know if it changed their side effects of cancer”.

When PR providers were asked if there were aspects of the interventions they would like to improve or add, 8 (28.6%) providers reported being satisfied with their interventions, while 20 (70.4%) mentioned a need for improvement in the PR programs. A total of 10 categories for improvement were identified, including the need for: research evidence (f = 5), continuity of care (f = 4), time for PR interventions (f = 4), specialized PT interventions (f = 4), staffing (f = 3), communication with interdisciplinary team (n = 3), grouped interventions (f = 3), education for physical therapists (f = 2), funding (f = 2), and access to rehabilitation services (f = 1). Detailed information on perception of interventions is available in Table 4.

Table 4. Perception of physical rehabilitation programs

	Overall ***n=28, 100%***
Do PR interventions help to reduce the burden of cancer side effects? ***(n, %)***	
Yes	25 (89.3%)
Other	3 (10.7%)
No	0 (0%)
Anything to be improved/added for the PR program for C&A with cancer? ***(n, %)***	
Yes	20 (71.4%)
No	8 (28.6%)
If yes: ***(Frequency, f)***	
Research evidence	5
Continuity of care	4
Time	4
Specialized Care	4
Staffing	3
Communication with team	3
Grouped interventions	3
Education for PTs	2
Funding	2
Access to rehabilitation services	1

Abbreviations: PR, Physical Rehabilitation; C&A, Children and adolescence

5.4.6 Outcome measurement tools used in physical rehabilitation

The survey included 13 outcome measurement categories in PR (Appendix I). The category *motor development* was reported as the most assessed outcome in PR (f = 62), using primarily the 'Alberta Infant Motor Scale (AIMS)' (f = 16), followed by the 'Bruininks Osteretsky Test of Motor Proficiency (BOT)' (f = 13), 'Peabody

Developmental Motor Scales (PDMS-2)', and 'Movement Assessment Battery for Children (MABC)' (f = 7). *Sensory function* was the second most assessed outcome in PR (f = 56), using primarily the 'sharp and dull test' (f = 17), followed by 'hot and cold test/temperature test' (f = 13), and 'vibration test' (f = 10). *Strength* was the third category most assessed in PR (f = 46), using primarily the 'manual muscle test' (f = 26), followed by 'hand-held dynamometry' (f = 10), 'sit-to-stand test' (f = 5), and 'up-and-down stairs test'. Additional outcome measures included: *balance,* primarily using the 'Berg Balance Scale (BBS)' (f = 14) and the 'Pediatric Balance Scale (PBS)' (f = 10); *pain,* primarily using the 'Visual Analog Scale (VAS)' (f = 23) and 'Faces Pain Scale' (f = 18); *flexibility/join range of motion,* primarily using 'goniometry' (f = 27); *aerobic capacity,* primarily using the '6-minute walk test' (f = 16); *fatigue,* primarily using the 'Rating of Perceived Exertion (RPE)' (F = 15), and *posture,* primarily using 'visual analysis' (f = 27). The least assessed outcomes reported by PR providers were *quality of life* (f = 26), *gait* (f = 16), *functional abilities* (f = 15), and *peripheral neuropathy* (f = 14).

5.4.7 Availability of PR programs and clinical practice guidelines

A total of 28 survey respondents were included in the analysis for this section. When asked about availability of a PR program in their work setting, 50% (n= 14/28) of HCPs reported having a PR program in their clinical setting. The main reasons for not having a PR program reported were 'Availability of resources/space' (f = 5/19, 26%) and 'Funding' (f = 4/19, 21%). Of the 28 survey respondents, 61% (n= 17) reported they do not follow any PR clinical practice guidelines. PR providers reported using guidelines in their settings including: the Pediatric Oncology Exercise Manual

(POEM)[8], general exercise booklets, and guidelines related to adult oncology although not specific to pediatric oncology. Detailed information on availability of PR programs and clinical practice guidelines is available in Table 5.

Table 5. Availability of PR programs and clinical practice guidelines

	PRO+PWAR ***n=28, 100%***
Number of work settings with PR program *(n, %)*	
Yes	14 (50%)
No	12 (42.9%)
Don't know	2 (7.1%)
Reasons for not having a PR program *(f, %)*	
Availability of resources/space	5 (26.3%)
Funding	4 (21.1%)
Other - Few admissions of children with cancer	3 (15.8%)
Patients referred to rehabilitation programs that are not oncology specific	3 (15.8%)
Small paediatric oncology population	3 (15.8%)
Lack of physical rehabilitation professionals with experience in paediatric oncology	1 (5.3%)
Lack of evidence to support physical rehabilitation interventions	0 (0%)
Number of HCP who follow clinical practice guidelines *(n, %)*	
No	17 (60.7%)
Yes	9 (32.1%)
Don't know	2 (7.1%)

Abbreviations: PR, physical rehabilitation; HCP, healthcare professional

5.4.8 Barriers and facilitators to implement oncology PR programs

When asked about existing facilitators in their settings to offer PR services, 'Space/Equipment' (f = 13/36, 36.1%) and 'Multidisciplinary team/Staffing' (f = 8/36, 22.2%) were the most common existing facilitators reported by PR providers. The most

common barriers identified were 'Inappropriate space for rehabilitation' (f = 10/42, 23.8%) and 'Lack of funding/resources' (f = 9/42, 21.4%). Detailed information on barriers and facilitators is available in Table 6.

Table 6. Barriers and facilitators to implement oncology PR programs

	PRO+PWAR ***n = 27, 100%***
Facilitators *(f, %)*	
Space/Equipment/Facilities	13 (36.1%)
Multidisciplinary team/Staffing	8 (22.2%)
No facilitators identified	8 (22.2%)
Specialized service/Teleconferences	3 (8.3%)
Oncology Rehabilitation program	3 (8.3%)
Guidelines	1 (2.5%)
Funding	0 (0%)
Total frequencies, *(f)*	**36**
Barriers *(f, %)*	
Inappropriate space for rehabilitation	10 (23.8%)
Lack of funding/resources	9 (21.4%)
Lack of time	6 (14.2%)
Lack of staffing	4 (9.5%)
Knowledge specific to oncology PR	4 (9.5%)
Continuity of care in the community/access to the service	2 (4.8%)
No barriers identified	2 (4.8%)
Lack of communication between professionals	2 (4.8%)
Gaps in delivery of service	2 (4.8%)
Patients' health status	1 (2.4%)
Lack of Specialized service	0 (0%)
Total frequencies, *(f)*	**42**

Abbreviations: PR, physical rehabilitation

5.4.9 Importance of oncology-specific PR clinical practice guidelines

A total of 27 survey respondents were included in the analysis. The majority of HCPs considered it 'Very important' to implement pediatric oncology-specific practice guidelines in PR (n= 14/27, 52%), and would 'Very likely' adopt/support the implementation of the guidelines in the future (n= 20/27, 74%). Detailed information on importance of oncology-specific PR guidelines is available in Table 7.

Table 7. Importance of oncology PR CPG

	PRO+PWAR ***n =27, 100%***
Importance of implementing CPG *(n, %)*	
Very important	14 (51.9%)
Moderately important	10 (37%)
Slightly important	3 (11.1%)
Not at all important	0 (0%)
Likelihood to adopt/support the implementation of CPG *(n, %)*	
Very likely	20 (74.1%)
I don't know	6 (22.2%)
Not likely	1 (3.7%)

Abbreviations: PR, physical rehabilitation; CPG, clinical practice guidelines

5.5 Discussion

To our knowledge, this is the first survey across Canada that aimed to explore pediatric oncology PR services and practice patterns. Our results identified 'limitations in activities' as the highest priority to be addressed in PR interventions for childhood cancer survivors. This finding aligns with those of a recent qualitative study[10] that investigated patients' and parents' views on supportive care for childhood cancer survivors. In the study, children were found to view school as very important to normal life, including being able to attend school and interact with classmates; however, hospitalization and fatigue were found as the main reasons for not attending school.

Patient-centered research trials in PR focusing on the 'limitations in activities' of childhood cancer survivors are beginning to emerge. A recent study conducted by Tanner et al[9] described the feasibility of a standard care PT program in children diagnosed with Acute Lymphoblastic Leukemia undergoing cancer treatment. The study guided their interventions based on the International Classification of Functioning, Disability, and Health (ICF) framework described by the World Health Organization. Results demonstrated that 1) the PT program was feasible; and 2) childhood cancer survivors who reported limitations in activities at an early stage of chemotherapy treatment and completed the PT program, improved their motor skills and scored well on age-norm-based motor function tests on their final follow up assessment. Positive results from the PT program were seen in patients' outcomes, and benefits for families in reducing additional visits through coordination of PT appointments with oncology follow-up visits.

Although, 'limitations in activities' was reported as the highest priority for PR, common PR interventions applied included flexibility, balance and ROM exercises and outcome measures for quality of life and functional abilities were least commonly used outcomes in pediatric oncology PR. Thus, there appears a disconnect between identified priorities and actual PR service provision. This may be explained by some identified barriers in clinical settings such as 'lack of time to provide PR intervention during inpatients service' and 'lack of continuity of care of childhood cancer survivors in outpatient setting'. These barriers may hinder PR providers to conduct thorough assessments and to design long-term PR interventions incorporating childhood cancer survivors' needs.

Peripheral neuropathy was also reported as one of the highest priorities for PR programs in children and adolescents with cancer.[11] Chemotherapy-induced peripheral neuropathy (CIPN) negatively impacts the child's quality of life and ability to participate in age-appropriate activities. Even though CIPN is one of the most reported negative effects of childhood cancer treatments, no research trials exist specifically addressing CIPN as a clinical entity, beyond basic strengthening exercises for motor neuropathy (foot drop). A few PR providers reported using interventions such as electrical stimulation for the recovery of CIPN symptoms and for foot drop. Thus, there is a need for further research investigating PR interventions for CIPN in childhood cancer survivors. CIPN was also one of least measured outcomes; despite availability of validated tools such as the pediatric–modified total neuropathy score (Ped-mTNS).[12]

HCPs reported administering PR interventions primarily during cancer treatments, followed by after cancer treatments. A small number of HCPs reported interventions in the prehabilitation phase of the cancer continuum of care and this is likely due to the short window of opportunity between the time of diagnosis and start of cancer treatment. One pilot study carried out during the prehabilitation phase on cancer continuum of care[14] demonstrated that 85% of children undergoing neo-adjuvant chemotherapy who were awaiting a limb-salvage procedure or amputation were able to complete the 10 to 12 weeks of prehabilitation. Improvements were seen in walking distance 9-Minute Walk/Run (9MRT) and Functional Mobility Assessment (FMA) scores, suggesting that this program may have potential to improve functional outcomes prior to surgery. Further research into the feasibility of prehabilitation in childhood

cancers is needed to examine the potential short and long-term benefits of early intervention.

The majority of survey respondents worked on inpatient service units, which was reflected in the total frequency of PR interventions provided to childhood cancer survivors. However, this also suggests a potential lack of outpatient services and continuity of care after hospital discharge that may impact the provision and quality of PR provided to children and adolescents with cancer. This finding is consistent with results from an epidemiologic study conducted by Montgomery et al, which demonstrated that only 9.3% of 5+ year survivors of childhood cancer reported accessing PR services.[15]

PR programs in both inpatient and outpatient settings primarily involved physical or therapeutic exercise interventions. Manual therapy techniques, neuromuscular re-education, and functional training were least reported by HCPs. This finding could be related by the lack of evidence supporting these PT interventions in childhood cancer[13]. As reported by the majority of PR providers, clinical practice guidelines related to pediatric oncology PR beyond exercise do not exist. Thus, the only resource used clinically was reported as the POEM guidelines[8] for general physical exercise prescription.

Functional mobility was reported as one of the least measured outcomes of PR interventions. Since 'limitations in activities' was reported as the highest priority for PR interventions, incorporating a tool to facilitate the clinical assessment of childhood cancer survivors may help with the design of patient-centered interventions in PR. The 'Functional Mobility Assessment (FMA)'[16] is a validated tool that includes six

categories: pain, function, use of assistive devices, satisfaction with walking quality, participation in activities, and endurance. Of note, none of the survey respondents reported using this tool, which could be implemented to assess and monitor improvements in mobility and participation in daily life activities including work, school, and sports. Moreover, Darcy et al[17] conducted a study that documented health and functioning in young childhood cancer survivors using the multidimensional framework and language of the ICF – Children and Youth (ICF-CY codes). The study identified a comprehensive code set that can be used by PR providers to facilitate the assessment of children and adolescents with cancer and ultimately aid in designing interventions according to the child's activity limitations and restrictions in life participation.

The majority of survey respondents (86%) indicated that they provide PR interventions individually or both individually and in groups, while only 1 respondent reported group based therapy alone. Although, individualized PR interventions aim to target specific needs of childhood cancer survivors, survey respondents reported the need for group interventions as a future area to improve their interventions. According to PR providers, children with cancer are less motivated to exercise alone, which may negatively impact adherence to PR programs. However, 'inappropriate space for pediatric rehabilitation' and 'lack of funding and resources' were two main barriers reported by PR providers that may impact feasibility of group intervention. Thus, future research is needed examining the feasibility and cost-effectiveness of group-based PR programs.

