

Physical Rehabilitation Practices for Children and Adolescents with Cancer in Canada

Paula A. Ospina, BScPT, MSc;* Lesley Wiart, PhD, PT;*

David D. Eisenstat, MA, MD, FRCPC;†‡ Margaret L. McNeely, PhD, PT*‡

ABSTRACT

Purpose: Children and adolescents with cancer who undergo cancer treatment are at high risk of developing adverse effects, many of which may be amenable to physical rehabilitation. We aimed to identify the current clinical physical rehabilitation practice patterns, services, and programmes available for children and adolescents with cancer in Canada. **Method:** A cross-sectional survey in English and French was conducted. Participants were health care professionals (HCPs) who provided physical rehabilitation services to children and adolescents with cancer in Canada. The survey included questions on the HCPs' practice patterns and the programmes and services they provided. **Results:** A total of 35 HCPs responded: 27 physical therapists (77%), 6 occupational therapists (17%), 1 exercise professional (3%), and 1 speech-language pathologist (3%). Overall, they reported activity limitations, alterations in motor performance, muscle weakness, peripheral neuropathy, and fatigue as the top priorities for rehabilitation services. HCPs believed that interventions were valuable in reducing the burden of cancer effects; however, issues such as space, resources, and lack of clinical practice guidelines were viewed as barriers to providing services. **Conclusions:** Paediatric oncology rehabilitation services exist in some regions in Canada. HCPs strongly support the need to develop clinical practice guidelines for paediatric oncology rehabilitation.

Key Words: child; neoplasms; outcome assessment; paediatrics; rehabilitation.

RÉSUMÉ

Objectif : les enfants et les adolescents en traitement oncologique sont très vulnérables à des effets indésirables, dont bon nombre répondent à la réadaptation physique. Les auteurs ont cherché à déterminer les modes de pratique clinique, de services et de programmes en réadaptation physique offerts aux enfants et aux adolescents atteints du cancer au Canada. **Méthodologie :** sondage transversal en français et en anglais. Les participants étaient des professionnels de la santé (PdS) qui donnaient des services de réadaptation physique à des enfants et des adolescents atteints du cancer au Canada. Le sondage contenait des questions sur les modes de pratique des PdS et sur les programmes et services fournis. **Résultats :** Au total, 35 PdS ont répondu : 27 physiothérapeutes (77 %), six ergothérapeutes (17 %), un professionnel de l'exercice (3 %) et un orthophoniste (3 %). Dans l'ensemble, ils ont déclaré que les limitations aux activités, les modifications de la performance motrice, la faiblesse musculaire, la neuropathie périphérique et la fatigue étaient les principales priorités des services de réadaptation. Selon eux, les interventions étaient utiles pour réduire le fardeau des effets du cancer, mais des problèmes comme l'espace, les ressources et l'absence de directives cliniques étaient considérés comme des obstacles aux services. **Conclusions :** des services de réadaptation en oncologie pédiatrique sont offerts dans certaines régions du Canada. Les PdS appuient fortement la création de directives cliniques pour la réadaptation en oncologie pédiatrique.

Children and adolescents with cancer who are undergoing cancer treatment are at high risk of developing serious late and long-term physical effects,¹ many of which may be amenable to physical rehabilitation. These effects include pain, fatigue, muscle weakness, and peripheral neuropathy; limitations in range of motion and function; and deficits in balance and gait.^{2,3} These complications may negatively affect children's ability to participate in

age-appropriate activities, including play, and greatly reduce their quality of life.^{1,2,4-6} As medical science has made improvements in cancer treatment, and as mortality rates have been decreasing among children and adolescents with cancer, addressing long-term outcomes has become of greater importance. Thus, there is a growing awareness of the need for rehabilitation services among this cancer population.⁷

From the: *Department of Physical Therapy, Faculty of Rehabilitation Medicine; †Department of Pediatrics, Faculty of Medicine and Dentistry, University of Alberta; ‡Department of Oncology, Cross Cancer Institute, Edmonton, Alta.

Correspondence to: Paula A. Ospina, Department of Physical Therapy, Faculty of Rehabilitation Medicine, University of Alberta, 2-50 Corbett Hall, Edmonton, AB T6G 2G4; pospina@ualberta.ca.

Contributors: All authors designed the study; or collected, analyzed, or interpreted the data; and drafted or critically revised the article and approved the final draft.

Competing Interests: None declared.

Acknowledgements: The authors acknowledge the assistance of the Canadian Physiotherapy Association's Oncology and Pediatric Divisions.

Physiotherapy Canada 2020; 72(2); 207-216; doi:10.3138/ptc-2018-0077

Few surveys have been conducted to explore the needs of adult and paediatric cancer survivors.⁸⁻¹⁰ Similar to findings among adult survivors,⁹ adolescents and young adults with cancer report unmet needs for counseling and guidance in self-care (e.g., exercise and fitness); these findings suggest that there is a gap in supportive care services.¹⁰ As a result, we set out to identify the current clinical physical rehabilitation practices, services, and programmes available for children and adolescents with cancer in Canada.

We first searched for studies that examined oncology rehabilitation services up to 2018 using three databases (MEDLINE, EMBASE, Physiotherapy Evidence Database), Google Scholar, and reference lists using the following key words: *rehabilitation, physical therapy, physiotherapy, cancer, oncology, child, pediatric, service, survey, and questionnaire*. To our knowledge, only one study has explored how widely oncology rehabilitation services are provided in Canada and identified the practice patterns and the perceived barriers to and facilitators of such services.⁹ This study consisted of a cross-sectional, online survey that examined rehabilitation services for adults with cancer, and it included responses from 62 of 116 (53%) identified Canadian facilities. Education and aerobic exercise were reported as the primary interventions offered by most of the oncology rehabilitation programmes across the country.⁹

The objective of this study was to identify the current clinical physical rehabilitation practice patterns of health care practitioners (HCPs) working with children and adolescents with cancer in Canada. Our aim was to collate information on existing clinical practices (e.g., practice location, number and frequency of patients seen), services (e.g., service priorities, cancer impairments treated, type of interventions), and programmes (e.g., formal programmes offered, practice guidelines used). Our specific focus was on physical rehabilitation interventions within the scope of practice of physical therapists, while recognizing that other interdisciplinary team members may deliver some of the interventions.

