Developing Physical Literacy while Living with a Chronic Medical Condition: The Paediatric Perspective

Angelica Blais

A thesis submitted in partial fulfillment of the requirements for the Doctorate in Philosophy degree in Human Kinetics

School of Human Kinetics
Faculty of Health Sciences
University of Ottawa

Abstract

It is well established that engaging in a physically active lifestyle benefits the long-term development and well-being of all children and youth. For children living with chronic medical conditions (CMCs), the benefits of participating in physical activity are critically important for achieving positive health outcomes and mitigating the risk of secondary chronic disease and more significant morbidity. Unfortunately, most children with CMCs are insufficiently active to achieve its associated benefits, often citing disease-related barriers to participation. To better understand how children with CMCs navigate their participation in physical activity, the concept of physical literacy can be applied as a helpful lens. In brief, physical literacy describes one's physical, cognitive, and affective capacities to engage in an active lifestyle. Despite facing unique risks and barriers in active contexts, some evidence suggests that children with CMCs can still achieve or excel in their physical literacy. This suggests that those who are struggling to navigate their participation in an active lifestyle would benefit from potential support in their physical literacy development. However, efforts to intervene could be misplaced or misguided without adequate contextual knowledge about how the lived experiences of children with CMCs inform their physical literacy development.

The overall purpose of this research was to comprehensively examine how physical literacy is developed among children with CMCs. Collectively, this is accomplished throughout the dissertation by contextualising, describing, and reflecting on how children with CMCs develop physical literacy. Margaret Whitehead's conceptualisation of physical literacy was the guiding framework for this work, built on a philosophical foundation combining monism, existentialism, and phenomenology. A pragmatic approach was applied to guide the research process, employing mixed and multiple methods. This research was conducted with school-aged children, 8 to 12 years old, living with CMCs and recruited from outpatient Cardiology, Endocrinology, Hematology, Cystic Fibrosis/Respirology, and

Neurology clinics at a local children's hospital in Ottawa, Ontario. Where applicable, physical literacy was measured using the second edition of the Canadian Assessment of Physical Literacy. Qualitative methods were strategically applied and combined throughout the research program, including interviews, focus groups, open-ended questionnaires and field notes.

This research was conducted during the COVID-19 pandemic, which dramatically influenced physical activity behaviours worldwide. Thus, the physical literacy development of children with CMCs could only be understood by first acknowledging the relative impact of the pandemic. The purpose of Article 1 was to evaluate and understand how the COVID-19 pandemic influenced the physical literacy development of children with CMCs during the first two years (2020-22). Compared to pre-pandemic matched pairs, the overall physical literacy levels of children with CMCs were significantly diminished during the pandemic, driven primarily by decreases in physical competence and daily behaviour. It was challenging for children with CMCs to play active games in the context of the pandemic, where they had to learn how to navigate additional constraints to prevent the spread of COVID-19. These precautions also constrained how children with CMCs developed social connections, which was cited as a reason that participants felt less motivated to engage in physical activities during the pandemic. Children with CMCs also spoke hesitantly about returning to pre-pandemic activities, as they perceived changes in their physical competence and the participation contexts would make it difficult to be engaged (i.e., mask-wearing requirements, uncertain safety rules, potentially sudden closures). Nonetheless, participants with CMCs maintained high levels of measured intrinsic motivation and confidence in physical activity.

Once the pandemic context was better understood, the purpose of Article 2 was to describe the overall physical literacy development of children with CMCs by examining measured outcomes and comparing the experiences and perspectives of those with high and low levels of physical literacy. Most children with CMCs (~80%) were beginning (< 17^{th} percentile) or progressing (<65^{th} percentile) in their physical literacy journey when compared to normative classifications. Total physical literacy seemingly contributed to a sense of self and how participants with CMCs approached new experiences. In the affective domain, attitudes towards physical activity were generally informed by prior experiences, and the meaningfulness of physical activity was more salient than enjoyment. In their physical competence, participants with CMCs found it particularly difficult to navigate bodily self-regulation alongside complex movement patterns and understood the implications of practice for sustained participation in physical activity. Cognitively, it is promising that children with CMCs adopted general definitions of physical activity, recognising the benefits of an active lifestyle for their health, and understood the relative importance of evaluating risks in active contexts. Participants with higher scores spoke more about physical activity experiences where the affective, cognitive, physical, and behavioural domains seemingly overlapped (i.e., curiosity in active settings, valuing practice experiences, performing complex movement patterns in game contexts, etc.). Overall, findings identified multiple areas where children with CMCs may be supported in their physical literacy development, including opportunities to practice bodily self-regulation strategies and develop confidence in risk evaluation.

Finally, the purpose of Article 3 was to reflect upon the acquired knowledge of physical literacy among children with CMCs by observing how it may be applied within a community-based setting. The “I Can Play Anything” multi-sport program was developed for the RA Centre, a community-based recreational facility in Ottawa, Ontario. The program was designed based on the concept of physical literacy and teaching principles drawn from various behaviour change theories, including self-determination theory. Descriptive, reflective and reflexive data were collected using a combination of interviews, focus groups, field notes and open-ended questionnaires. The developed themes represent the combined expectations, applications, and potential implications of the program for children with CMCs, which are: 1) Learning to play, 2) Inclusion supported by individualised variations, and 3) Understanding one's need for rest. Reported perceptions and experiences within the community-based multi-sport program reflect how children with CMCs may be effectively supported in similar, active contexts.

The final chapter of this dissertation integrates the results from all three articles, emphasising areas of physical literacy development which are particularly relevant to the lived experiences of children with CMCs. Salient ideas discussed throughout this dissertation were recognising and valuing skill progressions developed through practice, the influence of meaningful experiences on active behaviours, self-regulating activity intensities in active contexts, and applying a general definition of embodied participation to physical literacy. My research contributes valuable knowledge to the methodological, theoretical, and practical advancement of physical literacy research, particularly among children with CMCs. This dissertation emphasises and encourages the unique potential for collaboration between the health and recreation sectors to facilitate the ongoing physical literacy development of children living with CMCs.

Acknowledgements

I can say with confidence that I would not have been able to complete this journey without the support of so many people – whether they were by my side the whole time or just for a moment, all of them guided me in some way to this finish line.

Pat, I certainly would not have been able to go through this entire process without you there for every step. I could not have asked for a better supervisor, mentor, and friend to guide me through this entire process. Thank you for letting me forge my own path, even if I sometimes chose to take the longer way around. Thank you for trusting me, advocating for me, and supporting me from the moment I started as a (very confused, but cautiously optimistic) Master's student. Your mentorship has allowed me to think creatively, lead effectively, and pursue my (many) passions. The pandemic threw several curveballs at us, and even though we couldn't get past all of them, we still made it here. I will always be so proud of the work we've done and what we continue to share with patients and their families.

To the 101 children and their families who participated in physical activity research during a global pandemic – I will be forever grateful for your generosity of time and effort during such tumultuous circumstances. From sudden lockdowns to convoys, changing protocols to quarantines… thank you for your resilience, patience, and continued willingness to share your stories and ideas. We have learned so much from you and hope to encourage you to always keep playing and most importantly, keep exploring.

Thank you to all the CHEO staff, especially Joanne and Tianna, who helped make it possible for me to recruit in the outpatient clinics for months at a time (let's not forget, this was also in a hospital setting during a *global pandemic*). To the partnering physicians at CHEO, this work could not have been done without your support and belief in the importance of physical activity for all children to live their best lives.

To my thesis advisory committee, Diane Culver and Bradley Young. I learned so much in both of your classes and even more through the various meetings and defences along the way. Thank you for agreeing to be on my committee and for guiding me through each of the major milestones of this journey. I am especially grateful for your help when figuring out how to pivot my project so that I could ultimately still accomplish what I had intended to from the start.

To the students who helped me with every individual CAPL data collection session, and with recruitment when I wasn't able to be there: Vanessa, Javier, Busola and Olivia. Thank you for always coming to CHEO with a positive attitude, insightful questions, and of course, a willingness to run the beep test (special shoutout goes to Javier for running all 60 laps with one of our exceptional participants). You were all essential to this work. Thank you also to Kyleigh and Sarah for being there for the "I Can Play Anything" program; you helped make it such a meaningful experience for those kids. To Tess and Allie at the RA Centre – thank you for lending your expertise and enthusiasm to this program, the kids loved having you as their coaches. Finally, to Kelly at the RA Centre, thank you for pushing so hard for this program to happen and for providing the space and resources for these kids to really "play anything"!

To my uOttawa friends, of whom I'm truly blessed to have so many. Jenn, Maji, Wes, Bev, and Sieger, to name the few that have been there from the very beginning. Thank you for the dance parties, game nights, patios, potlucks, and concerts to remind us that we *can* still have fun even if we're "forever" students. You all made this time go by so much faster, in the best and most joyous ways. A special shoutout to my roommate Jason also, who helped me find clarity during my various "tangents of thought", especially over the past few months of writing.

To my very best “work” friend: Jenna, I truly do not know what I would have done without you these past few years. You have been a confidant, a cheerleader, and a dear friend through this whole journey. Thank you for listening to my thoughts in action (even if I would often go down rabbit holes), for being my presentation audience and roommate during our conference tours and for simply helping me cope through this degree with golf and books and wine and puzzles and dancing. You have been there for me during this whole process in a way that I will never forget and hope to repay someday.

To Nic – you have helped remind me of what is most important in this life. Thank you for always being there to listen and ground me when I was getting too stressed out, especially over things I had no control over. You are my calming force and I’m lucky to have you in my corner. You trusted me to get through this journey and now that it’s ending, I’m so excited to spend the rest of our lives together.

Finally, I would not even be close to finishing these last chapters without the support and love of my mom, dad, and brother. I am so grateful to you three for reasons that I can’t simply put into words. I certainly would not have discovered my love for movement without the many years of dance classes and performances, on top of all the other opportunities you gave me to pursue my passions and explore my surroundings through play. Thank you for cheering me on every single day, even when it felt like I was stuck and had nowhere to go. I’m so happy that you get to see me cross the finish line.

Table of Contents

List of Figures

Methodology:

Article 2:

Article 3:

General Discussion:

List of Tables

Methodology:

Article 1:

Article 2:

Article 3:

List of Appendices

Chapter One - Introduction & Literature Review

Introduction

The importance of physical activity for optimal physical, emotional, and social development throughout childhood is well established (Eime et al., 2013). However, children living with a chronic medical condition (CMC), who arguably stand to gain the most from the benefits of an active lifestyle, are unlikely to engage in physical activity and/or have limited access to sports (Bopp et al., 2019; Elmesmari et al., 2022; Lankhorst et al., 2019). Practitioners seeking to promote physical activity to their paediatric patients with CMCs should apply a comprehensive approach, targeting a vast range of physical and psychosocial factors (Lobelo et al., 2020). The multifaceted concept of physical literacy is known to facilitate an active lifestyle (Belanger et al., 2018; Cornish et al., 2020), offering one such approach.

The concept of physical literacy, most often defined as "the motivation, confidence, knowledge and understanding to value and take responsibility for engagement in physical activities for life" (Tremblay et al., 2018, p.16), can serve as a useful lens to understand how this vulnerable population approaches opportunities to be physically active. Few studies to date have explored the physical literacy development of children with CMCs (Do, Blais, et al., 2021; Fortnum et al., 2018; Pohl et al., 2019), calling attention to a wide gap in knowledge that should be addressed to support this population in their physical activity participation.

While current recommendations emphasise that physical activity should be promoted to children with CMCs during every clinical encounter (Lobelo et al., 2020), a lack of time, evidence-based recommendations, and resources may impede the ability of healthcare providers to deliver effective counselling (Cooper and Liem, 2019; Denford, Mackintosh, McNarry, et al., 2019; Ilkowitz et al., 2019; Jago et al., 2017). Healthcare providers, parents, and youth have suggested community-based opportunities for sport participation as ideal environments for children with CMCs to receive the support they need to engage in physical activity (MacMillan et al., 2016; Quirk et al., 2015). Such environments are also well suited for the development of physical literacy, encouraging not only skill and fitness development but also social participation (motivation) and active engagement (behaviour, confidence) (Arbour-Nicitopoulos, Boross-Harmer, et al., 2018). Children who participate in diverse physical activities, where they learn important physical literacy skills (Whitehead, 2010), are more likely to adopt active lifestyles and maintain them throughout adulthood (Cleland et al., 2012). Thus, the potential of community-based programs to influence physical literacy outcomes among children with CMCs warrants further examination.

Despite requiring lifelong medical follow-up, children with CMCs do not necessarily live with an evident disability. Disability is a complex phenomenon that can restrict participation, limit activities and be characterized by impairment(s) (World Health Organization, 2011). Certainly, covert activity restrictions and/or misplaced perceptions of physical capability often limit the participation of children with CMCs in active settings (Coleman et al., 2018; Moola et al., 2011; Moola et al., 2017; Omwanghe et al., 2017). However, individuals with CMCs can reasonably expect to experience more anonymity and integration in society than those with more visible disabilities or impairments (Peck et al., 2023; Svensson et al., 2020). To truly grasp the unique experiences of children with CMCs from a health and recreation perspective, their lived experiences should be understood separately from those who live with more evident disabilities. While the uniqueness of their experience is often the rationale for examining specific patient populations in physical activity research, there is distinct value in capturing the shared experiences of individuals with diverse diagnoses as they navigate similar phenomena (Shorey and Ng, 2020).

The overall purpose of this research was to comprehensively examine how physical literacy is developed among children with CMCs. The multidimensional concept of physical literacy draws from kinesiology's biophysical, behavioural, sociological, and pedagogical disciplines. The study and application of physical literacy within the field of kinesiology can therefore be characterized as interdisciplinary research (Corbin, 2016; Schary and Cardinal, 2015). The application of physical literacy throughout this research, as it pertains to the lived experiences of children with CMCs, is also uniquely interdisciplinary, as findings can be contextualized to both the health and recreation sectors. The following literature review begins with a summary of the clinical benefits of physical activity, recommendations, and observed behaviours among children and youth with CMCs. To further the reader's contextual understanding of their participation in physical activity, the review describes the unique challenges children with CMCs face when navigating participation in physical activity, including during the COVID-19 pandemic. A general review of the concept of physical literacy follows, as well as what is broadly known about its domains (affective, physical, and cognitive) among children with CMCs. Finally, the potential of community-based programs to provide additional physical activity support to children with CMCs by leveraging physical literacy principles is discussed, including important considerations for intervention design and delivery.

Literature Review

Active Lifestyles among Children with Chronic Medical Conditions

Clinical Relevance, Guidelines & Recommendations

Achieving an active lifestyle is associated with numerous positive health outcomes for all children and youth, including improvements in overall physical fitness, cardiometabolic indicators (i.e., cholesterol, blood pressure, fasting glucose) and bone health (Janssen and

Leblanc, 2010; Poitras et al., 2016; Tremblay et al., 2016). From a developmental perspective, participation in physical activity and cardiorespiratory fitness are also associated with greater levels of cognitive function (Chaddock-Heyman et al., 2014) and academic achievement (Kwak et al., 2009). Meanwhile, regular participation in physical activity during childhood is related to important benefits for psychosocial well-being and lower levels of psychological distress (Eime et al., 2013; Poitras et al., 2016). These associated benefits are especially relevant for children living with CMCs, as they have a higher risk of physical and psychosocial morbidity and mortality in comparison to otherwise healthy peers (Arigliani and Gupta, 2020; Bai et al., 2017; Marchese et al., 2021; Steele et al., 2019; Thurman et al., 2017). Regardless of diagnosis, there is consensus that regular engagement in physical activity is essential for the short- and long-term well-being of children with CMCs, (Coleman et al., 2018; Philpott et al., 2010; West et al., 2019).

Children with CMCs who adopt more physically active behaviours have demonstrated higher physical (Coleman et al., 2018; Dimitri et al., 2020; Gomes-Neto et al., 2016; Wanrooij et al., 2014; Williams and Stevens, 2013) and psychosocial functioning (Brown and Ronen, 2021; Brudy et al., 2021; Dulfer et al., 2014; Johnson et al., 2020; Khair et al., 2012; Mendes et al., 2010; Wanrooij et al., 2014; Zetterberg et al., 2018). Improvements in disease management (Kacperski et al., 2020; Nadella et al., 2017; Nyenhuis et al., 2022; Quirk et al., 2014) and diagnosis-specific health outcomes (Boyes et al., 2018; Liem et al., 2015; Ostman et al., 2018; Schneiderman et al., 2014) have also been observed among more active children with CMCs. Following one's transition into adulthood, the observed contributions of an active lifestyle in reducing the risk of acquired cardiovascular disease (Beraki et al., 2014; Harris et al., 2018; Kavey et al., 2006; Quirk et al., 2014) and mortality (Reddigan et al., 2012; Rosenthal et al., 2016; Williams and Stevens, 2013) become particularly important. Thus, mitigating the impact of disease early on often informs the rationale for clinical trials examining the effect of exercise training regimens among children with CMCs. The efficacy of exercise training on clinical health outcomes has been evaluated among some diagnostic groups (i.e., congenital heart disease, type I diabetes, cystic fibrosis; Duppen et al., 2013; Gomis et al., 2009; Joschtel et al., 2018; Kennedy et al., 2013; Radtke et al., 2017) more than others (i.e., sickle cell disease, epilepsy; Allendorfer and Arida, 2018; Connes et al., 2011; Johnson et al., 2020). However, without behaviour change strategies, exercise training does not impact physical activity outcomes (Anderson et al., 2022), even with significant improvements in cardiorespiratory fitness (Duppen et al., 2015). Also, an exercise intervention which exclusively applies fitness training principles is a particularly structured modality of movement (e.g., time spent on the treadmill, strength-based exercises, etc.). This regimen may not intuitively transfer to the dynamic, play-based activities most relevant to childhood behaviours.

According to the Canadian 24-hour Movement Guidelines for Children and Youth (Tremblay et al., 2016), it is recommended that children participate in several hours of light-intensity physical activity and at least 60 minutes of moderate-to-vigorous intensity physical activity (MVPA) each day with muscle and bone strengthening 2 to 3 days per week to gain the health benefits of an active lifestyle. If not otherwise specified based on their diagnosis or current health status (e.g., recovering from surgery, change in medication, etc.), it is generally recommended that children with CMCs also meet these 24-hr movement guidelines (West et al., 2019). However, the broad use of these guidelines has been criticized for the lack of evidence base to support their effectiveness for children with CMCs who have unique needs. As West and colleagues note: "Similar to pharmacotherapy, the dose of physical activity (i.e., frequency, type, intensity, and time) may change depending on the chronic disease, and the child's health and fitness levels" (West et al., 2019, p.2). Indeed, diagnostic-specific symptoms and/or health risks may require children with CMCs to adapt how they participate in physical activity. For example, it is recommended that children living with sickle cell disease avoid vigorous intensity activities (e.g., sprinting), as the sudden change in body temperature and blood flow creates a state of inflammatory distress that will lead to a pain crisis (Connes et al., 2011). These circumstances are why physical activity recommendations delivered to children with CMCs by their healthcare providers are usually individualised, often conservatively (Dubow and Kelly, 2003; Liem, 2018), and based on factors such as the history of symptoms, progression of disease and current activity (Coleman et al., 2018; Dimitri et al., 2020; Longmuir et al., 2013; Philpott et al., 2010; West et al., 2019).

Physical Activity Behaviours

There are inconsistencies in the literature about whether children and youth with CMCs are significantly less active than otherwise healthy peers. While objective measures have mostly captured significantly lower levels of MVPA, daily step counts and total time spent in physical activity (Johnson et al., 2020; Marchese et al., 2021; Torres-Castro et al., 2021), some studies have demonstrated greater levels (Kennedy et al., 2021) or no difference at all (Elmesmari et al., 2017; Vasconcello-Castillo et al., 2021) in these outcomes among children with CMCs in comparison to healthy peers. Given the wide range of studies included in these systematic reviews, heterogeneity in study quality, participant age, diagnostic severity, socioeconomic factors, and cultural context may explain these inconsistencies. It has also been noted that all children generally participate in low levels of physical activity and that the inconsistent findings across various diagnostic groups reflect the more sedentary standards of the modern age (Elmesmari et al., 2017). In the Canadian context, cross-sectional studies among children living with congenital heart disease (Longmuir et al., 2022), epilepsy (Brown and Ronen, 2021), asthma and type 1 diabetes (Bedard et al., 2022) have all reported insufficient participation in physical activity. There is more consistent evidence from case-control studies demonstrating that children with CMCs fail to adhere to 24-hour movement guidelines and are less likely to do so when compared to otherwise healthy peers (Brown and Ronen, 2021; Do, Webster, et al., 2021; Elmesmari et al., 2022). It is important to note that the cited evidence on physical activity behaviour was collected before the onset of the COVID-19 pandemic. Given the profound impact the pandemic had on physical activity behaviours worldwide (Paterson et al., 2021), it is worth examining whether this context provoked children with CMCs to further disengage from physical activities. The physical activity perceptions and behaviours of children with CMCs during the context of the COVID-19 pandemic should provide more insight into this emerging gap in knowledge, discussed further in this literature review.

Contextualizing Physical Activity Participation

Managing Risks of Participation

Depending on the context, children with CMCs face potential risks when participating in physical activity, and as such may be required to adapt activities to limit symptoms or prevent adverse events (Coleman et al., 2018; West et al., 2019). Vigorous physical activity can exacerbate disease-related symptoms for some children with CMCs (Broderick et al., 2012; Brousse et al., 2020; Connes et al., 2011; Philpott et al., 2010), requiring them to participate at lower intensities, take frequent breaks and/or pace themselves to symptoms (Bok et al., 2022). It is also for this reason that some children with CMCs are restricted from participating in competitive sport (Christian et al., 2018), where they may be subject to expectations and pressure to push beyond their physical limitations. Sports with a known element of body contact (i.e., football, rugby, etc.) are also not recommended to children living with blood disorders (Howell et al., 2017), or those who rely on pacemakers (Maron and Zipes, 2005) or anticoagulants (Longmuir et al., 2013). To manage symptoms and prevent adverse events, children with CMCs may require treatment before engaging in physical activity, such as using an inhaler to prevent an asthma attack (Jago et al., 2017) or taking the appropriate dose of insulin to maintain glycemic control (Tully et al., 2016). Proper hydration during physical activity is essential for all children but is particularly important for those with blood disorders (Diaw et al., 2014; Martin et al., 2018) or cardiac disease (Cheung et al., 2016; Maron, 2004). Finally, appropriate temperature and humidity can help to ensure that children with respiratory (Bar-Or et al., 1992; Warburton et al., 2011), endocrine (Driscoll et al., 2017; Jabbour et al., 2016), or haematologic (Connes et al., 2011) conditions can participate safely. Children with CMCs have to learn how to accommodate their physical activity participation in consideration of applicable risks (Bennett et al., 2021; Constantinou et al., 2021). Common accommodations for this population include maintaining appropriate activity intensities (i.e., bodily self-regulation), mitigating risk of hard bodily impacts, preparing for physical activity through proper disease management, and participating in an appropriate climate (Coleman et al., 2018; West et al., 2019).

