



Physical activity programs for children diagnosed with cancer: an international environmental scan

Amanda Wurz¹ · Julia Daeggelmann² · Natalia Albinati³ · Liam Kronlund³ · Carolina Chamorro-Viña⁴ · S. Nicole Culos-Reed^{3,5,6}

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Abstract

Background Physical activity programs for children diagnosed with cancer may enhance health and quality of life. However, it is unknown where and in what capacity such programs are being offered internationally.

Purpose To identify physical activity programs for children diagnosed with cancer and summarize program characteristics.

Methods Five data sources were searched to identify physical activity programs offered to children diagnosed with cancer. Following confirmation of eligibility, correspondents were sent a series of open-ended questions via email. Data were extracted from responses and summarized descriptively and narratively.

Results Of the 140 unique correspondents contacted, 46 programs, in 10 countries, met eligibility criteria. Responses to open-ended follow-up questions were obtained from 36 programs and were subsequently included in the content analysis. Internationally, the majority of programs are being offered to children in Europe, with mixed cancer types, at different stages of the cancer trajectory. There is relatively equal distribution with regard to the setting in which programs are offered (i.e., community, hospital, combination). All correspondents reported that their program is professionally supervised, and most require that children obtain medical clearance prior to participating. There is considerable variability in terms of other key program (e.g., funding) and physical activity characteristics (e.g., frequency).

Conclusions Findings from this environmental scan highlight where and in what capacity physical activity programs are being offered, providing guidance for those seeking to develop/implement physical activity programs themselves. Moreover, results highlight the current state of practice, underscoring the necessity of international networks, multi-site collaborations, and public relations to ensure all children diagnosed with cancer have access to physical activity programs.

Keywords Exercise · Pediatric · Community programs · Oncology · Knowledge translation

Physical activity for children diagnosed with cancer

Physical activity has been shown to be safe and feasible for children diagnosed with cancer [1–3]. Moreover, researchers

have found that physical activity may confer a range of physical, psychological, and social benefits among children diagnosed with cancer [1–3]—a finding bolstered by more than three decades of research showing physical activity is safe, feasible, and beneficial for adults diagnosed with cancer [4,

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✉ S. Nicole Culos-Reed
nculosre@ucalgary.ca

¹ Faculty of Health Sciences, School of Human Kinetics, University of Ottawa, Ottawa, Ontario, Canada

² Institute of Cardiology and Sports Medicine, Department of Molecular and Cellular Sports Medicine, German Sport University Cologne, Cologne, Germany

³ Faculty of Kinesiology, University of Calgary, Calgary, Alberta, Canada

⁴ Kids Cancer Care Foundation of Alberta, Calgary, Alberta, Canada

⁵ Department of Oncology, Cumming School of Medicine, University of Calgary, Calgary, Alberta, Canada

⁶ Alberta Health Services, Cancer Care, Tom Baker Cancer Centre, Department of Psychosocial Resources, Calgary, Alberta, Canada

5]. Although some children diagnosed with cancer may be able to maintain their physical activity and/or are able to safely transition back into physical activity following their treatment [6], many require additional assistance. This is due in large part to disease- and treatment-related symptoms and side effects that can impact physical activity engagement (e.g., fatigue, cardiotoxicity, changed body composition, elevated blood pressure, frailty, and lack of confidence or support to participate; [7–11]).

Physical activity programs

Physical activity programs developed with and for children diagnosed with cancer may be one way to help this population manage their side effects and safely maintain or return to physical activity [12]. Such programs consider treatment-related symptoms [7–11] and strive to enhance children's knowledge, skills, and confidence to be physically active [13]. As a result, these programs may overcome commonly cited barriers to physical activity [14]. Though researchers have argued more physical activity programs for this population are needed [13], the number being offered is unknown. Whereas some researchers have undertaken local efforts to synthesize information related to the availability of physical activity programs for children diagnosed with cancer in their city or country (e.g., Germany; [15]), no work has been done on an international scale.