METHODS

A cross-sectional Web-based survey in English and French was conducted using a secure Research Electronic Data Capture (REDCap) service, hosted at the University of Alberta.¹¹ REDCap provides (1) an intuitive interface for validated data entry, (2) audit trails for tracking data manipulation and export procedures, (3) automated export procedures for seamless data downloads to common statistical packages, and (4) procedures for importing data from external sources.

The study was approved by the Health Research Ethics Board at the University of Alberta: Cancer Committee. Electronic informed consent was obtained from all participants.

Participants

Eligible participants were HCPs across Canada who had provided physical rehabilitation services to children with cancer. We identified potential participants primarily by distributing an invitation to complete the survey through professional networks and organizations: the Canadian Physiotherapy Association's Oncology and Pediatric Divisions, C17 Council (Children's Cancer and Blood Disorders), Pediatric Oncology Group of Ontario, Stollery Children's Hospital (oncology professionals in the Northern Alberta Children's Cancer Program), Cross Cancer Institute (Rehabilitation Medicine Department), Cancer-Control Alberta, and Alberta Health Services. Moreover, we conducted an online search of additional organizations, institutions, and facilities that provide cancer care using the keywords *cancer rehabilitation OR physical rehabilitation AND children OR adolescents OR pediatric AND cancer care*. A total of 28 paediatric rehabilitation organizations, institutions, and facilities (cancer and non-cancer specific) were identified through the online search.

The survey was available for 3 months, from July 6 to October 6, 2017. We sent information about the study by email to HCPs who were known to be working in paediatric oncology or who had worked with children and adolescents with cancer. They were asked to share the request to complete the survey with other colleagues working in their area. Information about the survey was delivered in the newsletters and e-blasts of the previously mentioned organizations and associations. Electronic reminders were sent every 3 weeks to facilitate a higher response rate.

Sample size

Our proposed sample size was calculated on the basis of the response rate ($n = 62$) of the Canadian survey that had examined the rehabilitation of adults with cancer.⁹ Although we anticipated that fewer HCPs would be working in paediatric oncology because only about 3% of children and adolescents develop cancer, we considered our target sample size of 30 to be attainable.

Instrument and data analysis

The survey was available in English and French and is reproduced in the online Appendix. Our research team translated the survey into French, and two French-speaking clinicians then reviewed and edited the survey. The survey consisted of three sections with, collectively, 30-40 questions (36 close ended and 4 open ended), depending on the answers provided. The questions were designed on the basis of previous survey studies conducted in cancer rehabilitation.^{9,12}

The first section of the survey gathered data on practice patterns, including demographic information related to the professional designation of the HCP, location of practice, type of service, length of experience in the field, cancer continuum phase worked in, and number of childhood

cancers seen per year. The second section consisted of questions about providing rehabilitation services in the following domains: priorities for service, most common cancer effects addressed, type of interventions applied, type of physical agents applied, perceived effectiveness of treatment, and outcome measures or tests used for assessment and follow-up. The third section asked HCPs whether their work setting had adopted a paediatric oncology rehabilitation programme, their views on any evidence-based guidelines and protocols used for this population, and whether any barriers and facilitators existed that affected the provision of care or adoption of guidelines and protocols in their work setting.

The data consisted of continuous and categorical data, which were reported descriptively as frequencies. The categories were inductively developed for the open-ended questions. One study investigator (PO) categorized and counted the responses, and a second investigator (MM) verified the categories and calculations.

Working definitions

Our working definitions for the survey were as follows:

- *Health care providers*: health care providers working in paediatric oncology, such as physical therapists, occupational therapists, exercise professionals, speech-language pathologists, oncologists, and nurses
- *Physical rehabilitation services*: health care services that aim to enhance and restore functional ability and quality of life to individuals with physical impairments and disabilities
- *Children and adolescents with cancer*: Individuals aged 0–19 years who have been diagnosed with any type of cancer
- *Work locations*: public, non-profit organizations and private practices that provide health care to inpatients, outpatients, or both.

RESULTS

The results of this survey formed part of a larger study that was evaluating both physical rehabilitation practice and referral patterns. The data on referral patterns, gathered from oncologists and nurses, will be reported elsewhere. Not all questions or sections in the survey may have been relevant for a given HCP; as a result, the number of participants who provided responses in each section is indicated in the section headings.

Demographics

A total of 67 HCPs responded to the survey; 48 indicated that they provided physical rehabilitation services. Of these 48 respondents, 11 completed only the consent form (and did not respond to the survey), and 2 did not complete at least one full section of the survey. Thus, 35 survey responses were included in the study. Of the 35 surveys received, 3 were completed in French; they were translated into English by two bilingual members of the study team (PO, MM).

Table 1 Demographic Characteristics of Participants ($N = 35$)

Characteristic	n (%)
Province	
Alberta	17 (48.6)
British Columbia	4 (11.4)
Newfoundland and Labrador	1 (2.9)
Ontario	8 (22.9)
Quebec	5 (14.3)
Professional designation	
Physical therapist	27 (77.1)
Occupational therapist	6 (17.1)
Exercise professional	1 (2.9)
Speech-language pathologist	1 (2.9)
Work setting	
Acute care hospital	17 (48.6)
Rehabilitation hospital	9 (25.7)
Cancer hospital	7 (20.0)
Private practice	1 (2.9)
Community or primary care	1 (2.9)

A small majority of respondents ($n = 17$) were located in the province of Alberta (49%), 27 were physical therapists (77%), and 17 worked in an acute care hospital (49%). The length of professional experience in the paediatric oncology field varied from 0.6 to 37 years. A total of 15 HCPs (43%) reported seeing 10 or fewer paediatric oncology patients per year, 15 (43%) reported seeing 11–40 paediatric oncology patients per year, and 5 (14%) reported seeing more than 40 paediatric oncology patients per year.