Understanding Barriers to Participation

Despite individual differences in diagnosis and pathophysiology, one recent systematic review of qualitative studies by Shorey and Ng (2020) highlights how the experiences of children with CMCs in physical activity contexts are indeed similar. Unlike individuals living with visible disabilities who also report environmental barriers (Martin Ginis et al., 2016), intrapersonal and interpersonal barriers are most frequently reported by persons with CMCs (Constantinou et al., 2021; Moola et al., 2011; Westergren et al., 2017). Perceived fear of an adverse event occurring with exercise and losing control of disease management has influenced children with CMCs to either avoid or withdraw from physical activities (Goto et al., 2016; Jabbour et al., 2016; Livny et al., 2020; Moola et al., 2009; Olorunyomi et al., 2022; Peltier et al., 2020; Winn et al., 2018). Another relevant barrier across multiple diagnostic groups is exercise intolerance (i.e., significantly lower levels of muscular and/or cardiorespiratory fitness) when compared to otherwise healthy peers (Livny et al., 2020; Masood et al., 2022; McMullen et al., 2019; Moola et al., 2009; Shorey and Ng, 2020; Westergren et al., 2017). For some, intense pain or disease-related symptoms make it even more difficult to tolerate physical activity (Ameringer et al., 2014; Kornblit et al., 2018; Moola et al., 2011; Pittman et al., 2021; Swisher and Erickson, 2008). Finally, the amount of time spent receiving various treatments (Denford, Hill, et al., 2019; Moola et al., 2012) and periods of hospitalization (Fereday et al., 2009) are limiting factors which interfere with a child's time and ability to develop physical activity competence through regular practice and participation in physical activity.

The Paradox of Disclosure

Balancing potential risks and barriers to physical activity with one's inherent interest in participating can be difficult for young individuals with CMCs to navigate (Constantinou et al., 2021; Shorey and Ng, 2020). Unlike their otherwise healthy peers, children with CMCs are required to make choices about how they will adapt activities to successfully participate and more importantly, to whom they will disclose their diagnosis and subsequent needs during physical activity (i.e., teachers in gym class, friends during recess, etc.). Disclosure in physical activity contexts has been recognized as a dominant paradox existing within the experience of children with CMCs (Jago et al., 2017; Peck et al., 2023; Svensson et al., 2020; Walker and Reznik, 2014), resulting in both negative and positive consequences (Benson et al., 2015; Moola et al., 2011; Ryninks et al., 2015). The decision to disclose one's diagnosis is context-dependent (Peck et al., 2023) and informed by past experiences, normative social comparisons, and self-awareness of their own limitations (Jago et al., 2017; Moola et al., 2011; Shearer et al., 2013; Shorey and Ng, 2020). For example, while some children with CMCs have reported feeling supported by friends and teachers in physically active settings (Bennett et al., 2021; Denford, Hill, et al., 2019; Ryninks et al., 2015), many have described experiences of exclusion and stigmatization from peers and leaders due to their medical condition (Benson et al., 2015; Fereday et al., 2009; Johnson et al., 2021; Moola et al., 2011; Shorey and Ng, 2020; Yang et al., 2018). Others have chosen not to disclose their diagnosis in an attempt to maintain a normative image among their peers (Denford, Hill, et al., 2019; Peck et al., 2023; Shearer et al., 2013; Walker and Reznik, 2014). Unfortunately, active contexts are where children with CMCs are most likely to be differentiated from their peers, due to physical limitations and the possibility of experiencing symptoms, which can direct more attention to their physical impairment (Constantinou et al., 2021; Moola, 2020; Peck et al., 2023).

Children with CMCs have used self-awareness and their own judgement of physical activity modalities/contexts (i.e., vigorous, outdoors, impact, etc.) to help determine whether they should disclose their diagnosis (Jago et al., 2017; Quirk et al., 2016; Shearer et al., 2013). Exercising their choice to disclose allows children with CMCs to ensure they are receiving the necessary support and accommodations to participate at their own capacity (Fereday et al., 2009; Ryninks et al., 2015). Unfortunately, this decision also comes with the potential consequence of peers and coaches making inaccurate assumptions about their physical capabilities or enforcing unnecessary restrictions (Fereday et al., 2009; Moola et al., 2011; Ryninks et al., 2015). In contrast, refraining from disclosure can be either distressing or empowering for children with CMCs. Since physically active settings often accentuate differences in physical capability between individuals, withholding information about diagnosis-related limitations can lead to feelings of distress and isolation among children with CMCs (Moola et al., 2011; Peck et al., 2023). Conversely, when children with CMCs are able to maintain participation with peers, physical activity can be viewed an “escape” from their limitations (Denford, Hill, et al., 2019) and empowering for their self-esteem (Fereday et al., 2009; Ryninks et al., 2015).

Acknowledging Current and Ideal Selves in Active Settings

Recent exploratory studies that are particularly unique to the physical activity experiences of children with CMCs delve into their current and ideal selves. Constantinou (2021) and Moola (2020) both used the draw-and-write technique, asking children with sickle cell disease and congenital heart disease, respectively, to draw and describe their current and ideal selves when participating in physical activity. In both studies, children represented the ways in which they were currently differentiated from their peers in active settings, leading to social misconceptions and experiences of stigma. Interestingly however, participants did not illustrate the absence of their diagnoses or limitations in their ideal selves, but rather what it would feel or look like to participate in physical activity despite them. From a physical literacy perspective, this is an important representation of the unique, lived embodiment of children with CMCs, which considers all aspects of their being – including the parts of them which experience disease. Instead of "overcoming" their medical condition, most children illustrated their ideal selves as participating equally alongside their peers ("*all of us are the same, and no one is left out*" – Moola, 2020, p.5). This has important implications for the physical literacy development of children with CMCs, as they will never be "cured" of their disease but can certainly participate alongside otherwise healthy peers. Both studies demonstrated that participants accepted their medical condition but held an unfulfilled desire for more meaningful participation in physical activity, particularly in regard to social interactions.

When asked about their preferred activities and/or sports, children with CMCs often refer to non-competitive activities or individual sports (Moola et al., 2008; Wilfred et al., 2022). Such activities may be easier to adapt and more accommodating to their needs than competitive or team sports, which Moola and colleagues reason, makes them more enjoyable (Moola et al., 2008; Moola et al., 2012). Non-competitive settings may also encourage children with CMCs to disclose their diagnosis at their own discretion, eliminating the pressure of disclosing to avoid negative health consequences. Meanwhile, individual activities could help children with CMCs protect their self-concept in the absence of negative misconceptions about their abilities (Ferro and Boyle, 2013b), but the absence of collaborative or cooperative components may also limit opportunities to build valuable connections with peers.

Navigating Physical Activity During Unprecedented Times: The Impact of COVID-19

The COVID-19 pandemic created an extraordinarily difficult context for all children and youth to participate in physical activity, regardless of health status (Mitra et al., 2020; Riazi et al., 2021). Families experienced sudden changes in their daily routines (i.e., balancing work and school from home), difficulties navigating precarious public health restrictions, and an overall sense of fear and unease related to the spread of COVID-19 within communities (Riazi et al., 2021). These same experiences and concerns were shared amongst families of children with CMCs. In addition, these families experienced unique barriers such as the complexities of negotiating virtual/constrained health care, difficulties accessing medications and/or necessary health services, and the unknown risk severity of COVID-19 infection for children with existing chronic disease (Caveney et al., 2022; Reilly et al., 2021; Teach and St. Geme, 2021). Even though families generally understand the importance of physical activity for their child's prognosis and long-term health (Hatziagorou et al., 2021), these factors may have made it even more difficult for families of children with CMCs to prioritise physical activity during the pandemic. Reports of children with CMCs being among the last to return to in-person school and extracurriculars are not surprising, given parental anxieties about the potential impact of infection (Ferguson et al., 2022; Nicholas et al., 2022). Some families of children with CMCs even reported actively restricting physical activity to avoid triggering symptoms that would potentially require medical care during the pandemic

(Caveney et al., 2022). While children with CMCs may have already experienced isolation from active spaces due to their medical condition before the pandemic (Moola et al., 2022), additional restrictions to prevent COVID-19 infection may have exacerbated these feelings of isolation and further differentiated them from otherwise healthy peers.

While the above evidence provides some information regarding the impact of the COVID-19 pandemic on the physical activity behaviours of children with CMCs, important knowledge gaps remain. Specifically, 1) how participation in physical activity resumed once restrictions were lifted and 2) the longer-term implications this period will have on how children with CMCs navigate physical activity settings in the future. In a retrospective analysis of objective data, collected from implanted cardiac devices of children and youth with heart disease, Mazzella and colleagues (2022) found a brief improvement in daily minutes of physical activity when the initial lockdown ended in the United States in 2020. However, time spent in physical activity remained significantly lower than what was recorded from the same participants in 2019. While less time spent in physical activity can certainly be attributed to environmental factors (e.g., physical distancing and masking requirements) (Paterson et al., 2021; Riazi et al., 2021), the relative impact of other interpersonal or intrapersonal factors unique to the lived experiences of children with CMCs are unknown. Health-related impacts of the pandemic may have also made it more difficult for children with CMCs to return to pre-pandemic bouts of physical activity. For example, children living with type 1 diabetes experienced more challenges regulating blood glucose to account for changes in physical activity (Duarte et al., 2022), while some children with epilepsy reported an overall increase in seizure frequency during the pandemic (Reilly et al., 2021). Changes in health status, therefore, may have regressed their ability to navigate physical activity participation while accounting for the signs and symptoms of their medical condition. Conversely, some children with respiratory diagnoses, who found that isolation improved their overall physical health by mitigating exposure to acute respiratory illnesses, may have been reluctant to return to settings where there was a greater risk of transmission or of experiencing symptoms (Nicholas et al., 2022). We certainly will not have a full understanding of how the COVID-19 pandemic influenced the long-term physical activity behaviours of children with CMCs for years to come. However, examining current changes in physical literacy outcomes would give important insight into how to best support children with CMCs in this "post-pandemic" era, given the drastic changes in lifestyle experienced in recent years.

Physical Literacy among Children with Chronic Medical Conditions

The study of physical literacy has gained considerable momentum over the past 12 years, following Margaret Whitehead's conceptualization of the term (Whitehead, 2001; Whitehead, 2010). Introducing the concept of physical literacy was Whitehead's response to address the lack of physical activity observed worldwide, to promote embodied movement, and move physical education away from an increasingly sport-centric focus. In her seminal work, Whitehead emphasises the philosophical underpinnings which support the concept of physical literacy as a means to understand and promote a physically active lifestyle (Whitehead, 2001). Grounded in three philosophical ideas, physical literacy is a reciprocal and inseparable mind-body connection (monism), influenced by various interactions with social and physical environments (existentialism) and unique to one's own lived experience and perceptions (phenomenology) (Pot et al., 2018; Whitehead, 2007).

With more scholars adopting the concept of physical literacy to explain active behaviours, the concept's relevance and application has also been adapted across sectors, including education, sport, and most recently, health (Cornish et al., 2020; Martins et al., 2020). Consequently, the definition of physical literacy has been reinterpreted several times, with more targeted definitions often straying farther away from the concept's philosophical roots (Young et al., 2020). In Canada, there are two widely recognized approaches to understanding physical literacy. The "Whiteheadian" approach, emphasizes a dynamic, life-long journey of physical literacy development considering a wide range of experiences (Tremblay et al., 2018). ; The "long-term athletic development" approach identifies different foci of behavioural and movement skill development across childhood that align with participation in competitive sport (Higgs et al., 2019). The latter approach has been criticized as being misaligned with the philosophical ideas described earlier as a result of applying a narrower focus (Young et al., 2020). Most definitions stemming from the Whiteheadian approach, including that of the International Physical Literacy Association, maintain the intended philosophical underpinnings by emphasizing the combined importance of cognitive, affective, and physical attributes of physical literacy, in addition to its lifelong relevance for the individual person (International Physical Literacy Association, 2015). Since children with CMCs often experience barriers or limitations which can prevent them from athletic training at elite levels, the holistic, "Whiteheadian" approach was applied to represent a more comprehensive and nuanced understanding of their physical literacy development.

Several empirical methods to assess physical literacy have been applied throughout the literature, with none established as a "gold standard" (Edwards et al., 2018). Only one study to date has applied current methods to paediatric clinical populations. Using the Canadian Assessment for Physical Literacy (CAPL), researchers from multiple sites in Ontario found that among 259 children with medical conditions and disabilities, 71% were beginning or progressing in their physical literacy development (Do, Blais, et al., 2021). Overall, children were highly motivated to participate in physical activity but struggled to achieve the movement skills and fitness capabilities of otherwise healthy peers (Do, Blais, et al., 2021). While this study was the first to fill a large gap in the knowledge of physical literacy among children with medical conditions, it also included a widely heterogenous group of children with physical disabilities, mental health disorders and those seeking treatment for conditions that were considered mild in severity (i.e., no limitations or reported barriers to physical activity). Findings from this study emphasized the need for interventions targeting the physical competence of children who receive medical treatment. However, there remains a limited understanding of how the holistic and existentialist concept of physical literacy can be developed in children who experience on-going limitations to physical activity due to chronic disease. Reviewing the individual components of physical literacy observed among children with CMCs in the literature can provide additional context to an otherwise incomplete picture.

Physical Domain

The most widely studied component of physical literacy among children with CMCs is undoubtedly physical competence. Physical competence is generally separated into three domains: cardiorespiratory fitness, muscular strength, and motor skill; however, other competencies such as balance, agility and flexibility also contribute to one's overall movement competence. One of the primary findings of Do and colleagues in their multi-site study was that physical competence was the driving domain in reduced physical literacy levels observed among children with medical conditions and disabilities (Do, Blais, et al., 2021). Low levels of physical competence observed among children with CMCs have been attributed to diagnostic-specific sequelae (e.g., compromised cardiac physiology in complex heart disease or lung function in exercise-induced asthma) (Merlet et al., 2019; Schaan et al., 2017; Shei et al., 2019; Strike et al., 2016), effects of medications used for disease management (David and MacAllister, 2022; Decramer et al., 1994; Rothacker et al., 2021), and general deconditioning from sedentary lifestyles (Rosenblum et al., 2015; Welsh et al., 2004). Overall, research suggests that impairments in physical competence are prevalent across groups of children with CMCs (Marchese et al., 2021; West et al., 2019).

Aerobic fitness is of particular interest to health care providers, given its known association with long-term health outcomes (Warburton et al., 2006). Current research suggests that cardiorespiratory fitness varies across clinical groups, often depending on the severity of the diagnosis (Al Kitani et al., 2014; Rosenblum et al., 2015; Shei et al., 2019), the duration of the diagnosis (Van Ryckeghem et al., 2021) or the level at which the disease is controlled (Waltz et al., 2013). For example, the aerobic capacities (i.e., the amount of oxygen an individual can consume during high-intensity or maximal exercise) of children with type 1 diabetes (Michalak et al., 2019; Nguyen et al., 2015) or asthma (Pianosi and Davis, 2004; Santuz et al., 1997) are often reported as similar to healthy peers, but significantly lower when their diagnosis is not well controlled (Tagougui et al., 2015; Vahlkvist and Pedersen, 2009; Williams et al., 2011). Meanwhile, children may choose to participate in physical activity more frequently at submaximal levels, which could remain unaffected by diagnosis (Müller et al., 2013). Low cardiorespiratory fitness levels can lead children with CMCs to fatigue easily (Moola et al., 2011) or move less efficiently (Connes et al., 2011) during physical activity, making it much more difficult for them to keep up with their peers. As children progress into adolescence and young adulthood, these differences may become more pronounced in comparison to otherwise healthy peers (Villaseca-Rojas et al., 2022), indicating that low cardiorespiratory fitness will remain relevant to their long-term physical literacy development.

Other studies have looked at musculoskeletal fitness outcomes among children with CMCs, with mixed findings. Among children with blood disorders, muscular strength is consistently and significantly lower than otherwise healthy peers (Dougherty et al., 2011; Merlet et al., 2019; Rodriguez-Merchan, 2010). Reduced strength among these groups is attributed to muscle atrophy resulting from disease progression, especially surrounding affected joints (Rodriguez-Merchan, 2010). Findings within and between other clinical groups remain mixed; while some studies report similar or even better musculoskeletal fitness outcomes compared to healthy peers (Atay et al., 2018; Hanssen-Doose et al., 2021; Longmuir et al., 2015; Nguyen et al., 2015), many children with CMCs perform significantly worse on tests of musculoskeletal fitness (Gruber et al., 2021; Hock et al., 2018; Lukács et al., 2012; Sırtbaş et al., 2021) including muscular strength (Arikan et al., 2015; Dougherty et al., 2011). In children with asthma, deficits in muscular strength have been observed in those with exercise-induced symptoms (Sanz-Santiago et al., 2021) and regardless of how well their condition is clinically controlled (Sousa et al., 2021). Individual variability in physical activity duration and intensity provides a possible rationale for these mixed findings.

Finally, while several studies have evaluated motor skill among children with CMCs (Atay et al., 2018; Bjarnason-Wehrens et al., 2007; Bolduc et al., 2020; Corten and Morrow, 2019; Joschtel et al., 2021; Longmuir et al., 2022; Naef et al., 2017), study measures and outcomes (e.g., measures of agility, reaction time, etc.) are highly variable, making it difficult to compare findings between clinical groups. Motor skill and performance are traditionally measured using tasks which isolate specific skills (e.g., throwing to a target). Realistically, the physical activity contexts of childhood involve a dynamic combination of various movement skills (Raudsepp and Päll, 2006), highlighting a gap in how these skills have been assessed among children with CMCs. Despite these limitations, various factors inhibiting the motor skill development of children with CMCs have been identified. Among both children with congenital heart disease (Majnemer et al., 2006; Marino et al., 2012; Masood et al., 2022) and cystic fibrosis (De Almeida Thomazinho et al., 2011), prolonged periods of hospitalization, treatment, and malnutrition (Brief et al., 2022; Gruber et al., 2021) have been suggested as relevant factors associated with motor skill delays. For others, negative associations have been identified between motor performance and disease duration or progression (David and MacAllister, 2022; Padilla-Medina et al., 2013).

Cognitive Domain

Existing evidence suggests that few children with CMCs are knowledgeable about the recommended physical activity for achieving positive health outcomes (i.e., 60 minutes of moderate-to-vigorous intensity activity per day) (Kendall et al., 2007; Quirk et al., 2016). While general knowledge of physical activity is similar to otherwise healthy peers (Do, Blais, et al., 2021; Pohl et al., 2019), the additional knowledge required to ensure safe participation presents a cognitive aspect of physical literacy that is unique to children with CMCs. Although safety precautions are generally understood by children with CMCs (Constantinou et al., 2021; Fried et al., 2021; Jago et al., 2017; Moola et al., 2008), navigating them in practice and in relation to specific activity restrictions is less clear and may lead to a lack of participation (Blanchard et al., 2022; Brna et al., 2017; Fairweather and Jones, 2022; Roberts et al., 2017). In one study among children with cardiac disease, 54.8% did not know how much physical activity was appropriate for them, while some over-restricted or under-restricted their participation (27.9% and 6.7%, respectively) (Kendall et al., 2007). This could be due to ambiguous (Ameringer et al., 2019; Cooper and Liem, 2019; Quirk et al., 2015; Sparacino et al., 1997) or conflicting recommendations (Gualano et al., 2017; Longmuir and McCrindle, 2009) that children with CMCs receive from health care providers. It may also be difficult for children with CMCs, alongside their caregivers, to retain specialized information about physical activity during regular clinic visits, due to the prioritization of acute health concerns (e.g., disease progression, potential need for surgery) and clinical time constraints (Lobelo et al., 2020). Indeed, children with CMCs may not be receiving enough education about tailoring treatment to physical activity (i.e., taking medication or insulin prior to exercise) (Köiter et al., 2009; Longmuir and McCrindle, 2009; Roberts et al., 2017). Finally, children with CMCs who need to self-regulate their activity intensities may not know which strategies are best to guide exercise cessation (Ameringer et al., 2019). For example, children living with congenital heart disease have reported using a “trial and error” system of interpreting physical sensations in relation to their exercise intensity (Bennett et al., 2021), but this same system could have more adverse consequences among those living with sickle cell disease (Constantinou et al., 2021; Martin et al., 2018). Despite uncertainties, most children living with CMCs recognize the general importance of physical activity for their overall health and well-being (Köiter et al., 2009; Moola et al., 2008; Ryninks et al., 2015).

Affective Domain

In their recent study, Do and colleagues (2021) found that the affective domain (motivation and confidence) was the dominant influence on overall physical literacy scores and significantly higher than that of otherwise healthy peers. Sources of motivation for physical activity among children with CMCs are similar to otherwise healthy children, which include adequate levels of social support and inherent enjoyment (Denford, Hill, et al., 2019; Quirk et al., 2016; Westergren et al., 2017). While not a motivator on its own, having a more explicit understanding and desire for the health benefits of physical activity may be one reason why children with CMCs are particularly motivated to be active (Denford, Mackintosh, Mcnarry, et al., 2019; Quirk et al., 2015). Another potential motivator for physical activity that is unique to this population is the potential to foster an identity that exists in direct contrast to having a chronic disease (Moola et al., 2011). For example, one study among children with cystic fibrosis found that a desire to overcome the stigma associated with their diagnosis was a dominant motive for being physically active (Denford, Hill, et al., 2019). Meanwhile, participating in physical activity presents opportunities for normalcy, in a childhood experience that is clearly differentiated from peers who do not receive on-going medical treatment (Denford, Hill, et al., 2019; Moola et al., 2011).