The need for an international environmental scan

A critical first step is to understand where and in what capacity physical activity programs are being offered. Environmental scans are one way to identify and collate a large body of information seeking to achieve such an aim [16, 17]. Moreover, they are a useful way to inform strategic planning, provide evidence about the direction of a field, and raise awareness about gaps in program/service availability [18, 19]. Therefore, we conducted an international environmental scan to identify physical activity programs being offered for children diagnosed with cancer as a means of highlighting the current state of practice.

Methods

Guidelines for conducting environmental scans [20] and systematic reviews [21, 22] were followed. Favoring sensitivity over specificity, programs were identified in one of five ways: (1) study team members and their professional networks; (2) Internet searches; (3) reference lists of relevant systematic

reviews; (4) systematic searching of relevant electronic databases; and (5) snowball sampling. Though reference list scanning and systematic reviews are not required when conducting environmental scans [20], we chose to include these data sources to ensure that researchers who are publishing in this area (and who may be offering or know of physical activity programs) were identified.

Eligibility criteria

To be included, the individuals contacted (i.e., correspondents) had to confirm that their program: (1) offered physical activity to children diagnosed with cancer between the ages of 0–18 years, though others could partake (e.g., siblings, friends); (2) was sustainable, defined as established and ongoing (when a program started as research project, correspondents had to confirm that it was translated into practice); (3) incorporated cardiovascular, resistance, and/or coordination and flexibility training through traditional physical exercise or via yoga, sports, and games; and (4) contained a team member who could speak English or German. For the purposes of this environmental scan, when programs were identified with participants > 18 years of age (e.g., adolescent, adolescent and young adult programs), at least 50% of participants had to be between the ages of 0 and 18 years to be included. Physiotherapy programs were excluded as they are considered a distinct service [23].

Procedure

Data sources

The five data sources were searched in three sequential steps. First, study team members (source 1) identified all programs for children diagnosed with cancer that they were aware of, and reached out to their professional networks to gain additional information (i.e., contact information for correspondents of potential programs). Second, the Internet searches, reference list scanning, and systematic review were performed concurrently. With regard to the Internet searches (source 2), two independent researchers entered pre-specified combinations of keywords (see Supplementary File 1) into Google and Google Scholar. The searches were mined for possible programs that met the eligibility criteria. The first 20 links were reviewed for possible programs and if a potential program was identified, then the next 10 links were reviewed. If another program was identified, then the next 10 links were reviewed until no additional potential programs were identified. Once a set of search terms was exhausted, a different combination of terms was entered into Google and Google Scholar, and the same process was repeated. Upon completion, the researchers met to compare their findings, discuss the final programs to be included, and locate correspondent contact information. For

reference list scanning (source 3), 13 relevant reviews¹ on the topic of physical activity for children diagnosed with cancer were identified. These were identified through the systematic review (described in greater detail below) and the authors' knowledge of the literature in this area. Two researchers scanned the reference lists of these 13 reviews at the title level to determine eligibility. When more details were required to determine eligibility, the researchers located and screened full-texts. With regard to the systematic review (source 4), five electronic databases were searched from database inception through to July 14, 2017 in Medical Literature Analysis and Retrieval System Online (MEDLINE), SportDiscus, PsychINFO, Cumulative Index to Nursing and Allied Health Literature (CINAHL), and Education Source, Excerpta Medica Database (EMBASE). Medical subject heading and keywords that were used can be found in Supplementary File 1. Recommendations for the conduct and reporting of systematic reviews were followed throughout [21, 22]. The search strategies for each database were developed based on the study teams' prior work conducting systematic reviews (e.g., [24]), relevant systematic reviews in the field (e.g., [1–3]) and in consultation with an expert librarian. Of note, in addition to the eligibility criteria specified above, citations had to be published in English from 2005 onward. Third, snowball sampling (source 5) was performed wherein correspondents of potential programs were contacted and were asked to provide names for any organizations or individuals they believed were offering (or likely to be offering) physical activity programs for children diagnosed with cancer.