A total of 17 (49%) HCPs worked in hospital inpatient units only, 9 (26%) worked in the outpatient setting only, 8 (23%) worked in both inpatient and outpatient settings, and 1 (3%) did not respond to this question. Demographic information is available in [Table 1](#).

Priorities for paediatric oncology rehabilitation ($N = 35$)

HCPs reported that the top five priorities for physical rehabilitation interventions were (1) limitations in activities of daily living (e.g., functional activities of daily living including self-care), (2) alterations in motor performance (such as gait deficits), (3) muscle weakness (decrease in muscle strength), (4) peripheral neuropathy (damage to, or disease affecting, sensory, motor, or autonomic nerves), and (5) cancer-related fatigue (a subjective, distressing, persistent sense of tiredness resulting from cancer treatment).^{13,14} Details on the frequency with which these priorities were reported are shown in [Table 2](#).

Inpatient services

One section of the questionnaire asked about inpatient physical rehabilitation interventions. Responses specific to this section are provided next.

Table 2 Top Priorities for Physical Rehabilitation ($N = 35$)

Priority	No. (%) of responses
Limitations on activities of daily living	18 (17.3)
Alterations 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 (8.7)
Balance alterations	8 (7.7)
Pain	7 (6.7)
Gait alterations	6 (5.8)
Decrease in flexibility	1 (1.0)
Total	104 (100.0)

Physical rehabilitation interventions ($n = 25$)

When asked what type of interventions they had provided to childhood cancer survivors before, during, and after cancer treatment (unlimited selection), respondents reported multiple interventions, with a larger number of different interventions reported during cancer treatment. The most common intervention provided before, during, and after treatment was range of motion (passive, active, or active assisted), followed by functional strengthening, balance training, flexibility exercises, and gait training or re-education. Detailed information on inpatient interventions is shown in [Figure 1](#).

Physical agents ($n = 21$)

Thermal (applying heat or cold) and electrotherapeutic agents (applying ultrasound or electrical stimulation) address impairments and promote functional recovery. A total of 12 HCPs (57%) reported not using any physical agents in childhood cancer survivors. Of those who did

use physical agents, the most common one was cryotherapy, followed by thermotherapy, electrical muscle stimulation, transcutaneous electrical nerve stimulation (TENS), ultrasound, and paraffin wax bath.

The rationale provided for using cryotherapy and thermotherapy was to relieve pain in general and to increase comfort before exercise. In a palliative care setting, TENS was also used to relieve pain. Ultrasound was used to treat hand-foot syndrome secondary to chemotherapy and to heal scars before manual therapy. Electrical stimulation was used to treat motor neuropathy, including foot drop, a common side effect of chemotherapy-induced peripheral neuropathy (CIPN), and for postoperative nerve damage. Paraffin wax was used to treat neuropathic pain in the hands, joint stiffness, and chronic graft against any host disease affecting the hands.

Outpatient services

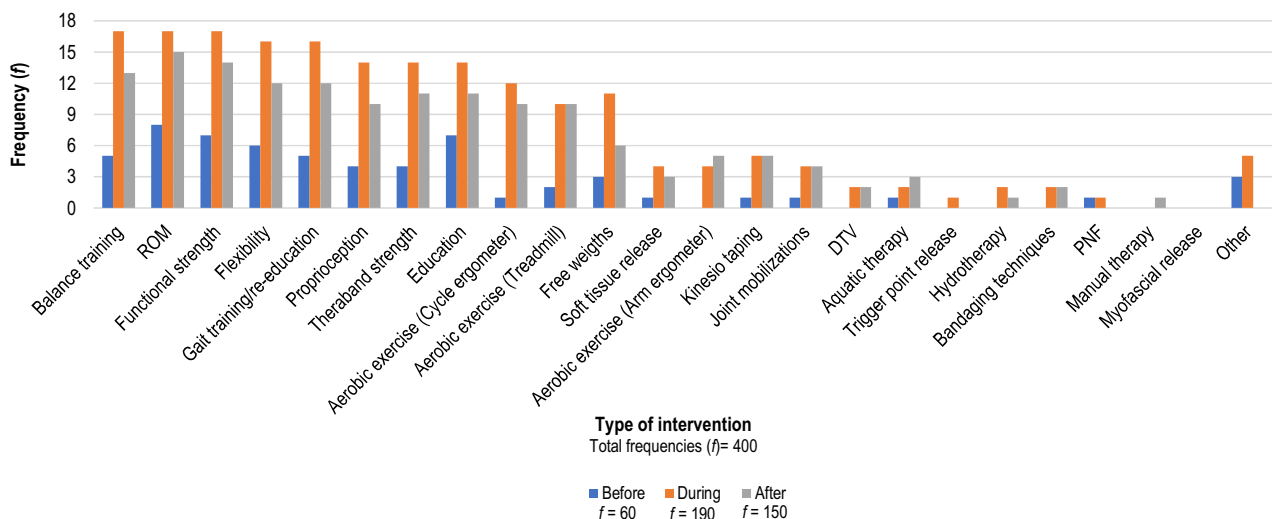
Another section of the questionnaire asked about outpatient physical rehabilitation interventions. Responses specific to this section are provided here.

Physical rehabilitation interventions ($n = 17$)

When we asked what type of interventions they had provided to childhood cancer survivors before, during, and after cancer treatment in outpatient settings, the most common intervention reported was flexibility exercises, followed by balance training, range of motion (passive, active, or active assisted), functional strengthening, gait training or re-education, elastic band strengthening, and proprioceptive exercises. Further details on outpatient interventions are shown in [Figure 2](#).

Physical agents ($n = 16$)

A total of 13 (81%) respondents reported not using any physical agents with childhood cancer survivors. The

**Figure 1** Type of interventions provided in inpatient settings.

ROM = range of motion; DTV = deep transverse friction; PNF = proprioceptive neuromuscular facilitation.