Several limitations were identified in our study. First, we did not ask PR providers which types of cancer and the average developmental stage of childhood cancer survivors seen in their clinical setting. Our results may be biased by the fact that some HCPs did not report assessing some outcomes which may be related to the types of cancer cases referred to PR in their work settings, rather than due to a lack of knowledge or time to assess outcomes. Second, although the survey was pilot-tested prior distribution, the question gathering information about facilitators to implement pediatric oncology PR programs was unclear for some survey respondents. Third, to protect the right of privacy and confidentiality, the survey was anonymous. Therefore, we were not able to follow-up with survey respondents when responses were unclear or incomplete. Fourth, we did not receive responses from all provinces, which suggests that our results may not be representative of all pediatric oncology PR programs across Canada. A strength of the study involved the higher than anticipated response rate that exceeded our planned sample size.

5.6 Future directions

Our study may serve as a basis to guide future research in the field, taking in consideration the priorities identified by PR providers as well as barriers and facilitators to service provision within the health system. Clinical practice guidelines specific to pediatric oncology PR are needed.

5.7 Conclusion

This survey identified the current practice patterns in PR across Canada. Consistent with our hypothesis, expertise exists among HCPs working in pediatric oncology rehabilitation in some regions within the country. Respondents reported

'limitations in activities', 'alterations in motor performance', 'muscle weakness' and 'peripheral neuropathy' as the top priorities for pediatric oncology PR programs. Currently, PR interventions for children with cancer are primarily carried out during the time of hospitalization and findings suggest a lack of outpatient services and continuity of care after hospital discharge. While providers perceive interventions help to reduce the burden of cancer side effects, issues such as space and resources are reported as barriers to the provision of care. HCPs providing PR strongly support the development and adoption of pediatric oncology PR practice guidelines in the clinical setting.

Declarations of interest

The authors report no declarations of interest.

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CHAPTER 6: DISCUSSION

6.1 Main findings

The main findings of this thesis relate to research evidence supporting physical therapy for children and adolescents with cancer as well as physical rehabilitation (PR) referral patterns, and service provision including facilitators and barriers to PR services in the clinical setting. We hypothesized that:

1) There would be limited high quality research evidence supporting the benefit of physical therapy for children and adolescents with cancer;

2) That expertise would exist among physical therapists (PTs) and healthcare providers (HCPs) working in the pediatric oncology field and that specialized interventions are currently being delivered in some clinical settings.

Consistent with our first hypothesis, high-quality research examining physical therapy interventions in childhood cancer is sparse. The majority of the studies included in the scoping review were considered Level 3 evidence suggesting the need for high quality large-scale randomized trials. Studies included in the review primarily focused on feasibility of PT interventions, and varied greatly in terms of types of interventions and prescriptions, which made it difficult to make comparisons and to draw conclusions to inform clinical practice.

Findings from the scoping review also revealed that the majority of the included studies were conducted during cancer treatments, often taking place in the inpatient hospital setting. This finding was consistent with the results from the survey where the

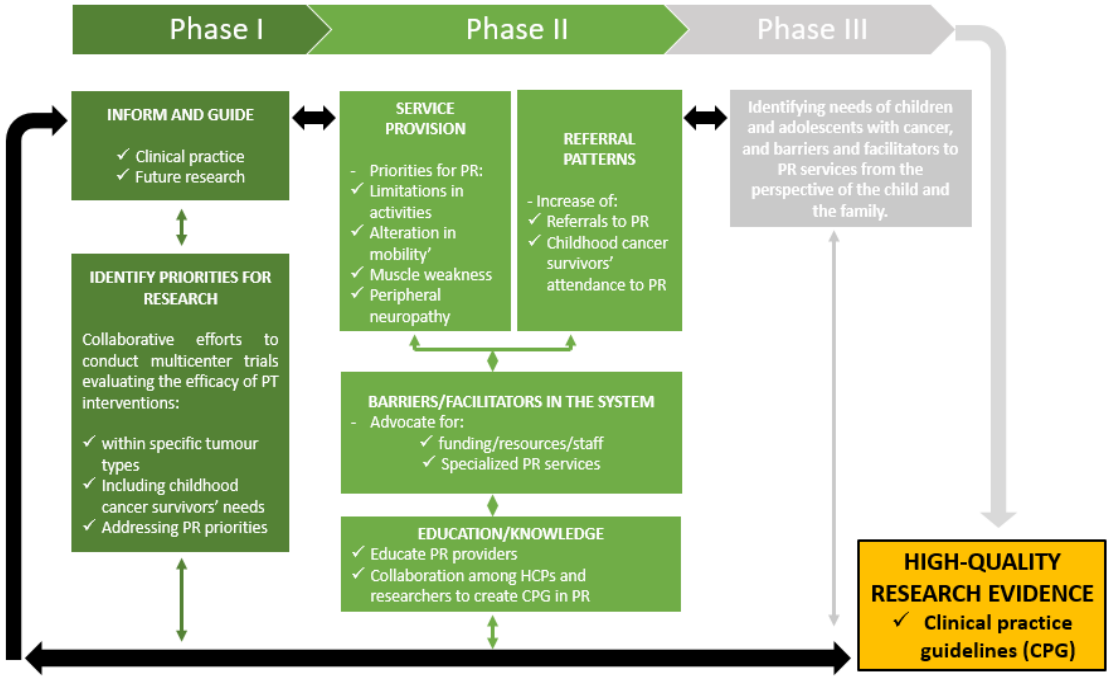
majority of PR interventions were provided during the time of hospitalization. Few interventions appear to occur in the prehabilitation phase of the cancer care and this is likely due to the short window of opportunity between the time of diagnosis and start of cancer treatment. One pilot study included in the scoping review was carried out during the prehabilitation phase during neoadjuvant chemotherapy, prior to surgery, and showed benefit for walking distance and FMA scores.[1] Engaging PTs in the care of children with cancer from the time of cancer diagnosis may allow for the design of patient-centered interventions, better outcomes related to tolerance of cancer treatments, and allow for better continuity of care. Moreover, improving communication between members of the healthcare team may help to better address the priorities of childhood cancer survivors' care over the course of hospital-stay and upon discharge and/or referral to outpatient services.

Consistent with our second hypothesis, expertise exists among HCPs providing PR interventions particularly in the areas of physical and therapeutic exercise, with pediatric oncology PR interventions currently being delivered in many regions in Canada. To our knowledge, we have performed the first survey in Canada to explore the gaps in the literature, service provision, referral patterns, and practice patterns in PR for children and adolescents with cancer. Findings from the literature review were reflected in the results gathered from the survey. HCPs reported that clinical practice guidelines related to pediatric oncology PR do not exist. The only resource reported to support PR interventions was the use of the POEM guidelines[2] for general exercise prescription. Manual therapy techniques, neuromuscular re-education, and functional training were least reported by PR providers. This finding is also supported by a recent

systematic review that concluded that while literature exists supporting exercise and physical activity, a paucity of research exists related to physical therapy (PT) interventions.[3]

'Limitations in activities' was identified in the survey as the highest priority to be addressed in PR interventions for childhood cancer survivors. This finding is consistent with the key findings from the literature review, indicating that the majority of research in pediatric PT has focused on documenting aspects related to the feasibility of PT interventions, rather than the efficacy of interventions. Therefore, a need exists for prioritization of childhood cancer survivors' rehabilitation needs so that future research efforts can ultimately inform clinical practice. Designing PR programs incorporating the needs of childhood cancer survivors and their families may serve to encourage participation and adherence to PT programs, and may benefit outcomes related to participation in daily life activities and quality of life. Patient-centered research trials in PR for childhood cancer survivors are beginning to emerge with one study[4] identified in the scoping review that guided their PT interventions based on the International Classification of Functioning, Disability, and Health (ICF) framework described by the World Health Organization. Importantly, adoption of outcome measurement tools to assess limitations in activities will help PR providers to design targeted, individualized, and continued PR interventions for childhood cancer survivors. Barriers identified by our survey, however, such as lack of time, insufficient staffing, inappropriate equipment/space, and lack of continuity of care in outpatient services may ultimately prevent HCPs from providing appropriate and timely PR interventions.

A lack of high-quality research evidence was identified as the biggest gap and barrier to progress in pediatric oncology PR. Figure 1 represents a multidirectional diagram of the key findings from Phases I and II that demonstrate gaps in the field. Phases I and II of this thesis identified current gaps in the literature, priorities for PR services, existing barriers and facilitators in the practice setting, and needs of HCPs for pediatric oncology-specific PR training. If researchers and clinicians can collaborate to develop and conduct multicenter trials with large sample sizes, it will be possible to (1) provide an evidence-base to support pediatric oncology PR, (2) inform PR clinical practice guidelines, (3) facilitate development of specialized PR services, (4) provide



evidence to support efforts to advocate for resources/equipment, funding, staffing, and (5) build capacity to address increased referrals to the PR services.

Figure 1. Proposed Process Model Informing Alignment of Research to Practice

6.2 Knowledge-to-Action Framework

The series of projects comprising this thesis work were informed by the Knowledge-to-Action (KTA) Framework[5] (Figure 2) adopted by the Canadian Institutes of Health Research (CIHR). This framework is a dynamic model, which outlines the steps in the process of knowledge creation and knowledge application, allowing researchers to move forward from one step in knowledge, and back again to ease the uptake of knowledge.[6] The framework illustrates a model to refine knowledge and makes it useful for clinical implementation, which is followed by an action cycle illustrating methods for knowledge application. The model starts with a knowledge creation funnel, in which the first two steps consist of 1) *Knowledge Inquiry,* representing primary research of the field; and 2) *Knowledge Synthesis,* representing attempts to summarize the evidence via methods such as systematic reviews and meta-analysis, as well as to identify existing gaps in the literature that may inform the design of future research in the field. The former steps were adopted in Phase I of our study, with the synthesis of available evidence specific to pediatric oncology PR to (1) help inform practice, as well as (2) to identify current gaps in the literature to inform future research. The last section of the funnel represents the development of *knowledge tools/products*, corresponding to clinical-practice guidelines available in the field. Phase II of the study explored current practice patterns and available clinical-practice guidelines specific to pediatric oncology PR. Results from Phase I (scoping review) and Phase II (survey of HCPs) demonstrated that the current evidence supporting pediatric oncology PR is limited and is not sufficiently strong enough to be translated into clinical practice. Thus, as a first step, more primary research is needed in the field.

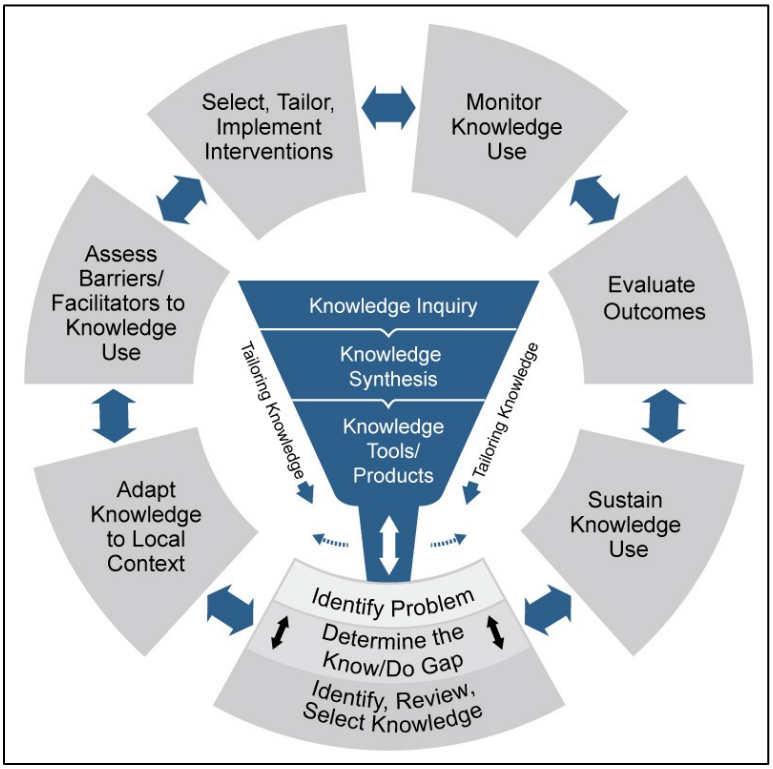


Figure 2. Knowledge-to-Action (KTA) Framework

The knowledge creation funnel leads to the action cycle, which focuses on activities needed to create knowledge. Phase II of the study identified current barriers and facilitators to implementation of PR programs, which allowed us to determine the current issues facing HCPs in their clinical settings. This information will allow us to plan research that also considers the frontline issues of HCPs and ensure PR interventions are feasible for future implementation.

Results from the survey showed that 'Parents/patients' choice' was listed as the main reason children and adolescents with cancer did not receive PR services, a finding also reported in a previous study.[7] This finding raises further questions regarding

possible reasons some parents do not access oncology PR services when their child is referred. In the scoping review, only one study reported adherence (50%)[8] and one, completion rates (32%)[9] with both reporting less than optimal levels. Therefore, to identify the needs and values of children and adolescents with cancer and their families in terms of PR, as well as the priorities for PR services, is critical. Designing PR interventions that take into consideration preferences and barriers of families will ensure research that is patient-oriented.