With regards to general confidence towards participation in physical activity, there is little information available in the literature surrounding children with CMCs specifically. Among the few studies that have discussed confidence, there is also discordance; some have highlighted diagnosis-specific barriers to physical activity which are perceived to limit confidence (Keshawarz et al., 2018; Moola et al., 2011; Winn et al., 2018), while others reject this narrative by emphasizing that children with CMCs can ultimately "do anything" that their peers can do (Fereday et al., 2009; Ryninks et al., 2015). Fewer studies have measured perceived competence for physical activity and/or sport among children with CMCs, reporting significantly lower perceived endurance and sport competence in comparison to otherwise healthy peers (Khair et al., 2017; Lee et al., 1997).

Meanwhile, observations and discussions about self-efficacy for physical activity among children with CMCs have been emerging. Self-efficacy has even been acknowledged as a potentially more relevant predictor of physical activity among children with CMCs than diagnosis or disease severity (Bar-mor et al., 2000; Olorunyomi et al., 2022; Ray and Henry, 2011; te Velde et al., 2018). While the positive correlation between self-efficacy and physical activity is widely accepted among typically healthy children (Voskuil and Robbins, 2015), it was recently suggested that this relationship may be stronger among children with CMCs. For example, among children with congenital heart disease and healthy controls, levels of self-efficacy explained 26.6% and 12% of the variance in physical activity, respectively (Moschovi et al., 2019). In contrast, negative experiences attributed to diagnostic-related barriers may exacerbate existing feelings of hopelessness related to one's medical condition, thus contributing to lower self-efficacy (Denford, Hill, et al., 2019; Fairweather and Jones, 2022; Moola et al., 2008; Moola et al., 2012). However, not all children with CMCs, nor those who share a diagnosis, will experience barriers to physical activity in the same way (e.g., a child who enjoys playing competitively may feel more limited/constrained in a soccer game than a child who does not enjoy competition). This might explain why lower levels of self-efficacy for physical activity have been found in some (Banks et al., 2012; Kitsantas and Zimmerman, 2000; Quirk et al., 2018; Stephens et al., 2016), but not all (Fereday et al., 2009; Moschovi et al., 2019) groups of children with CMCs when compared to otherwise healthy peers. The link between self-efficacy and participation emphasizes the importance of facilitating mastery experiences for all children with CMCs to elicit positive experiences, build self-efficacy, and promote continued engagement in physical activity.

The Understudied Potential of Community-Based Physical Literacy Interventions

The potential of non-competitive, community-based settings to provide safe and enjoyable activities for children with CMCs has been recognized by parents, patients, and healthcare providers alike (MacMillan et al., 2016). Unlike traditional rehabilitation settings, which are typically diagnosis-specific and more clinically focused, community-based physical activity or sport programs present a unique opportunity to improve physical activity outcomes among a wide variety of children with CMCs. In the Netherlands, Zwinkels and colleagues (2018) reported their findings from a controlled trial, studying the effects of a once-weekly, school-based sports program specifically designed for children with physical disabilities and/or CMCs. The sport program was feasible with generally good adherence (86%) and no adverse events were reported. While there were no changes in physical activity behaviour following participation in the intervention, there was a significant improvement in lower body mean and peak power. This is a particularly meaningful improvement in physical competence, given children typically participate in short and powerful bursts of activity. However, there were no psychosocial measures nor contextual details informing how participants perceived their own participation during the study. From a physical literacy perspective, therefore, a sizeable gap remains in how these findings can be interpreted and applied to other community-based physical activity or sport settings.

Intervention Design

A dominant, underlying theory informing prior exercise and/or physical activity interventions for children with CMCs is that by improving physical competence outcomes (i.e., fitness, motor skill, strength), individuals will be better equipped to participate in sports and physical activities with their peers. While this hypothesis is well-intended, interventions which have focused on enhancing physical activity participation primarily through fitness training principles or developing movement skills through active games have been mostly ineffective at enabling physical activity behaviour change among children with CMCs (Ash et al., 2019; van Deutekom and Lewandowski, 2021; Williams et al., 2020). In contrast, the concept of physical literacy is well situated to accommodate intervention strategies informed by behaviour change theories, exercise physiology, pedagogy, and motor development (Pot, Whitehead, and Durden-Myers, 2018). Thus, applying a physical literacy-based lens to the design and delivery of a community-based intervention could comprehensively target the physical, cognitive, and affective factors which are known to mediate or moderate participation in overall physical activity (Carl et al., 2022; Cornish et al., 2020).

Effectively translating the philosophical components of physical literacy to an intervention design can be a complex process (Pot, Whitehead, and Durden-Myers, 2018). While Pot and colleagues have briefly described how the philosophical underpinnings of monism, existentialism and phenomenology apply to physical education, there are contextual factors of health-based interventions that may complicate this practice (e.g., systemic pressure to design interventions which significantly address health outcomes, limited resources, time constraints). A recent systematic review of physical literacy-based interventions found that physical competence was the most frequently addressed domain, included in 84% of the 44 included studies (Carl et al., 2022). More specifically, 21 of the included studies (48%) targeted physical competence alongside only one or no other domain

(Carl et al., 2022). While physical competence is certainly one of the more straightforward components of the concept, especially among children with CMCs, focusing on one domain ultimately means that the holistic intention of applying a physical literacy lens to an intervention's design is nullified. Promisingly, the remaining 16 studies (36%) from the review aimed to represent all domains of physical literacy alongside physical competence in their intervention outcomes (Carl et al., 2022). As Pot and colleagues (2018, p.249) state: "Developing movement patterns is an essential part of all teaching to foster physical literacy, but this focus alone does not constitute the sum total of the work".

Intervention Delivery

Physical literacy interventions addressing the unique health needs of children with CMCs in recreation spaces can draw from a wide range of coaching strategies; focusing on positive feedback and reinforcement to help children change negative self-perceptions during physical activity, decreasing exercise intensity when necessary, and adapting movement skills to avoid exacerbating symptoms have all been reported as meaningful in the delivery of community-based interventions to children with CMCs (Blais, Lougheed, Adamo, et al., 2020; Brynjulfsen et al., 2021; Hutzal et al., 2009). Other strategies that may promote physical literacy development, suggested in the broader literature among children with CMCs, are encouraging physical activity for fun, emphasizing personal developments in skill progressions, and working alongside children with CMCs to build trust in their embodied knowledge of physical activity (Bennett et al., 2021; Moola et al., 2011; Moola et al., 2012; Quirk et al., 2016). How these strategies are incorporated into the delivery of a community-based physical literacy intervention for children with CMCs has been only briefly reported among children with congenital heart disease (Blais, Lougheed, Adamo, et al., 2020) but has been more thoroughly described among children living with disabilities (Arbour-Nicitopoulos, Boross-Harmer, et al., 2018). Overall, the gaps in knowledge regarding the design and delivery of community-based, physical literacy interventions for children with CMCs are considerably larger than what is currently known.

Example Case Study: "Igniting Fitness Possibilities"

The only study identified in the review that targeted all components of physical literacy in its design and included a small proportion of children with CMCs (~6% of total sample) was "Igniting Fitness Possibilities" reported by Arbour-Nicitopolous and colleagues (Arbour-Nicitopoulos, Boross-Harmer, et al., 2018; Arbour-Nicitopoulos et al., 2023). The intervention was comprised of two components: 1) group-based sessions, where participants tried various movement skills and played cooperative games; and 2) individual-based sessions, where coaches helped participants identify other activities of personal interest outside of the intervention. There was a notable emphasis on physical competence in the intervention design (Carl et al., 2022) which successfully led to observed improvements in this domain (Arbour-Nicitopoulos et al., 2023). The group-based sessions were also designed to promote inclusion and enjoyment of physical activity, following a self-determination theoretical framework. Aligning with the intervention strategies used, participants in the "Igniting Fitness Possibilities" program demonstrated greater levels of self-determined motivation and more time spent engaging in moderate intensity physical activity following the intervention, with small and small-to-medium effects reported, respectively (Arbour-Nicitopoulos et al., 2023). These findings highlight the utility and effectiveness of a pragmatic, physical literacy-inspired approach to designing a community-based physical activity intervention for children with disabilities or CMCs. Throughout the "Igniting Fitness Possibilities" program, coaches had to draw on a wide breadth of strategies, encompassing 36 unique behaviour change techniques, to effectively deliver the intervention and address physical literacy outcomes (Weissman et al., 2022). The authors emphasized the importance of being flexible with coaching strategies to be able to effectively deliver a physical literacy-based program to children of varying needs and abilities (Arbour-Nicitopoulos, Boross-Harmer, et al., 2018; Weissman et al., 2022).

Description of Articles

There are three articles included in this dissertation, which collectively aim to a) contextualize, b) describe, and c) reflect on how children with CMCs develop physical literacy. Results from the first two articles were analysed and interpreted simultaneously, while the final article later integrated and applied findings from the previous ones.

The purpose of Article #1 is to contextualise the physical literacy development of children with CMCs during the first two years of the COVID-19 pandemic. This mixed method study contributes valuable insight into how children with CMCs are equipped to participate in physical activity once pandemic-related prevention measures have ended. The degree to which they might have regressed in their physical literacy development, in comparison to children with CMCs assessed before the onset of the COVID-19 pandemic, is also examined. Understanding how physical literacy outcomes and perceptions might have changed because of the pandemic contextualises the more in-depth description of physical literacy development that follows in Article 2.

Article 2 describes the overall physical literacy development of children with CMCs by comparing measured outcomes alongside the experiences and perspectives of those with high and low levels of physical literacy. This study is the first, to our knowledge, to use the concept of physical literacy to comprehensively describe how children living with chronic disease navigate their participation in physical activity.

Finally, Article 3 is a reflection of physical literacy among children with CMCs in an applied, community-based program . Insights and contextual knowledge from the first two articles, as well as from the reviewed literature, are collectively woven into the reflective narrative. This final article represents an accumulation of theoretical and descriptive knowledge about physical literacy to an applied context of particular interest for children with CMCs.

Chapter Two - Methodology

Research Assumptions

Researcher Positioning

Understanding and addressing the inevitable biases, assumptions, and expectations underlying this research is essential to its credibility and requires transparency about my lived experiences (Berger, 2015; Holmes, 2020). I am a Caucasian woman who grew up in a suburban community and am currently living in an urban region, where active lifestyles are prioritized within my local community. Growing up in a middle-to-high income family, I had access to many types of physical activities, regularly played in forests and parks, and was always enrolled in recreational or competitive programming (day camps, sports, performing arts). However, I did not feel as though I was very good at sports and so I became much less interested in them than my peers. Expanding on this feeling, I recall how I began to identify as “not athletic”, when over time I would reflect and recognize that I did not have the same physicality, skills, sport-specific knowledge or desire to participate in sports as those who would identify as “athletic”. This was also evidenced by my mentality of a “dancer”, which indeed was part of my identity, as being in a completely separate category from “athlete”. In my early twenties, I gradually began playing recreational sports and continue to enjoy them to this day. My perspectives on extracurricular physical activities and sports throughout this research were therefore informed by a retrospective of my lived experiences. For example, during interviews with children who had higher levels of physical literacy, I found myself drawing more from my more recent perspectives of sport and physical activity to relate to their experiences. Meanwhile, I would also refer to my prior experiences about struggling with physical activity to connect with children who had lower levels of physical literacy, as that aligned more with my experience at that age. At eight years old I was also diagnosed with a congenital heart defect (coarctation of the aorta) which required catheterization and on-going follow-up. While it was not considered moderate-to-severe in complexity (as per the inclusion criteria of this research), when I received the diagnosis and shortly after my coarctation was corrected, my approach to physical activity was certainly more cautious. I used reflective notes throughout data collection and analyses to better understand the influence of these personal experiences on my findings.

Philosophical Assumptions

This research was conducted using a pragmatic approach. While pragmatism has multiple origins (Giacobbi et al., 2005), John Dewey's transactional approach towards experience and knowledge (i.e., the combination of action and reflection) is most often used to frame pragmatism as a relevant paradigm in social and health research (Allemang et al., 2022; Morgan, 2014). Pragmatism informed by Dewey's theory of knowing can be applied in a way that acknowledges on-going, reciprocal relationships between actions and consequences in the formation of individual experiences (Biesta, 2010).

Pragmatism is frequently cited as the preferred paradigm for mixed methods research (Creswell and Plano Clark, 2018; Florczak, 2014), given its permission to employ "what works" in the methodology and allowing research questions to inform the research process. Indeed, pragmatism allowed me to consider the designs, methods and strategies that would enable meaningful participation by children with CMCs, including the collection and interpretation of data that would be readily applicable to the research context. However, using pragmatism as a paradigm has also been argued as inadequate to justify the overarching, philosophical conflicts of mixing methods (Morgan, 2007). Biesta (2010) for example, contends that using pragmatism as a blanketed, "wholesale" justification for mixed methods research does not hold merit because it cannot represent a specific philosophical position.

Indeed, rather than being a position from which to build a social system (i.e., a paradigm), pragmatism can be viewed as a set of philosophical tools that aim to address problems.

In response to paradigmatic questions about the appropriateness of pragmatism for mixed methods research, Biesta (2010) examined the philosophical assumptions of mixing methods at seven levels of research inquiry (i.e., data, methods, design, epistemology, ontology, purpose of research, and practical roles of research). He then situated how pragmatism can support and/or thwart each one. For transparency on the pragmatic approach that I applied to this research, I have similarly outlined the research assumptions and corresponding decisions made at each level of the research process. Table 1 outlines how pragmatism was thoughtfully applied throughout this mixed methods research as a strategy to inform methodology, epistemology/ontology, and axiology.

Finally, my thesis was built around the concept of physical literacy, which holds its own philosophical assumptions. The ideas of monism, phenomenology and existentialism are intertwined to create a foundation from which physical literacy can be understood and applied (Pot et al., 2018; Whitehead, 2001, 2010). These philosophical assumptions informed the overall ontology of this dissertation. A more in-depth explanation of how these philosophical ideas inform physical literacy is described later in this chapter (see: conceptual and theoretical positioning).

Adopting and Embracing Interdisciplinary Research

In part, what necessitated the pragmatic approach for this project was that I had situated myself in the role of an interdisciplinary researcher. This dissertation was completed to fulfill the doctoral candidate requirements at the School of Human Kinetics at the University of Ottawa, which contains a uniquely multi-disciplinary faculty with expertise in biophysical, behavioural, sociological, and pedagogical subdisciplines, all related to human movement. Unlike an *intra*disciplinary approach, where different research techniques, models and assumptions are applied within one subdiscipline, adopting the role of an interdisciplinary researcher allowed me to draw from various subdisciplines to gather and interpret my findings.

Table 1. *Research Assumptions and Corresponding Decisions Following a Pragmatic Approach*

Research Level	Relevant questions about mixing methods posed by Biesta (2010, p.8)	How pragmatism can be applied, according to Biesta (2010)	Current Application of Pragmatic Approach		
			Article 1	**Article 2**	**Article 3**
Data	Is it possible to have numbers and text within the same research?	Numbers and text are both meaningful forms of information.	Quantitative & Qualitative	Quantitative & Qualitative	Qualitative
Methods	Is it possible to have data collection methods that generate numbers and text within the same research? Is it possible to have data analysis methods for the analysis of numbers and text within the same research?	A combination of measurement and interpretation can be applied if it is appropriate for the data collected.	Movement/fitness assessments, questionnaires, activity tracker (pedometer), interviews.		Semi-structured interviews, field notes, open-ended questionnaires, focus groups.
Design	Is it possible to have interventionalist and noninterventionalist designs within the same research?	Pure observation without intervention is not possible, but there can be naturalistic (noninterventionalist) elements within a research project.	Descriptive comparative design (study 1) and exploratory qualitative design (study 2)	Explanatory sequential design	Mini-ethnographic case study of a community-based intervention.
Epistemology	Which epistemological set of ideas is most appropriate to account for the knowledge generated through a mixed approach?	Knowledge is gained from experience, which is the combination of action and reflection.	Pragmatism: knowledge about physical literacy can be gained by combining measurable outcomes (action) with individual perceptions of those outcomes (reflection)		Constructivism: experiences within the program are socially and individually constructed.
Ontology	Is it possible to combine different assumptions about reality within the same research?	Research that is conducted in an open, dynamic system has complex factors which may or may not be predictable.	The physical literacy development of children with CMCs is informed by the combined, philosophical principles of monism, existentialism, and phenomenology.		In a physical literacy-based program, interactions throughout the intervention (existentialism) are related to individual physicality, affect and cognition (monism).

Purpose of Research	Is it possible to combine the intention to explain with the intention to understand?	The intention is to gain knowledge about the relationships between actions and consequences (explanatory).	To explain the influence of the COVID-19 pandemic on the physical literacy development of children with CMCs.	To describe the physical literacy development of children with CMCs.	To reflect on how children with CMCs can develop physical literacy through community-based programming.
Practical Roles of Research	Can research be orientated toward both a technical and a cultural role?	A cultural role may inform future techniques, tools, and practices. Likewise, achieving a technical role can inform enhanced cultural understanding.	Knowing how the COVID-19 pandemic impacted the physical literacy development of children with CMCs will provide relevant context to healthcare practitioners for clinical physical activity counselling.	Knowing how children with CMCs develop physical literacy can highlight important areas of intervention for healthcare and recreation practitioners.	Knowing the relevant components of a physical literacy program for children with CMCs can help recreation and healthcare practitioners support this population as they navigate their participation in community-based physical activity programming.

To elucidate this research as interdisciplinary, it may be helpful to refer to a working definition of interdisciplinary research, proposed by Schary and Cardinal (2015) for the field of kinesiology:

> "Interdisciplinary research is any study or group of studies from two or more distinct academic disciplines. The research is a synthesis (or derivative) of concepts, models, and/or theoretical frameworks from those disciplines, uses study design and methodology that is not limited to any one discipline, and requires the use of perspectives and skills of the involved disciplines throughout multiple phases of the research process (i.e., research, analysis, and interpretation of the results)" (Schary and Cardinal, 2015, p.177).

Physical literacy as a *concept* is the synthesis of various philosophical, theoretical, and scientific principles within the biophysical and behavioural disciplines of kinesiology and physical education (Whitehead, 2001, 2010). Meanwhile, physical literacy as an *outcome* can be addressed by drawing from various theories, models, and frameworks in sport and/or exercise psychology, exercise physiology, motor control and pedagogy (Corbin, 2016; Cornish et al., 2020). For example, the physical literacy assessment used to collect outcomes during this research was developed following a Delphi process with experts in paediatric exercise, physical activity/fitness measurement, motor skill development, cognition, and health/disability (Francis et al., 2016). Overall, this project employed a diverse methodology to examine both: a) physical activity experiences using a physical literacy conceptual lens; and b) physical literacy as an outcome.

Schary and Cardinal (2015) also note how the degree of collaboration between disciplines can vary across research projects and/or studies. To facilitate more transparency about interdisciplinary approaches, they propose a continuum following Lattuca’s (2001) typology. This typology ranges from less interdisciplinary (i.e., informed disciplinarity, synthetic disciplinarity) to more interdisciplinary types of research (i.e., transdisciplinarity, conceptual disciplinarity) (Lattuca, 2001; Schary and Cardinal, 2015). According to their continuum, this dissertation would be categorized as transdisciplinarity, which is where multiple theories, concepts and/or methods from two or more disciplines are applied to synthesize knowledge (Schary and Cardinal, 2015).

Conceptual and Theoretical Positioning

Whitehead's (2010) conceptualisation of physical literacy was the guiding framework applied throughout this research. In the years since Whitehead's (2001) seminal paper, the concept has been widely adopted to inform physical activity initiatives, particularly in physical education and grassroots community sports organizations. However, contrasting definitions and interpretations of physical literacy have created an uncoupling of the term from its original conceptualisation (Young et al., 2020). The International Physical Literacy Association's definition of the term is widely accepted as the "Whiteheadian" definition (Edwards et al., 2017), which is that physical literacy is "the motivation, confidence, physical competence, knowledge and understanding to value and take responsibility for engagement in physical activities for life" (https://www.physical-literacy.org.uk/). To understand the breadth and depth of physical literacy as it was applied to this research, it is essential to acknowledge Whitehead's philosophical underpinnings and attributes which inform the conceptual meaning of the term.

The philosophical foundation of physical literacy combines monism, existentialism, and phenomenology to describe one's potential embodiment; both as an instrument and as lived (Whitehead, 2010). Monism rejects the dualistic perspective of the mind and body to define every individual as a holistic being. In practice, this means that no person can be considered “nonembodied” and thus no person is physically *ill*iterate (Pot, Whitehead, and Durden-Myers, 2018). Instead, individuals possess an embodied potential that they may or may not meet in any given circumstance. This philosophical position is particularly relevant to children with chronic medical conditions or disabilities whose embodied potentials may differ from typically healthy peers (Whitehead, 2010). Existentialism posits that an individual is formed through interactions with their surroundings, while phenomenology explains that individuals will draw from prior experiences to build a unique perspective of their world. Whitehead (2010) connects these philosophical views, describing that “phenomenologists explain why and how it is that, in existentialist terms, we are as we are, on account of the accumulated experiences we have had in effective interaction with the world” (p. 25). A common criticism of physical literacy research is that the concept’s underlying philosophy is loosely acknowledged or missing altogether from the methodology (Carl et al., 2022; Shearer et al., 2018). To summarise the philosophical foundation of this dissertation; we cannot understand how certain lived experiences influence children with CMCs (existentialism), without also understanding the context or meaningfulness of those interactions (phenomenology) and how they impact all domains of physical literacy (monism). Applying a pragmatic approach allows for a clearer understanding of the embodied actions and consequences which promote individual learning and thus, physical literacy development (Edwards et al., 2018).

The attributes informing physical literacy can be broken down into three domains: affective, physical, and cognitive (Whitehead, 2019). Affective attributes of physical literacy can be described as: a) the disposition to maximize innate movement potential and apply intrinsic value to physical activity pursuits, including those which are challenging; and b) confidence in one’s ability to learn new skills and activities, and assurance that those pursuits will be worthwhile (self-efficacy). Physical attributes are described in relation to the self, social and environmental contexts. These include a) the ability to move efficiently and effectively in a wide range of situations, including those which are challenging; b) thoughtful perceptions of the physical environment and the ability to respond with movement appropriately and creatively; and c) the ability to work independently and with others in active contexts, whether they are collaborative or competitive. Finally, there are two cognitive attributes informing the concept of physical literacy: a) the ability to identify the components of a successful movement or physical outcome; and b) understanding the principles of a balanced lifestyle with regards to one's embodied health (Whitehead, 2019). These attributes were intended to provide clarification to the concept, and as such, should not be interpreted in silos but in how they interact with one another (Whitehead, 2019, 2010). The reciprocal and interdependent relationships between these attributes contribute to the holistic nature of physical literacy.