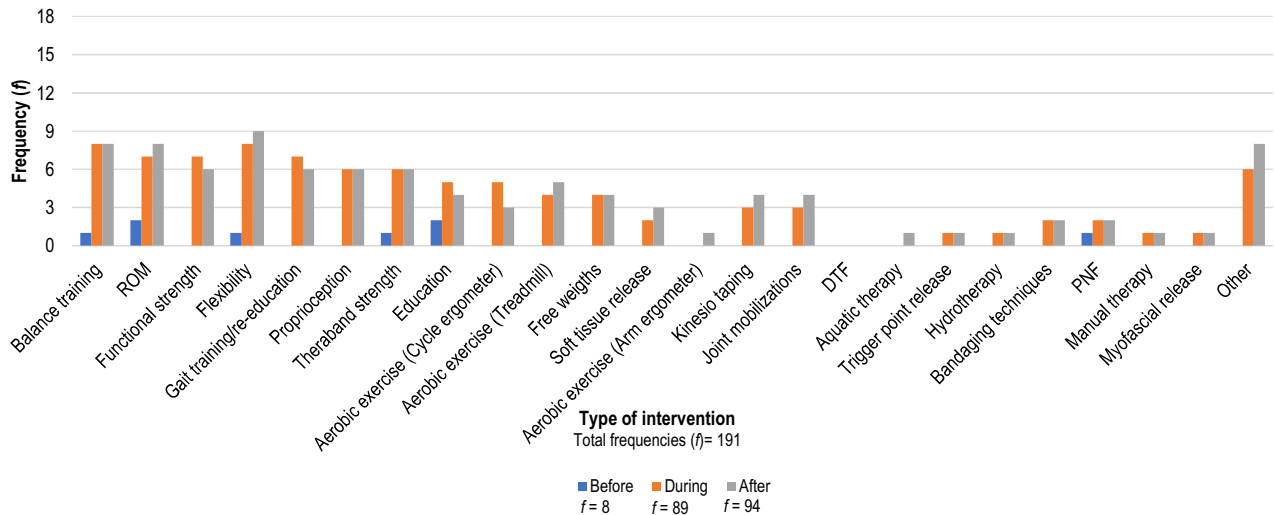


Figure 2 Types of interventions provided in outpatient settings.

ROM = range of motion; DTF = deep transverse friction; PNF = proprioceptive neuromuscular facilitation.

three respondents who did use physical agents indicated that they used thermotherapy, electrical stimulation, and paraffin wax bath. Their rationale for using thermotherapy and electrical stimulation was not reported; a paraffin wax bath was used to treat neuropathic pain in the hands and joint stiffness.

Perception of the value of rehabilitation programmes (n = 28)

Of the 28 survey respondents who completed this section, 25 (89%) believed that their interventions helped to reduce the short-term burden of cancer side effects in children and adolescents; however, they had some uncertainty about the long-term benefits because of a lack of follow-up data. Three HCPs provided context for their perceptions:

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.

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

I don't see [the children] long term so I would not know if it changed their side effects of cancer.

Of these 28 HCPs, 20 reported the need for improving rehabilitation programmes in the following areas: research evidence, continuity of care, increased time for interventions, specialized interventions, communication with the interdisciplinary team, grouped interventions, education for physical therapists, funding (e.g. increased staffing), and access to rehabilitation services.

Outcome measurement tools (n = 28)

The survey included 13 outcome measurement categories in physical rehabilitation. The category motor development was reported as the most assessed out-

come, using primarily the Alberta Infant Motor Scale,^{15,16} followed by the Bruininks–Oseretsky Test of Motor Proficiency, Peabody Developmental Motor Scales, and Movement Assessment Battery for Children.^{17,18} Sensory function was the second most assessed outcome, using primarily the sharp and dull test; followed by the hot and cold, or temperature, test; and the vibration test.^{19,20} Strength was the third most assessed outcome category, using primarily manual muscle testing,^{21,22} followed by hand-held dynamometry,²³ and the sit-to-stand test.²⁴

Availability of rehabilitation programmes and clinical practice guidelines

The third section of the survey asked about available guidelines and current barriers.

Availability of programmes and practice guidelines used (n = 28)

Half of the HCPs (n = 14) who provided responses in this section reported having a paediatric rehabilitation programme in their clinical setting. The main reasons reported for not having a rehabilitation programme were availability of resources or space and funding. Of the 28 survey respondents, 17 (61%) reported that they did not follow any rehabilitation clinical practice guidelines. Seven HCPs reported using guidelines in their settings: two (7%) used the Pediatric Oncology Exercise Manual (POEM); 4 (14%) used guidelines related to adult oncology, not specific to paediatrics; and 1 (4%) used general exercise booklets.⁸ Other than the POEM, further information on which specific guideline or booklet was used was not provided.

Importance of paediatric-specific programmes and use of guidelines (n = 27)

Table 3 provides detailed information on the availability of rehabilitation programmes and use of clinical

Table 3 Availability of Physical Rehabilitation Programmes and Use of Clinical Practice Guidelines ($n = 28$)

Availability and use	No. (%) [*]
Does your work setting have a paediatric oncology physical rehabilitation programme?	
Yes	14 (50.0)
No	12 (42.9)
Don't know	2 (7.1)
If not, why not ($n = 19$), no. (%)	
Availability of resources or space	5 (26.3)
Funding	4 (21.1)
Other – few admissions of children with cancer	3 (15.8)
Patients referred to rehabilitation programmes 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 (0.0)
Do you follow clinical practice guidelines in physical rehabilitation?	
No	17 (60.7)
Yes	9 (32.1)
Don't know	2 (7.1)

* Unless otherwise specified.

practice guidelines. A total of 14 HCPs (52%) considered it very important to implement paediatric oncology-specific practice guidelines in rehabilitation, and 20 (74%) reported that they would very likely adopt or support the implementation of the guidelines in their programme.

Barriers to and facilitators of implementing rehabilitation programmes ($n = 27$)

When we asked about the existing facilitators in their settings for offering paediatric oncology rehabilitation services, space or equipment and multidisciplinary team or staffing were most commonly reported. The most common barriers identified were inappropriate space for rehabilitation and lack of funding or resources. [Table 4](#) provides further details on these barriers and facilitators.