According to the evidence, it takes approximately 17 years for research evidence to be implemented into clinical practice and be adopted by the public.[10] However, involving HCPs as well as children with cancer and their families in the planning of research at the outset will help facilitate the knowledge translation process and hopefully reduce the time from knowledge generation to practice implementation.[11]

6.3 Future directions

Our study may serve as a basis to guide future research in the field. Collaborative efforts are needed on the part of researchers and clinicians to propose and conduct national and international multicenter trials examining the efficacy of PR interventions with consideration of the following identified needs:

1) Examination of PR interventions within specific cancer tumour types;
2) Focus on the priorities for PR interventions as identified by HCPs;
3) Consideration of HCPs barriers and facilitators to pediatric oncology PR service provision within the health system.

Results obtained from this thesis work (Phase I and II) will serve as a basis for the development of a Phase III study (Figure 3). The primary aim of the Phase III is to design a PR intervention study for childhood cancer survivors incorporating the current gaps in the literature, priorities for PT programs, and barriers and facilitators within the health system (Figure 1). A qualitative component will be incorporated to identify the needs of childhood cancer survivors and their families for PR as well as the current barriers and facilitators to PR services and programs. Findings will help in the creation of new evidence that (1) aligns with the needs of childhood cancer survivors and their families, and (2) advances the field of pediatric oncology PR.

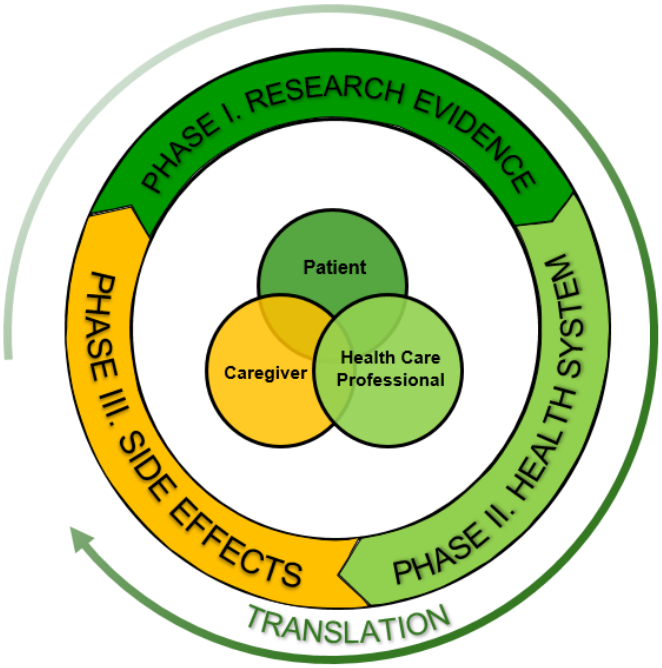


Figure 3. Future directions – Phase III study

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APPENDICES

APPENDIX A – SEARCH STRATEGIES SCOPING REVIEW

MEDLINE – Search strategy

1. exp Neoplasms/

2. (oncolog* or neoplas* or carcinom* or tumour* or tumour* or cancer* or malignan* or hemato-oncological or hematolo* or bone marrow transplant* or leukemi* or leukaemi* or AML or lymphom* or hodgkin* or T-cell or B-cell or non-hodgkin or sarcom* or Ewing* or osteosarcom* or wilms* or nephroblastom* or neuroblastom* or rhabdomyosarcom* or teratom* or hepatom* or hepatoblastom* or medulloblastom* or PNET* or retinoblastom* or meningiom* or gliom*).mp.

3. 1 or 2

4. breast*.ti. or exp breast neoplasms/

5. 3 not 4

6. exp Physical Therapy Modalities/

7. physical therapy specialty/

8. "physical and rehabilitation medicine"/

9. gait/

10. proprioception/ or postural balance/

11. muscle stretching exercises/

12. short-wave therapy/ or exp ultrasonic therapy/

13. ((exercis* adj8 (therapeutic or strength or balance or gait or stretch* or function* or "range of motion")) or manual therap* or physical therap* or physiotherap* or stability training or muscle training or strength training or locomotion* or functional therap* or functional mobili* or weight lifting or kinesiotherap* or spinal manipulation* or short-wave-therap* or electrotherap* or ultraso* therap* or (rehab* adj6 physical)).tw,kf.

14. or/6-13

15. adolescent/ or exp child/ or exp infant/

16. (infan* or neonat* or newborn or baby or babies or child* or schoolchild* or kid or kids or toddler* or adoles* or teen* or boy* or girl* or minor* or underag* or under ag*

or juvenil* or youth* or kindergar* or puber* or pubescen* or prepubescen* or prepuberty* or pediatrics or pediatric* or paediatric* or peadiatric* or school* or preschool* or highschool*).mp.

17. (pediatric* or paediatric* or child* or adolesc*).jw.

18. or/15-17

19. 5 and 14 and 18

20. limit 19 to yr="2002 -Current"

EMBASE – Search strategy

1. exp neoplasm/

2. (oncolog* or neoplas* or carcinom* or tumour* or tumour* or cancer* or malignan* or hemato-oncological or hematolo* or bone marrow transplant* or leukemi* or leukaemi* or AML or lymphom* or hodgkin* or T-cell or B-cell or non-hodgkin or sarcom* or Ewing* or osteosarcom* or wilms* or nephroblastom* or neuroblastom* or rhabdomyosarcom* or teratom* or hepatom* or hepatoblastom* or medulloblastom* or PNET* or retinoblastom* or meningiom* or gliom*).mp.

3. 1 or 2

4. breast*.ti. or exp breast tumour/

5. 3 not 4

6. exp physiotherapy/

7. physical medicine/ or electrostimulation therapy/ or exp kinesiotherapy/ or exp manipulative medicine/ or exp ultrasound therapy/

8. gait/

9. proprioception/

10. exp body equilibrium/

11. stretching exercise/

12. exp diathermy/

13. ((exercis* adj8 (therapeutic or strength or balance or gait or stretch* or function* or "range of motion")) or manual therap* or physical therap* or physiotherap* or stability training or muscle training or strength training or locomotion* or functional therap* or functional mobili* or weight lifting or kinesiotherap* or spinal manipulation* or short-wave-therap* or electrotherap* or ultraso* therap* or (rehab* adj6 physical)).tw,kw.

14. or/6-13

15. adolescent/ or exp child/ or exp infant/

16. (infan* or neonat* or newborn or baby or babies or child* or schoolchild* or kid or kids or toddler* or adoles* or teen* or boy* or girl* or underag* or under ag* or juvenil* or youth* or kindergar* or puber* or pubescen* or prepubescen* or prepuberty* or pediatrics or pediatric* or paediatric* or peadiatric* or school* or preschool* or highschool*).mp.

17. (pediatric* or paediatric* or child* or adolesc*).jx.

18. or/15-17

19. 5 and 14 and 18

20. limit 19 to yr="2002 -Current"

PEDro – Search strategy

Search A

1. paediatric* <Abstract & Title> field

2. oncology <Subdiscipline> field

3. stretching, mobilisation, manipulation, massage <Therapy> field.

4. clinical trial <Method> field

Search B

1. child* <Abstract & Title> field

2. oncology <Subdiscipline> field

3. stretching, mobilisation, manipulation, massage <Therapy> field.

4. clinical trial <Method> field

Search C

1. adolescent* <Abstract & Title> field

2. oncology <Subdiscipline> field

3. stretching, mobilisation, manipulation, massage <Therapy> field.

4. clinical trial <Method> field

APPENDIX B – ETHICS APPROVAL

HREBA Health Research Ethics Board of Alberta Cancer Committee

Health Research Ethics Board of Alberta
Cancer Committee
1500, 10104 - 103 Avenue NW
Edmonton, Alberta, T5J 4A7
Telephone: (780) 423-5727
Fax: (780) 429-3509
Email: cancer@hreba.ca

Certification of Ethics Approval

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

Ethics ID:	HREBA.CC-17-0218
Principal Investigator:	Margaret McNeely
Co-Investigator(s):	David Eisenstat
Student Co-Investigator(s):	Paula Ospina
Study Title:	Physical therapy interventions for children and adolescents with cancer: linking patient needs, clinical expertise, and research evidence
Sponsor (if applicable):	

Effective: June 21, 2017 **Expires:** June 20, 2018

Study reviewed by delegated review on 21 June 2017

The following documents have been approved:

- Consent Form English Version, May 30, 2017, May 30, 2017
- Consent Form French , May 29, 2017, May 30, 2017
- Survey French Version , May 29, 2017, May 30, 2017
- Survey English Version, March 27, 2017, May 30, 2017
- Protocol Version , March 17, 2017, May 30, 2017
- Department Approval Form, May 30, 2017

The Committee determined that consent will be obtained from participants for the disclosure of personal identifiable health information to be used in the research.

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

Department of Health and Human Services (HHS), Office for Human Research Protections (OHRP), IRB # 00009687.

Deliberations of the HREBA-CC included elements described in Section 50 of the HIA. The Committee found the research to be in accordance with requirements of the Act.

Please note:

The relevance for the self-limited questionnaire is not clear - i.e. There is no further follow up contact from the PI for individual participants (e.g. For more one-on-one interviews). That being the case, it is recommended to the study team to consider "implicit consent" as an alternative to the signed ICF. That is, the return of the questionnaire implies participant consent to study. The questionnaire will need to include an introduction section stating purpose and data confidentiality, but will save the participant somewhat onerous task of going over ICF before getting to the actual study survey.

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

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

This approval is subject to the following conditions:

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

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

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

Approved on behalf of CC by, **Date:**

Jackson Wu , HREBA-CC June 21, 2017

Note: This correspondence includes an electronic signature (validation and approval via an online system).

APPENDIX C – CONSENT FORM (ENGLISH VERSION)

Informed Consent Form for Participation in a Research Study

Physical therapy interventions for children and adolescents with cancer: linking patient needs, clinical expertise, and research evidence

(A survey to health care providers to collect information on physical rehabilitation programs, barriers, and facilitators specific to pediatric oncology rehabilitation)

Protocol ID: HREBA-CC-17-0218

Principal Investigator: Dr. Margaret McNeely, PT, PhD

Department of Physical Therapy/ Department of Oncology

University of Alberta & Cross Cancer Institute

Phone: 780-248-1531

Sponsor/Funder(s): University of Alberta

You are being invited to participate in a research study because you are a healthcare professional who either refers to, or provides physical rehabilitation to patients with pediatric cancer. This consent form provides detailed information about the study to assist you with making an informed decision. Please read this document carefully and ask any questions you may have. All questions should be answered to your satisfaction before you decide whether to participate.

The study staff will tell you about timelines for making your decision.

Taking part in this study is voluntary. You may choose not to take part or, if you choose to participate, you may leave the study at any time without giving a reason.

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

WHAT IS THE BACKGROUND INFORMATION FOR THIS STUDY?

Research evidence supporting physical therapy interventions in children and adolescents with cancer is currently lacking. Available research in the area is limited to the extent of the feasibility and benefits of exercise mostly in children with leukemia, undergoing cancer treatment, and addressing few cancer complications e.g. muscle weakness and decreased range of motion. Studies have identified the need for research in physical rehabilitation in different cancer continuum phases, in other types of cancer different from leukemia, and involving other short and long-term complications. Supporting this statement, a national survey involving healthcare professionals working with children and adolescents with cancer will help to collect the current practices and clinical programs specific to pediatric oncology rehabilitation that can be used to inform clinical practice and future research.

WHY IS THIS STUDY BEING DONE?

The purpose of this study is to collect information on current clinical rehabilitation practice patterns and service provision offered by physical therapists and healthcare practitioners working with children and adolescents with cancer across Canada. Additionally, the study aims to identify existing barriers and facilitators that may impact the implementation of pediatric oncology rehabilitation programs. By identifying the issues from the perspective of the health care provider may allow for potential strategies that can be implemented to support and address practice change. Through this research, we hope to have a better understanding of the current practices in physical rehabilitation in children and adolescents with cancer. This will allow health practitioners and researchers to design, implement, and test protocols to improve outcomes before, during, and after cancer treatments.

HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?

Around 30 people will take part in this study.

STUDY PROCEDURES

Survey
You will be provided with a survey that is subdivided in three sections. Questions may vary depending if the healthcare professional who refers to or one who provides physical rehabilitation interventions for children with cancer. The three sections include questions about (1) practice patterns and demographic information (professional designation, location of practice, length of experience), (2) service provision (common pediatric cancer side effects, physical rehabilitation interventions, outcome measures), and (3) available evidence-based guidelines in

the area, pediatric physical rehabilitation programs, barriers, and facilitators. The purpose of the survey is to identify service provision, barriers, and facilitators of pediatric oncology rehabilitation programs. The survey will take about 20 minutes to complete depending on your answers.

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

Even though you may have provided information on the survey, these responses will not be reviewed by individuals not involved in this study, e.g., your colleagues or manager.

The survey will be available in English depending on your language preference.

WHAT ARE THE BENEFITS OF PARTICIPATING IN THIS STUDY?