Most interventions inspired by or based upon the concept of physical literacy have used at least one additional theory or framework to help inform practice (Carl et al., 2022). This makes sense given the interdisciplinary nature of physical literacy, as the affective, physical, and cognitive attributes may all be addressed by scientific and/or theoretical principles of the biophysical and behavioural sciences. Thus, there is no need to "reinvent the wheel", as evidence-based techniques may already, effectively target a particular domain of physical literacy. For motor learning components, dynamic systems theory (Thelen and Smith, 2006) and differential learning theory have been drawn from to inform interventions (Carl et al., 2022). From a behaviour change perspective, techniques drawn from self-determination theory are most frequently applied to physical literacy interventions (Carl et al., 2022). The satisfaction of basic needs (i.e., autonomy, competence, relatedness), which underlines self-determination theory (Deci and Ryan, 1985), would reasonably contribute to the affective and physical domains of physical literacy. Possessing more self-regulated sources of motivation for physical activity could also bring one closer to their individual, embodied potential in the affective domain. Thus, the influence of self-determination theory on the interpretation of study findings is particularly evident throughout this dissertation. It is important, however, to acknowledge that other theories and frameworks, such as Eccles's (Eccles, 2007; Eccles et al., 1983) expectancy-value theory, Epstein's TARGET framework (Epstein, 1989), the socioecological approach (Bronfenbrenner, 1979) or social cognitive theory (Bandura, 1986), could also be applied within the concept of physical literacy .

Physical Literacy Development

This dissertation contributes to the growing literature of physical literacy development, which contrary to the term's use in other scientific contexts, does not necessarily imply any longitudinal examination of physical literacy. Rather, development in this context is based on the notion that physical literacy is a journey, and various experiences along that journey will shape one's potential and lived embodiment (Whitehead, 2001). We can look at childhood development through a similar lens: how a child develops is dependent on a combination of interpersonal, intrapersonal, sociocultural, and environmental factors. Similarly, there are experiences, perspectives, and capabilities throughout the life course which inform and *develop* physical literacy. The development of physical literacy is therefore an appropriate term to describe the varying levels one might embody on their personal journey of physical literacy.

While the development of physical literacy in childhood occurs in tandem with physical, cognitive, and emotional growth, there is no specific endpoint of physical literacy once an individual reaches adulthood. Whitehead (2019) clarifies that physical literacy is not a goal in the sense that once it is attained, it will be sustained. She emphasises that "physical literacy as a disposition cannot be established 'once and for all', but needs to be nurtured, as appropriate, through all phases of life" (Whitehead, 2019, p.26). This viewpoint seemingly conflicts with the rationale of examining physical literacy as an outcome. However, as previously implied, assessing physical literacy is justified as a means by which to determine where an individual is situated in their personal development/journey (Giblin et al., 2014; Robinson and Randall, 2017).

Population

There were two categories of assumptions made when selecting the inclusion criteria for this research. The first was selecting an age group that would be relevant in the current physical literacy literature, and the second was selecting clinical groups which would have had similar experiences navigating their medical conditions, specifically including relevant barriers and facilitators to physical activity.

Preadolescent children at or under 12 years old have been the most frequently assessed age group in physical literacy research (Edwards et al., 2018). This was speculated by Edwards et al. (2018) as perhaps due to the convenience of recruiting and conducting research with this age group in school-based settings, where physical education is one of the most popular contexts to apply physical literacy-based knowledge. While that is reasonable from a pragmatic perspective, the literature on self-concept and physical activity participation in preadolescence also suggests a more theoretical rationale for their inclusion in most physical literacy research. For example, the relationship between perceived competence and physical activity participation is strongest in middle-to-late childhood (Babic et al., 2014). Meanwhile, as children develop through middle childhood, they can more accurately compare themselves to peers in active contexts (Stodden et al., 2008), thus influencing self-perceptions and potentially impacting physical literacy. From a motor development perspective, the relative importance of developing physical literacy at this age also aligns with other models of physical literacy (i.e., long-term athletic development; Edwards et al., 2017; Young et al., 2020) and the developmental model of sport participation (Côté and Fraser-Thomas, 2007), which situate preadolescence as a critical period for learning a wide breadth of movement competencies.

As discussed in chapter one, this dissertation was designed to highlight the experiences of children who encounter on-going limitations to physical activity due to chronic disease. While there were several outpatient clinics that could have been included in the recruitment strategy based on this criterion, sampling was ultimately limited to cardiology, neurology, respirology/cystic fibrosis, endocrinology (diabetes specifically), and hematology. The only other research, to date, to assess physical literacy among a heterogeneous group of children with CMCs (Do, Blais, et al., 2021) found no significant differences in outcomes between participants recruited from various outpatient clinics (although endocrinology was not originally included in their analysis). Endocrinology outpatients, specifically those living with diabetes, were included in the current research due to reported physical activity experiences which are comparable to other CMC groups (Fereday et al., 2009; Shorey and Ng, 2020). Do et al. (2021) also included rheumatology and oncology patients in their findings, of which the former was originally included in the proposed research for this dissertation. However, recruiting from the rheumatology outpatient clinic at the children's hospital during the COVID-19 pandemic was ultimately not feasible, due to the department's inability to add recruitment for another research project into their clinic workflow. As for the oncology clinic, the physical activity limitations of these patients are uniquely related to the course of their treatment (Stössel et al., 2020), and unlike the other clinical groups, these children may be cured of their condition after successful treatment. Furthermore, Do and colleagues (2021) found that children recruited from oncology were more likely to have higher levels of total physical literacy than matched peers; a finding that was not shared among other outpatient groups included in this research.

Methods

There are two epistemologies commonly applied to physical literacy research: idealism and pragmatism. The former rejects any quantifiable measure of physical literacy while the latter embraces it, acknowledging that on-going development of current practices can only be supported by evidence (Edwards et al., 2018). However, both approaches seem to agree that the complexity of physical literacy cannot be captured with one single method, justifying the use of study designs which incorporate mixed and/or multiple methods. This dissertation embraces a pragmatic epistemology throughout the first two articles, which employ a quantitative assessment of physical literacy further explained by qualitative data. Meanwhile, the third article applies a constructivist epistemology to capture participants' experiences in a physical literacy-based program. The following describes the selection and combined use of methods to capture and characterise physical literacy development throughout this dissertation.

Measuring Physical Literacy

There is currently no "gold standard" to measure physical literacy. Given the on-going debates and varying interpretations about how to best capture such a complex concept, there likely never will be (Edwards et al., 2018; Robinson and Randall, 2017). The Canadian Assessment of Physical Literacy, or CAPL, is one of few valid and reliable assessments of physical literacy, and the only which attempts to present a combined and holistic representation of the attributes of physical literacy (Corbin, 2016). The CAPL is a battery of multiple tasks to capture the various attributes (domains) of physical literacy, and its model is a representation of how the domain scores inform total physical literacy (Longmuir et al., 2015, 2018).

As previously mentioned in this chapter, the CAPL model (Appendix A) was developed following a Delphi process with experts in applicable disciplines (i.e., paediatric exercise, child development, etc.). The CAPL model was designed to align with Whitehead's (2010) definition, wherein the affective, physical, and cognitive domains overlapped and informed physical activity behaviour. However, the main difference between the CAPL model and Whitehead's conceptualisation is the inclusion of a behavioural domain. The creators of the CAPL argue that the inclusion of physical activity behaviour indeed aligns with the International Physical Literacy Association's definition, wherein being physically active is evidence of an individual taking responsibility for engaging in physical activity (Gunnell, Longmuir, Barnes, et al., 2018). The second edition of the CAPL (CAPL-2) is a streamlined, up-to-date version of the assessment, wherein the original CAPL model was revised following confirmatory factor analyses (Gunnell, Longmuir, Barnes, et al., 2018; Longmuir et al., 2018). The current CAPL-2 model represents total physical literacy as four correlated domains, with a relative weighting of 30% each for motivation/confidence, physical competence, and daily behaviour and 10% for knowledge/understanding. The sum of all four domain scores is then considered the total physical literacy score.

Besides the inclusion of daily behaviour as a domain in the CAPL-2 model, there are two pertinent criticisms of the assessment. The first is the use of a classification system, based on comparisons to age- and gender-based normative data, for the interpretation of the domain and total physical literacy scores. Scores may be classified as beginning, progressing, achieving, or excelling, which as noted Edwards et al. (2018), has the potential to "create a comparative environment if administered in the incorrect manner […] this contradicts the philosophical underpinnings of the concept as there should be a concentration on individualized ability and progress” (p. 677). In this dissertation, the CAPL-2 classifications are used to situate the physical literacy scores of the study group (children with CMCs) in reference to the general population. However, these classifications should not be used to define where individual participants are on their physical literacy journey; just because a child is classified as beginning in every domain of their physical literacy does not mean that they are not meeting their full embodied potential.

The second criticism of the CAPL-2 is the use of separate measures for each domain, which are summed to produce a total physical literacy score. Separating the domains in this way has been criticized for dismissing Whitehead's physical literacy's “holistic” nature (Edwards et al., 2018). To this point, it has also been argued that the CAPL-2 employs a more dualistic perspective of physical literacy assessment, “treating the body as an object” (Robinson et al., 2017, p.51). However, that each domain is scored separately does not mean that the assessments themselves do not account for multiple domains at one time. This was argued by the lead investigators of the CAPL in their response to Robinson and colleagues:

> "Our understanding of monism is that the body and mind are understood as one entity, with all parts working together in an integrated and reciprocal fashion. This monistic approach is reflected in our choice of the CAPL protocols (i.e., plank, shuttle run, sit and reach) which are specifically designed to require the mind and body to work together in order to optimise performance” – Tremblay and Longmuir, 2017, p.174

For example, to complete the PACER fitness test to maximal volition as intended, a child must maintain a certain level of motivation to continue past uncomfortable bodily sensations (i.e., breathlessness, sore muscles), while also having the knowledge and understanding to keep an optimal pace and then know when they are not able to continue running. In this example, while the PACER score is included as part of the physical domain, it should be conceptually understood that the other aspects of physical literacy (i.e., affect, cognition) also helped inform this score. Nonetheless, this criticism continues to permeate ongoing debates about physical literacy assessment (Barnett et al., 2023), highlighting the value of including qualitative data that would supplement the CAPL-2 results and continue to prioritise the holistic perspective of physical literacy development.

Qualitative Analyses

Braun and Clarke's (2019) reflexive thematic analysis was the primary method used to analyse the qualitative data collected throughout this research. From a pragmatic perspective, this method was selected because it was not entwined with any particular methodology, and it aligned with the project's purpose, theoretical assumptions, and research question(s). Indeed, the reflexiveness of thematic analysis is theoretically flexible (Braun and Clarke, 2019), which was important for this research as the multi-faceted concept of physical literacy can situate multiple theories across various disciplines.

There are six, reflexive stages of Braun and Clarke's thematic analysis: 1) Familiarizing yourself with the data; 2) Generating initial codes; 3) Searching for themes; 4) Reviewing themes; 5) Defining and naming themes; and 6) Producing the report (Braun and Clarke, 2006). Also differentiating their method is how Braun and Clarke define themes as unique to domains (i.e., "type of", one-word identifiers, topic summaries). Where domains highlight diversity within a topic of interest, themes represent a shared pattern of meaning (Braun and Clarke, 2019). While developing and reporting themes for all studies (stages 4 through 6), I was especially aware of this distinction alongside the pragmatic applications of my findings. Thus, the resulting themes from this research are more descriptive in nature and may therefore be perceived as descriptive categories by qualitative researchers unfamiliar with this approach.

Rigour

Regarding overall quality, especially of the qualitative components, this research followed a relativist approach (Sparkes and Smith, 2009). This approach aligned with how pragmatism was adopted throughout the entire research process, as relativism acknowledges that criteria of quality are not tied to any particular paradigm and should be applied in a way that is contextually situated and flexible (Burke, 2016). The quality criteria that guided this research, alongside worthiness of topic and significant contribution of topic, included credibility, rich rigour, sincerity, and meaningful coherence (Tracy, 2010). Further, this research aimed for resonance through discussions of transferability (articles 1 and 2) and naturalistic generalizations (i.e., insight gained by reflecting on the context of a particular case; articles 1 and 3).

The concept of credibility in qualitative research is most like internal validity in quantitative research, as it centers around the idea that the researcher's interpretation of the data should accurately represent participant realities (Burke, 2016). Techniques for credibility (Lincoln and Guba, 1985) that were applied throughout all articles of this research included data source and methodological triangulation, the amount and quality of time spent with participants, and progressive subjectivity (i.e., reflecting on biases/assumptions in relation to the research topic). Rich rigour was evidenced throughout the dissertation by the diverse sample of participants, the descriptions of context and the theoretical applications of physical literacy among the data. Sincerity was demonstrated in the self-reflexivity and transparency of challenges encountered throughout the research process. Finally, meaningful coherence was achieved in how the purpose, methods and interpretations of each article were aligned and the various points of integration within each article.

Integrating Mixed and Multiple Methods

Mixed methods are typically used to simultaneously combine the strengths and mitigate the weaknesses of quantitative and qualitative methods (Pluye and Hong, 2014). It has been suggested that without the use of quantitative and qualitative methods, the combined operationalisation and contextualisation of physical literacy cannot be effectively captured (Edwards et al., 2018). The guiding rationale for employing mixed methods in this dissertation was to represent individual experiences within an established operationalisation of physical literacy (i.e., the CAPL-2), while also capturing the nuanced social interactions surrounding physical activity participation and the disease-specific experiences of children with CMCs. The first two articles, therefore, employ mixed methods to address the first two research objectives: to a) contextualise and b) describe physical literacy development among children with CMCs.

Integration is an essential component of mixed methods research, which should be thoughtfully considered during the design, methods, and interpretation/reporting of results (Fetters et al., 2013). Creswell and Plano Clark's (2018) typology-based approach was used to define study design and point of interface, wherein the type of integration follows Fetters' (2013) principles and practices. In the first article, data from two studies were not integrated until the interpretation/reporting phase (Figure 1), aligning with a convergent typology, and employing a narrative, contiguous approach to integration. This article presents two separate studies as one did not inform the other, despite there being some overlap in participants, but both contributed meaningful knowledge to the same research question. Meanwhile, the study in the second article used an explanatory sequential design (Figure 2) where integration was embedded in the sampling of participants for the semi-structured interviews and again in the analysis. At the interpretation/reporting phase, the results of the second study were integrated once more in a weaving narrative as well as a joint display table.

Figure 1. *Convergent Mixed Method Design (Article 1)*

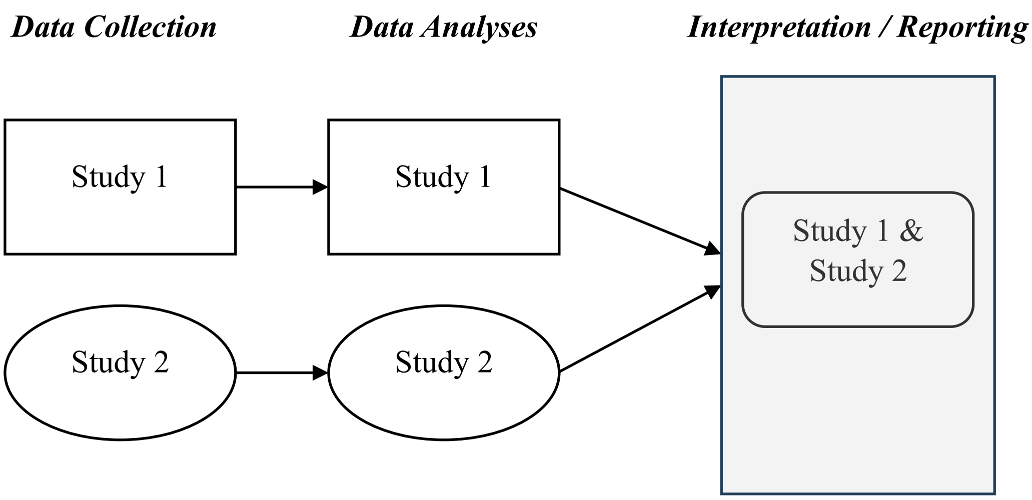
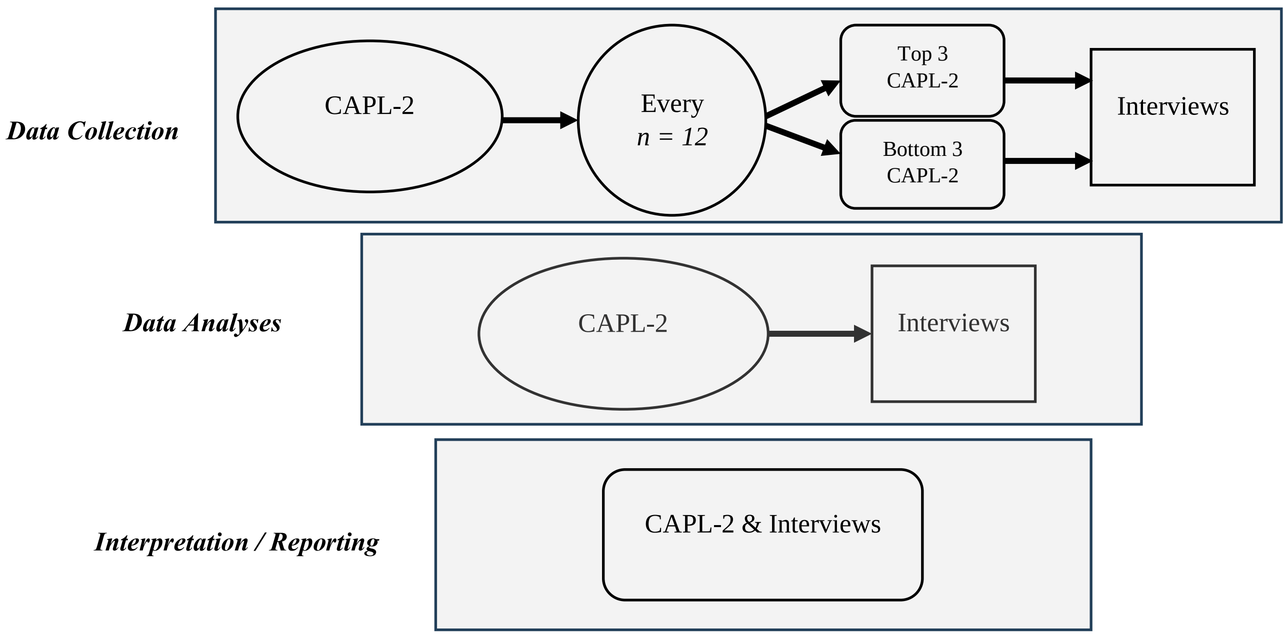


Figure 2. *Explanatory Sequential Mixed Method Design (Article 2)*



The purpose of the third study was to reflect on physical literacy development using the application of a community-based physical literacy program among children with CMCs. This was not an implementation nor a traditional intervention study, therefore the use of quantitative methods was not pertinent to answering the research question. Instead, only the use of qualitative methods suited the axiology, ontology, and epistemology of this study (Table 1). Given the various stages of designing and delivering a community-based physical literacy program, as well as relevant considerations when conducting qualitative research with children (Kirk, 2007; Morgan et al., 2002; Schelbe et al., 2015), the use of multiple qualitative methods were incorporated and integrated throughout the third study design.

A common concern when conducting research using qualitative methods with children is that they may not possess the cognitive and verbal competencies to adequately communicate or relate their experiences to the researcher (Angell et al., 2015; Kirk, 2007). From my own experiences conducting qualitative research with children and youth, I believe it is not about the competencies they “lack”, but rather the unique, imaginative, and abstract ways in which children perceive the world. This view is shared by other researchers and used as a rationale to employ creative, participatory, and task-based methods to research with children, such as the “draw and tell”, photovoice and mapping techniques (Moola, 2020; Noonan et al., 2016; Strack et al., 2004). Moreover, these methods are often employed in combination with other, ethnographic and/or interview methods. Incorporating multiple methods has been suggested as particularly helpful to allow researchers to gain different, but complementary information about children’s activities from multiple sources (Darbyshire et al., 2005). In qualitative research, using multiple methods in this way is considered a form of methodological triangulation (Flick, 2018), which is particularly relevant in ethnographic methodologies (i.e., article 3 of this research). Overall, employing multiple and mixed methods which integrate at various points throughout this doctoral research process was intended to enhance rigour and illustrate a complete picture of physical literacy development among children with CMCs.

Chapter Three - Results

Article 1: The Impact of a Pandemic Context on the Physical Literacy Development of Children with Chronic Medical Conditions

Abstract

Background: Precautions related to the COVID-19 pandemic disrupted the physical activity behaviours of most Canadian children. Meanwhile, children living with chronic medical conditions were already less likely to achieve recommended levels of physical activity in comparison to their otherwise healthy peers. Looking at the context of the pandemic (i.e., lockdown protocols, fear of contracting the disease) from a physical literacy lens can help identify relevant areas of support for these children.

Methods: A descriptive-comparative design with convergent mixed methods was applied to examine the physical literacy of outpatients 8- to 12-years-old recruited from cardiology, respirology/ cystic fibrosis, hematology, endocrinology, and neurology clinics. Participants recruited during the COVID-19 pandemic were matched 1:1 by clinical group, age, gender, and season of testing (where applicable) to children with chronic medical conditions who were assessed pre-pandemic. A subsample of participants in the pandemic group with higher and lower physical literacy scores were purposively selected for semi-structured interviews.

Results: Movement skill and agility scores, as well as mean daily step counts, were significantly lower in the pandemic group. There were significant differences between endocrinology and hematology outpatients in total physical literacy score, but no other between group differences in domain scores. Discordance between qualitative and quantitative data was found; there were no differences in the motivation/confidence domain scores between groups, despite interview participants from the pandemic group describing less motivation to participate in physical activity. Themes surrounding the perceived impact of the pandemic on participants were 1) physical distancing limited how children socially connected through physical activity; 2) pandemic-related prevention measures changed physical activity-based opportunities for development; and 3) even after restrictions are lifted, returning to physical activity is not simple.