Contacting potential programs

A *master list* compiling program correspondent names and contact information from (1) study team members and their professional networks; (2) Internet searches; (3) reference lists of relevant systematic reviews; and (4) systematic searching of electronic databases was created. An email was then sent to all correspondents on the *master list* asking if they were currently offering a physical activity program and/or if they knew of anyone else who might also be offering a physical activity program (i.e., snowball sampling). Any additional names identified via snowball sampling (source 5) were also added to the *master list*. These correspondents received the same email asking if they were currently offering a physical activity program and if they knew of anyone else who might also be offering a physical activity program. This continued until no new correspondents were identified.

The first and second authors made decisions regarding eligibility upon reviewing the correspondents' responses to the initial email. If the program was deemed ineligible, it was

excluded, and the correspondent received an email thanking them for their time. In cases where responses were unclear and/or when more information was required to make a decision regarding eligibility, the correspondent was re-contacted to clarify/confirm eligibility. When a program was deemed eligible, correspondents were sent a follow-up email containing a series of brief open-ended questions asking about the structure and content of their program. Questions covered organizational aspects (e.g., *What is the name of the program? How long have you been offering the program?*), program participant information (e.g., *Who accesses the program?*), and physical activity program information (e.g., *What does a typical session/program look like?*). These questions can be found in Supplementary File 2. Throughout all stages of data collection, if no response was received after the first follow-up email, correspondents were re-contacted (approximately 3 weeks apart) up to three times. After the third contact attempt, no further attempts were made.