Participation in this study may or may not be of personal benefit to you.

The expected benefit from taking part in this study is to learn more about the current practices, as well as the barriers and facilitators to practice in the area of physical rehabilitation in children and adolescents with cancer. There is no guarantee that involvement in this study will be of direct benefit to you or your clinical work. However, based on the results of this study, it is hoped that in the long-term, patient care can be improved.

WHAT ARE MY RESPONSIBILITIES AS A STUDY PARTICIPANT?

If you choose to participate in this study, you will be expected to complete the survey online.

HOW LONG WILL I BE PARTICIPATING IN THIS STUDY?

The survey will take around 20 minutes to complete.

HOW WILL MY PERSONAL INFORMATION BE KEPT CONFIDENTIAL?

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

Records identifying you, including information we collect from you will be kept confidential to the extent permitted by the applicable laws, will not be disclosed or made publicly available, except as described in this consent document.

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

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

To protect your identity, the information that will be on your survey will be anonymous. If the results of this study are published, your identity will remain confidential. It is expected that the information collected during the study will be published in a scientific journal.

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

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

Participation in this study will not involve any additional costs to you.

WILL I BE COMPENSATED FOR PARTICIPATING IN THIS STUDY?

You will not be paid for taking part in this study.

WHAT ARE MY RIGHTS AS A PARTICIPANT IN THIS STUDY?

You have the right to be informed of the results of this study once the entire study is complete. If you would like to be informed of the results, please indicate it within the survey.

IS THERE CONFLICT OF INTEREST RELATED TO THIS STUDY?

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

WHO DO I CONTACT FOR QUESTIONS?

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

Margaret McNeely	780-248-1531
Name	Telephone

Paula Ospina

Name	Telephone

Signature of Person Conducting the Consent Discussion	PRINTED NAME	Date

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

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

SIGNATURES

Part 1 - to be completed by the potential participant.

	Yes	**No**
Do you understand that you have been asked to take part in a research study?	☐	☐
Do you understand why this study is being done?	☐	☐
Do you understand the potential benefits of taking part in this study?	☐	☐
Do you understand what you will be asked to do should you decide to take part in this study?	☐	☐
Do you understand that by signing this consent form that you do not give up any of your legal rights?	☐	☐
Have you had enough opportunity to ask questions and discuss this study?	☐	☐

By signing this form I agree to participate in this study.

_____	_____	_____
Signature of Participant	PRINTED NAME	Date

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

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

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

APPENDIX D – CONSENT FORM (FRENCH VERSION)

Formulaire de consentement éclairé pour la participation à une étude de recherche

Interventions de physiothérapie pour les enfants et les adolescents atteints de cancer: Correlation entre les besoins des patients, l'expertise clinique et les preuves de recherche

(Sondage auprès des fournisseurs de soins de santé pour recueillir des informations sur les programmes de réadaptation physique et les facteurs qui facilitent ou entravent la réadaptation en oncologie pédiatrique)

ID du protocole: HREBA-CC-17-0218

Chercheur principal: Dr. Margaret McNeely, PT, PhD
Département de physiothérapie / Département d'oncologie
Université de l'Alberta et Cross Cancer Institute
Téléphone: 780-248-1531

Commanditaire / Bailleur de fonds: Université de l'Alberta

Vous êtes invité à participer à une étude de recherche car vous êtes un professionnel de la santé qui réfère ou offre des services en réadaptation aux patients atteints de cancer pédiatrique. Ce formulaire de consentement fournit des informations détaillées sur l'étude pour vous aider à prendre une décision éclairée. Lisez attentivement ce document et posez toutes les questions que vous pourriez avoir. Toutes questions doivent être clarifiés avant de décider de participer.

Le personnel de l'étude vous informera des échéanciers pour prendre votre décision.

Votre participation à cette étude est volontaire. Vous pouvez choisir de ne pas participer ou, si vous choisissez de participer, vous pouvez quitter l'étude à tout moment sans donner de raison.

L'enquêteur de l'étude, qui est l'un des chercheurs, discutera de cette étude avec vous et répondra aux questions que vous pourriez avoir. Si vous consentez à

participer à cette étude, vous devrez signer et dater ce document de consentement. Vous recevrez une copie du formulaire signé.

QUELLES SONT LES INFORMATIONS GÉNÉRALES POUR CETTE ÉTUDE?

Des données de recherche appuyant les interventions en réadaptation chez les enfants et les adolescents atteints de cancer font actuellement défaut. Les recherches disponibles dans le domaine sont limitées dans la mesure de la faisabilité et les avantages de l'exercice principalement concernant les enfants avec la leucémie, recevant des traitements pour leur cancer, et le traitement de complications relié à ce dernier, par exemple , faiblesse musculaire et diminution de l'amplitude des mouvements. Des études ont identifié la nécessité d'effectuer des recherches dans le domaine de la réadaptation durant les différentes étapes de l'évolution du cancer, dans d'autres types de cancer que la leucémie et impliquant d'autres complications à court et long terme. Pour appuyer cette déclaration, nous croyons qu'une enquête nationale menée auprès de professionnels de la santé travaillant avec des enfants et des adolescents atteints de cancer, aiderait à recueillir des informations sur les pratiques actuelles et les programmes cliniques spécifiques offerts en réadaptation oncologique pédiatrique. Ces données pourront être utilisées pour guider la pratique clinique et les recherches futures.

POURQUOI FAITES-VOUS CETTE ÉTUDE?

Premièrement, l'objectif de cette étude est de recueillir des informations sur les modèles actuels de réadaptation clinique et sur les services offerts par les physiothérapeutes et les professionnels de la santé, qui travaillent avec des enfants et des adolescents atteints de cancer, partout au Canada. Deuxièmement, l'étude vise à identifier les facteurs déjà en place, qui pourraient avoir un impact sur la mise en œuvre de programmes de réadaptation en oncologie pédiatrique. En identifiant les problèmes du point de vue du fournisseur de soins de santé, il sera possible de mettre en place des stratégies potentielles pour soutenir et guider les changements de pratique cliniques. Grâce à cette recherche, nous espérons avoir une meilleure compréhension des pratiques actuelles en matière de réadaptation physique chez les enfants et les adolescents atteints de cancer. Cela permettrait aux professionnels de la santé et aux chercheurs de concevoir, mettre en œuvre et tester des protocoles pour améliorer les résultats avant, pendant et après les traitements contre le cancer.

COMBIEN DE PERSONNES PARTICIPERONT À CETTE ÉTUDE?

Nous estimons à 30, le nombre de personnes qui participeront à cette étude.

PROCÉDURES D'ÉTUDES

Sondage

Vous recevrez un sondage subdivisé en trois sections. Les questions peuvent varier en fonction du fait que le professionnel de la santé réfère ou offre des services de réadaptation oncologique pédiatrique. Les sections comprennent des questions sur (1) les modèles de pratique et les informations démographiques (titre professionnel, lieu de pratique, années d'expérience), (2) services offerts (effets secondaires fréquents reliés au cancer pédiatrique, interventions en réadaptation et méthodes d'évaluation) et (3) les lignes directrices, fondées sur des données probantes disponibles dans le domaine, les programmes de réadaptation physique en pédiatrie et les facteurs qui facilitent ou entravent la réadaptation dans ce domaine. Le but de ce sondage est d'identifier les services offerts, les obstacles et les facteurs favorisants des programmes de réadaptation en oncologie pédiatrique. Le sondage prendra environ de 10 à 20 minutes, selon vos réponses.

Les informations que vous fournissez sont à des fins de recherche uniquement et resteront strictement confidentielles.

Considérant le fait que vous puissiez fournir des informations en répondant à ce questionnaire, vos réponses ne seront pas examinées par des individus qui ne sont pas impliqués dans cette étude, par exemple, vos collègues ou votre employeur.

Le sondage sera disponible en anglais ou en français en fonction de votre préférence linguistique.

QUELS SONT LES AVANTAGES DE PARTICIPER À CETTE ÉTUDE?

La participation à cette étude peut ou non vous intéresser personnellement.

Les avantages de prendre part à cette étude sont d'en apprendre d`avantage sur les pratiques actuelles, les obstacles et les facteurs facilitant la réadaptation chez les enfants et les adolescents atteints de cancer. Il n'y a pas de garantie que la participation à cette étude vous profitera directement ou aura un impact sur votre travail clinique. Cependant, dépendamment des résultats de cette étude, nous espérons voir une amélioration des soins aux patients à long terme.

QUELLES SONT MES RESPONSABILITÉS EN TANT QUE PARTICIPANT À CETTE ÉTUDE?

Si vous choisissez de participer à cette étude, vous devrez compléter un questionnaire en ligne.

COMBIEN DE FOIS AURAIS-JE À PARTICIPER À CETTE ÉTUDE?

Le sondage prendra entre 10 et 20 minutes et devra être complété qu'une seule fois.

EST-CE QUE MES INFORMATIONS PERSONNELLES DEMEURERONT CONFIDENTIELLES

Si vous décidez de participer à cette étude, le chercheur et le personnel de l'étude ne recueilleront que les informations qui leurs sont nécessaires.

Les documents qui vous identifient, y compris les informations que nous recueillerons auprès de vous, seront gardés confidentiels dans la mesure permise par les lois applicables, ne seront divulgués ou rendus publics, sauf dans les cas prévus dans le présent document de consentement.

Les représentants autorisés des organisations suivantes ont accès au site ou les résultats de cette recherche sont garder et pourraient se pencher sur vos résultats anonymes à des fins d'assurance de la qualité et / ou pour vérifier que l'information recueillie pour l'étude est correcte et suit les lois et lignes directrices appropriées:

- Membres de l'équipe de réglementation / vérification du Cross Cancer Institute à des fins d'assurance de la qualité;
- Le Conseil d'éthique de la recherche en santé de l'Alberta - Comité du cancer, qui supervise la conduite éthique de cette étude;

Pour protéger votre identité, l'information contenue dans votre sondage restera anonyme. Si les résultats de cette étude sont publiés, votre identité restera confidentielle. Nous prevoyons que les informations recueillies lors de cette étude soient publiées dans un journal scientifique.

Bien que la possibilité que quelqu'un puisse vous identifier à partir des données existe, elle est très petite et ne peut jamais être complètement éliminée. Tous les moyens seront mis en oeuvre pour garder vos informations identifiables confidentielles et anonymes, et suivre les règles éthiques et juridiques concernant la collecte, l'utilisation et la divulgation de ces informations.

FRAIS RELIÉ À| LA PARTICIPATION À CETTE ÉTUDE

La participation à cette étude n'entraînera aucun coût supplémentaire pour vous.

SERAI-JE DÉDOMMAGÉ POUR PARTICIPER À CETTE ÉTUDE?

Aucune compensation monétaire ne vous sera offerte pour votre participation à cette étude.

QUELS SONT MES DROITS EN TANT QUE PARTICIPANT À CETTE ÉTUDE?

Vous avez le droit d'être informé des résultats de cette étude une fois l'étude complètement terminée. Si vous souhaitez être informé des résultats, veuillez l'indiquer dans le sondage.

EXISTE-T-IL DES CONFLITS D'INTÉRÊTS RELATIF À CETTE ÉTUDE?

Il n'y a aucun conflit d'intérêt déclaré entre les chercheurs de l'étude et les commanditaires supportant celle-ci.

QUI DEVRAIS-JE CONTACTER POUR DES QUESTIONS?

Si vous avez des questions sur la participation à cette étude, n'hésitez pas à contacter l'enquêteur principal ou le personnel de l'étude:

Margaret McNeely	780-248-1531
Nom	Téléphone
Paula Ospina	
Nom	Téléphone

Si vous avez des questions sur vos droits en tant que participant, des questions éthiques liées à cette étude ou que vous souhaitez parler à une personne qui n'est pas impliquée dans la conduite de l'étude, veuillez communiquer avec le Bureau du Conseil d'éthique de la recherche en santé de l'Alberta - Comité du cancer à:

Téléphone: 780-423-5727 Sans frais: 1-877-423-5727

SIGNATURES

Partie 1 - à remplir par le participant potentiel.

	Oui	**Non**
Comprenez-vous que vous avez été invité à participer à une étude de recherche?	□	□
Comprenez-vous pourquoi cette étude existe?	□	□
Comprenez-vous les avantages potentiels de participer à cette étude?	□	□
Comprenez-vous ce qu'on vous demandera de faire si vous décidez de participer à cette étude?	□	□
Comprenez-vous qu'en signant ce formulaire de consentement, vous ne renoncez pas à vos droits légaux?	□	□
Avez-vous eu l'occasion de poser des questions et de discuter de cette étude?	□	□

En signant ce formulaire, j'accepte de participer à cette étude.

Signature du participant	NOM IMPRIMÉ	Date

Partie 2 - être complété par le médecin de l'étude ou la personne désignée qui a mené la discussion sur le consentement éclairé. Seulement concurrence cette section si le participant potentiel a **accepté** de participer.

Je crois que la personne qui signe ce formulaire comprend ce qui est impliqué dans l'étude et a librement décidé de participer.