DISCUSSION

To our knowledge, our survey is the first in Canada to explore paediatric oncology rehabilitation practice patterns, services, and programmes. Our results identified limitations in activities of daily living as the highest priority to be addressed in rehabilitation interventions for childhood cancer survivors. This finding aligns with those from a recent qualitative study that investigated patients' and parents' views on supportive care for childhood can-

Table 4 Barriers to and Facilitators of Implementing Oncology Physical Rehabilitation Programmes ($n = 27$)

Barrier or facilitator	No. (%)
Facilitator	
Space, equipment, facilities	13 (36.1)
Multidisciplinary team or staffing	8 (22.2)
No facilitators identified	8 (22.2)
Specialized service or teleconferences	3 (8.3)
Oncology rehabilitation programme is available at site	3 (8.3)
Guidelines	1 (2.8)
Funding	0 (0)
Total	36 (100.0)
Barrier	
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)
Lack of knowledge specific to oncology physical rehabilitation	4 (9.5)
Lack of 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 (0.0)
Total	42 (100.0)

Note: Percentages do not total 100 because of rounding.

cer survivors.²⁵ In that study, children viewed attending school and interacting with classmates as being very important to normal life; however, hospitalization and fatigue were reported as the main barriers to attending school.

Although the priorities identified in this survey revolved around function and participation in life, the respondents also reported interventions that largely targeted issues at the level of impairment. Addressing the impairments that limit physical performance was viewed as a logical first step toward addressing functional limitations. Moving forward, what is needed is a more comprehensive and systematic care plan for rehabilitation, one that considers the impact of impairments on function, participation in life, and long-term survivorship.²

As an example, a recent study conducted by Tanner and colleagues described the feasibility of a standard care physical therapy (PT) programme for children diagnosed with acute lymphoblastic leukemia who were undergoing cancer treatment.²⁶ The programme was coordinated with oncology follow-up visits and the researchers used the *International Classification of Functioning, Disability and Health (ICF)* framework to guide their interventions. The results demonstrated that (1) the PT programme was

feasible and (2) children who reported limitations on their activities and who completed the programme improved their motor skills and scored better on age-norm-based motor function tests on their final follow-up assessment. The PT programme also appeared to reduce the burden of additional clinic visits for families.

Darcy and colleagues conducted a study that documented health and functioning in childhood cancer survivors using the multidimensional framework and language of the *ICF-Children and Youth* codes.²⁷ The study identified a comprehensive set of codes that could be used by HCPs to facilitate the assessment of children and adolescents with cancer and ultimately help to design interventions according to their activity limitations and restrictions on their participation in daily life.

Peripheral neuropathy was reported as one of the highest priorities for rehabilitation intervention in children and adolescents with cancer. CIPN can have a negative impact on quality of life and a child's ability to participate in age-appropriate activities.²⁸ Even though CIPN is one of the most frequently reported negative effects of childhood cancer treatments, no research trials exist that specifically address it as a clinical entity (including motor, sensory, and autonomic symptoms).²⁹ Although a paucity of evidence exists for physical agents in CIPN, some HCPs reported using electrical stimulation for CIPN-related symptoms and foot drop.^{26,29–32} Further research trials are needed that examine the effects of physical agents and exercise on this condition.

CIPN was also not a commonly measured outcome despite the high reported incidence of neuropathy among children, and the availability of the validated paediatric-modified total neuropathy score (Ped-mTNS).³³ Using this tool may allow clinicians to monitor the impact of chemotherapy on the peripheral nervous system and plan rehabilitation interventions for children who have developed CIPN.

Our survey results demonstrated that rehabilitation programmes in both inpatient and outpatient settings primarily involved physical or therapeutic exercise interventions. The POEM guideline for prescribing general physical exercise was the only resource found to be used clinically.³⁴ HCPs reported rarely using manual therapy techniques, neuromuscular re-education, or functional training. This could be related to lack of time, which they reported as being a barrier to implementing paediatric oncology rehabilitation services, as well as to lack of research evidence that supports the benefits of therapeutic interventions among childhood cancer survivors.^{7,26,35,36}

These findings can be correlated with the results from a systematic review conducted by Wacker and colleagues, which showed that more than half the studies examining rehabilitation interventions to improve physical impairments and functional mobility limitations in children and

adolescents undergoing treatment for non-central nervous system cancers were exercise or physical activity programmes, and just a few were therapeutic interventions (e.g., neuromuscular re-education).³⁶

The HCPs reported administering rehabilitation interventions primarily during cancer treatments. Only a few reported interventions in the prehabilitation phase before treatment; this is likely a result of the short window of opportunity between the time of diagnosis and start of cancer treatment. However, a pilot study carried out during the prehabilitation phase before limb salvage or amputation surgery demonstrated that 85% of children undergoing neoadjuvant chemotherapy for osteosarcoma, Ewing sarcoma, or chondroblastoma were able to complete 10–12 weeks of prehabilitation.³⁷ In this study, improvements were seen in walking distance in the 9-minute walk-run test and Functional Mobility Assessment (FMA) scores, suggesting that this programme has the potential to improve functional outcomes before surgery.

The majority of survey respondents worked in inpatient hospital units, and they indicated that availability of outpatient services in their facilities was lacking. This finding is consistent with the results of an observational study conducted by Montgomery and colleagues, which demonstrated that only 9.3% of survivors of childhood cancer reported accessing outpatient rehabilitation services.³⁸

Although individualized rehabilitation interventions aim to target the specific needs of childhood cancer survivors, HCPs reported that the need for group interventions was an area in which they could improve service delivery in the future. They believed that children with cancer were more motivated to exercise with their peers and that this might positively affect their engagement in rehabilitation programmes. However, they also reported that inappropriate space for paediatric rehabilitation and lack of funding and resources were barriers to providing services, barriers that might have an impact on the feasibility of group interventions.

We hypothesize that the lack of dedicated space and resources may be due to the limited research evidence supporting the benefit of PT interventions for survivors of childhood cancers.³⁵ Thus, future research is needed to examine the effectiveness and cost effectiveness of PT programmes. In addition, further exploration of optimal timing (prehabilitation, on treatment, post-treatment) and mode of delivery (one-on-one, group-based, or home-based interventions) is required to optimize rehabilitation care.