Conclusions: Children with chronic medical conditions have maintained relatively similar levels of physical literacy compared to the pre-pandemic group, despite observed declines in movement skills and physical activity behaviour during the COVID-19 pandemic. However, participants described lifestyle changes resulting from the pandemic which may thwart their on-going physical literacy development.

Introduction

Regular participation in physical activity is essential for a healthy childhood, but especially important for children living with chronic medical conditions. An active lifestyle can help mitigate the negative impact of pediatric chronic disease by promoting health-related fitness (Gomes-Neto et al., 2016; Schneiderman et al., 2014), disease management (Coleman et al., 2018; Nadella et al., 2017) and psychosocial well-being (Bai et al., 2017), while also preventing the long-term onset of secondary diseases related to sedentary behaviours (Janssen and LeBlanc, 2010). Unfortunately, children living with chronic medical conditions are less likely to achieve sufficient levels of physical activity for health benefits (Elmesmari et al., 2017; West et al., 2019). Exercise-related symptoms, medically necessary activity restrictions, disease management during physical activity (i.e., monitoring blood glucose levels), parental overprotection, and periods of hospitalization are all experiences unique to children with medical conditions which could limit their overall participation in physical activity.

The COVID-19 pandemic significantly disrupted the nature and frequency of physical activity participation among most children (Paterson et al., 2021), including those with medical conditions (Cahal et al., 2021; Ferraro et al., 2022; Mazzella et al., 2022). As participation in active spaces resumes (i.e., school, extracurricular clubs, sports), it is important to acknowledge how children living with medical conditions may have been disproportionately affected by pandemic-related lifestyle changes in comparison to their otherwise healthy peers. Indeed, the fear of contracting COVID-19 combined with the unknown effect of the disease on long-term health outcomes may have had a greater impact on the lifestyles of children who were already medically vulnerable (Caveney et al., 2022). For example, children with medical conditions have reportedly been among the last to return to in-person school and extracurricular activities, in an effort to limit their risk of contracting COVID-19 (Nicholas et al., 2022). While precautions to limit the spread of COVID-19 had an immediate effect on daily physical activity levels (Hemphill et al., 2020; Mitra et al., 2020), they may have also had a lasting, negative impact on other factors related to physical activity behaviours.

The concept of physical literacy provides a comprehensive understanding of factors which contribute to an individual's pursuit of an active lifestyle. The Canadian consensus definition of physical literacy is "the motivation, confidence, physical competence, knowledge and understanding to value and take responsibility for engagement in physical activities for life" (Tremblay, Costas-Bradstreet, et al., 2018). Children with medical conditions demonstrate overall lower levels of physical literacy in comparison to otherwise healthy peers, especially in aspects of physical competence (Do, Blais, et al., 2021). Thus, it is important to evaluate how the recent pandemic may have further impacted the physical literacy outcomes of children with medical conditions. Given the absence of traditional physical activity opportunities when emergency public health measures are in place (i.e., quarantines, social distancing), it is also helpful to understand which factors contribute positively to physical literacy development among children who are more medically vulnerable. Therefore, the purpose of this research was to evaluate and understand how the COVID-19 pandemic influenced the physical literacy development of children living with chronic medical conditions.

Methods

Design

This research was conducted in two parts (Study 1 & 2). Study 1 used a descriptive-comparative design to evaluate how the COVID-19 pandemic influenced the physical literacy development of children living with chronic medical conditions. Study 2 was an exploratory, qualitative design that aimed to provide additional context about how the COVID-19 pandemic influenced the physical activity behaviours and subsequent physical literacy of children with chronic medical conditions. This research was approved by the institutional research ethics boards of the University of Ottawa and the CHEO Research Institute, and written informed consent was obtained for all participants.

Study 1

Participants

Retrospective (pre-pandemic) physical literacy data were pulled from existing records of prior participants with medical conditions recruited for three other studies before the onset of the pandemic (2013-2019) (Blais, Lougheed, Adamo, et al., 2020; Do, Blais, et al., 2021; Tremblay, Longmuir, et al., 2018). Pandemic data were collected from participants recruited between December 2020 and August 2022 (pandemic group), from outpatient Endocrinology, Hematology, Respirology/Cystic Fibrosis, Cardiology and Neurology clinics at a local children's hospital. Eligible participants were 8 to 12 years of age and living with a chronic medical condition considered moderate to significant in severity/complexity (i.e., requiring continuous follow-up). To meet eligibility criteria, potential participants were required to have a stable health status and be cleared by their responsible physician to participate in physical activity. Potential participants were excluded if they understood neither French nor English or were living with a significant physical or intellectual disability. Eligible patients in the pandemic group were recruited either in-person during clinic appointments or remotely with study information letters and phone calls. All pandemic participants were enrolled in a larger research program, where the primary outcome was to understand the physical literacy development of children with chronic medical conditions.

Physical Literacy Assessment

The second version of the Canadian Assessment of Physical Literacy (CAPL-2; https://www.activehealthykids.org/capl-2-training-materials/) is a comprehensive tool with evidence of validity (Longmuir et al., 2018) to measure domains of physical literacy among 8 to 12-year-old children. A physical competence score was determined using raw scores from the PACER beep test (Scott et al., 2013), the Canadian Agility and Movement Skill Assessment (CAMSA) (Longmuir et al., 2017), and a maximal timed plank hold (Boyer et al., 2013). Motivation and confidence as well as knowledge and understanding were measured with the CAPL-2 questionnaire (Gunnell, Longmuir, Woodruff, et al., 2018). Daily physical activity behaviour was measured using pedometer step counts over a period of 7 days and self-reported days per week of at least 60 minutes of moderate-to-vigorous physical activity. A total CAPL-2 score was computed as the sum of each of the four domain scores (physical competence, motivation and confidence, knowledge and understanding, and daily behaviour). Each domain score as well as the total score can be interpreted as beginning, progressing, achieving, or excelling in the child's physical literacy journey, based on normative standards according to age and sex (Longmuir et al., 2018).

Statistical Analyses

Participants in the pandemic group were matched 1:1 by age, gender, and clinical group to the pre-pandemic group. Where possible, participants were also matched within 2 months of testing date, to account for known differences in physical activity with change of season (Atkin et al., 2016). Since not all participants could be matched within 2 months of testing date, season of testing was included as a fixed factor. The physical competence and daily behaviour scores of pre-pandemic children with medical conditions who completed the first edition of the CAPL (Longmuir et al., 2015) were recalculated from the raw data using the CAPL-2 criteria. Given there were also different items between the two questionnaires, the CAPL motivation/confidence and knowledge/understanding scores were adjusted by relative weight in the CAPL-2 model (from 20% of total score for each to 30% and 10%, respectively). Factorial ANOVAs, considering season of testing and test group (i.e., pre-pandemic or pandemic) as fixed factors, were used to compare physical literacy outcomes between matched pairs. Statistical significance was p <0.05 for analyses of total physical literacy. To account for the analyses of multiple domain scores, a Bonferroni correction was applied, setting significance at p <0.0125. Chi-square analyses determined whether there were differences in how many children with medical conditions were meeting (i.e., achieving, excelling) or not meeting (i.e., beginning, progressing) normative guidelines before and after the onset of the COVID-19 pandemic.

Study 2

Participants

Children with chronic medical conditions who were approached to participate in the semi-structured interviews met all of the eligibility criteria outlined in Study 1. Among every 12 children with chronic medical conditions who completed the physical literacy assessment as part of the larger research program, those with the 3 highest and 3 lowest scores were invited to participate in a semi-structured interview. This sampling method resulted in a total of 23 interviews being conducted. The differentiation between high- and low-scoring participants was designed to purposively elicit the perspectives of children who would have had greater capacities to participate in physical activity during the pandemic in contrast to those who would have most benefitted from additional support. Having these contrasting perspectives represented in the data was meant to capture a greater breadth of experiences relevant to a heterogeneous group of children with chronic medical conditions.

Semi-Structured Interviews

Most interview questions did not directly prompt participants to speak about COVID-19, given the purpose of the larger research program was to describe overall physical literacy development (see Chapter 3, p.79). However, the pandemic was a considerable contextual factor which would have influenced interview data and was expected to be referenced frequently throughout the discussions. To ensure it was discussed, participants were asked "What types of physical activity did you do before COVID-19, during, and what types of physical activity do you do now?". Interviews were audio recorded and transcribed verbatim. Most participants chose to have their parents present for the interviews, which took place either virtually or in-person at the children's hospital. Interviews were between 30 and 90 minutes in total length, of which 5-15 minutes were discussions that were explicitly related to the influence of the COVID-19 pandemic on participants' lives; the data included in this research.

Qualitative Analyses

Qualitative data from all interview participants were analysed according to Braun and Clarke's method for thematic analysis (Braun and Clarke, 2006, 2019) using Nvivo software

[QSR International Pty Ltd., October 2022]. An inductive approach was applied to code data and develop themes. While most codes were semantic (i.e., surface-level descriptions), some were also latent, drawing from the first author's understanding of participants' health status, prior interactions with participants and their families, and an understanding of how physically active settings changed due to the pandemic. Data from both low-scoring and high-scoring participants were coded and analysed together. Although the analysis was inductive (data driven), the authors' knowledge of physical literacy development and prior research with this population were reflected upon and acknowledged when interpreting the results. It was also pertinent to acknowledge the prior expectation/hypothesis that COVID-19 would impede physical literacy development.

Results

Study 1

Among all participants who completed the CAPL-2 in the pandemic group (n=99), 53 could be matched by age, gender, and clinical group with a participant in the pre-pandemic group (Table 1). Two participants tested during the pandemic presented as girls and were assigned female at birth but self-reported their gender as non-binary. Given their presentation and age (10 years), participants were matched with girls from the pre-pandemic dataset. Nonetheless, a sensitivity analysis was completed with and without these two participants (Appendix H), which confirmed that the study results did not change whether they were excluded from the analysis or matched with girls. In the pandemic group, one participant had an incomplete physical competence score and 9 of the 53 participants (17%) were missing daily behaviour scores. Nine participants in the pre-pandemic dataset were also missing daily behaviour scores. Most participants from the pandemic group (67%) completed their CAPL-2 testing while Ontario public health restrictions were enforced in public spaces (Table 2). The experiences of thirteen participants from the pandemic group (24.5%) were also represented in the qualitative data collected for Study 2.

Table 1. *Demographics of matched participants from the pre-pandemic and pandemic groups*

Clinic	N per group	N Girls per group (%)	Pre-Pandemic Group	Pandemic Group
			Mean Age +/- SD (years)	Mean Age +/- SD (years)
Cardiology	19	9 (47%)*	9.53 +/- 1.26	9.53 +/- 1.26
Respirology	7	3 (43%)	10.7 +/- 0.76	10.7 +/- 0.76
Hematology	13	8 (62%)	10.2 +/- 1.57	10.2 +/- 1.57
Endocrinology	4	2 (50%)	10.3 +/- 0.50	10.3 +/- 0.50
Neurology	10	6 (60%)*	10.0 +/- 1.15	10.0 +/- 1.15
Total	53	28 (53%)	9.98 +/- 1.26	9.98 +/- 1.26

Note. *Indicates one pandemic group participant from each identified clinic who reported gender as non-binary but was included according to their gender presentation, which aligned with their sex at birth, during early childhood (girl) for the matched pairs analyses.

Physical Literacy Outcomes

When accounting for season of testing, total physical literacy was significantly lower among the pandemic group (Δ mean = 7.99, $F(1,101)=8.91$, $p= .004$, $\eta^2=0.08$). Between all four domains, only physical competence was significantly different and lower among the pandemic group (Δ mean = 3.36, $F(1,100)=9.42$, $p= .003$, $\eta^2=0.09$). There was a mean difference of 3.53 points between the pre- and post-pandemic daily behaviour scores, but this difference was not significant after applying the Bonferroni correction ($F(1,92)=4.68$, $p= .03$, $\eta^2=0.05$). Within the daily behaviour and physical competence domains, only daily steps and movement skill and agility were significantly different, respectively (Table 3). There were no differences between groups in the motivation and confidence (Δ mean = 1.07, $F(1, 101)=1.24$, $p= 0.27$), nor knowledge and understanding (Δ mean = 0.25, $F(1,101)=.208$, $p= 0.65$) domains. There were no differences between groups in the proportion of participants who were beginning/progressing or achieving/excelling in any physical literacy outcomes (Table 4).

Study 2

Twenty-three children with chronic medical conditions completed a semi-structured interview about physical literacy within the context of the pandemic, of which thirteen (57% of interview participants) were matched to the pre-pandemic cohort in Study 1. Eleven of the twenty-three participants interviewed (48%) were from the low-scoring quartile of the larger research program. Some interviews took place during lockdown periods (Table 2). Three of the twenty-three participants interviewed (13%) were too young to recall what their physical activity had been like before March 2020. One of these participants was in the high-scoring quartile, while the other two had low physical literacy scores. Since these participants could not describe the physical activity changes they experienced as a result of the pandemic, there were no reliable data from these interviews to be used for the analysis. Thus, results are based on the remaining twenty children with CMCs (60% girls, mean age = 10.1 +/- 2.68 years), regardless of if they were matched or not to the pre-pandemic group in Study 1.

Three themes were generated to describe the physical activity experiences of children with chronic medical conditions during the COVID-19 pandemic, which may have subsequently influenced their overall physical literacy development. They are 1) physical distancing limited how children socially connected through physical activity, 2) pandemic-related prevention measures changed physical activity-based opportunities for development, and 3) even after restrictions are lifted, returning to physical activity is not simple.

Physical distancing limited how children socially connected through physical activity

Children interviewed during the pandemic attributed differences in their physical activity (pre-pandemic versus pandemic) primarily to physical/social distancing requirements. There were many activities that children felt they simply could not do because of physical distancing, as the rules/constraints of most active games (i.e., tag, hide and seek, etc.) were not conducive to always maintaining at least 2 meters of distance from other players. Since physical activity was largely considered the best way to build authentic social connections, participants felt that physical distancing simultaneously limited both personal levels of physical activity and interpersonal relationships. Participants noted how connecting with peers virtually could not replicate or replace the uniqueness of being physically close to one another. One participant (12-year-old girl, cystic fibrosis) explained this when she said: "In taekwondo we used to be in a school but now it's completely online, and you can just see everyone now on a screen, and they're not beside you, so it's kind of sad. To not have anyone beside you". Another participant (11-year-old girl, cystic fibrosis) highlighted how physical distancing changed the quality of her social interactions in unstructured active spaces, like recess, when she said, "we weren't really allowed to touch each other and so [when we're playing with friends] we can't really give each other hugs or high-fives anymore". Overall, almost all children agreed that because of social distancing, they felt little to no motivation to participate in physical activity during the pandemic ("If we don't really have friends to do it, we don't really want to."- 9-year-old girl, endocrinology). Family members were the main source of social motivation for participants to engage in physical activity ("I'm [active] with my brother, but my dad usually wants me to walk the dog or do two laps around the neighbourhood or something" – 11-year-old boy, cystic fibrosis).

Table 2. *Number of Data Collection Sessions for Both Studies According to Ontario's COVID-19 Public Health Measures*

	Study 1			Study 2		
Setting	Open with little to no restrictions	Open with moderate to stringent restrictions	Lockdown (Full restrictions & closures)	Open with little to no restrictions	Open with moderate to stringent restrictions	Lockdown (Full restrictions & closures)
School*	17	9	7	1	8	6
Indoor Recreational Spaces	17	21	15	2	16	5
Team/Outdoor Sports	10	32	11	2	18	3
Outdoor Recreational Spaces	44	9	0	20	0	3
Social Gatherings	17	32	4	2	18	3

Note. *The total number of participants assessed during the school year does not include 20 CAPL-2 sessions and 8 interviews that were completed during the summer months, when children were not attending school.

Table 3. *Results of Factorial ANOVAs Between Groups for the CAPL-2 Domain Scores, Physical Competence and Daily Behaviour Tasks*

CAPL-2 domain score or task	Pre-pandemic group mean (SE)	Pandemic group mean (SE)	p-value	95% Confidence Interval	Partial eta squared
Physical Competence	12.68 (0.74)	9.32 (0.84)	.003*	[1.19, 5.53]	0.09
Motivation & Confidence	23.10 (0.62)	22.03 (0.70)	.268	[-.80, 2.85]	0.01
Daily Behaviour	16.26 (1.13)	12.76 (1.18)	.033	[.29, 6.76]	0.05
Knowledge & Understanding	6.65 (0.36)	6.40 (0.41)	.065	[-0.82, 1.30]	0.00
PACER shuttle run test (laps)	16.95 (1.56)	11.61 (1.73)	.021	[0.82, 9.85]	0.06
CAMSA score (out of 28 possible points)	19.00 (0.69)	15.63 (0.79)	.001**	[1.33, 5.42]	0.10
Maximal plank hold (seconds)	46.01 (3.88)	36.08 (4.35)	.087	[-1.46, 21.30]	0.03
Daily Steps	11378 (614)	9262 (681)	.022†	[314, 3919]	0.06
Self-reported physical activity (days per week)	3.30 (0.30)	3.71 (0.33)	.346	[-1.27, 0.45]	0.01

Note. CAPL-2 = Canadian Assessment of Physical Literacy, Second Edition; CAMSA = Canadian Agility and Movement Skill Assessment; SE = Standard Error; * indicates statistical significance at $p < 0.0125$; ** indicates statistical significance at $p < 0.0167$; † indicates statistical significance at $p < 0.025$

Table 4. *Difference in CAPL-2 Domain and Total Classifications Between Pre-Pandemic and Pandemic Groups*

Physical Literacy Domain	Physical Literacy Classification (n)				Chi-square statistic	*P* – value
	Pre-Pandemic		Pandemic			
	Beginning/Progressing	Achieving/Excelling	Beginning/Progressing	Achieving/Excelling		
Motivation and Confidence	24	29	30	23	1.36	.244
Physical Competence	46	6	52	1	3.93	.047*
Daily Behaviour	33	11	38	9	0.45	.501
Knowledge and Understanding	28	25	32	19	1.05	.306
Total Score	39	14	44	9	1.39	.239

** Indicates statistical significance at $p < 0.05$.*

Pandemic-related prevention measures changed physical activity-based opportunities for development

Adhering to public health measures, including public facility closures, changed the ways in which participants developed their physical, environmental, and social awareness during physical activity. Participants recalled having to adapt and learn how to successfully navigate the spaces they were being active in. For example, the rules and dynamics of playground games would change depending on the space available, and children had to re-learn (often unsuccessfully) how to play within those constraints ("We don't normally [play like that] because we can't see people when we're all spaced out" – 8-year-old boy, neurology). Most participants talked about how the pandemic allowed fewer opportunities for them to explore new spaces (i.e., indoor playgrounds, field trips, family travels) and/or gain new skills (i.e., gym class restrictions, cancelled lessons and drama club performances). Alternatively, some participants pursued more opportunities for outdoor play than they normally would have before the pandemic, learning to better appreciate being active in outdoor spaces. As one participant (9-year-old boy, endocrinology) enthusiastically stated: "I didn't used to do activities in the winter, because going outside was very cold… but [after] COVID, I now do a lot of activities in the winter". The few participants who were more involved in higher-level extracurricular activities (i.e., hockey, cheerleading, soccer) also took the lockdowns as an opportunity to pursue other interests, without the added pressure of feeling accountable to a team or coach.

Even after restrictions are lifted, returning to physical activity can be complicated

Most participants were interviewed as they were returning, or about to return, to school, extracurricular activities and/or sport. For those who were in the younger age ranges (8-9 years old), returning to organized sport felt like trying something new for the first time, even if it was a sport that they had already learned ("I didn't remember a lot – I didn't really remember that experience [of taking lessons], so it was new" – 8-year-old girl, cardiology). However, there were many children who did not return to their pre-pandemic activities, even when facilities had fully reopened. While some of these children had simply decided to pursue other interests, others hesitated to enroll because they were worried that activities would be cancelled for another lockdown. Others still did not want to participate because they would have to wear masks for protection, and they felt as though masking made it difficult for them to play within their physical capabilities ("you get tired more easily" – 11-year-old girl, cystic fibrosis). Participants who had decided to return to their pre-pandemic activities recognized there would be some adjustment period before they could participate at their full potential, as one child (10-year-old boy, respirology) reflected: "I found it kind of hard to pick up where I left off. The first time I tried hitting the ball or swinging the bat, it just felt odd… [like] I couldn't remember how to do it". When asked if their otherwise healthy peers would have also experienced a similar decline in their physical abilities due to the pandemic, there was agreement amongst most participants, with one (10-year-old girl, cardiology) saying:

> *"[During] the first lockdown... I was just very motivated to keep going and I think others needed a little bit more time to get back to it? And the second time, the others practiced [more] and I didn't as much".*

Finally, changes in health status could have further impacted a child's willingness and/or ability to return to pre-pandemic physical activities. One participant (10-year-old girl, endocrinology) describes this compounding effect with her own experience returning to her team's soccer practices after experiencing a decline in health during the pandemic:

> *"I felt a little behind, because with COVID we didn't improve as much as we would have in person, and I [also] felt behind partially because of my [medical] condition;*

not being there for a couple months when they were. So, both of those things kind of set me back a little."

Discussion

In the two years following the onset of the COVID-19 pandemic, children living with chronic medical conditions experienced a decrease in their overall physical literacy development, driven by a significant decrease in physical competence, specifically agility and movement skill, and daily behaviour. In the second study, children reported that adhering to pandemic prevention measures challenged their ability to play most active games within given constraints (i.e., rule adjustments, spatial awareness). Once children with medical conditions were allowed to return to their activities, this was also not an easy or simple adjustment. Participants spoke about feeling less motivated to participate in physical activity with pandemic-related prevention strategies in place (i.e., social distancing, mask-wearing, etc.), yet CAPL-2 motivation and confidence scores were unchanged. The significant declines in physical literacy outcomes observed might be explained by the unprecedented constraints to active games and environments described by participants in the second study. Combining findings from both studies enhances our understanding of the quality of physical activity among children with medical conditions during an unprecedented pandemic context.