Signature de la personne qui effectue la discussion sur le consentement	NOM IMPRIMÉ	Date

** Vous recevrez une copie de cet daté et signé le formulaire de consentement avant de participer à cette étude. **

APPENDIX E – SURVEY COMMUNICATION (ENGLISH AND FRENCH)

English version:

Dear Physical Therapists and Healthcare Providers,

We are clinicians/researchers from the Faculty of Rehabilitation Medicine at the University of Alberta. We are contacting you because we want to learn more about the current physical rehabilitation practices and service provision offered by healthcare professionals working with children and adolescents with cancer (0 to 19 years-old) across Canada.

You are eligible to complete the survey if you are a **physical therapist, occupational therapist, nurse, kinesiologist, exercise physiologist/specialist, oncologist, or surgeon** who **PROVIDES** and/or **REFERS CHILDREN AND ADOLESCENTS TO:** pediatric rehabilitation services, pediatric oncology rehabilitation services, oncology rehabilitation services, or general rehabilitation services. The survey will take approximately 15-20 minutes to complete.

Ethics approval was granted from the Health Research Ethics Board of Alberta (HREBA) – Cancer Committee (CC). Before responding the survey, an informed consent form will appear outlining the confidentiality, anonymity, and right to withdraw.

Click the link below to start the consent process and survey:

https://redcap.ualberta.ca/surveys/?s=CHJHXP3NR7

Thank you for taking the time to help with this survey. Your expertise is of great value for this study.

Sincerely,

Paula Ospina, BscPT

MSc student – Faculty of Rehabilitation Medicine

Margaret McNeely, PT, PhD

Associate Professor – Department of Physical Therapy

David Eisenstat, MD, MA, FRCPC

Professor– Departments of Medical Genetics and Pediatrics

Lesley Wiart, PT, PhD

Assistant Professor – Department of Physical Therapy

French version:

Chers physiothérapeutes et fournisseurs de soins de santé,

Nous sommes cliniciens/ chercheurs à la Faculté de médecine de réadaptation à l'Université de l'Alberta. Nous vous contactons car nous voulons en savoir plus sur les pratiques actuelles en réadaptation et les services offerts par les professionnels de la santé travaillant avec des enfants et adolescents (0 à 19 ans) atteints de cancer à travers le Canada.

Vous êtes éligible à participer à ce sondage si vous êtes un physiothérapeute, ergothérapeute, infirmière, kinésiologue, physiologiste/ spécialiste de l'exercice, oncologue, ou chirurgien qui **OFFRE ET/OU** qui **RÉFÈRE** des enfants à des: services de réadaptation pédiatrique, services de réadaptation en oncologie, ou services de réadaptation générale. Le sondage prend environ 15 à 20 minutes à compléter.

L'approbation éthique pour ce projet de recherche a été accordée par le Health Research Ethics Board of Alberta (HREBA) - Cancer Committee (CC). Avant de répondre au questionnaire, un formulaire de consentement éclairé apparaîtra décrivant les principes tels que la confidentialité, l'anonymat et le droit de se retirer du projet à tout moment.

Cliquez sur le lien ci-dessous pour débuter le processus de consentement et compléter le sondage:

https://redcap.ualberta.ca/surveys/?s=CHJHXP3NR7

Merci de prendre le temps de répondre à ce sondage. Votre expertise dans le domaine est d'une grande valeur pour cette étude.

Cordialement,

Paula Ospina, BscPT

Étudiante MSc – Faculté de Médecine de réadaptation

Margaret McNeely, PT, PhD

Professeure Associée – Département de Physiothérapie

David Eisenstat, MD, MA, FRCPC

Professeur– Départments de Génétique Médicale et de Pédiatrie

Lesley Wiart, PT, PhD

Professeur Adjoint – Département de Physiothérapie

APPENDIX F – SURVEY COMMUNICATION REMINDER

Dear Healthcare Professional,

Three weeks ago you received an email invitation to participate in a national survey to collect information about current practices and service provision in pediatric oncology rehabilitation across Canada. We are still in need of more survey respondents.

Thank you to everyone who has completed the survey already. If you have started but not yet finished the survey, we would greatly appreciate your response.

If you are willing to complete the survey, please refer to the information and follow the link provided below. Remember you can start the survey, save your responses, and continue later.

Sincerely,

Paula Ospina, BscPT
MSc student – Faculty of Rehabilitation Medicine

Margaret McNeely, PT, PhD
Associate Professor – Department of Physical Therapy

David Eisenstat, MD, MA, FRCPC
Professor– Departments of Medical Genetics and Pediatrics

Lesley Wiart, PT, PhD
Assistant Professor – Department of Physical Therapy

APPENDIX G – SURVEY INSTRUMENT (ENGLISH VERSION)

Physical rehabilitation in children and adolescents with cancer

This survey will take approximately 15-20 minutes to complete. You are allowed to stop the survey at any time and return to it later. In order to save your answers and to continue where you left off, you must scroll down to the end of the page and click the "Save and Return Later" button.

If you do not complete the questionnaire, a code will be automatically created to you. Please write it down. You may bookmark this page to return to the survey, OR you can have the survey link emailed to you by providing your email address. When you are ready to return, please click on the link provided to you. You will be asked to type the code to access your questionnaire.

For any questions or concerns, please contact us:

Paula Ospina, MSc Student: pospina@ualberta.ca

Dr. Margaret L. McNeely: mmcneely@ualberta.ca

Dr. David Eisenstat: eisensta@ualberta.ca

Dr. Lesley Wiart: lwiart@ualberta.ca

The aim of this survey is to learn more about the current physical rehabilitation practices and service provision offered by healthcare professionals working with children and adolescents with cancer (0 to 19 years-old) across Canada.

Please remember that the information collected in this survey will be used solely for academic purposes. Any information you disclose on this survey will be anonymous. If the results of this study are published, your identity will remain confidential.

SECTION 1. DEMOGRAPHIC INFORMATION

In what city do you work? _____

In what province/territory do you work? _____

What is your professional designation?

◯ Oncologist
◯ Nurse
◯ Physiotherapist
◯ Occupational therapist
◯ Other

(Please select one that applies, if your answer is not stated, select "Other" and provide your designation)

Other: _____
(Please indicate your professional designation)

In which setting do you work?

- ◯ Acute Care Hospital
- ◯ Cancer hospital
- ◯ Private practice
- ◯ Community/Primary Care
- ◯ Rehabilitation hospital
- ◯ Other

(Please select one that applies, if your answer is not stated, select "Other" and provide your type of work setting)

Other:

_____
(Please indicate your type of work setting)

How long have you been working with children and adolescents with a diagnosis of cancer?

- ◯ Months
- ◯ Years

(Please indicate in which unit you would like to provide your answer)

Please type the number of MONTHS:

_____

Please type the number of YEARS:

_____

Please indicate if you PROVIDE or REFER children and adolescents with cancer to PHYSICAL REHABILITATION?

- ◯ Provide
- ◯ Refer
- ◯ Both

How many children and adolescents with cancer do you see on average per year?

- ◯ 1 - 5
- ◯ 6 - 10
- ◯ 11 - 20
- ◯ > 20 (if greater than 20 please provide the number)

Total number:

_____

HOW OFTEN do you refer children and adolescents with cancer TO PHYSICAL REHABILITATION?

- ◯ Often
- ◯ Sometimes
- ◯ Rarely
- ◯ Never
- ◯ Don't know

On average, how many children and adolescents with cancer do you REFER to PHYSICAL REHABILITATION SERVICES per YEAR?

- ◯ 1 - 5
- ◯ 6 -10
- ◯ 11 - 20
- ◯ > 20 (if greater than 20 please provide the number)

Total number:

_____

To which location/ type of service do you REFER children and adolescents with cancer?

- ☐ Community/Primary Care
- ☐ Rehabilitation hospital
- ☐ Cancer hospital
- ☐ Private practice
- ☐ Acute Care Hospital
- ☐ Other

Other:

_____

What PERCENTAGE of children and adolescents with cancer referred to PHYSICAL REHABILITATION, actually DID RECEIVE physical rehabilitation?

- ◯ 75-100%
- ◯ 50-75%
- ◯ 25-50%
- ◯ < 25%
- ◯ Don't know

What are the REASONS why children and/or adolescents referred DID NOT RECEIVE physical rehabilitation?

◯ Parents choice
◯ Financial resources
◯ Physiotherapist did not deem necessary
◯ Don't know
◯ Other
(Please select one that applies, if your answer is not stated, select "Other" and provide the reason(s))

Other

_____

Which CANCER SIDE EFFECTS in children and adolescents will prompt you to refer to PHYSICAL REHABILITATION SERVICES?

_____

SECTION 2. PHYSICAL REHABILITATION INTERVENTIONS

On average, how many children and adolescents with cancer do you provide PHYSICAL REHABILITATION to per YEAR?

◯ 1 - 5
◯ 6 -10
◯ 11 - 20
◯ > 20 (if greater than 20 please provide the number)

Total number: _____

SIDE EFFECTS related to cancer and its treatments

Which of the following side effects do you consider should be the HIGHEST PRIORITY for physical rehabilitation in children and adolescents with cancer?

If your answer is not stated, select "Other" and provide your answer

- ◯ Cancer-related fatigue
- ◯ Gait alterations
- ◯ Pain
- ◯ Muscle weakness
- ◯ Decrease in flexibility
- ◯ Alteration in motor performance
- ◯ Limitation in Activities of Daily Living
- ◯ Balance alterations
- ◯ Proprioception alterations
- ◯ Peripheral neuropathy
- ◯ Motor development alterations
- ◯ Muscular stiffness
- ◯ Other

Other: _____

Which of the following side effects do you consider should be the SECOND PRIORITY for physical rehabilitation in children and adolescents with cancer?

If your answer is not stated, select "Other" and provide your answer

- ◯ Cancer-related fatigue
- ◯ Gait alterations
- ◯ Pain
- ◯ Muscle weakness
- ◯ Decrease in flexibility
- ◯ Alteration in motor performance
- ◯ Limitation in Activities of Daily Living
- ◯ Balance alterations
- ◯ Proprioception alterations
- ◯ Peripheral neuropathy
- ◯ Motor development alterations
- ◯ Muscular stiffness
- ◯ Other

Other: _____

Which of the following side effects do you consider should be the THIRD PRIORITY for physical rehabilitation in children and adolescents with cancer?

If your answer is not stated, select "Other" and provide your answer

- ◯ Cancer-related fatigue
- ◯ Gait alterations
- ◯ Pain
- ◯ Muscle weakness
- ◯ Decrease in flexibility
- ◯ Alteration in motor performance
- ◯ Limitation in Activities of Daily Living
- ◯ Balance alterations
- ◯ Proprioception alterations
- ◯ Peripheral neuropathy
- ◯ Motor development alterations
- ◯ Muscular stiffness
- ◯ Other

Other: _____

In which setting do you provide PHYSICAL REHABILITATION to children and adolescents with cancer?

- ◯ Inpatient
- ◯ Outpatient
- ◯ Both

INPATIENT physical rehabilitation interventions

What types of PHYSICAL REHABILITATION are you providing for children and adolescents with cancer?

Select all that apply, if your answer is not stated, select "Others" and provide the type(s) of intervention(s).

	BEFORE CANCER TREATMENT	DURING CANCER TREATMENT	AFTER CANCER TREATMENT
Passive/Active/Active assistive range of motion (ROM) exercises	☐	☐	☐
Joint mobilizations and manipulations	☐	☐	☐
Manual therapy/distraction techniques	☐	☐	☐
Myofascial release	☐	☐	☐
Soft tissue massage	☐	☐	☐
Trigger point therapy	☐	☐	☐
Deep transverse friction	☐	☐	☐
Flexibility exercises	☐	☐	☐
Balance training	☐	☐	☐
Proprioception exercises	☐	☐	☐
Theraband/theratubing strengthening exercises	☐	☐	☐
Free weights strengthening exercises	☐	☐	☐
Functional strengthening	☐	☐	☐
Aerobic exercise using treadmill	☐	☐	☐
Aerobic exercise using cycle ergometer	☐	☐	☐
Aerobic exercise using arm ergometer	☐	☐	☐
Gait training/re-education	☐	☐	☐
Aquatic therapy	☐	☐	☐
Hydrotherapy	☐	☐	☐
Bandaging techniques	☐	☐	☐
Proprioceptive Neuromuscular Facilitation (PNF)	☐	☐	☐
Kinesio taping	☐	☐	☐
Education	☐	☐	☐
Other	☐	☐	☐

Please indicate other type(s) of physical intervention(s) you provide BEFORE CANCER TREATMENT: _____

Please indicate other type(s) of physical intervention(s) you provide DURING CANCER TREATMENT: _____

Please indicate other type(s) of physical intervention(s) you provide AFTER CANCER TREATMENT _____

Do you apply any of the following PHYSICAL AGENTS to treat the side effects of cancer and its treatment(s) in children with any type of cancer?

Select all that apply, if your answer is not stated, select "Others" and provide the type(S) of PHYSICAL AGENT(S).