Functional mobility was one of the least measured outcomes reported by our respondents. Because limitations on activities were deemed a high priority for rehabilitation, incorporating a tool to facilitate the clinical assessment of childhood cancer survivors may help with

designing patient-centered interventions. As an example, the FMA is a reliable and validated tool for assessing childhood cancer survivors with lower extremity sarcoma. The target age is 13 years or older, but reference data have been reported for children aged younger than 10 years.³⁹ This tool consists of six categories: pain, function, use of assistive devices, satisfaction with walking quality, participation in activities, and endurance.⁴⁰ Although none of the survey respondents reported using this tool, this may be because of the low number of children diagnosed with sarcoma in Canada.

Unfortunately, the FMA has not been validated in children aged younger than 13 years. However, other functional mobility measures in younger children can be used clinically: the timed up-and-go test for those aged 3–12 years,^{41,42} Functional Independence Measure for Children (WeeFIM) for those aged 6 months–7 years or older, as long as a child's functional abilities are below those expected,⁴³ and the Pediatric Evaluation of Disability Inventory (PEDI) for those aged 6 months–7.5 years. The PEDI has a Computer-Adaptive Test version,⁴⁴ which is appropriate for those aged birth to 21 years; it incorporates not only a wider age range but also new items and different computer-based measurement methodologies.

Clinical practice guidelines specific to paediatric oncology rehabilitation beyond general exercise are lacking, and use of the one existing guideline on exercise appears limited.³⁴ Therefore, strong research evidence that supports the benefits of physical rehabilitation for children with cancer is needed, including a focus on the top five priorities for paediatric oncology rehabilitation identified in this survey: limitations in activities of daily living, motor performance, muscle weakness, peripheral neuropathy, and cancer-related fatigue. Moreover, further research examining prehabilitation interventions would be of great value because it would inform physical therapists about potential strategies to (1) minimize the severity and occurrence of side effects from aggressive cancer treatments and (2) educate parents about the importance of engaging children in an active lifestyle in the recovery process. We also encourage communication between researchers and clinicians so that they can reach a consensus on the outcome measurement tools used in paediatric oncology rehabilitation: researchers can design studies using tools that can be used in health care settings, and clinicians can be informed about validated and reliable tools that can be used in practice.

Several limitations were identified in our study. First, we did not ask the HCPs whether they worked exclusively in the cancer area, which types of cancer they tended to see, or the average age of children seen in their clinical settings. Our results may be biased by the fact that some HCPs did not report assessing some outcomes; this is likely a result of the types of cancer cases and ages of children seen in their work settings. For example, the HCPs

working with children with lower extremity osteosarcoma may have reported outcome measures such as the FMA tool, whereas those working with children undergoing chemotherapy for acute lymphoblastic leukemia may have reported outcome measures such as the PED-mTNS. Second, although the survey was pilot tested before we distributed it, two respondents reported that the question about the facilitators of implementing paediatric oncology rehabilitation programmes was unclear.

A third limitation was that, to protect the respondents' right to privacy and confidentiality, the survey was anonymous. Therefore, we were unable to follow up with the respondents when their responses were unclear or incomplete. Fourth, our sample size was small and we did not receive responses from all provinces; this suggests that our results may not be representative of all paediatric oncology rehabilitation programmes across Canada. At this point, it is unclear whether such services do not exist in those provinces or whether we simply did not reach HCPs working there. Finally, our results consisted of responses primarily from physical therapists (77%); a limited number of other HCPs responded to the survey. However, this is not surprising given that we focused on physical rehabilitation interventions in the scope of practice of physical therapists.

CONCLUSIONS

Our survey identified the current practice patterns in paediatric oncology rehabilitation in Canada. Our results may serve as a basis for future research in the field, taking into consideration the priorities identified by the HCPs as well as the barriers to and facilitators of providing services in their clinical setting. The HCPs reported that certain conditions – limitations on activities, alterations in motor performance, muscle weakness, peripheral neuropathy, and fatigue – were the top priorities for their paediatric oncology rehabilitation programmes. Currently, rehabilitation interventions for children with cancer are primarily carried out while they are hospitalized, and our findings suggest that prehabilitation, outpatient services, and continuity of care after they are discharged are inadequate.

Although the HCPs believed that interventions helped to reduce the burden of cancer side effects, issues such as space and resources were reported as barriers to providing care. Beyond general exercise, clinical practice guidelines specific to paediatric oncology rehabilitation are lacking, and use of the one existing guideline on exercise appears limited. Therefore, strong research evidence that addresses the five priorities for physical rehabilitation in children with cancer is needed. A useful starting point for research could include single-subject, repeated-measures designs, as well as qualitative approaches, to address the gaps in knowledge in this area.

KEY MESSAGES

What is already known on this topic

Children and adolescents undergoing cancer treatment are at high risk of developing adverse effects that may have a negative impact on their quality of life and participation in age-appropriate activities. Paediatric oncology physical rehabilitation is an emerging area that may help children regain muscle strength and overall function, as well as prevent or attenuate the impact of the adverse effects of cancer and its treatments. The extent of paediatric oncology rehabilitation programmes and services across Canada is still unknown.

What this study adds

This is the first national Web-based survey that aimed to identify the current practice patterns in paediatric oncology physical rehabilitation in Canada. A total of 35 health care providers (HCPs) responded to the survey, which identified the top priorities for rehabilitation, current practices, and outcome measures, as well as the existing barriers to and facilitators of the implementation of paediatric oncology rehabilitation programmes in health care settings. Currently, rehabilitation interventions for children with cancer are primarily carried out while they are in hospital, and our findings suggest a lack of prehabilitation, outpatient services, and continuity of care after they are discharged. Although the HCPs believed that interventions reduced the burden of cancer side effects, they reported that issues such as space and resources were barriers to providing care. Research is needed to address the five priorities they identified for physical rehabilitation in children with cancer.