Data extraction and analysis

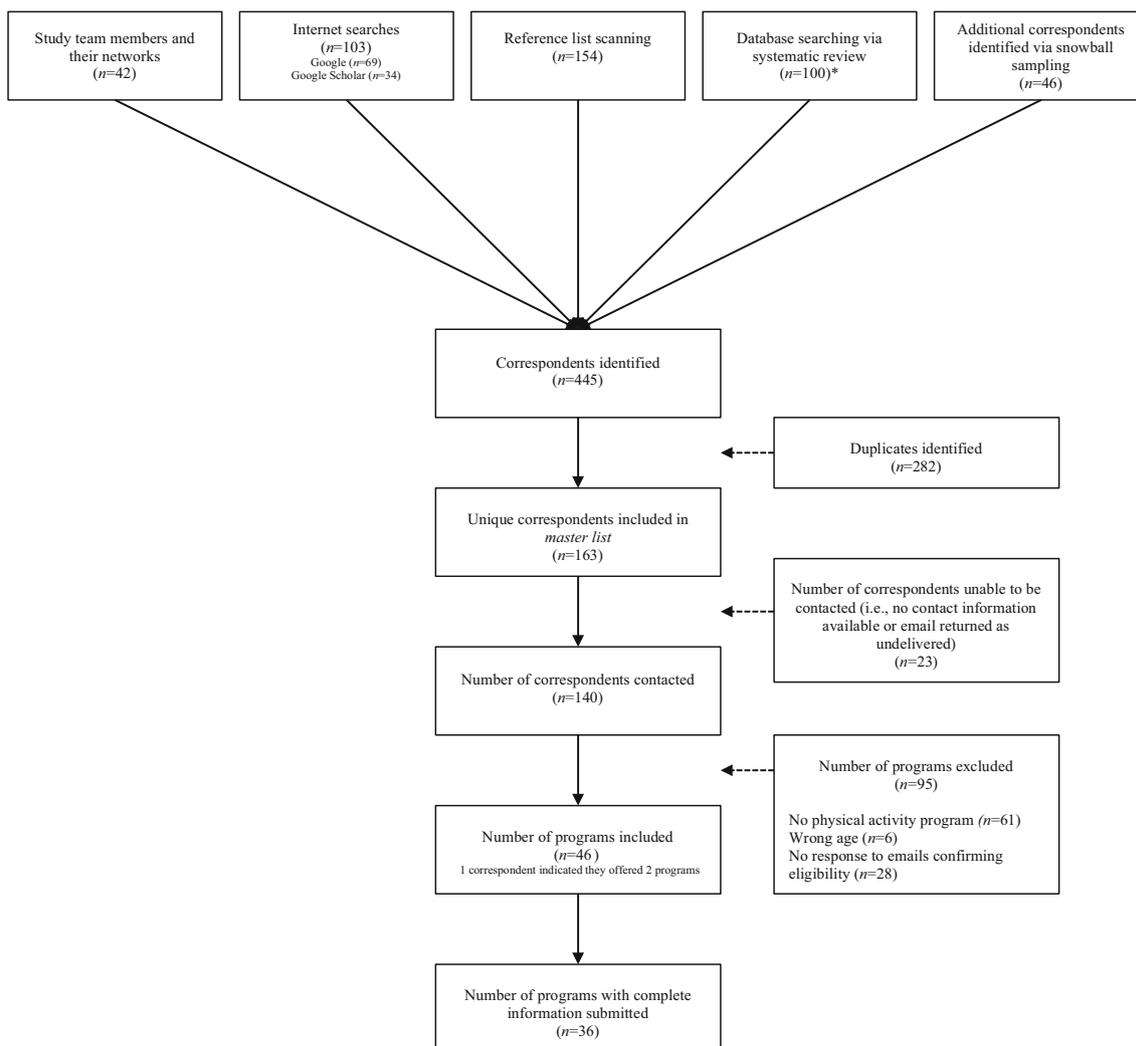
Information was extracted from the *master list* regarding the number of programs identified, and the number of programs for which there was complete information. Two researchers (LK, NA) then used a standardized data extraction form to consolidate correspondents' responses to the follow-up email questions and transferred the information into an excel spreadsheet. These responses were analyzed using qualitative content analysis [25], wherein the raw data (i.e., participants responses) were assigned codes according to a classification scheme. Following this, codes were counted (quantitatively) and summarized descriptively and narratively [26]. The findings and identified knowledge gaps were discussed among co-authors and compared with physical activity guidelines/recommendations for children diagnosed with cancer (e.g., [27]). This was done to enhance the credibility of the synthesis and ensure that the summary of findings was appropriately situated in the context of current knowledge.

Results

Program identification

Figure 1 presents a flow diagram of search results. After removing duplicates, a total of 163 unique correspondents were identified across all five data sources. Of these, 140 were contacted and 112 responded (80% response rate). Forty-five correspondents indicated that their program met eligibility criteria, with one correspondent responding that they had two programs meeting our eligibility criteria. Thus, 46 programs were included, and follow-up information was

¹ The list of 13 relevant systematic reviews is available upon request from the corresponding author.



*The PRISMA diagram for the systematic review is available upon request to the corresponding author.

Fig. 1 Flow diagram of search results. *The PRISMA diagram for the systematic review is available upon request to the corresponding author

collected on the design and conduct of 36 from programs (78% response rate).

Program details

General program characteristics

As seen in Fig. 2, of the 46 physical activity programs identified, most are taking place in Europe ($n = 32$; 70%), with over 66% of these being offered in Germany ($n = 21$). The results from this point onward describe the 36 programs for which responses to the follow-up questions were obtained (see Table 1). There was a relatively even distribution with regard to how long the programs have been offered (i.e., < 5 years, 5–10 years, or > 10 years), ranging from 1 year to upwards of 30 years. Although several programs reported that they published data from their programs (e.g., program evaluations),