- ☐ None
- ☐ Electrical stimulation
- ☐ Ultrasound
- ☐ Cryotherapy (e.g. cold packs)
- ☐ Thermotherapy (e.g. hot packs)
- ☐ Infrared light therapy
- ☐ Ultraviolet therapy
- ☐ Diathermy
- ☐ Paraffin wax bath
- ☐ Transcutaneous Electrical Nerve Stimulation (TENS)
- ☐ Other

Other: _____
(Please indicate other type(s) of PHYSICAL AGENT(S) you provide)

IF you selected any of the previous physical agents, please provide a brief RATIONALE FOR USE in children and adolescents with cancer. _____

OUTPATIENT physical rehabilitation interventions

What types of PHYSICAL REHABILITATION are you providing to treat or help children presenting with cancer?

Select all that apply, if your answer is not stated, select "Others" and provide the type(s) of intervention(s).

	BEFORE CANCER TREATMENT	DURING CANCER TREATMENT	AFTER CANCER TREATMENT
Passive/Active/Active assistive range of motion (ROM) exercises	☐	☐	☐
Joint mobilizations and manipulations	☐	☐	☐
Manual therapy/distraction techniques	☐	☐	☐
Myofascial release	☐	☐	☐
Soft tissue massage	☐	☐	☐
Trigger point therapy	☐	☐	☐
Deep transverse friction	☐	☐	☐
Flexibility exercises	☐	☐	☐
Balance training	☐	☐	☐
Proprioception exercises	☐	☐	☐
Theraband/theratubing strengthening exercises	☐	☐	☐
Free weights strengthening exercises	☐	☐	☐
Functional strengthening	☐	☐	☐
Aerobic exercise using treadmill	☐	☐	☐
Aerobic exercise using cycle ergometer	☐	☐	☐
Aerobic exercise using arm ergometer	☐	☐	☐
Gait training/re-education	☐	☐	☐
Aquatic therapy	☐	☐	☐
Hydrotherapy	☐	☐	☐
Bandaging techniques	☐	☐	☐
Proprioceptive Neuromuscular Facilitation (PNF)	☐	☐	☐
Kinesio taping	☐	☐	☐
Education	☐	☐	☐
Other	☐	☐	☐

Please indicate other type(s) of physical intervention(s) you provide BEFORE CANCER TREATMENT: _____

Please indicate other type(s) of physical intervention(s) you provide DURING CANCER TREATMENT: _____

Please indicate other type(s) of physical intervention(s) you provide AFTER CANCER TREATMENT _____

Do you apply any of the following PHYSICAL AGENTS to treat the side effects of cancer and its treatment(s) in children with cancer?

Select all that apply, if your answer is not stated, select "Others" and provide the type(S) of PHYSICAL AGENT(S).

- ☐ None
- ☐ Electrical stimulation
- ☐ Ultrasound
- ☐ Cryotherapy (e.g. cold packs)
- ☐ Thermotherapy (e.g. hot packs)
- ☐ Infrared light therapy
- ☐ Ultraviolet therapy
- ☐ Diathermy
- ☐ Paraffin wax bath
- ☐ Transcutaneous Electrical Nerve Stimulation (TENS)
- ☐ Other

Other:

_____
(Please indicate other type(s) of PHYSICAL AGENT(S) you provide)

IF you selected any of the previous physical agents, please provide a brief RATIONALE FOR USE in children and adolescents with any type of cancer.

_____

Please check the statement that best describes your physical rehabilitation intervention:

- ◯ All patients presenting SIMILAR symptoms receive a similar intervention
- ◯ All patients presenting DIFFERENT symptoms receive a similar intervention
- ◯ Each patient receives an individualized intervention according to their needs

Do you provide interventions to children and adolescents with cancer in GROUPS or INDIVIDUALLY?

- ◯ Groups
- ◯ Individually
- ◯ Both
- ◯ Other

Other:

_____

Do you BELIEVE that the physical rehabilitation interventions you provide help to REDUCE the burden of CANCER SIDE EFFECTS?

Please select one that applies, if your answer is not stated, select "Other" and provide your answer

- ◯ Yes
- ◯ No
- ◯ Other

Other:

_____

Is there anything about your physical rehabilitation program for children and adolescents with cancer that you would like to IMPROVE or ADD?

- ◯ Yes
- ◯ No

If you answered YES, please add the information:

_____

OUTCOME MEASURES USED IN PHYSICAL REHABILITATION

Which TESTS or OUTCOMES MEASURES do you use to ASSESS and/or MONITOR the progress in children and adolescents with cancer?

AEROBIC CAPACITY

Please select all that apply, if your answer is not stated, select "Other" and provide your answer

- ☐ 6-min-Walk-test
- ☐ 9-min-Walk-test
- ☐ Timed Up and Down Stairs (TUDS)
- ☐ YMCA test
- ☐ Rockport test
- ☐ None
- ☐ Other

Other: _____

GAIT

Please select all that apply, if your answer is not stated, select "Other" and provide your answer

- ☐ Electronic gait analysis
- ☐ Manual gait analysis (e.g. walking on a brown wrapping paper with feet covered in talcum powder)
- ☐ Dynamic Gait Index
- ☐ None
- ☐ Other

Other: _____

POSTURE

Please select all that apply, if your answer is not stated, select "Other" and provide your answer

- ☐ Visual analysis
- ☐ None
- ☐ Other

Other: _____

BALANCE

Please select all that apply, if your answer is not stated, select "Other" and provide your answer

- ☐ Berg Balance Scale (BBS)
- ☐ Romberg test
- ☐ Paediatric Balance Scale (PBS)
- ☐ The Flamingo Balance Test
- ☐ Tinetti balance assessment tool
- ☐ None
- ☐ Other

Other: _____

STRENGTH

Please select all that apply, if your answer is not stated, select "Other" and provide your answer

- ☐ Manual muscle testing
- ☐ Hand-held MYOMETRY
- ☐ Hand-held DYNAMOMETRY
- ☐ Biodex
- ☐ The spring scale
- ☐ The lateral step-up test
- ☐ The sit-to-stand test
- ☐ The up-and-down stairs test
- ☐ The minimum chair height test
- ☐ The incremental shuttle walking test
- ☐ None
- ☐ Other

Other: _____

FLEXIBILITY/JOINT RANGE OF MOTION

Please select all that apply, if your answer is not stated, select "Other" and provide your answer

- ☐ Goniometry
- ☐ Sit and reach test
- ☐ None
- ☐ Other

Other: _____

MOTOR DEVELOPMENT

Please select all that apply, if your answer is not stated, select "Other" and provide your answer

- ☐ Test of Gross Motor Development (TGMD)
- ☐ Bruininks Osteretsky Test of Motor Proficiency (BOT)
- ☐ Movement Assessment Battery for Children (MABC)
- ☐ Peabody Developmental Motor Scales (PDMS-2)
- ☐ Alberta Infant Motor Scale (AIMS)
- ☐ Miller Function and Participation Scales (MFUN-PS)
- ☐ None
- ☐ Other

Other: _____

FUNCTIONAL ABILITIES

Please select all that apply, if your answer is not stated, select "Other" and provide your answer

- ☐ Functional Mobility Assessment (FMA)
- ☐ Pediatric Evaluation of Disability Inventory (PEDI)
- ☐ Functional Independence Measure for Children (WeeFIM)
- ☐ Vineland Adaptive Behavior Scale
- ☐ Timed Up and Go (TUG)
- ☐ None
- ☐ Other

Other: _____

QUALITY OF LIFE

Please select all that apply, if your answer is not stated, select "Other" and provide your answer

- ☐ Pediatric Quality of Life Inventory (PedsQL)
- ☐ Child Health Questionnaire (CHQ)
- ☐ DISABKIDS Chronic Generic Measure - 37 (DCGM)
- ☐ DISABKIDS Chronic Generic Measure - 12 (DCGM)
- ☐ KINDL-R
- ☐ None
- ☐ Other

Other: _____

PAIN

Please select all that apply, if your answer is not stated, select "Other" and provide your answer

- ☐ Faces Pain Scale
- ☐ Visual Analog Scale (VAS)
- ☐ None
- ☐ Other

Other: _____

SENSORY FUNCTION

Please select all that apply, if your answer is not stated, select "Other" and provide your answer

- ☐ Myofilament test
- ☐ Hot and cold test/temperature test
- ☐ Sharp and dull test
- ☐ Vibration test
- ☐ None
- ☐ Other

Other: _____

FATIGUE

Please select all that apply, if your answer is not stated, select "Other" and provide your answer

- ☐ Rating of Perceived Exertion (RPE)
- ☐ Kids Fatigue Severity Scale (K-FSS)
- ☐ PedsQL Multidimensional Fatigue Scale
- ☐ Childhood Cancer Fatigue Scale (CCFS)
- ☐ Fatigue Scale for a child (FS-C)/ adolescents (FS-A)/ for parents (FS-P)
- ☐ None
- ☐ Other

Other: _____

PERIPHERAL NEUROPATHY

Please select all that apply, if your answer is not stated, select "Other" and provide your answer

- ☐ Paediatric Modified Total Peripheral Neuropathy Score (ped-mTNS)
- ☐ Total Neuropathy Score-Pediatric Vincristine (TNS-PV)
- ☐ Total Neuropathy Score (TNS)
- ☐ None
- ☐ Other

Other: _____

SECTION 3. AVAILABLE GUIDELINES AND CURRENT BARRIERS IN THE HEALTH SYSTEM

Does your work setting have a PHYSICAL REHABILITATION program in Paediatric Oncology?

- ◯ Yes
- ◯ No
- ◯ Don´t know

If YES, please provide a brief description about it:

_____

If NO, please select the possible reasons:

- ☐ Small paediatric oncology population
- ☐ Lack of evidence to support physical rehabilitation interventions
- ☐ Lack of physical rehabilitation professionals with experience in paediatric oncology
- ☐ Availability of resources/space
- ☐ Funding
- ☐ Patients referred to rehabilitation programs that are not oncology specific
- ☐ Other

Other: _____

Do you follow any clinical practice guidelines in PHYSICAL REHABILITATION?

- ◯ Yes
- ◯ No

If YES, please provide a brief description about it:

_____

Do you have any resources that you are willing to share?

Are there any FACILITATORS (ALREADY EXISTING) in your work setting that support offering services in PHYSICAL REHABILITATION for children and adolescents with cancer?

_____

Please indicate any facilitators

(e.g. "My clinical setting has an appropriate facility and equipment for physical rehabilitation for children")

Are there any BARRIERS in your work setting that may impact your ability to offer PHYSICAL REHABILITATION PROGRAMS for children and adolescents with cancer?

_____

Please indicate any barriers

(e.g. "My clinical setting does not have enough resources for rehabilitation for children with cancer")

How important do you consider it is to IMPLEMENT clinical practice guidelines in PHYSICAL REHABILITATION for children and adolescents with cancer?

- ◯ Very important
- ◯ Moderately important
- ◯ Slightly important
- ◯ Not at all important

In the FUTURE, how likely are you to ADOPT/SUPPORT the implementation of clinical practice guidelines in PHYSICAL REHABILITATION INTERVENTION for children and adolescents with cancer?

◯ Very likely
◯ I don't know
◯ Not likely

When the study is complete, would you like to receive a summary of the findings?

◯ Yes
◯ No

Email: _____

Additional comments or suggestions of this survey

_____

APPENDIX H – SURVEY INSTRUMENT (FRENCH VERSION)

Réadaptation physique chez les enfants et les adolescents atteints de cancer

Ce sondage prend environ 15-20 minutes à compléter. Vous pouvez quitter le sondage à tout moment et revenir plus tard. Afin de sauvegarder vos réponses et de continuer où vous avez quitté, vous devez vous rendre au bas de la page et cliquer sur le bouton "Save and Return Later".

Si vous quitter le sondage avant de l'avoir completé, un code sera automatiquement créé pour vous, veuillez le prendre en note. Vous pouvez sauvegarder cette page dans vos "favoris" pour pouvoir y accèder plus tard ou vous pouvez inscrire votre courriel pour recevoir le lien de cette page. Lorsque vous êtes prêt à revenir, ouvrez le courriel et cliquez sur le lien qui vous est fourni. Vous devrez inscrire votre code pour accéder à votre questionnaire.

Pour toute information ou question, contactez-nous:

Paula Ospina, Étudiante MSc : pospina@ualberta.ca

Dr. Margaret L. McNeely: mmcneely@ualberta.ca

Dr. David Eisenstat: eisensta@ualberta.ca

Dr. Lesley Wiart: lwiart@ualberta.ca

Le but de ce sondage est d'en apprendre davantage sur les pratiques actuelles en réadaptation physique et les services offerts par les professionnels de la santé travaillant avec des enfants et des adolescents atteints d'un cancer (0 à 19 ans) partout au Canada.

Rappelez-vous que les informations recueillies dans ce sondage seront utilisées uniquement à des fins académiques. Toute information que vous divulguez restera anonyme. Si les résultats de cette étude sont publiés, votre identité restera confidentielle.

SECTION 1. INFORMATIONS DÉMOGRAPHIQUES

Dans quelle ville travaillez-vous? _____

Dans quelle province travaillez-vous? _____

Quel est votre titre professionnel?

◯ Oncologue
◯ Infirmier(ère)
◯ Physiothérapeute
◯ Thérapeute en réadaptation physique
◯ Autre

Si autre, veuillez spécifier votre titre professionnel: _____

Votre lieu de travail?