Similar to pre-pandemic findings (Do, Blais, et al., 2021), high levels of motivation and confidence drove overall physical literacy development among children living with chronic medical conditions during the COVID-19 pandemic. It is promising that CAPL-2 affective outcomes (feelings of adequacy and predilection for physical activity) were sustained, despite pandemic participants reflecting on how they felt less motivated to be physically active when they could not participate with friends. Although social relationships have been examined as important correlates to physical activity behaviour among children and youth (Sterdt et al., 2014), evidence of peer influence as a long-term determinant of physical activity behaviour remains unclear (Craggs et al., 2011). Indeed, no differences in the affective domain were observed between the pre-pandemic and pandemic groups, indicating that changes in how children connected with one another over the course of the pandemic may not have significantly influenced their adequacy, predilection, perceived competence, or intrinsic motivation for physical activity. Instead, interview data suggested that family influences and parental encouragement contributed to sustained motivation for physical activity during the pandemic. These findings align with previous research indicating that supporting families of children with chronic medical conditions to continuously encourage, support and model physical activity is a valuable intervention strategy among this population (Brown et al., 2016). Such an intervention would be especially relevant for parents who may be inclined to impose unnecessary activity restrictions out of fear that participation will lead to adverse health outcomes for their child (Caveney et al., 2022; Longmuir and McCrindle, 2009).

Participants described how opportunities to explore new environments and/or physical activities were limited during the pandemic. This could explain the significant decline in physical competence observed, since diverse physical activity experiences are known to be strongly associated with motor competence (Melby et al., 2021). This is also why a key facilitator of physical literacy development is interacting with diverse environments and contexts, to build a well-informed understanding of how to physically respond in active settings (Whitehead, 2010). At the height of the pandemic, children rarely left their home environments. Even when active spaces and activities reopened, public health guidelines limited how children could physically interact with one another and their environments. From a socioecological perspective, policy decisions about in-person learning and activities would be expected to have important consequences at interpersonal and intrapersonal levels.

Promisingly, interview data suggested that most participants learned how to adapt to these new constraints during deliberate play, and some even pursued activities they may not have considered before the pandemic. While these adaptations may have mitigated declines in the daily behaviour domain and fitness outcomes, participating in primarily home-based physical activity during the pandemic was likely not sufficient to facilitate movement skill development in a broad spectrum of environments. Further, the ability of participants with CMCs to adapt to the pandemic context demonstrates a resilience that has not been observed among all children (Shoychet et al., 2023). Alongside familial resources and contextual factors (Masten, 2021), their ability to adapt to this context might also be explained by the unique resilience required to effectively manage and live with a CMC (Hilliard et al., 2014); a phenomenon worth further consideration in the study of physical activity behaviours among this population.

Other studies conducted within the first year of the COVID-19 pandemic mostly found significant declines in physical activity behaviour among children and youth (Paterson et al., 2021). Likewise in this research, daily step counts were significantly lower among children with chronic medical conditions during those first two years of the pandemic, however self-reported quantities of physical activity remained similar to pre-pandemic values. Given most behavioural data from prior studies were also self-reported (Paterson et al., 2021). This contrast was surprising; despite relying on validated questionnaires, it may be worth considering that the unprecedented experience of a lockdown may have created a temporary change in the association between subjective and objective measures of physical activity. Indeed, the ability of otherwise healthy youth to accurately perceive their participation in physical activity during the pandemic has been problematized (Cocca et al., 2021). When daily behaviour data were collected for our first study, only about 30% of pandemic participants were experiencing closures in schools. Participants in the second study were able to reflect on changes in their physical activity during these closures, recalling how they were much less active during lockdown periods but eventually increased their activity levels once schools and extracurricular activities reopened. When Mazzella et al. (2022) collected objective physical activity data from children with cardiac disease, they similarly found that daily activity increased when restrictions were lifted, but never caught up to pre-pandemic levels. Therefore, the *perceived* quantity of physical activity may have returned to pre-pandemic levels once restrictions were lifted, but changes in the nature and/or quality of participation, as described by participants in the current study, may have influenced the objectively measured quantity of daily physical activity behaviour. This discrepancy has important implications for how clinicians may counsel children with chronic medical conditions about their physical activity behaviours following periods of isolation or strict activity restrictions (e.g., post-surgery).

It has been suggested that higher levels of physical competence may have been important for children and youth to maintain sufficient physical activity behaviours during the lockdown period (Elnaggar et al., 2022). Unfortunately, children with chronic medical conditions had already demonstrated significantly lower levels of physical competence in comparison to otherwise healthy peers (Do, Blais, et al., 2021). Following the onset of the COVID-19 pandemic, further declines in aerobic capacity were observed among children with cardiac disease (Burstein et al., 2022). Among children with chronic medical conditions, lower levels of physical competence were characterized by low levels of aerobic endurance and significantly lower movement skill/agility when compared to the pre-pandemic matched group. Promisingly, unless they had experienced a recent change in their health status, interview participants were confident that their physical competence would not have declined any more than their otherwise healthy peers. While otherwise healthy children experienced similar declines in physical fitness following the pandemic (Basterfield et al., 2022; Jarnig et al., 2022; Raine et al., 2023), it is important to acknowledge the additional difficulties that children with medical conditions may encounter while trying to improve their physical competence. Following prolonged periods of sedentary behaviour, such difficulties may include greater levels of fatigue (Nap-Van Der Vlist, Dalmeijer, et al., 2021) and/or unpredictable symptoms and disease management during or following exercise (Aman et al., 2009). Enhanced symptoms may require children with medical conditions to participate in even shorter bouts of activity compared to peers, thus providing less time to adequately develop physical competence. While our small sample of participants did not allude to these difficulties in their interviews, they are nonetheless important to consider.

Limitations

There are limitations to be aware of when interpreting these results. First, the added consideration of gender was not incorporated into the qualitative data analyses. With reported gender differences in organized sport participation before the pandemic (Vilhjalmsson and Kristjansdottir, 2003), it is important to consider that boys and girls may have also had different approaches to their physical activity participation when extracurricular activities were cancelled. Further, the perspectives of the two non-binary participants were not represented in the qualitative data as they were not selected for the interview. Given the unique context of the COVID-19 pandemic, these findings should be interpreted as only a glimpse of how physical literacy developed during a precarious time, where active spaces were not always accessible and attitudes towards the relative risk of contracting COVID-19 were constantly changing. For families of children living with chronic medical conditions, stressors such as financial instability, interpersonal hardships, and worsening anxiety have been reported following the COVID-19 pandemic (Caveney et al., 2022). Indeed, many families who declined participation in this research cited similar stressors related to the pandemic as reasons for not enrolling and/or completing the in-person assessment. These families may have been even less inclined to support or encourage their children with chronic medical conditions to participate in physical activity during the pandemic, representing an important perspective missing from the results. Given the challenges of recruiting from a paediatric hospital during this time, we relied on convenience sampling and pairs were matched post-hoc, meaning not all children tested during the pandemic could be matched. Although CAPL-2 data collection sessions could not be conducted during quarantines or stay-at-home orders, some virtual interviews were held during those times. Overall, this research contributes important and novel information about the impact of the COVID-19 pandemic physical activity restrictions on the physical literacy of medically vulnerable children, with varying diagnoses.

Conclusion

Following the onset of the COVID-19 pandemic, significantly lower levels of physical competence were observed among children with chronic medical conditions. Children described fewer opportunities to engage in traditional physical activities, which may explain this decline. Participants also described a more controlled approach to physical activity in recreational spaces during the pandemic, which may have limited children's potential to build physical competence and, subsequently, develop overall physical literacy. Despite greater family-based but decreased peer social support described by interview participants, those who were assessed remained motivated to engage in physical activity. Children with medical conditions would benefit from support to improve their movement skills and aerobic fitness, as the observed decline in these competencies may make it difficult for them to return to sport and/or extracurricular activities after the pandemic.

References

Aman, J., Skinner, T. C., de Beaufort, C. E., Swift, P. G. F., Aanstoot, H.-J., and Cameron, F. (2009). Associations between physical activity, sedentary behavior, and glycemic control in a large cohort of adolescents with type 1 diabetes: the Hvidoere Study Group on Childhood Diabetes. *Pediatric Diabetes*, *10*(4), 234–239. https://doi.org/10.1111/j.1399-5448.2008.00495.x

Atkin, A. J., Sharp, S. J., Harrison, F., Brage, Sø., and Van Sluijs, E. M. F. (2016). Seasonal Variation in Children's Physical Activity and Sedentary Time. *Medicine and Science in Sports and Exercise*, *48*(3), 449–456. https://doi.org/10.1249/MSS.0000000000000786

Bai, G., Herten, M. H. Van, Landgraf, J. M., Korfage, I. J., and Raat, H. (2017). Childhood chronic conditions and health- related quality of life: Findings from a large population-based study. *PloS One*, *12*(6), e0178539. https://doi.org/10.1371/journal.pone.0178539

Basterfield, L., Burn, N. L., Galna, B., Batten, H., Goffe, L., Karoblyte, G., Lawn, M., and Weston, K. L. (2022). Changes in children's physical fitness, BMI and health-related quality of life after the first 2020 COVID-19 lockdown in England: A longitudinal study. *Journal of Sports Sciences*, *40*(10), 1088–1096. https://doi.org/10.1080/02640414.2022.2047504

Blais, A. Z., Lougheed, J., Adamo, K. B., and Longmuir, P. E. (2020). Participation in a Community-Based Sport Program is Feasible for Children with Congenital Heart Disease and May Benefit Physical Literacy Development: A Pilot Study. *Exercise Medicine*, *4*, 8. https://doi.org/10.26644/em.2020.008

Boyer, C., Tremblay, M., Saunders, T. J., McFarlane, A., Borghese, M., Lloyd, M., and Longmuir, P. (2013). Feasibility, validity and reliability of the plank isometric hold as a field-based assessment of torso muscular endurance for children 8-12 years of age. *Pediatric Exercise Science*, *25*(3), 407–422. https://doi.org/10.1123/pes.25.3.407

Braun, V., and Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Brown, H. E., Atkin, A. J., Panter, J., Wong, G., Chinapaw, M. J. M., and van Sluijs, E. M. F. (2016). Family-based interventions to increase physical activity in children: A systematic review, meta-analysis and realist synthesis. *Obesity Reviews*, *17*(4), 345–360. https://doi.org/10.1111/obr.12362

Burstein, D. S., Edelson, J., O'Malley, S., McBride, M. G., Stephens, P., Paridon, S., and Brothers, J. A. (2022). Cardiopulmonary Exercise Performance in the Pediatric and Young Adult Population Before and During the COVID-19 Pandemic. *Pediatric Cardiology*, *43*, 832–1837. https://doi.org/10.1007/s00246-022-02920-1

Cahal, M., Amirav, I., Diamant, N., Be'er, M., Besor, O., and Lavie, M. (2021). Real-time effects of COVID-19 pandemic lockdown on pediatric respiratory patients. *Pediatric Pulmonology*, *56*(6), 1401–1408. https://doi.org/10.1002/ppul.25310

Caveney, B., Halterman, J. S., Fagnano, M., Stern, J., and Frey, S. M. (2022). Caregiver Experiences Managing Persistent Childhood Asthma During the COVID-19 Pandemic. *Clinical Pediatrics*, *61*(4), 313–319. https://doi.org/10.1177/00099228211070659

Cocca, A., Greier, K., Drenowatz, C., and Ruedl, G. (2021). Relationship between objectively and subjectively measured physical activity in adolescents during and after COVID-19 restrictions. *Behavioral Sciences*, *11*(12), 177. https://doi.org/10.3390/bs11120177

Coleman, N., Nemeth, B. A., and Leblanc, C. M. A. (2018). Increasing Wellness Through Physical Activity in Children with Chronic Disease and Disability. *Current Sports Medicine Reports*, *17*(12), 425–432. https://doi.org/10.1249/JSR.0000000000000548

Craggs, C., Corder, K., Van Sluijs, E. M. F., and Griffin, S. J. (2011). Determinants of change in physical activity in children and adolescents: A systematic review. *American Journal of Preventive Medicine*, *40*(6), 645–658. https://doi.org/10.1016/j.amepre.2011.02.025

Do, J., Blais, A., Feldman, B., Brandão, L. R., Lougheed, J., Pohl, D., … Longmuir, P. E. (2021). Characterization of physical literacy in children with chronic medical conditions compared with healthy controls: A cross-sectional study. *Applied Physiology, Nutrition and Metabolism*, *46*(9), 1073–1082. https://doi.org/10.1139/apnm-2020-0957

Elmesmari, R., Reilly, J. J., Martin, A., and Paton, J. Y. (2017). Accelerometer measured levels of moderate-to-vigorous intensity physical activity and sedentary time in children and adolescents with chronic disease: A systematic review and meta-analysis. *PLOS ONE*, *12*(6), e0179429. https://doi.org/10.1371/journal.pone.0179429

Elnaggar, R. K., Alqahtani, B. A., Mahmoud, W. S., and Elfakharany, M. S. (2022). Prospective analysis of physical activity levels and associated fitness factors amid COVID-19 pandemic and social-distancing rules. A special focus on adolescents. *Science and Sports*, *37*(2), 131–138. https://doi.org/10.1016/j.scispo.2021.07.002

Ferraro, V. A., Zanconato, S., and Carraro, S. (2022). Impact of COVID-19 in Children with Chronic Lung Diseases. *International Journal of Environmental Research and Public Health*, *19*(18), 11483. https://doi.org/10.3390/ijerph191811483

Gomes-Neto, M., Saquetto, M. B., da Silva e Silva, C. M., Conceição, C. S., and Carvalho, V. O. (2016). Impact of Exercise Training in Aerobic Capacity and Pulmonary Function in Children and Adolescents After Congenital Heart Disease Surgery: A Systematic Review with Meta-analysis. *Pediatric Cardiology*, *37*(2), 217–224. https://doi.org/10.1007/s00246-015-1270-x

Gunnell, K. E., Longmuir, P. E., Woodruff, S. J., Barnes, J. D., Belanger, K., and Tremblay, M. S. (2018). Revising the motivation and confidence domain of the Canadian assessment of physical literacy. *BMC Public Health*, *18*(Suppl 2), 1045. https://doi.org/10.1186/s12889-018-5900-0

Hemphill, N. M., Kuan, M. T., and Harris, K. C. (2020). Reduced Physical Activity During COVID-19 Pandemic in Children with Congenital Heart Disease. *The Canadian Journal of Cardiology*, *36*(7), 1130–1134. https://doi.org/10.1016/j.cjca.2020.04.038

Hilliard, M. E., McQuaid, E. L., Nabors, L., and Hood, K. K. (2014). Resilience in youth and families living with pediatric health and developmental conditions: Introduction to the special issue on resilience. *Journal of Pediatric Psychology*, *40*(9), 835–839. https://doi.org/10.1093/jpepsy/jsv072

Janssen, I., and Leblanc, A. G. (2010). Systematic review of the health benefits of physical activity and fitness in school-aged children and youth. *The International Journal of Behavioral Nutrition and Physical Activity*, *7*(1), 40. https://doi.org/10.1186/1479-5868-7-40

Jarnig, G., Kerbl, R., and van Poppel, M. N. M. (2022). The Impact of COVID-19-Related Mitigation Measures on the Health and Fitness Status of Primary School Children in Austria: A Longitudinal Study with Data from 708 Children Measured before and during the Ongoing COVID-19 Pandemic. *Sports*, *10*(3), 43. https://doi.org/10.3390/sports10030043

Longmuir, P. E., Boyer, C., Lloyd, M., Borghese, M. M., Knight, E., Saunders, T. J., Boiarskaia, E., Zhu, W., and Tremblay, M. S. (2017). Canadian Agility and Movement Skill Assessment (CAMSA): Validity, objectivity, and reliability evidence for children 8–12 years of age. *Journal of Sport and Health Science*, *6*, 231–240. https://doi.org/10.1016/j.jshs.2015.11.004

Longmuir, P. E., Boyer, C., Lloyd, M., Yang, Y., Boiarskaia, E., Zhu, W., and Tremblay, M. S. (2015). The Canadian Assessment of Physical Literacy: methods for children in grades 4 to 6 (8 to 12 years). *BMC Public Health*, *15*(1), 767. https://doi.org/10.1186/s12889-015-2106-6

Longmuir, P. E., Gunnell, K. E., Barnes, J. D., Belanger, K., Leduc, G., Woodruff, S. J., and Tremblay, M. S. (2018). Canadian Assessment of Physical Literacy Second Edition: A streamlined assessment of the capacity for physical activity among children 8 to 12 years of age. *BMC Public Health*, *18*(Suppl 2), 1047. https://doi.org/10.1186/s12889-018-5902-y

Longmuir, P. E., and McCrindle, B. W. (2009). Physical activity restrictions for children after the Fontan operation: Disagreement between parent, cardiologist, and medical record reports. *American Heart Journal*, *157*(5), 853–859. https://doi.org/10.1016/j.ahj.2009.02.014

Masten, A. S. (2021). Family Risk and Resilience in the Context of Cascading COVID-19 Challenges: Commentary on the Special Issue. *Developmental Psychology*, *57*(10), 1748–1754. https://doi.org/10.1037/dev0001259

Mazzella, A. J., Gehi, A. K., Lampert, R., Buck, S., and Rosman, L. (2022). Effects of COVID-19 pandemic on physical activity in children and young adults with implanted devices. *Heart Rhythm*, *19*(1), 165–166. https://doi.org/10.1016/j.hrthm.2021.09.037

Melby, P. S., Elsborg, P., Nielsen, G., Lima, R. A., Bentsen, P., and Andersen, L. B. (2021). Exploring the importance of diversified physical activities in early childhood for later motor competence and physical activity level: a seven-year longitudinal study. *BMC Public Health*, *21*(1), 1492. https://doi.org/10.1186/s12889-021-11343-1

Mitra, R., Moore, S. A., Gillespie, M., Faulkner, G., Vanderloo, L. M., Chulak-Bozzer, T., Rhodes, R. E., Brussoni, M., and Tremblay, M. S. (2020). Healthy movement behaviours in children and youth during the COVID-19 pandemic: Exploring the role of the neighbourhood environment. *Health and Place*, *65*, 102418. https://doi.org/10.1016/j.healthplace.2020.102418

Nadella, S., Indyk, J. A., and Kamboj, M. K. (2017). Management of diabetes mellitus in children and adolescents: Engaging in physical activity. *Translational Pediatrics*, *6*(3), 215–224. https://doi.org/10.21037/tp.2017.05.01

Nap-Van Der Vlist, M. M., Dalmeijer, G. W., Grootenhuis, M. A., Van Der Ent, K., Van Den Heuvel-Eibrink, M. M., Swart, J. F., Van De Putte, E. M., and Nijhof, S. L. (2021). Fatigue among children with a chronic disease: a cross-sectional study. *BMJ Paediatrics Open*, *5*, e000958. https://doi.org/10.1136/bmjpo-2020-000958

Nicholas, D. B., Zulla, R. T., Conlon, O., Dimitropoulos, G., Urschel, S., Rapoport, A., Katz, S. L., Bruce, A., West, L. J., Belletrutti, M., Cullen, E., and Zwaigenbaum, L. (2022). Mental health impacts of the COVID-19 pandemic on children with underlying health and disability issues, and their families and health care providers. *Paediatrics and Child Health*, *27*(S1), S33–S39. https://doi.org/10.1093/PCH/PXAB103

Paterson, D. C., Ramage, K., Moore, S. A., Riazi, N., Tremblay, M. S., and Faulkner, G. (2021). Exploring the impact of COVID-19 on the movement behaviors of children and youth: A scoping review of evidence after the first year. *Journal of Sport and Health Science*, *10*(6), 675–689. https://doi.org/10.1016/J.JSHS.2021.07.001

Raine, L. B., Erickson, K. I., Grove, G., H Watrous, J. N., McDonald, K., Kang, C., Jakicic, J. M., Forman, D. E., Kramer, A. F., Burns, J. M., Vidoni, E. D., McAuley, E., and Hillman, C. H. (2023). Cardiorespiratory fitness levels and body mass index of pre-adolescent children and older adults during the COVID-19 pandemic. *Frontiers in Public Health*, *10*, 1052389. https://doi.org/10.3389/fpubh.2022.1052389

Schneiderman, J. E., Wilkes, D. L., Atenafu, E. G., Nguyen, T., Wells, G. D., Alarie, N., Tullis, E., Lands, L. C., Coates, A. L., Corey, M., and Ratjen, F. (2014). Longitudinal relationship between physical activity and lung health in patients with cystic fibrosis. *European Respiratory Journal*, *43*(3), 817–823. https://doi.org/10.1183/09031936.00055513

Scott, S. N., Thompson, D. L., and Coe, D. P. (2013). The ability of the PACER to elicit peak exercise response in the youth. *Medicine and Science in Sports and Exercise*, *45*(6), 1139–1143. https://doi.org/10.1249/MSS.0b013e318281e4a8

Shoychet, G., Kimber, M., Weiss, J., Honest, O., and Prime, H. (2023). Empirical support for a model of risk and resilience in children and families during COVID-19: A systematic review and narrative synthesis. *Development and Psychopathology*. https://doi.org/10.1017/S0954579423000767

Sterdt, E., Liersch, S., and Walter, U. (2014). Correlates of physical activity of children and adolescents: A systematic review of reviews. *Health Education Journal*, *73*(1), 72–89. https://doi.org/10.1177/0017896912469578

Tremblay, M. S., Costas-Bradstreet, C., Barnes, J. D., Bartlett, B., Dampier, D., Lalonde, C., Leidl, R., Longmuir, P., McKee, M., Patton, R., Way, R., and Yessis, J. (2018).

Canada's Physical Literacy Consensus Statement: process and outcome. *BMC Public Health*, *18*(Suppl 2), 1034. https://doi.org/10.1186/s12889-018-5903-x

Tremblay, M. S., Longmuir, P. E., Barnes, J. D., Belanger, K., Anderson, K. D., Bruner, B., Copeland, J. L., Delisle Nyström, C., Gregg, M. J., Hall, N., Kolen, A. M., Lane, K. N., Law, B., MacDonald, D. J., Martin, L. J., Saunders, T. J., Sheehan, D., Stone, M. R., and Woodruff, S. J. (2018). Physical literacy levels of Canadian children aged 8-12 years: Descriptive and normative results from the RBC Learn to Play-CAPL project. *BMC Public Health*, *18*(Suppl 2), 1036. https://doi.org/10.1186/s12889-018-5891-x

Vilhjalmsson, R., and Kristjansdottir, G. (2003). Gender differences in physical activity in older children and adolescents: the central role of organized sport. *Social Science and Medicine*, *56*(2), 363–374. https://doi.org/10.1016/S0277-9536(02)00042-4

West, S. L., Banks, L., Schneiderman, J. E., Caterini, J. E., Stephens, S., White, G., Dogra, S., and Wells, G. D. (2019). Physical activity for children with chronic disease; A narrative review and practical applications. *BMC Pediatrics*, *19*, 12. https://doi.org/10.1186/s12887-018-1377-3

Whitehead, M. (2010). *Physical Literacy: Throughout the life course.*. Routledge. https://doi.org/10.4324/9780203881903

Article 2: Understanding the Physical Literacy Development of 8- to 12-year-old Children Living with Chronic Medical Conditions: A Comprehensive, Mixed Methods Inquiry

Abstract

Background: Physical literacy is a concept used to describe the combined physical, affective, and cognitive capacities one holds, which facilitate an active lifestyle. Physical activity participation is essential for children living with chronic medical conditions, but knowledge of physical literacy among this group is scarce.