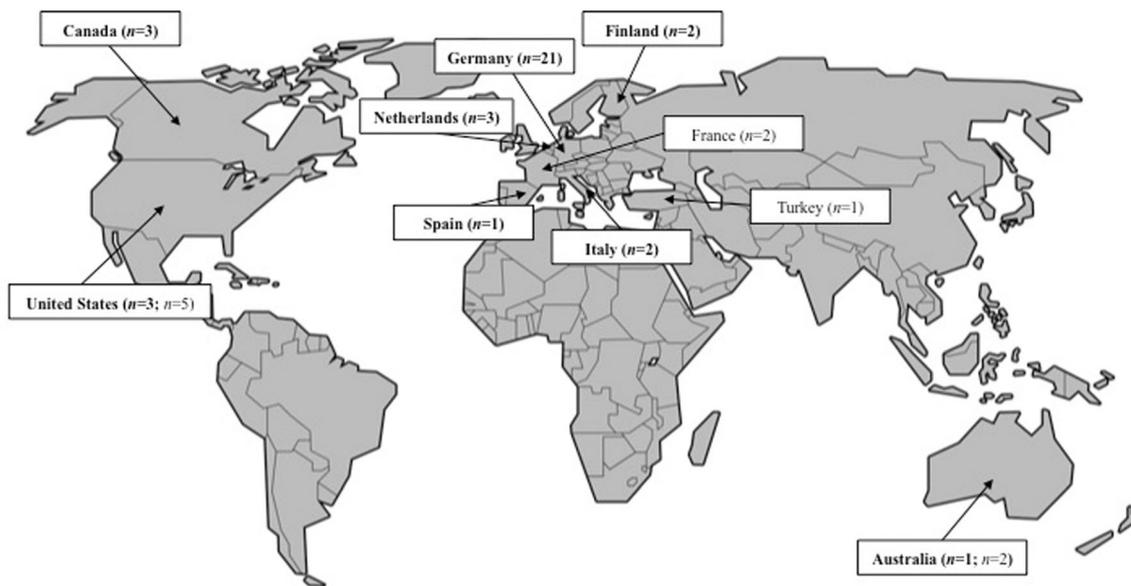
only 14% ($n = 5$) of the included programs were translated from research (see [28–31]²). Though varying from program-to-program, most program correspondents reported that their program relies on a single source of funding ($n = 26$, 72%; e.g., clinical billing, donation, out-of-pocket) and that anywhere from 0³ to approximately 400 children diagnosed with cancer access the program each year.

Physical activity characteristics

Of those correspondents who provided frequency and duration information ($n = 11$; 31%), there was

² One program that reported being translated from a research project did not have an associated publication.

³ The program is open to children diagnosed with cancer, but has not yet had any participants.



Notes. Programs identified and included in the scan are denoted in **bold-text**, programs identified and excluded (because correspondents did not respond to the second email; i.e., failed to provide more information about their program) are denoted in plain-text; **1 included program is offered in multiple countries (e.g., Italy, France, Switzerland, and Algeria)**; 1 excluded program is offered in multiple countries (e.g., Canada, United States, Italy, Israel, South Africa).

Fig. 2 Physical activity programs identified

considerable variability in terms of how many times participants accessed the program/week and the length of the program. For example, two correspondents reported that their program was offered 1 time/week ($n = 2$; 8%); others reported offering their program daily (or multiple times/day) for a fixed time frame (e.g., 1 week skiing retreat or swimming camp; $n = 4$; 11%), while some programs operated year round on a rolling recruitment/drop-in basis, with no set frequency or duration ($n = 3$; 8%). There was a relatively even number of programs being offered in-hospital ($n = 13$; 36%), the community ($n = 11$; 30%), or reporting a combination of the two (i.e., hospital- and community-based; $n = 12$; 33%). Most correspondents reported that their program included aerobic, resistance, and/or balance/flexibility training either through traditional exercises or sports/play ($n = 27$; 75%). Examples of sports/play provided by correspondents included soccer, hockey, and badminton. The remaining correspondents reported that their program focused on one type of activity (e.g., yoga, skiing, dance, swimming, martial arts; $n = 9$; 25%).