◯ Hôpital- Unité de soins intensifs
◯ Hôpital spécialisé en cancérologie
◯ Pratique privée
◯ Communauté/Soins primaires
◯ Hôpital/Centre de réadaptation
◯ Autre

Si Autre, veuillez spécifier votre lieu de travail: _____

En considérant les différentes phases de l'évolution du cancer, depuis combien de temps travaillez-vous avec les enfants et adolescents atteints de cancer?

◯ Mois
◯ Années
(Veuillez indiquer dans quelle unité vous souhaitez répondre)

Entrez le nombre de MOIS: _____

Entrez le nombre d' ANNÉES: _____

Veuillez indiquer si vous OFFREZ des SERVICES DE RÉADAPTATION PHYSIQUE ou REFÉREZ les enfants et adolescents,vers des SERVICES DE RÉADAPTATION?

◯ Offre
◯ Réfère
◯ Les deux

Combien d'enfants et d'adolescents, atteints de cancer, voyez-vous en moyenne par année?

◯ 1 - 5
◯ 6 - 10
◯ 11 - 20
◯ > 20

Si plus de 20, veuillez spécifer le nombre: _____

Avec quelle fréquence, référez-vous les enfants et adolescents vers des services de réadaptation physique?

◯ Souvent
◯ Parfois
◯ Rarement
◯ Jamais
◯ Je ne sais pas

En moyenne, combien d'enfants et d'adolescents, atteints de cancer, RÉFÉREZ-VOUS vers des SERVICES DE RÉADAPTATION PHYSIQUE par année?

◯ 1 - 5
◯ 6 -10
◯ 11 - 20
◯ > 20

Si plus de 20, veuillez fournir le nombre total de patients référés en réadaption: _____

Vers quelles institutions, RÉFÈREZ-VOUS les enfants et adolescents atteints de cancer?

☐ Communauté/Soins primaires
☐ Hôpital/Centre de réadaptation
☐ Hôpital spécialisé en cancérologie
☐ Pratique privée
☐ Hôpital- Unité de soins intensifs
☐ Autre

Si Autre, veuillez indiquer vers quelle institution vous référez vos patients: _____

Selon vous, quel POURCENTAGE des enfants référés vers des services de réadaptation physique, ont RÉELLEMENT reçu des traitements?

◯ 75-100%
◯ 50-75%
◯ 25-50%
◯ < 25%
◯ Je ne sais pas

Selon vous, pour quelles RAISONS les patients référés, N'ONT-ILS PAS REÇU de tels services?

- ◯ Le choix des parents
- ◯ Les ressources financières
- ◯ Le physiothérapeute ne jugeait pas nécessaire d'offrir ces services
- ◯ Je ne sais pas
- ◯ Autre

Si Autre, veuillez spécifier la raison: _____

Quels sont les EFFETS SECONDAIRES RELIÉS AU CANCER qui vous poussent à référer vers des SERVICES DE RÉADAPTATION PHYSIQUE? _____

SECTION 2. LES INTERVENTIONS EN RÉADAPTATION PHYSIQUE

En moyenne, combien d'enfants et d'adolescents atteints de cancer, reçoivent des traitements en REHABILITATION PHYSIQUE par ANNÉE?

- ◯ 1 - 5
- ◯ 6 - 10
- ◯ 11 - 20
- ◯ > 20

Si plus de 20, veuillez indiquer le nombre total de patients: _____

EFFETS SECONDAIRES reliés au cancer et ses traitements

Lequel des effets secondaires suivants, considérez-vous comme étant votre PRINCIPALE priorité en réadaptation chez les enfants et adolescents atteints du cancer?

- ◯ Fatigue liée au cancer
- ◯ Troubles de la marche
- ◯ Douleur
- ◯ Faiblesse musculaire
- ◯ Diminution de la flexibilité
- ◯ Troubles de la performance motrice
- ◯ Limitation dans les activités de la vie quotidienne
- ◯ Troubles de l'équilibre
- ◯ Troubles de proprioception
- ◯ Neuropathie périphérique
- ◯ Troubles du développement moteur
- ◯ Rigidité musculaire
- ◯ Autre

Veuillez spécifier: _____

Lequel des effets secondaires suivants, considérez-vous comme étant votre DEUXIÈME priorité en réadaptation chez les enfants et adolescents atteints du cancer?

- ◯ Fatigue liée au cancer
- ◯ Troubles de la marche
- ◯ Douleur
- ◯ Faiblesse musculaire
- ◯ Diminution de la flexibilité
- ◯ Troubles de la performance motrice
- ◯ Limitation dans les activités de la vie quotidienne
- ◯ Troubles de l'équilibre
- ◯ Troubles de proprioception
- ◯ Neuropathie périphérique
- ◯ Troubles du développement moteur
- ◯ Rigidité musculaire
- ◯ Autre

Veuillez spécifier: _____

Lequel des effets secondaires suivants, considérez-vous comme étant votre TROISIÈME priorité en réadaptation chez les enfants et adolescents atteints du cancer?

- ◯ Fatigue liée au cancer
- ◯ Troubles de la marche
- ◯ Douleur
- ◯ Faiblesse musculaire
- ◯ Diminution de la flexibilité
- ◯ Troubles de la performance motrice
- ◯ Limitation dans les activités de la vie quotidienne
- ◯ Troubles de l'équilibre
- ◯ Troubles de proprioception
- ◯ Neuropathie périphérique
- ◯ Troubles du développement moteur
- ◯ Rigidité musculaire
- ◯ Autre

Veuillez spécifier: _____

Dans quel milieu fournissez-vous des services de RÉADAPTATION PHYSIQUE ?

- ◯ Milieu Hospitalier-Patients hospitalisés
- ◯ Soins Ambulatoires-Externes
- ◯ Les deux

LES INTERVENTIONS EN RÉADAPTATION PHYSIQUE CHEZ LES PATIENTS HOSPITALISÉS

Quels types de RÉADAPTATION PHYSIQUE offrez-vous pour traiter ou aider les enfants atteints de cancer?

Vous pouvez sélectionner plusieurs réponses.

	AVANT LE TRAITEMENT DU CANCER	PENDANT LE TRAITEMENT DU CANCER	APRÈS LE TRAITEMENT DU CANCER
Exercices passifs, actif-assistés ou actifs	☐	☐	☐
Mobilisations et manipulations articulaires	☐	☐	☐
Techniques de thérapie manuelles /distraction	☐	☐	☐
Étirements myofasciaux	☐	☐	☐
Massage de tissus mous	☐	☐	☐
Traitement des points "trigger"	☐	☐	☐
Friction transversale profonde	☐	☐	☐
Exercices de flexibilité	☐	☐	☐
Exercices d'équilibre	☐	☐	☐
Exercices de proprioception	☐	☐	☐
Exercices de renforcement avec élastiques	☐	☐	☐
Exercices de renforcement avec poids libres	☐	☐	☐
Renforcement fonctionnel	☐	☐	☐
Entrainement aérobie en utilisant un tapis roulant	☐	☐	☐
Entrainement aérobie utilisant un vélo stationnaire	☐	☐	☐
Entrainement aérobie utilisant l'ergonomètre à bras	☐	☐	☐
Rééducation de la marche	☐	☐	☐
Thérapie aquatique	☐	☐	☐
Hydrothérapie	☐	☐	☐
Techniques de bandage	☐	☐	☐
Facilitation neuromusculaire proprioceptive (FNP)	☐	☐	☐
Utilisation du tape kinésio	☐	☐	☐
Éducation	☐	☐	☐
Autre	☐	☐	☐

Veuillez indiquer les autres types d'interventions que vous utilisez avec vos patients, AVANT LE DÉBUT DES TRAITEMENTS DU CANCER: _____

Veuillez indiquer les autres types d'interventions que vous utilisez avec vos patients DURANT LE TRAITEMENT DU CANCER: _____

Veuillez indiquer les autres types d'interventions que vous utilisez avec vos patients APRÈS LE TRAITEMENT DU CANCER: _____

Veuillez sélectionner les AGENTS PHYSIQUES que vous utilisez pour le traitement des effets secondaires reliés au cancer les enfants et adolescents.

Vous pouvez sélectionner plusieurs réponses.

- ☐ Aucun
- ☐ Stimulation électrique
- ☐ Ultrasons
- ☐ Cryothérapie (compresse froide)
- ☐ Thermothérapie (compresse chaude)
- ☐ Thérapie par la lumière infrarouge
- ☐ Thérapie par la lumière ultraviolette
- ☐ Diathermie
- ☐ Utilisation du bain de paraffine
- ☐ Stimulation nerveuse électrique transcutanée (TENS)
- ☐ Autre

Si Autre, veuillez spécifier les autres agents physiques utilisés: _____

Veuillez fournir une brève explication sur l'utilisation de chaque agent physique mentionné précédemment. _____

LES INTERVENTIONS EN RÉADAPTATION PHYSIQUE CHEZ LES PATIENTS EN SOINS AMBULATOIRES.

Quels types de RÉADAPTATION PHYSIQUE offrez-vous pour traiter ou aider les enfants atteints de cancer?

Vous pouvez sélectionner plusieurs réponses.

	AVANT LE TRAITEMENT DU CANCER	PENDANT LE TRAITEMENT DU CANCER	APRES LE TRAITEMENT DU CANCER
Exercices passifs, actifs-assistés/actifs	☐	☐	☐
Mobilisations et manipulations articulaires	☐	☐	☐
Techniques de thérapie manuelle /distraction	☐	☐	☐
Étirements myofasciaux	☐	☐	☐
Massage de tissus mous	☐	☐	☐
Traitement des points "trigger"	☐	☐	☐
Friction transversale profonde	☐	☐	☐
Exercices de flexibilité	☐	☐	☐
Exercices d'équilibre	☐	☐	☐
Exercices de proprioception	☐	☐	☐
Exercices de renforcement avec des élastiques	☐	☐	☐
Exercices de renforcement avec des poids libres	☐	☐	☐
Renforcement fonctionnel	☐	☐	☐
Entrainement aérobie en utilisant un tapis roulant	☐	☐	☐
Entrainement aérobie utilisant un vélo stationnaire	☐	☐	☐
Entrainement aérobie utilisant l'ergonomètre à bras	☐	☐	☐
Rééducation de la marche	☐	☐	☐
Thérapie aquatique	☐	☐	☐
Hydrothérapie	☐	☐	☐
Techniques de bandage	☐	☐	☐
Facilitation neuromusculaire proprioceptive (FNP)	☐	☐	☐
Utilisation du tape kinésio	☐	☐	☐
Éducation	☐	☐	☐
Autre	☐	☐	☐

Veuillez indiquer les autres types d'interventions que vous utilisez avec vos patients, AVANT LE DÉBUT DES TRAITEMENTS DU CANCER: _____

Veuillez indiquer les autres types d'interventions que vous utilisez, DURANT LE TRAITEMENT DU CANCER: _____

Veuillez indiquer les autres types d'interventions que vous utilisez APRÈS LE TRAITEMENT DU CANCER: _____

Veuillez sélectionner les AGENTS PHYSIQUES que vous utilisez pour le traitement des effets secondaires reliés au cancer chez les enfants et adolescents.

Vous pouvez sélectionner plusieurs réponses.

- ☐ Aucun
- ☐ Stimulation électrique
- ☐ Ultrasons
- ☐ Cryothérapie (compresse froide)
- ☐ Thermothérapie (compresse chaude)
- ☐ Thérapie par la lumière infrarouge
- ☐ Thérapie par la lumière ultraviolette
- ☐ Diathermie
- ☐ Utilisation du bain de paraffine
- ☐ Stimulation nerveuse électrique transcutanée (TENS)
- ☐ Autre

Si Autre, veuillez spécifier les autres agents physiques utilisés:

_____

Veuillez fournir une brève explication sur l'utilisation de chaque agent physique, mentionné précédemment, chez les enfants et les adolescents atteints de cancer.

_____

Veuillez sélectionner l'énoncé qui décrit le mieux vos interventions en réadaptation physique avec les enfants et adolescents atteints de cancer:

- ◯ Tous les patients présentant des symptômes SIMILAIRES reçoivent une intervention similaire
- ◯ Tous les patients présentant des symptômes DIFFÉRENTS reçoivent une intervention similaire
- ◯ Chaque patient reçoit une intervention individualisée selon ses besoins

Vos interventions sont-elles offertes de façon individuelles ou plutôt en groupe?

- ◯ Groupe
- ◯ Individuelle
- ◯ Les deux
- ◯ Autre

Si Autre, veuillez spécifier le type d'intervention:

_____

Croyez-vous que les interventions de réadaptation physique que vous fournissez MINIMISENT l'impact des EFFETS SECONDAIRES RELIÉS AU CANCER?

- ◯ Oui
- ◯ Non
- ◯ Autre

Veuillez spécifier:

_____

En regardant l'ensemble de votre programme d'interventions en réadaptation physique, existe-t-il certains aspects que vous voudriez AMÉLIORER OU certaines composantes que vous aimeriez AJOUTER ?