REFERENCES

- Skinner R. Long-term effects of cancer therapy in children – functional effects, late mortality and long-term follow-up. *Paediatr Child Health*. 2012;22(6):248–52. <https://doi.org/10.1016/j.paed.2012.02.008>.
- Wilson CL, Gawade PL, Ness KK. Impairments that influence physical function among survivors of childhood cancer. *Children (Basel)*. 2015;2(1):1–36. <https://doi.org/10.3390/children2010001>. Medline:25692094
- Van Cleve L, Muñoz CE, Savedra M, et al. Symptoms in children with advanced cancer: child and nurse reports. *Cancer Nurs*. 2012;35(2):115–25. <https://doi.org/10.1097/ncc.0b013e31821aedba>. Medline:21760496
- Ness KK, Mertens AC, Hudson MM, et al. Limitations on physical performance and daily activities among long-term survivors of childhood cancer. *Ann Intern Med*. 2005;143(9):639–47. <https://doi.org/10.7326/0003-4819-143-9-200511010-00007>. Medline:16263886
- Moody K, Meyer M, Mancuso CA, et al. Exploring concerns of children with cancer. *Supportive Care Cancer*. 2006;14(9):960–6. <https://doi.org/10.1007/s00520-006-0024-y>. Medline:16639553
- Ness KK, Gurney JG. Adverse late effects of childhood cancer and its treatment on health and performance. *Annu Rev Public Health*. 2007;28(1):279–302. <https://doi.org/10.1146/annurev.publhealth.28.021406.144049>. Medline:17367288
- Krivitzky LS, Blaufuss MM, VanDenHeuvel S. Rehabilitation considerations in pediatric cancer survivors. In: Mucci G, Torno L, editors. *Handbook of long term care of the childhood cancer survivor, specialty topics in pediatric neuropsychology*. Boston: Springer; 2015.
- Ashbury FD, Findlay H, Reynolds B, et al. A Canadian survey of cancer patients' experiences: are their needs being met? *J Pain Symptom Manage*. 1998;16(5):298–306. [https://doi.org/10.1016/s0885-3924\(98\)00102-x](https://doi.org/10.1016/s0885-3924(98)00102-x). Medline:9846024
- Canestraro A, Nakhle A, Stack M, et al. Oncology rehabilitation provision and practice patterns across Canada. *Physiother Can*. 2013;65(1):94–102. <https://doi.org/10.3138/ptc.2011-53>. Medline:24381389
- Zebrack B. Information and service needs for young adult cancer survivors. *Supportive Care Cancer*. 2009;17(4):349–57. <https://doi.org/10.1007/s00520-008-0469-2>. Medline:18543006
- Harris PA, Taylor R, Thielke R, et al. Research Electronic Data Capture (REDCap) – a metadata-driven methodology and workflow process for providing translational research informatics support. *J Biomed Inform*. 2009;42(2):377–81. <https://doi.org/10.1016/j.jbi.2008.08.010>. Medline:18929686
- Gohar SF, Marchese V, Comito M. Physician referral frequency for physical therapy in children with acute lymphoblastic leukemia. *Pediatr Hematol Oncol*. 2010;27(3):179–87. <https://doi.org/10.3109/08880010903580209>. Medline:20367261
- Mock V, Atkinson A, Barsevick A, et al. NCCN practice guidelines for cancer-related fatigue. *Oncology-Ny*. 2000;14(11a):151–61.
- Ye ZH, Du FR, Wu YP, et al. Interpretation of NCCN clinical practice guidelines in oncology: cancer-related fatigue. *J Int Transl Med*. 2016;4(1):1–8. doi:10.11910/2227-6394.2016.04.01.01.
- Darrah J, Bartlett D, Maguire TO, et al. Have infant gross motor abilities changed in 20 years? A re-evaluation of the Alberta Infant Motor Scale normative values. *Dev Med Child Neurol*. 2014;56(9):877–81. <https://doi.org/10.1111/dmcn.12452>. Medline:24684556
- Darrah J, Piper M, Watt MJ. Assessment of gross motor skills of at-risk infants: predictive validity of the Alberta Infant Motor Scale. *Dev Med Child Neurol*. 2008;40(7):485–91. <https://doi.org/10.1111/j.1469-8749.1998.tb15399.x>. Medline:9698062
- Griffiths A, Toovey R, Morgan PE, Spittle AJ et al. Psychometric properties of gross motor assessment tools for children: a systematic review. *BMJ Open*. 2018;8(10):e021734. <https://doi.org/10.1136/bmjopen-2018-021734>. Medline:30368446
- Wuang YP, Su CY, Huang MH. Psychometric comparisons of three measures for assessing motor functions in preschoolers with intellectual disabilities. *J Intellect Disabil Res*. 2012;56(6):567–78. <https://doi.org/10.1111/j.1365-2788.2011.01491.x>. Medline:21988314
- Ridehalgh C, Sandy-Hindmarch OP, Schmid AB. Validity of clinical small-fiber sensory testing to detect small-nerve fiber degeneration. *J Orthop Sports Phys Ther*. 2018;48(10):767–74. <https://doi.org/10.2519/jospt.2018.8230>. Medline:29932873
- Stubblefield MD, Burstein HJ, Burton AW, et al. NCCN task force report: management of neuropathy in cancer. *J Natl Compr Canc Netw*. 2009;7(Suppl 5):S1–S26. <https://doi.org/10.6004/jnccn.2009.0078>. Medline:19755042
- Cuthbert SC, Goodheart GJ. On the reliability and validity of manual muscle testing: a literature review. *Chiropr Osteopat*. 2007;15(1):4. <https://doi.org/10.1186/1746-1340-15-4>. Medline:17341308
- Manikowska F, Chen BP, Jozwiak M, et al. Validation of manual muscle testing (MMT) in children and adolescents with cerebral palsy. *NeuroRehabilitation*. 2018;42(1):1–7. <https://doi.org/10.3233/nre-172179>. Medline:29400673
- van den Beld WA, van der Sanden GA, Sengers RC, et al. Validity and reproducibility of hand-held dynamometry in children aged 4–11 years. *J Rehabil Med*. 2006;38(1):57–64. <https://doi.org/10.1080/16501970510044043>.
- Wang TH, Liao HF, Peng YC. Reliability and validity of the five-repetition sit-to-stand test for children with cerebral palsy.