Though not explicitly asked within the questionnaire, 17 (47%) program correspondents mentioned the importance of fun and the importance of fostering physical literacy. Further, every correspondent mentioned the individualized nature of his/her program (i.e., that children's unique needs and capacities were taken into account). Finally, all program correspondents noted that their programs were supervised by a healthcare providers, physical activity professionals, and/or researchers.

Participant characteristics

Program correspondents reported that children of all cancer diagnoses ($n = 30$; 83%) and at varying stages of the cancer trajectory could access their programs and most reported being open to children on- and off-treatment ($n = 24$; 67%). Medical clearance was required to participate in 24 programs (67%), and 27 programs (75%) allowed support persons (e.g., friend, family member) to participate. Employing multiple modes of recruitment (e.g., healthcare provider referral, word of mouth, posters) was common ($n = 23$; 64%), though two program correspondents indicated their physical activity program was integrated into childhood cancer care ($n = 2$; 5%) and did not comment on recruitment strategies in their response.

Discussion

The purpose of this international environmental scan was to identify where and in what capacity physical activity programs are being offered for children diagnosed with cancer. To this end, we sought to identify programs and summarize their characteristics. Results highlight that programs are still rare, with only 46 programs being offered across 10 countries internationally. Moreover, programs are not evenly distributed, with the majority operating in Europe. Most programs are being delivered to children with mixed cancer types across all phases of the cancer trajectory (i.e., on-/off-treatment) and are open to support persons. Programs are supervised by trained

Table 1 General program, physical activity, and participant characteristics

General characteristics	No. (%)
Number of years program has been offered	
< 5	12 (33%)
5–10	11 (31%)
> 10	13 (36%)
Funding source	
Single	26 (72%)
Multiple	10 (28%)
Number of participants accessing the program per year	
< 10	3 (8%)
10–50	6 (17%)
> 50	13 (36%)
Not reported ^a	14 (39%)
Physical activity characteristics	
Setting	
In-hospital	13 (36%)
Community-based	11 (31%)
Combination	12 (33%)
Supervision	
Yes	36 (100%)
No	0 (0%)
Medical clearance	
Yes	24 (67%)
No	12 (33%)
Participant characteristics	
Cancer type	
Single cancer type	2 (6%)
Mixed cancer types	30 (83%)
Not reported	4 (11%)
Treatment status	
On-treatment	5 (14%)
Off-treatment	3 (8%)
Mixed (on- and off-treatment)	24 (67%)
Not reported	4 (11%)
Support persons allowed to participate	
Yes	27 (75%)
No	9 (25%)
Recruitment	
Integrated (i.e., standard of care)	2 (5%)
Healthcare provider referral	11 (31%)
Multiple (i.e., healthcare provider, word of mouth, community)	23 (64%)

Note. ^a $n = 1$ not reported; $n = 9$ reported children/month (range = 1–40); $n = 3$ reported children/week (range = 4–20); $n = 1$ reported children/program (30/activity)

individuals and typically require medical clearance. Beyond this, programs were variable in terms of general program characteristics (i.e., number of years in operation, funding sources,

number of participants accessing the program), physical activity characteristics (i.e., duration, frequency, setting, type), and how participants are recruited to the program.

The variability across programs is unsurprising considering the variety of healthcare systems, the range of infrastructure available to researchers and organizations, and the heterogeneity of the population. Notably, though not explicitly asked, a common thread among correspondents was their programs' focus on fun and physical literacy. Both have been shown to be important for the acquisition of motor/movement skills, psychosocial and cognitive health benefits, and physical activity participation [32–35]. However, children diagnosed with cancer encounter barriers to engaging in fun/playful pursuits and have significantly lower motor/movement skills than normative referents [36]. Physical activity programs seemingly are seeking to address this. Several resources to support integration of fun and physical literacy in physical activity programs can be found online (e.g., <http://physicalliteracy.ca/>), and readers are referred to recent publications for relevant examples [13, 37].