Methods: An explanatory, sequential mixed methods design was used to comprehensively describe the physical literacies of paediatric Cardiology, Respirology/Cystic Fibrosis, Neurology, Hematology, and Endocrinology outpatients. All participants completed the Canadian Assessment of Physical Literacy (2nd Edition), and those with higher and lower scores were purposively invited to a semi-structured interview. A deductive-inductive thematic analysis was applied using Whitehead's (2010) conceptualisation of physical literacy.

Results: Using normative strata, 79.8% of the 99 children assessed (mean age = 9.97 ± 1.3 years, 48% girls) were considered beginning or progressing in their overall physical literacy (mean score = 56.5 ± 13.8/100). Meanwhile, physical literacy informed participants' approach to new, active experiences and may have contributed to a strong sense of self. There was a significant difference between endocrinology and hematology patients on total physical literacy score, but not domain scores. Participants scored highly on motivation/confidence (mean = 22.9 ± 5.0/30) but obtained low physical competence (mean = 11.8 ± 5.6/30) and daily behaviour scores (n=72, mean = 15.5 ± 7.1/30). Main themes represent salient experiences of children with CMCs within the affective, cognitive, physical, and behavioural domains of physical literacy, including how children evaluated active contexts and managed physical limitations.

Conclusions: Most children with CMCs would benefit from additional support to achieve their embodied physical literacy potential. Findings suggest that interventions which help children with CMCs develop bodily self-regulation skills and appropriately evaluate risks in active settings would be particularly important for their physical literacy development.

Introduction

An active lifestyle is imperative for children living with chronic medical conditions (CMCs) to prevent sedentary behaviour sequelae, promote well-being, and enhance quality of life (Coleman et al., 2018). Physical literacy has gained recent attention in the field of paediatric health research (Cornish et al., 2020) as a multi-faceted concept describing the cognitive (i.e., knowledge, understanding), affective (i.e., motivation, confidence) and physical factors (i.e., strength, endurance, agility) contributing to an active lifestyle. Physical literacy has a reciprocal relationship to physical activity, whereby psychosocial and/or physical aspects of physical literacy influence activity participation and vice versa (Pot, Whitehead, and Durden-Myers, 2018). Physical literacy development during childhood is particularly important due to its association with habitual activity participation (Belanger et al., 2018) and the establishment of healthy movement behaviours (Whitehead, 2001).

Current knowledge of physical literacy among children with CMCs is limited to a small number of observational studies (Arbour-Nicitopoulos et al., 2023; Do, Blais, et al., 2021; Pohl et al., 2019), concluding that significant deficits observed in physical competence have a negative impact on overall physical literacy. While qualitative inquiry has described how physical activity opportunities are utilized by children with CMCs to develop physical literacy (Bennett et al., 2021), there lacks outcome measures connecting the impact of how these opportunities are utilized on physical literacy development. There is also a minority of children with CMCs who are indeed achieving desired levels of physical literacy (Do, Blais, et al., 2021), but it remains unclear which factors are influencing this development. The purpose of this research was to define the physical literacy development of children with CMCs, followed by a comparative examination of the experiences and perspectives that inform those with higher and lower levels of physical literacy.

Methods

This prospective study used an explanatory sequential design to describe and understand the physical literacy development of children with CMCs. All participants completed physical literacy assessments, which were administered outdoors at a children's hospital or inside a recreational sports facility. Data collection took place in Ottawa, Ontario from March 2021 to October 2022. The study was approved by the Children's Hospital of Eastern Ontario Research Institute and University of Ottawa Research Ethics Boards and written informed consent obtained for all participants (Appendix B).

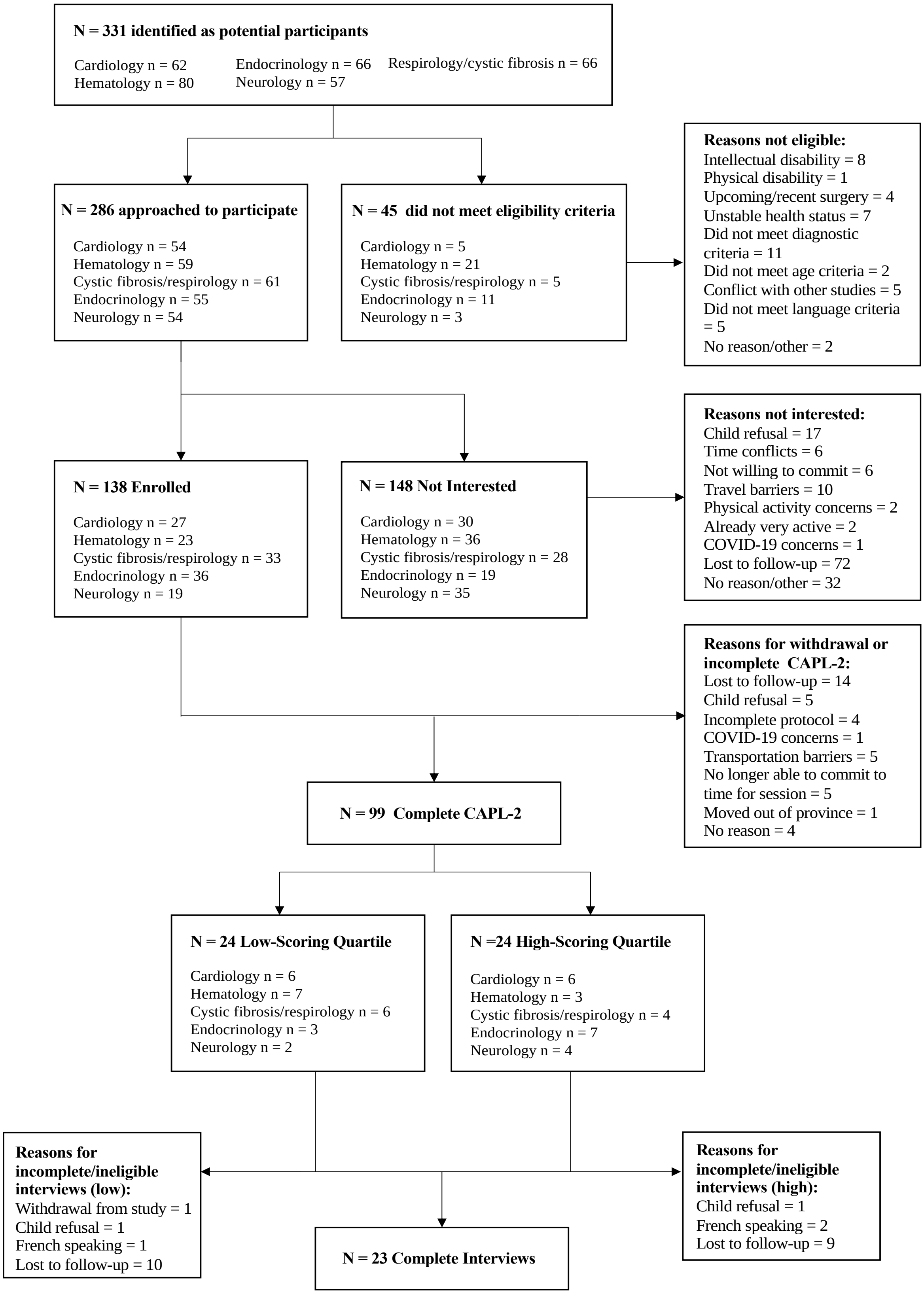
Participants

Children living with CMCs, 8 to 12 years of age, were recruited from outpatient Cardiology, Respirology/Cystic Fibrosis, Hematology, Neurology and Endocrinology clinics if their responsible physician rated their CMC as moderate to significant in severity (i.e., requiring on-going follow-up and/or medical intervention). English or French-speaking participants were required to have a stable health status and be cleared for physical activity by their responsible physician. Children with a physical (e.g., paraplegia) or intellectual disability (e.g., Trisomy 21) were excluded. Eligible patients were approached either a) in person during their scheduled clinic visit; or b) remotely with a study information letter and subsequent phone call. Once individual physical literacy scores were calculated for enrolled participants, a subset of those with higher and lower scores were invited to participate in a semi-structured interview.

Physical Literacy Assessment

The Canadian Assessment of Physical Literacy, 2nd Edition (CAPL-2) has established validity and reliability for children ages 8 to 12 years (Longmuir et al., 2018). The CAPL-2 produces a total physical literacy score from the sum of 4 domain scores: physical competence (30 points), motivation and confidence (30 points), daily behaviour (30 points) and knowledge and understanding (10 points). Protocol details have previously been published (Longmuir et al., 2018) and are briefly summarized here. Physical competence was determined using the PACER beep test (measure of cardiorespiratory endurance; Scott et al., 2013), the Canadian Agility and Movement Skill Assessment (CAMSA; measure of motor skill and agility; Longmuir et al., 2017), and a maximal timed plank hold (measure of musculoskeletal endurance; Boyer et al., 2013). Motivation and confidence were assessed using items from the Children's Self-Perceptions of Adequacy in and Predilection for Physical Activity questionnaire (Hay, 1992) and Likert scale measures of intrinsic motivation and perceived competence (Sebire et al., 2013). Knowledge and understanding items evaluated participants' knowledge of physical activity guidelines, exercise-specific terminology, and methods to enhance physical competence. Daily behaviour was determined by self-reported number of days spent in moderate-to-vigorous physical activity during the previous week and wearing a waist-worn pedometer for one week. All CAPL-2 assessments were administered individually due to pandemic restrictions. When data from one protocol were missing (i.e., a child did not return their pedometer, but completed all other CAPL-2 tasks), a missing data procedure was applied to calculate the total CAPL-2 score (Francis et al., 2016).

Figure 1. *Flow Diagram Summarizing the Recruitment and Sub-Sample Selection Processes*



Semi-Structured Interviews

After every twelve participants obtained a total CAPL-2 score, English-speaking participants from the high- and low-scoring quartiles (i.e., top three and bottom three scores) were purposively selected for an interview. Since the time to schedule and conduct twelve assessments varied by season (i.e., more assessments took place in the summer than winter), participants were invited to complete the interviews between one to four months after their CAPL-2 assessment. The semi-structured interview guide (Appendix C) was designed with eight primary questions and suggested probes, which prompted participants to speak on each domain of physical literacy (i.e., physical competence, cognition, affect and behaviour). To lead with direct probing questions, the physical literacy levels of participants were known during all interviews. Interviews were conducted until all eligible participants from the top and bottom quartiles were approached. Participants were encouraged to draw or write out their responses during the interview and reflect upon them orally. All interviews were audio-recorded and transcribed verbatim.

The first author (AB), who had prior experience facilitating focus groups and interviews among children with heart disease, conducted all interviews. Preliminary rapport with interview participants had been established during CAPL-2 administration. Interviews were conducted virtually except for one in-person interview. During data collection and analysis, the first author continuously reviewed her personal biases using reflective notes, such as her own experiences with physical activity as a child and her knowledge of disease severity and physical capabilities.

Statistical Analyses

Descriptive statistics were computed for all scores. Multivariable linear regression analyses were used to assess differences in domain scores between clinics and according to other factors known to impact physical activity, including age, self-reported gender, and season of testing. Tukey's HSD post-hoc tests were used to determine between-group differences and statistical significance was established at $p < 0.05$ for all analyses. All scores were classified as either beginning, progressing, achieving, or excelling, based on normative data referencing age and gender to aid in the interpretation of children's performance relative to peers (Longmuir et al., 2015).

Qualitative Analysis

Interview data were analysed using a deductive-inductive thematic analysis (Braun and Clarke, 2006). The data were first analyzed deductively, using codes derived from Whitehead's ideology of affective, physical, and cognitive factors contributing to physical literacy development (Whitehead, 2010). Since the theoretical model informing the CAPL-2 was designed to align with Whitehead's definition (Francis et al., 2016), using this deductive framework (Appendix D) allowed for greater synergy between the mixed method data. The qualitative data were then coded a second time inductively to capture more nuanced experiences with physical literacy development. Most codes were organized into affective, cognitive, physical, or behavioural domains, to reflect the CAPL-2 model (Francis et al., 2016). In this way, it was also possible for data to be coded to multiple domains (i.e., "I don't like physical activity because I get tired easily" would be coded to both physical and affective domains). Other inductive codes that did not fit into any one domain, but instead applied to multiple domains, were organised within a total physical literacy domain. The first author coded all data and created all themes.

Table 1. *Demographics of participants who completed the CAPL-2 and Semi-structured interview*

	CAPL-2 Complete			Interviews Complete			
	N	Mean Age +/- SD	Girls n (%)	Higher Quartile (n)	Lower Quartile (n)	Mean Age +/- SD	Girls n (%)
Respirology	25	10.0 +/- 1.37	14 (56%)	4	2	10.2 +/- 1.7	4 (67%)
Cystic Fibrosis	18						
Asthma	4						
Other	3						
Cardiology	20	9.5 +/- 1.24	9* (45%)	3	3	9.83 +/- 1.8	3 (50%)
Marfan's Syndrome	3						
Hypoplastic left heart syndrome (status post Fontan repair)	2						
D-transposition of the great arteries	2						
Tetralogy of Fallot	2						
Ebstein's anomaly	2						
Other	9						
Endocrinology	21	10.5 +/- 1.25	9 (43%)	3	1	10.0 +/- 1.4	1 (25%)
Type I Diabetes	21						
Hematology	18	10.0 +/- 1.53	10 (56%)	1	4	9.2 +/- 1.6	4 (80%)
Sickle cell disease	12						
Hemophilia A	2						
Other	4						
Neurology	15	9.67 +/- 1.05	6* (40%)	1	1	9.0 +/- 1.4	1 (50%)
Epilepsy	13						
Other	2						

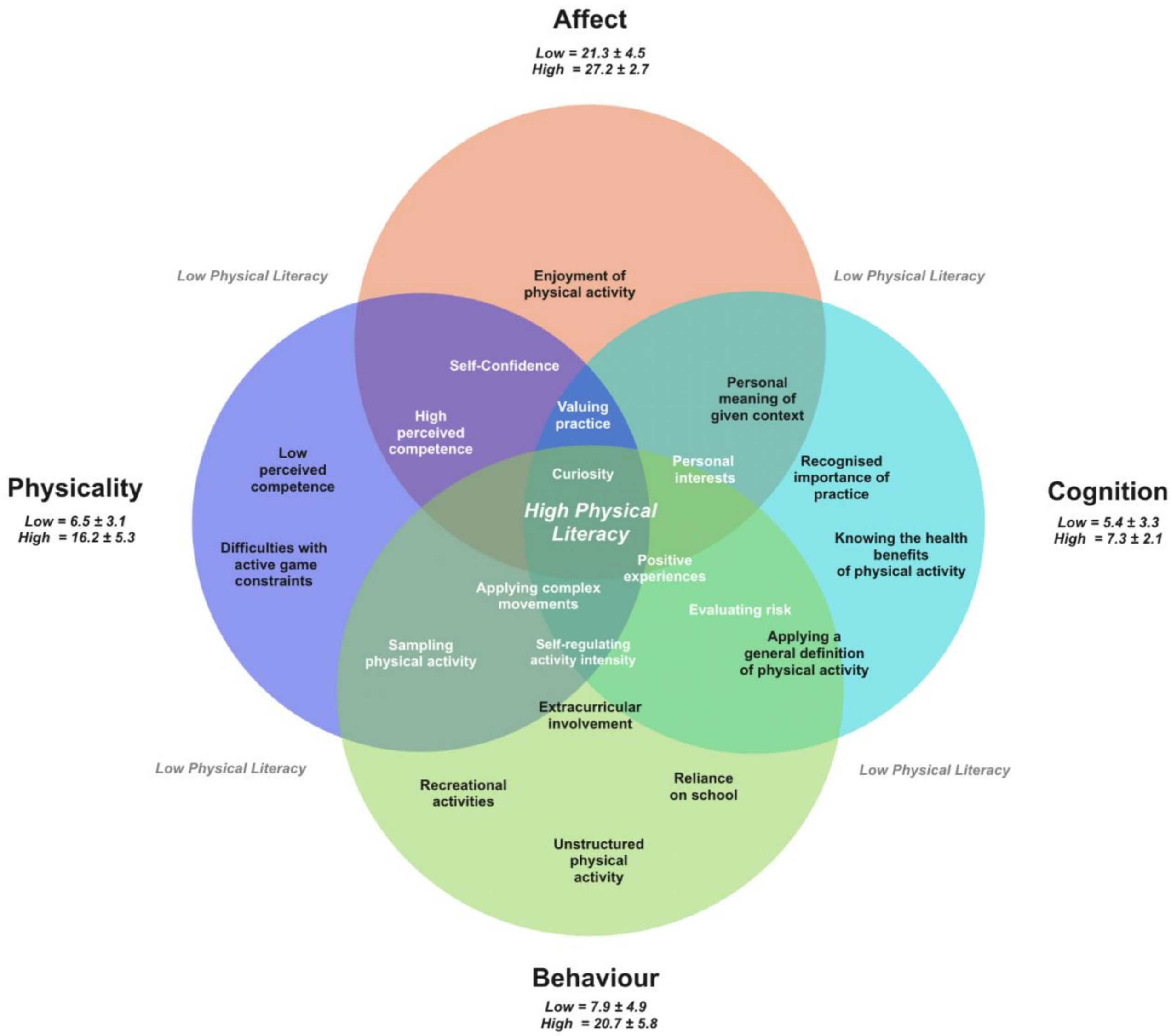
Note: * Indicates one participant from that clinic who reported gender as non-binary but was included according to their assigned sex (girl)

Results

Ninety-nine children (9.97 +/- 1.33 years old (48% girls)) with CMCs completed the CAPL-2 (Table 1). Daily behaviour domain scores were missing from 15 participants (15.2%) who did not return their pedometers and were lost to follow-up. Two participants could not be scheduled for an in-person assessment and therefore have missing physical competence scores (all other assessments were completed remotely). One participant refused to complete the entire CAPL-2 questionnaire, resulting in an incomplete knowledge and understanding score. The CAPL-2 missing data procedure was applied to produce total CAPL-2 scores for all participants with an incomplete domain score (Delisle Nyström et al., 2018). Two participants self-reported their gender as non-binary but presented most similarly to girls and were assigned female at birth. While gender is known to influence physical activity, there is little information in the published literature surrounding the experiences of non-binary, preadolescent children in active settings. Nonetheless, sensitivity analyses were completed to identify potential outcome changes when categorizing these two datasets as participant sex at birth (girls) versus excluding them from the regression models (insufficient numbers to include as a separate class). The significance values representing physical competence outcomes were only marginally different when including the non-binary participants as "girls" versus excluding them from the analysis (p-values of .049 and .054, respectively; see Appendix E, Table 2). Thus, taking a conservative approach similar to other physical literacy research (Tang et al., 2023), these datasets were excluded from the regression analyses. Neither of the non-binary participants scored in the bottom or top quartiles and therefore were not asked to participate in an interview.

A sub-sample of 23 of 48 invited participants (48%) agreed to participate in a semi-structured interview. There were no significant differences in demographics (i.e., age, gender, clinic) nor mean physical literacy scores between those who did or did not participate in the interview ($p > 0.05$). Interviews were 40 to 83 minutes in duration. Main results from the CAPL-2 and interviews are presented in Table 2. Main ideas from developed themes were collated and imposed onto the corresponding domains of the CAPL-2 model to illustrate experiences within and between each domain that were described among participants with CMCs. As illustrated in Figure 2, some of the ideas identified among participants with higher physical literacy scores are clustered in the centre of the diagram where there is much greater overlap between domains. The comments from these participants, such as "I like it when there's a game, and then you have to go fast, and you have to take it and then you have to pass; you have to think fast" (*11-year-old girl, cystic fibrosis*), suggest that these participants have adopted a holistic view of their participation in physical activity, aligning with what it means to be physically literate.

Figure 2. *A Schematic Representation of the CAPL-2 Model Incorporating Main Ideas from Developed Themes.*



Note. Figure adapted with permission from Longmuir et al., 2018. Main ideas in white text were more prominent ideas among children with higher scores, whereas those in black text were more prominent among children with lower scores. Mean domain scores and standard deviations for low- and high-scoring interview participants are reported below domain titles.

Total Physical Literacy

Only 21 children with CMCs were achieving or excelling in their overall physical literacy journey, of which 62% (n=13 of 21) were still beginning or progressing in their physical competence. When accounting for season of testing ($F(3,88) = 2.13$, $p = .102$, $\eta_p^2 = 0.07$), clinic was a significant predictor ($F(4,88) = 2.61$, $p = .04$, $\eta_p^2 = .10$) with participants from endocrinology scoring significantly higher than those recruited from hematology (mean difference = 12.70 +/- 4.20, $p = .03$). Gender also significantly predicted total physical literacy score, with boys scoring higher overall than girls ($F(1,88) = 4.64$, $\beta = 6.01$ +/- 2.79, $p = 0.03$, $\eta_p^2 = .05$). Total physical literacy scores did not differ by age ($F(4,84) = .546$, $p = .70$, $\eta_p^2 = .03$).

Physical literacy contributes to a sense of self and one's identity

Participants with higher scores identified themselves as active individuals, despite not always being able to perform the required skills ("I just liked the thrill of dribbling fast with the basketball and shooting, even though I missed 99% of the shots" – *10-year-old girl, endocrinology*). Two participants also described how their identity as an active individual took precedence over their medical condition, with one emphasizing that "medical conditions don't define the person you are" – *12-year-old boy, endocrinology*. While some participants with higher scores described feeling self-conscious at times, they knew those feelings were context-specific or temporary and so they built boundaries for themselves ("I think just seeing everyone else ahead of me? I got a little discouraged… [so] I just don't like being competitive at stuff" – *10-year-old girl, cardiology*). Meanwhile, children with lower physical literacy scores identified an interest in some physical activities but did not consider themselves to be "active kids". Physical activity was described as something that did not come naturally, with many feeling self-conscious or uncomfortable in active settings ("I didn't like hockey because I was sweating really hard when I got off and there was this [huge] crowd I had to walk through" – *9 year-old boy, cardiology*).