- Clin Rehabil. 2012;26(7):664–71. <https://doi.org/10.1177/0269215511426889>. Medline:22080526
25. Tenniglo LJA, Loeffen EAH, Postma A, et al. Patients' and parents' views regarding supportive care in childhood cancer. *Supportive Care Cancer*. 2017;25(10):3151–60. <https://doi.org/10.1007/s00520-017-3723-7>. Medline:28456909
 26. Tanner L, Sencer S, Hooke MC. The Spotlight Program: a proactive physical therapy intervention for children with acute lymphoblastic leukemia. *J Pediatr Oncol Nurs*. 2017;34(5):347–57. <https://doi.org/10.1177/1043454217698093>. Medline:28459187
 27. Darcy L, Enskär K, Granlund M, et al. Health and functioning in the everyday lives of young children with cancer: documenting with the International Classification of Functioning, Disability and Health – Children and Youth (ICF-CY). *Child: Care Health Dev*. 2015;41(3):475–82. <https://doi.org/10.1111/cch.12191>. Medline:25219405
 28. Gilchrist L. Chemotherapy-induced peripheral neuropathy in pediatric cancer patients. *Semin Pediatr Neurol*. 2012;19(1):9–17. <https://doi.org/10.1016/j.spn.2012.02.011>. Medline:22641071
 29. Behrend SW. New guidelines for chemotherapy-induced peripheral neuropathy. *Oncol Nurs Forum*. 2014;41(5):559–60. <https://doi.org/10.1188/14.onf.559-560>. Medline:25158663
 30. Marchese VG, Chiarello LA, Lange BJ. Effects of physical therapy intervention for children with acute lymphoblastic leukemia. *Ped Blood Cancer*. 2004;42(2):127–33. <https://doi.org/10.1002/pbc.10481>. Medline:14752875
 31. Tanner LR, Hooke MC, Hinshon S, et al. Effect of an ankle foot orthosis intervention for children with non-central nervous system cancers: a pilot study. *Pediatr Phys Ther*. 2015;27(4):425–31. <https://doi.org/10.1097/pep.000000000000180>. Medline:26397091
 32. Casanova-Garcia C, Lerma Lara S, Perez Ruiz M, et al. Non-pharmacological treatment for neuropathic pain in children with cancer. *Med Hypotheses*. 2015;85(6):791–7. <https://doi.org/10.1016/j.mehy.2015.10.007>. Medline:26604028
 33. Gilchrist LS, Tanner L. The pediatric-modified Total Neuropathy Score: a reliable and valid measure of chemotherapy-induced peripheral neuropathy in children with non-CNS cancers. *Supportive Care Cancer*. 2013;21(3):847–56. <https://doi.org/10.1007/s00520-012-1591-8>. Medline:22993026
 34. Chamorro Viña C, Keats M, Culos-Reed SN. *Pediatric Oncology Exercise Manual (POEM)*. Alberta: University of Calgary; 2015.
 35. Braam KI, van der Torre P, Takken T, et al. Physical exercise training interventions for children and young adults during and after treatment for childhood cancer. *Cochrane Database Syst Rev*. 2016;3:CD008796. <https://doi.org/10.1002/14651858.cd008796.pub3>. Medline:27030386
 36. Wacker K, Tanner L, Ovans J, et al. Improving functional mobility in children and adolescents undergoing treatment for non-central nervous system cancers: a systematic review. *PM and R*. 2017;9(9 Supplement 2):S385–S97. <https://doi.org/10.1016/j.pmrj.2017.05.011>. Medline:28942910
 37. Corr AM, Liu W, Bishop M, et al. Feasibility and functional outcomes of children and adolescents undergoing preoperative chemotherapy prior to a limb-sparing procedure or amputation. *Rehabil Oncol*. 2017;35(1):38–45. <https://doi.org/10.1097/01.reo.0000000000000050>.
 38. Montgomery M, Huang S, Cox CL, et al. Physical therapy and chiropractic use among childhood cancer survivors with chronic disease: impact on health-related quality of life. *J Cancer Surviv*. 2011;5(1):73–81. <https://doi.org/10.1007/s11764-010-0151-9>. Medline:20922492
 39. Marchese VG, Oriol KN, Fry JA, et al. Development of reference values for the functional mobility assessment. *Pediatr Phys Ther*. 2012;24(3):224–30. <https://doi.org/10.1097/pep.0b013e31825c87e7>. Medline:22735469
 40. Victoria GM, Shesh NR, Claire AC, et al. Assessing functional mobility in survivors of lower-extremity sarcoma: reliability and validity of a new assessment tool. *Pediatr Blood Cancer*. 2007;49(2):183. <https://doi.org/10.1002/pbc.20932>. Medline:16779807
 41. Nicolini-Panisson RD, Donadio MV. Normative values for the Timed “Up and Go” test in children and adolescents and validation for individuals with Down syndrome. *Dev Med Child Neurol*. 2014;56(5):490–7. <https://doi.org/10.1111/dmcn.12290>. Medline:24206424
 42. Nicolini-Panisson RD, Donadio MV. Timed “Up & Go” test in children and adolescents. *Rev Paul Pediatr*. 2013;31(3):377–83. <https://doi.org/10.1590/s0103-05822013000300016>. Medline:24142322
 43. Williams KS, Young DK, Burke GAA, et al. Comparing the WeeFIM and PEDI in neurorehabilitation for children with acquired brain injury: a systematic review. *Dev Neurorehabil*. 2017;20(7):443–51. <https://doi.org/10.1080/17518423.2017.1289419>. Medline:28277891
 44. Kramer JM, Liljenquist K, Coster WJ. Validity, reliability, and usability of the Pediatric Evaluation of Disability Inventory–Computer Adaptive Test for autism spectrum disorders. *Dev Med Child Neurol*. 2016;58(3):255–61. <https://doi.org/10.1111/dmcn.12837>. Medline:26104112

Copyright of Physiotherapy Canada is the property of University of Toronto Press and its content may not be copied or emailed to multiple sites or posted to a listserv without the copyright holder's express written permission. However, users may print, download, or email articles for individual use.