In conjunction with recently published reviews and recommendations (e.g., [38]), findings make noteworthy practical contributions and have implications for informing future research and care. First, physical activity programs should be age-specific and individually tailored to respect motor skill acquisition and key developmental milestones and enhance/maintain physical, psychological, and social health. As well, physical activity should be adapted to the child's current physical fitness, which may need to take into account the child's treatment stage, side effects, preferences, and past physical activity participation [39]. Though individualized physical activity programming is important to ensure safety, program correspondents also acknowledged children's varied physical activity preferences and sought to promote choices to foster feelings of autonomy [40] and motivate children's physical activity participation [41]. Tailoring physical activity and encouraging choice may be important program components and should be examined further in research.

Second, although not systematically assessed, several correspondents indicated that their program was group-based, which could have benefits. Group-based physical activity may promote sustainability and recruitment rates, as children diagnosed with cancer comprise a small population [42]. Similarly, most programs included support persons (e.g., family member/sibling, friend), which could increase numbers, but is also known to enhance physical activity confidence and participation in both the child diagnosed with cancer and their support person [43–45]. Finally, providing opportunities for children diagnosed with cancer to engage in physical activity with other people may ensure that their social needs are met, while enabling them to accrue the physical and psychological benefits of physical activity. Notwithstanding these benefits, there can be challenges to offering group-based

physical activity to children diagnosed with cancer, which may be especially pertinent during treatment. For example, immune system concerns may contraindicate group-based activities. Learning how existing physical activity programs ensure participant safety and respect isolation, while offering children undergoing treatment the opportunity to engage in physical activity would be a worthwhile endeavor. In a similar vein, it would be interesting to determine if/how programs differ according to participants' treatment status.

Third, correspondents indicated that medical clearance and appropriate supervision were important and in some cases, necessary. The decision to require medical clearance was dependent on the program location (e.g., in-hospital, community), participant-specific considerations (e.g., stage along cancer trajectory, type of cancer diagnosed, treatment-related considerations/contraindications), and the type of physical activity (e.g., exercise, yoga, sport). Ample guidance regarding medical screening and clearance is available, and readers are referred to work by researchers, such as Kilka et al. [38], Götte et al. [46], and Beulertz et al. [47] and to existing resources (e.g., [39]). With regard to supervision, all correspondents reported that their program was supervised—a factor likely to enhance attendance/adherence [1, 48]. Considering the complexity of childhood cancer, ensuring the individual supervising the physical activity program has the knowledge, skills, and ability to provide condition- and age-appropriate programming is critical. Unfortunately, the types and distribution of individuals supervising physical activity programs in this environmental scan are unknown. Future work to gather this information will provide a better understanding of care and will aid in the development of training programs and communities of practice.

Fourth, incorporating healthcare providers into recruitment strategies was consistently reported. Given that children and their families rely heavily on their healthcare team, healthcare providers may be well placed to refer children to physical activity programs. Referral pathways to enhance access and engagement have been developed and recommended for adults diagnosed with cancer [49], and an early model has been published for children [38]. Regardless of whether referral pathways are in place at an institution or not, correspondents underscored the importance of making connections with healthcare providers as a means of improving recruitment. In areas where no programs exist, healthcare providers are urged to refer to relevant research when making recommendations (e.g., [38, 46, 47]) and to refer their childhood patients and families to national guidelines (e.g., https://pics.org.au/wp-content/uploads/2018/04/PICS-Physical-Activity-booklet_Final.compressed.pdf) or local networks (e.g., <http://activeoncokids.de/>) for more information regarding safe and beneficial physical activities.

Fifth, programs should be modified as required to the site. In this scan, some programs were integrated into standard cancer care (i.e., healthcare model), others only proceeded and ran

when there was sufficient demand and when registration fees would cover operation costs (i.e., cost-recovery model), and others reported operating in partnership with local foundations or sports associations (i.e., partnership models). Regardless of the model used, most programs had been offered for ≥ 5 years and commented that an important factor to consider was the cost of the program to participants—with most being free or low-cost. This is likely due to the tremendous economic burden childhood cancer poses on families [50].