- ◯ Oui
- ◯ Non

Si OUI, veuillez détailler les changements ou ajouts:

_____

TECHINIQUES D'ÉVALUATION UTILISÉES EN RÉADAPTATION PHYSIQUE

Quels TESTS ou TECHNIQUES utilisez-vous pour ÉVALUER et/ou OBSERVER la condition des enfants et adolescents atteints de cancer?

CAPACITÉ AÉROBIE

Vous pouvez sélectionner plusieurs réponses.

- ☐ Test de marche de six minutes (6 MWT)
- ☐ Test de marche de neuf minutes (9 MWT)
- ☐ Temps de montée et descente d'escaliers (Timed U and Down Stairs (TUDS))
- ☐ Test YMCA-vélo stationnaire
- ☐ Test de Rockport
- ☐ Aucun
- ☐ Autre

Spécifiez: _____

PATRON DE MARCHE

Vous pouvez sélectionner plusieurs réponses.

- ☐ Analyse électronique de la marche
- ☐ Analyse manuelle de la marche (Marche sur un papier brun avec des pieds recouverts de poudre)
- ☐ Index de marche dynamique (GDI)
- ☐ Aucun
- ☐ Autre

Spécifiez: _____

POSTURE

Vous pouvez sélectionner plusieurs réponses.

- ☐ Analyse visuelle
- ☐ Aucun
- ☐ Autre

Spécifiez: _____

ÉQUILIBRE

Vous pouvez sélectionner plusieurs réponses.

- ☐ Échelle d'évaluation de l'équilibre de Berg (Berg Balance Scale (BBS))
- ☐ Test de Romberg
- ☐ Échelle d'équilibre pédiatrique (Paediatric Balance Scale (PBS))
- ☐ Test d'équilibre flamingo (EFL)
- ☐ Le test de Tinetti
- ☐ Aucun
- ☐ Autre

Spécifiez: _____

FORCE

Vous pouvez sélectionner plusieurs réponses.

- ☐ Le test musculaire manuel
- ☐ Dynamomètre manuel
- ☐ Biodex
- ☐ Dynamomètre à ressort
- ☐ Test de step-up latéral
- ☐ Test assis-debout (30 secondes)
- ☐ Test de montée-descente d'escalier (TUDS)
- ☐ Test du lever de la chaise (FTSST)
- ☐ Le test de navette
- ☐ Aucun
- ☐ Autre

Spécifiez: _____

FLEXIBILITÉ/MOBILITÉ

Vous pouvez sélectionner plusieurs réponses.

- ☐ La goniométrie
- ☐ Test de flexion du tronc en position assise (sit and reach)
- ☐ Aucun
- ☐ Autre

Spécifiez: _____

DÉVELOPPEMENT MOTEUR

Vous pouvez sélectionner plusieurs réponses.

- ☐ Le Test de développement de la motricité globale (TGMD)
- ☐ Test de d'abileté mortice Bruininks Osteretsky Test of Motor Proficiency (BOT)
- ☐ Batterie d'évaluation des mouvements chez l'enfant (M-ABC)
- ☐ Échelle de development moteur Peabody Developmental Motor Scales (PDMS-2)
- ☐ Échelle de la motricité de l'enfant de l'Alberta Infant Motor Scale (AIMS)
- ☐ Échelle de participation et de fonction Miller Function and Participation Scales (MFUN-PS)
- ☐ Aucun
- ☐ Autre

Spécifiez: _____

HABILETÉS FONCTIONNELLES

Vous pouvez sélectionner plusieurs réponses.

- ☐ L'évaluation de la mobilité fonctionnelle (Functional Mobility Assessment (FMA))
- ☐ L'inventaire des incapacités motrices dans l'évaluation pédiatrique (PEDI)
- ☐ Mesure de l'indépendance fonctionnelle pour enfants (MIF Mômes)/(WeeFIM)
- ☐ Échelle des comportements adaptifs Vineland Adaptive Behavior Scales (VABS)
- ☐ Timed Up and Go (TUG)
- ☐ Aucun
- ☐ Autre

Spécifiez: _____

QUALITÉ DE VIE

Vous pouvez sélectionner plusieurs réponses.

- ☐ L'inventaire de la qualité de vie pédiatrique (PedsQL)
- ☐ Child Health Questionnaire (CHQ)
- ☐ Mesure générique chronique DISABKIDS Chronic Generic Measure - 37 (DCGM)
- ☐ DISABKIDS Chronic Generic Measure - 12 (DCGM)
- ☐ KINDL-R
- ☐ Aucun
- ☐ Autre

Spécifiez: _____

DOULEUR

Vous pouvez sélectionner plusieurs réponses.

- ☐ Échelle de douleur-Expressions faciales (Faces Pain Scale (FPS))
- ☐ Echelle visuelle analogique (EVA)
- ☐ Aucun
- ☐ Autre

Spécifiez: _____

FONCTION SENSORIELLE

Vous pouvez sélectionner plusieurs réponses.

- ☐ Test au monofilament
- ☐ Test de chaud/froid -Test de température
- ☐ Test pointu et arrondi Sharp and dull test
- ☐ Test de vibration au diapason
- ☐ Aucun
- ☐ Autre

Spécifiez: _____

FATIGUE

Vous pouvez sélectionner plusieurs réponses.

- ☐ Echelle d'évaluation subjective de l'effort perçu (Rating of Perceived Exertion (RPE))
- ☐ Échelle de sévérité de la fatigue de l'enfant Kids Fatigue Severity Scale (K-FSS)
- ☐ Échelle de fatigue multidimensionnelle-PedsQL
- ☐ Échelle de fatigue liée au cancer chez l'enfant - Childhood Cancer Fatigue Scale (CCFS)
- ☐ Échelle de fatigue de l'enfant - Fatigue Scale for a child (FS-C)/ adolescents (FS-A)/ for parents (FS-P)
- ☐ Aucun
- ☐ Autre

Spécifiez: _____

NEUROPATHIE PÉRIPHÉRIQUE

Vous pouvez sélectionner plusieurs réponses.

- ☐ Score total modifié de neuropathie périphérique pédiatrique - Paediatric Modified Total Peripheral Neuropathy Score (ped-mTNS)
- ☐ Score total de neuropathie pediatrique Vincristin - Total Neuropathy Score-Pediatric Vincristine (TNS-PV)
- ☐ Score total de neuropathie - Total Neuropathy Score (TNS)
- ☐ Aucun
- ☐ Autre

Spécifiez: _____

SECTION 3. LES LIGNES DIRECTRICES ET LES BARRIÈRES RENCONTRÉES DANS LE SYSTÈME DE SANTÉ

Votre lieu de travail offre-t-il un programme de RÉADAPTATION PHYSIQUE en oncologie pédiatrique?

◯ Oui
◯ Non
◯ Je ne sais pas

Si OUI, veuillez fournir une brève description:

_____

Si NON, sélectionnez les raisons possibles:

☐ Le faible nombre de patients en oncologie pédiatrique.
☐ Le manque de preuves pour soutenir les interventions en réadaptation physique.
☐ Le manque de professionnels en réadaptation physique ayant une expérience en oncologie pédiatrique
☐ La disponibilité des ressources/espace
☐ Le financement
☐ Les patients sont référés vers des programmes de réadaptation qui ne sont pas spécifiques à la cancérologie
☐ Autre

Spécifiez:

_____

Suivez-vous les lignes directrices de pratique clinique en RÉHABILITATION PHYSIQUE?

◯ Oui
◯ Non
◯ Je ne sais pas

Si OUI, veuillez fournir une brève description à ce sujet:

_____

Avez-vous des ressources que vous souhaitez partager?

Existe-t-il des FACTEURS, dans votre milieu de travail, qui favorisent l'offre de services en RÉADAPTATION oncologique pour une clientèle pédiatrique?

_____

(ex. "Mon environnement clinique offre un espace et l'équipement nécessaire pour la réadaptation physique pour enfants")

Existe-t-il des obstacles dans votre travail qui pourraient avoir une incidence sur votre capacité à proposer des PROGRAMMES DE RÉADAPTATION pour les enfants et adolescents atteints de cancer?

_____

(ex. "Mon milieu clinique n'a pas suffisamment de ressources pour la réadaptation chez les enfants atteints de cancer")

Quelle importance accordez-vous à la MISE EN PLACE de lignes directrices en RÉADAPTATION PHYSIQUE pour les enfants et les adolescents atteints de cancer?

◯ Très grande importance
◯ Importance modérée
◯ Peu d'importance
◯ Pas du tout d'importance

Dans le futur, quelle est la probabilité que vous ADOPTIEZ / SOUTENIEZ la mise en place de lignes directrices concernant les INTERVENTIONS DE RÉADAPTATION PHYSIQUE chez les enfants et les adolescents atteints de cancer?

◯ Très grande probabilité
◯ Je ne sais pas
◯ Faible probabilité

Souhaitez-vous recevoir un résumé des résultats, une fois l'étude terminée?

◯ Oui
◯ Non

Courriel: _____

Commentaires ou suggestions

_____

APPENDIX I – OUTCOME MEASUREMENT TOOLS USED IN PHYSICAL REHABILITATION

Outcome measures and tools in physical rehabilitation

	Overall ***n=28, 100%***
AEROBIC CAPACITY	***Frequency, f***
6-min-Walk-test	16
None	9
Timed Up and Down Stairs (TUDS)	3
Other- visual analysis	2
Other- 2-min walk test	1
Other- 3 min step test	1
9-min-Walk-test	0
YMCA test	0
Rockport test	0
TOTAL	**32**
GAIT	
None	16
Other- Visual analysis	9
Electronic gait analysis	2
Manual gait analysis	1
Dynamic Gait Index	1
TOTAL	**29**
POSTURE	
Visual analysis	27
None	1
Other	0
TOTAL	**28**
BALANCE	
Berg Balance Scale (BBS)	14
Paediatric Balance Scale (PBS)	10
Romberg test	4
Other - Community Balance and Mobility Scale	4
None	3
The Flamingo Balance Test	2
Other - Visual analysis	2
Other - Gross Motor Function Measure	1
Other - Single leg balance firm surface, pad, eyes open and closed	2
Other - Balance subset BOT-2	1

Tinetti balance assessment tool	0
TOTAL	**43**
STRENGTH	
Manual muscle testing	26
Hand-held DYNAMOMETRY	10
The sit-to-stand test	5
The up-and-down stairs test	3
None	1
Other - Fitnessgram battery test	1
Hand-held MYOMETRY	0
Biodex	0
The spring scale	0
The lateral step-up test	0
The minimum chair height test	0
The incremental shuttle walking test	0
TOTAL	**46**
FLEXIBILITY/JOINT RANGE OF MOTION	
Goniometry	27
Sit and reach test	3
Other- Knee to wall test	1
Other - Inclinometer	1
None	0
TOTAL	**32**
MOTOR DEVELOPMENT	
Alberta Infant Motor Scale (AIMS)	16
Bruininks Osteretsky Test of Motor Proficiency (BOT)	13
Peabody Developmental Motor Scales (PDMS-2)	13
Movement Assessment Battery for Children (MABC)	7
None	6
Miller Function and Participation Scales (MFUN-PS)	2
Other - Gross Motor Function Measure	2
Other - Hawaii Early Learning Profile	1
Other- Bayley Scales of Infant and Toddler Development III	1
Other - Talbot Evaluation Battery (Batterie D' Evaluation Talbot)	1
Test of Gross Motor Development (TGMD)	0
TOTAL	**62**
FUNCTIONAL ABILITIES	
None	15
Timed Up and Go (TUG)	7
Functional Independence Measure for Children (WeeFIM)	5

Pediatric Evaluation of Disability Inventory (PEDI)	2
Functional Mobility Assessment (FMA)	0
Vineland Adaptive Behavior Scale	0
Other	0
TOTAL	**29**
QUALITY OF LIFE	
None	26
Pediatric Quality of Life Inventory (PedsQL)	1
Other - EQ-5D	1
Child Health Questionnaire (CHQ)	0
DISABKIDS Chronic Generic Measure - 37 (DCGM)	0
DISABKIDS Chronic Generic Measure - 12 (DCGM)	0
KINDL-R	0
TOTAL	**28**
PAIN	
Visual Analog Scale (VAS)	23
Faces Pain Scale	18
None	2
Other	0
TOTAL	**43**
SENSORY FUNCTION	
Sharp and dull test	17
Hot and cold test/temperature test	13
Vibration test	10
Myofilament test	5
None	7
Other - Light touch	2
Other - Stereognosis	1
Other - Localization	1
TOTAL	**56**
FATIGUE	
Rating of Perceived Exertion (RPE)	14
None	13
PedsQL Multidimensional Fatigue Scale	1
Other - Self reported and observed	1
Kids Fatigue Severity Scale (K-FSS)	0
Childhood Cancer Fatigue Scale (CCFS)	0
Fatigue Scale for a child (FS-C)/ adolescents (FS-A)/ for parents (FS-P)	0
TOTAL	**29**
PERIPHERAL NEUROPATHY	
None	14

Paediatric Modified Total Peripheral Neuropathy Score (ped-mTNS)	6
Total Neuropathy Score-Pediatric Vincristine (TNS-PV)	2
Total Neuropathy Score (TNS)	1
Other - Manual and visual analysis	1
TOTAL	**24**