With mounting evidence suggesting that physical activity is safe, feasible, and potentially beneficial [1–3], steadily increasing survival rates [42], and the results from this scan, it is clear that more concerted efforts are needed to ensure all children diagnosed with cancer have access to physical activity programs. International networks and multi-site collaborations will be an important next step. Further, individuals working in this field should actively engage in public relations to ensure that the public, healthcare, and policy sectors are aware of the importance of physical activity throughout the cancer trajectory. Doing so may increase the number of voices advocating for physical activity, ultimately enhancing implementation efforts. Moving forward, those interested in this area should consider if/how they wish to translate their findings into programs [51] and whether their programs have potential to be scaled up or into standard care. Knowledge-to-action frameworks may provide guidance (see <http://www.cih-irsc.gc.ca/e/29418.html>) on this, and vetted frameworks could be used to evaluate programs to better determine the features that make them successful and sustainable [52, 53].

Limitations and considerations of this environmental scan should be taken into account when interpreting these findings. First, identifying, contacting, and following-up with correspondents is labor- and time-intensive. Most notably, snowball sampling is an iterative process, which involved several lapses in time between contacting and following-up with correspondents. It is possible that new programs emerging within the past year may not have been identified in this scan. Second, an ability to correspond in English or German languages was part of the eligibility criteria. This could partially explain the number of program correspondents who provided responses from Germany. However, to better understand the reasons underlying the differences in the number of programs identified across countries, a better knowledge of differing healthcare systems/structures may be instructive. Third, some programs that included “adolescents and young adults” were excluded based on our eligibility criteria. These programs may have offered additional insights. Fourth, we did not include physiotherapy programs/services, as they are a distinct service. However, within the context of cancer care, physiotherapy programs/services may have similar aims (e.g., enhancing physical functioning), and as a result, additional important data might have been lost by this omission. Future work to examine physiotherapy programs/services (either in isolation

or in conjunction with physical activity programs) as a means of enhancing physical functioning in children diagnosed with cancer should be considered. Fifth, the second email contact consisted of a series of brief, open-ended questions asking about the structure and content of the physical activity program. Considering the preliminary information gleaned from this scan, it might be useful to consider asking correspondents more structured close-ended questions (i.e., quantitative) to ensure meaningful comparisons can be made and to reduce potential misinterpretation of responses. As well, performing brief telephone or Skype interviews (i.e., qualitative) in the future would allow for richer open-ended responses and provide opportunity to gain insight into unique contexts.

Conclusion

This international environmental scan provides an overview of where and in what capacity physical activity programs are being offered for children diagnosed with cancer. Currently, 10 countries are offering 46 physical activity programs for children diagnosed with cancer. Though the findings provide guidance to those seeking to enhance access to physical activity for this population, as a whole, there are still several gaps in research and services. As evidence continues to build around the safety, feasibility, and benefits of physical activity for children diagnosed with cancer and more researchers translate this evidence to practice, efforts are required to address the challenges inherent in working with this population (e.g., small sample sizes). There is a pressing need for international networks, multi-site collaborations, and public relations to strengthen the case for implementing physical activity as part of care for children diagnosed with cancer, ultimately ensuring this population has access to physical activity programs as a means of enhancing their health and quality of life.

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Compliance with ethical standards

Conflict of interest All co-authors have reviewed the International Committee of Medical Journal Editors Form for Disclosure of Potential Conflicts of Interest and declare that they have nothing to disclose.

Ethical approval All procedures performed in this study were in accordance with the ethical standards of the institutional research committee (study identification: HREBA.CC-17-0329) and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent Informed consent was waived for this study and was implied by specific action (i.e., responding to emails).

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