Physical literacy informs how to approach new experiences in physically active settings

All children with CMCs described feeling nervous when trying new activities. While children with higher scores knew how to overcome those feelings, participants with lower scores emphasized their shyness and reservations, especially when trying something new with peers. Children with lower physical literacy scores also had a difficult time identifying new activities to try and relied on others (i.e. family, peers) to introduce them to physical activities, whereas children with higher scores had a strong desire to learn new skills ("If I don't know how to play, I want to learn how to play" – *8 year-old girl, cardiology*) and could easily list activities they were interested in trying.

Affective Domain

Almost half (48.5%, n=47/97) of participants were classified as achieving or excelling in their motivation/confidence. The motivation and confidence domain score accounted for the largest proportion of points (42%) within total CAPL-2 scores. There was a significant interaction between clinic and season of testing on this domain score ($F(18,73) = 2.12$, $p = .01$, $\eta_p^2 = .34$). When accounting for this interaction as well as age ($F(4,73) = 1.48$, $p = .22$, $\eta_p^2 = .08$), gender was a significant predictor of the motivation and confidence score ($F(1,73) = 3.66$, $p = .02$, $\eta_p^2 = .07$), with boys again scoring higher than girls ($\beta = 2.43 \pm 1.04$).

Physical activity is generally enjoyable but should also be personally meaningful

Most (but not all) participants mentioned they enjoyed physical activity ("every kid in the world likes to play" – *8-year-old boy, hematology*), however enjoyment alone was an insufficient reason for participation among children with lower scores. Children with lower scores felt physical activity was meaningful only when other contextual factors (i.e., escaping boredom, being rewarded, social inclusion) occurred. Children from both interview groups felt that being with friends and/or family was one of the most meaningful aspects of physical activity. Children with higher scores spoke about applying a curiosity towards physical activity that was driven by ideas (i.e., learning new skills, setting goals) and feelings (i.e., going fast, hitting hard) that were personally meaningful and independent of social context.

Attitudes towards physical activity are heavily drawn from prior experiences

Enjoyment of physical activity, and especially sports, was influenced by prior experiences. Children with lower scores more often recalled not being able to play games/sports at the same skill level as their peers. For these participants, it was evident that perceived competence negatively interfered with their enjoyment ("Most times I do enjoy it. I think – but sometimes I'm not good at it or, people are just better. And I can't really learn, cause they're just doing it so fast" – *12-year-old boy, cardiology*). Some children in the low-scoring group (n = 5) disliked activities that resulted in fatigue because of their medical condition.

> "I've tried playing soccer, but I don't really like that either… at the beginning I enjoyed soccer, but I realized that [because of my asthma] I ran out of breath really quickly…and I would have to stop playing" – *11-year-old boy, respirology*

In contrast, feeling successful informed positive attitudes and optimism ("It's like a chain reaction, you learn one trick and then you want to learn another one" – *12-year-old girl, cystic fibrosis*). Among children with higher physical literacy, positive attitudes persisted even when success was unlikely, as one participant stated: "I like a lot of sports. But I'm definitely not good at a lot of them" – *10-year-old girl, endocrinology*. These participants knew from prior experiences that with time to learn and practice, they would eventually be able to participate in any activity, from figure skating to pole vaulting. "If I've never done the activity before, then I can learn it. I just like to know how to do it. I like challenge." – *8-year-old girl, cardiology*.

Physical Domain

The performance of participants with CMCs was lowest on measures of physical competence, accounting for 20% rather than 30% of participants' total CAPL-2 scores. Season was the only significant predictor of physical competence, after accounting for age and gender ($F(8,86)=2.93$, $p = .006$, $R^2= 0.21$). Children with CMCs scored higher in this domain during the summer months in comparison to the fall (mean difference = 4.83 +/- 1.66, $F(3,86) = 3.42$, $p = .02$, $\eta_p^2 = .11$). There were no significant differences in physical competence between clinical groups ($F(4,82) = 1.53$, $p = .20$, $\eta_p^2 = .07$).

There is a need to learn how to self-regulate activity intensity alongside complex movement patterns and game constraints

Ninety-one percent of interview participants were in the beginning (n=10) or progressing (n=11) stages of cardiovascular endurance, having completed a mean of 19.0 +/- 13.5 laps on the 15-m PACER test. This was reflected in interviews, especially among lower-scoring participants, as they mentioned how difficult it was to maintain participation in activities that required a lot of running. Although most children were comfortable taking breaks when needed ("I just tell everybody I'm gonna take a break and sit on the bench." – *9-year-old boy, cardiology*), others did not want to sit out if it meant they would be excluded from the game. As one child with asthma explains: "I couldn't take a break… [I mean] if I wanted to switch out with someone else on my team I could, but I also really wanted to be included" – *12-year-old boy, respirology*.

The need to self-regulate activity intensity during active games is further complicated when complex movement patterns are required for participation (e.g., skating and stick handling during a hockey game). Participants with higher physical literacy scores understood how to apply complex movement patterns and basic biomechanical principles (i.e., balance, anatomical positioning) to physical activities, while being mindful of their physiological limitations. Meanwhile, children with lower scores found it difficult to execute combined or complex skills, and desired more basic training, "like dribbling the ball, how to hold the hockey stick properly" – *11-year-old girl, hematology*. Participating in active game contexts where they consistently could not execute skills before other players was also overwhelming. As one participant says about dodgeball, "I'm good at it but people are always like, faster to grab the ball before me" – *12-year-old boy, cardiology*. Children interviewed with lower scores also spoke about not understanding certain rules/strategies and were confused about how to appropriately respond to game plays. In direct contrast, higher-scoring participants knew to "think quickly" during active games and appropriately respond to game plays ("You really have to use your brain." – *8-year-old girl, cystic fibrosis*). This observed difference could have important implications for children's self-efficacy to maintain control of their physical body, including symptoms related to their medical condition, during physical activity.

Practice is essential for skill progression, which is valuable for on-going participation

All participants understood that practice was essential if they wanted to progress in physical activity. Most children with lower scores preferred independent practice to cooperative/group practice, because it provided them with the space and time to focus on performing their skills at their own pace ("Because no one is there to trip the ball when you're trying to learn or do something" – *8-year-old girl, cystic fibrosis*). Children with higher scores more often cited examples where they realized the benefit of practice and appreciated the opportunities for continued participation that practice provided. One participant who enjoyed horseback riding reflected on learning a practiced skill, saying: "I was really happy, because that meant I could continue during the winter. And then I could [continue to] learn. And then I had my first competition that spring" – *11-year-old girl, hematology*. Children with higher scores also recognized which practiced skills/competencies would be transferrable to other sports or activities. As one participant, who was interested in trying snowboarding for the first time, described: "It's really interesting to me how [snowboarding] would affect me in other sports too… could I actually improve my balance by doing it more?" – *10-year-old girl, endocrinology*. Through practice, children with higher scores understood that they would be equipped to participate in a wide range of physical activities and engage in participation that was personally meaningful to them.

Cognitive Domain

Many participants (66%, n=63/96) were beginning or progressing in the knowledge and understanding component of the CAPL-2. When accounting for gender, there were significant differences observed in the cognitive domain score by age and season ($F(8,87) = 5.94$, $p < .001$, $R^2 = 0.35$). Younger participants (i.e., 8 to 9 years old) scored significantly lower ($p < .01$) than older participants (i.e., 11 to 12 years old) ($F(4,87) = 5.30$, $p < .001$, $\eta_p^2 = .20$). Meanwhile, knowledge and understanding was significantly lower ($p <.05$) in the Fall when compared to the spring/summer months ($F(3,87) = 4.94$, $p = .003$, $\eta_p^2 = .15$).

Physical activity can be defined in general terms

Participants with lower physical literacy scores typically adopted a more general definition of physical activity (i.e., moving, playing). Meanwhile, children with higher scores commonly defined physical activity as exercise, sports, and gross motor skills (i.e., running, jumping). The former found it more difficult to illustrate or define movements during interviews in comparison to the latter. All participants generally recognized physical activity as moving one's body for any reason, but children with lower scores emphasized its importance for engaging with others and/or the surrounding environment. This engagement was not related back to sports or exercise, but rather playing games, exploration, and even arts and crafts. Overall, a general perspective of movement was prominent in these data, as one participant pointed out; “you could basically consider everything as exercise” – *12-year-old boy, cardiology*.

Movement benefits overall health and well-being

All interview participants agreed that moving their bodies benefitted overall health and well-being. Participants knew physical activity was important for their general health (“I have to [be active] if I want to stay healthy” – *12-year-old boy, cardiology*), but only one participant, living with cystic fibrosis, briefly mentioned its importance for his CMC diagnosis. Some children with CMCs thought that physical activity only benefitted them when they had the energy for it (“You don’t want to break yourself” – *11-year-old girl, cystic fibrosis*), but others realized that physical activity was a means to ease negative energy (“It helps me get my nerves away, like my stress away” – *9-year-old boy, endocrinology*). Becoming stronger through an active lifestyle was desirable for future growth and independence. While the importance of physical activity for health and well-being was appreciated by children with lower scores (“I might not want to [be active], but I kinda have to, if I want to stay healthy” – *12-year-old boy, cardiology*), these benefits appeared to be more intrinsically valued by those with higher scores. As one child described: “I really think it’s important to stay in shape, and exercising is one of the things that will help with that. And I want to be strong.” – *8-year-old girl, cardiology.*

Evaluating movement context and risk of injury

Children who were interviewed from the higher-scoring cohort were able to evaluate and accept the risk of injury that is typically associated with physical activity. They were more comfortable with evaluating their surroundings for potential hazards while simultaneously engaging in physical activity. In sport contexts specifically, participants highlighted scenarios where they knew to change positions or introduce activity variations to mitigate their risk of injury. Meanwhile, some children with lower scores deliberately avoided scenarios where they perceived a greater risk of experiencing symptoms or injury ("Sometimes I just say no because I don't want to get a headache" – *10-year-old girl, neurology*), while others emphasized the importance of starting an activity slowly or in more controlled environments to mitigate risk. All children understood that participating at a maximal effort would introduce a greater risk of injury but emphasized that every person should be able to determine that limit for themselves ("Push yourself to a limit that is good enough for you" – *11-year-old boy, cystic fibrosis*). Overall, especially among children with higher scores, participating in sport was thought to be worth the associated risk because any potential injuries would be temporary.

Behavioural Domain

Participants with CMCs accumulated an average of 10,301 ± 3,737 steps per day and self-reported 3.98 ± 1.7 days of meeting moderate-to-vigorous physical activity guidelines per week. As such, most participants (68%) did not meet recommended levels of physical activity (12,000 steps per day). Age was the only significant predictor of this domain score ($F(4,79) = 3.09$, $p = .02$, $\eta_p^2 = .14$), with 11 and 12-year-old participants obtaining significantly lower scores than 9-year-old participants ($p < .05$).

Relying on school programs for physical activity means primarily participating in unstructured, recreational games.

All participants spoke about how they were achieving 30 to 60 minutes of physical activity at school each day. A couple of children (n=2) even felt as though getting "enough" physical activity was the responsibility of their teachers, with one saying: “It’s teachers who are deciding time [spent in physical activity]… they’re making sure we’re active [enough]” – *8-year-old boy, cardiology*. Participants played mostly recreational games at school (i.e., dodgeball, four square, races), which could also be less structured than traditional sport (e.g., shooting into the net with a soccer ball instead of playing a soccer game). Children who relied on school programs to meet physical activity guidelines were limited by what their school had to offer, as one participant explained, “I would maybe try out for a swimming team if my school has one, but it doesn’t” – *12-year-old boy, cardiology*. Meanwhile, children with higher scores spoke about bringing their extracurricular interests to the schoolyard and sharing those activities with their peers.

Extracurricular involvement in physical activity is driven by prior exposure to sport, accessibility and/or personal interests

Among all interview participants, 83% (n=10/12) of children with higher scores spoke about being enrolled in extracurricular activities in contrast to only 27% (n=3/11) of children with lower scores. Outside of school, participants with lower physical literacy scores spoke mostly about experiences in unstructured activities, like swimming and skating, or loosely structured activities, like imaginative games (i.e., field games, obstacle courses, etc.) and sports that were easily accessible in their neighbourhood (i.e., basketball, soccer, baseball). If these participants played neighbourhood sports, the rules of game play were typically more flexible, and they could stop playing at any time they chose. Meanwhile, participants from the higher-scoring group had all participated in multiple extracurricular activities. Most were enrolled in specialized, competitive leagues (i.e., hockey, cheerleading, soccer, equestrian), but had also been enrolled in other community-based programming at some point in the last few years (i.e., swimming, skating, martial arts, gymnastics). Children spoke about choosing to enroll, or remain enrolled, in activities that were interesting to them. Once they found an activity that they liked the most, participants with higher scores wanted to spend most of their time specializing in it. However, they remained open and eager to participate in other activities they found interesting, especially in less structured environments. Sampling a wide variety of sports was considered important for these children because it allowed them to find activities they enjoyed and learn new things.

Table 2. *Joint Display of Physical Literacy Domain Scores, Classifications and Themes*

Domain	Variable (Total possible points)	Mean ± SD or Median [IQR]	Number of participants per classification (% total N)	Themes	Quotes
Motivation and Confidence (Affective)	Intrinsic Motivation (7.5)	6.5 [2.5]	10 Beginning (10.1%) 41 Progressing (41.4%) 14 Achieving (14.1%) 34 Excelling (34.3%)	Physical activity is generally enjoyable but should also be personally meaningful	"I really like sports because I always have a specific goal I'm trying to do and there's just something I really wanna achieve during that time. I either want to get a [point] or stop one, or just try my best…. I feel motivated by how I feel once I reach those goals, or how I feel when I get something new, by doing any physical activity" – *10-year-old girl, high physical literacy score*
	Perceived Competence (7.5)	5.5 [2.0]			
	Predilection (7.5)	5.2 [2.9]			
	Adequacy (7.5)	5.5 [2.6]		Attitudes towards physical activity are heavily drawn from prior experiences	"I tried playing basketball, but I didn't like it… I couldn't even score. I couldn't even get the ball into the net." – *11-year-old boy, low physical literacy score*
	Total score (30)	22.90 ± 4.98			

Physical Competence	PACER score (10)	2.0 [3.0]	67 Beginning (68.4%) 22 Progressing (22.4%) 6 Achieving (6.1%) 3 Excelling (3.1%)	There is a need to learn how to self-regulate activity intensity alongside complex movement patterns and game constraints	"I'm okay with sitting out, but if I'm sitting out for an hour or something, then that's where it's like, I'm not going to want to do that." – *9-year-old boy, low physical literacy score*
	Plank score (10)	2.0 [4.0]			
	CAMSA score (10)	6.8 [2.9]		Practice is essential for skill progression, which is valuable for on-going participation	"I get really proud because, like it's weird to think about, [but] only a couple of years ago I was learning how to back walkover and I just now learned how to back flip" – *10-year-old girl, high physical literacy score*
	Total score (30)	11.81 ± 5.65			
Knowledge and understanding	Total score (10)	6.0 [4.0]	35 Beginning (35.7%) 29 Progressing (29.6%) 14 Achieving (14.3%) 20 Excelling (20.4%)	Physical activity can be defined in general terms	"[Physical activity means to] be physical with people and like always getting involved when someone's playing with another" – *11-year-old girl, low physical literacy score*

				Movement benefits overall health and well-being	"Basically, there's two types of tiredness at the end of the day. There's the tiredness that you get from being active all day and then there's the tiredness that you get from not doing anything all day. And with the tiredness from activity, you feel a lot better overall than with the tiredness from just doing nothing" *– 12-year-old boy, low physical literacy score*
				Evaluating movement context and risk of injury	"Something can always happen but that's literally life… I'm gonna take a risk because what if I really like this? What if I really like doing this sport or doing this activity? And [trying] it would be worth the risk." *– 12-year-old girl, high physical literacy score*
Daily Behaviour	Step Score (25)	12.8 ± 6.4	20 Beginning (23.5%) 48 Progressing (56.5%)	Relying on school programs for physical activity means primarily participating in unstructured, recreational games.	"I think I should [do 30 minutes to an hour of physical activity]. And I usually do get that, with like recess and gym class" *– 12-year-old boy, low physical literacy score*

	Self-reported Physical Activity Score (5)	3.0 [3.0]	12 Achieving (14.1%)	Extracurricular involvement in physical activity is driven by prior exposure to sport, accessibility and/or personal interests	"My mom just wanted me to try a couple different sports but now I'm going back [to gymnastics] because I didn't really find [another] one that suited me" – *12-year-old girl, high physical literacy score*
	Total Score (30)	15.52 ± 7.02	5 Excelling (5.9%)		
Total Physical Literacy	Total Score (100)	56.5 ± 13.8	33 Beginning (33.3%) 46 Progressing (46.5%) 13 Achieving (13.1%) 7 Excelling (7.1%)	Physical literacy contributes to a sense of self and one's identity.	"Someone like me with a heart defect, I don't find myself different than others. So, I would say [to someone who is nervous about physical activity], you're not any different, if anything you're even better." – *10-year-old girl, high physical literacy score*
				Physical literacy informs how to approach new experiences in physically active settings	"I always wanted to learn. It's something I'm good at, learning. I love learning new things so I can use it in games or at school as strategies and stuff" – *12-year-old boy, high physical literacy score*

Discussion

Most children with CMCs were assessed as beginning or progressing in their overall physical literacy journey, emphasizing the need for additional support. Where the relative contribution of the affective and domain scores to the total physical literacy score was expected to be proportionate (approximately 30% of the total score each) (Gunnell, Longmuir, Barnes, et al., 2018), our findings were similar to Do and colleagues (2021), where the motivation/confidence domain accounted for the largest proportion of total physical literacy among children with CMCs. Between clinics, total physical literacy score was only significantly different between endocrinology and hematology patients, which was subsequently reflected in the clinic distribution within the interview cohorts (Table 1). Qualitative differences between lower- and higher-scoring participants were generally evident in the behavioural domain, but also when navigating new experiences, perceiving risks in physically active settings, and in their overall attitudes towards physical activity. Participants whose interview data contained more overlap between the domains of physical literacy were among those with higher physical literacy scores (Figure 2).

Children with CMCs generally understood that participation in physical activity is beneficial for overall health, but this knowledge alone did not drive their behaviour. A comprehensive approach to physical activity counselling for pediatric patients with CMCs, which includes establishing meaningful goals, providing resources to help families overcome barriers, and referring patients to community-based programming, is therefore recommended (Lobelo et al., 2020). Based on the differences between children with higher and lower levels of physical literacy in the current study, specific strategies for promoting physical literacy to children with CMCs might also include: 1) adopting individualized, strengths-based approaches to physical activity promotion (i.e., focus on child’s interests and physical/emotional strengths when discussing opportunities for physical activity); 2) teaching skills for self-regulation, risk assessment and movement modification; and 3) encouraging patients to recognize and reflect on success when practicing active skills.

The only significant difference observed between clinical groups was in the total physical literacy scores of endocrinology and hematology patients. Despite what was anticipated from prior reviews of the literature (Bennett et al., 2021; Constantinou et al., 2021; Shorey and Ng, 2020), conversations about physical activity with participants were not centered around their diagnoses nor medical limitations. Therefore, the qualitative data collected did not provide much explanation for this between-clinic difference. Many participants would mention fatigue as a general symptom but had to be prompted to discuss how their experiences living with a CMC, including related symptoms like fatigue, influenced their participation in certain activities. Without further explanation from the interview participants, we speculate that the observed difference between groups may be due to the combined activity restrictions and consequent pain crises potentially experienced by children with sickle cell disease when participating in higher intensities of physical activity (Constantinou et al., 2021). Meanwhile, children with type 1 diabetes are often provided with physical activity education to help manage symptoms during high intensity activities (Livny et al., 2020). Surprisingly, clinical group had no effect on physical competence, despite known differences in pathophysiology (West et al., 2019). This suggests that living with a CMC during childhood may impact physical competence in ways that are indirectly related to diagnosis. For example, children with CMCs who are excluded from play contexts that are deemed potentially unsafe are not afforded the same opportunities to develop physical competence through practice as their typically healthy peers.

Physical competence is often a primary outcome of interest in clinical research for children with CMCs because of its relationship to health outcomes and meeting physical activity guidelines (Janssen and LeBlanc, 2010). Yet, among participants who were achieving or excelling in their total physical literacy and meeting daily physical activity guidelines, most (~73%) were still considered beginning or progressing in their physical competence. While a baseline level of physical competence helps facilitate active play, children with CMCs may not need to meet the same fitness standards or skill criteria as otherwise healthy peers to meaningfully participate in physical activity and gain subsequent health benefits. Themes developed within the physical domain also highlight an individualistic perspective of physical competence that was embodied by children with CMCs; learning how to participate in physical activity at a self-directed pace and comparing oneself to personal metrics/milestones can be helpful tools to develop physical competence. This reinforces and emphasizes the concept of physical literacy as a lifelong journey (Whitehead, 2010) and the importance of designing physical activity interventions following established theories of behaviour change (Rhodes and Nigg, 2011), rather than traditional methodologies based on fitness training principles.

The affective domain was the main contributor to total physical literacy scores and the most prominent domain coded throughout the interview data. Participants with lower scores still enjoyed physical activity but relied more heavily on extrinsic motivation. This aligns with self-determination theory (Deci and Ryan, 1985), positing that motivation is strongest when more internalized (less extrinsic) factors are driving behaviour. Meanwhile, contexts which promote a sense of competence, autonomy and relatedness are more likely to promote intrinsic sources of motivation, including among children with CMCs (Brynjulfsen et al., 2021; Gauthier et al., 2020). Prior experiences informing the attitudes of participants with CMCs in the current study similarly contained elements of relatedness (e.g., being able to play with peers), competence (e.g. learning skills) and autonomy (e.g. practicing skills at their own pace). These and other principles can be drawn upon to characterize how individuals derive personal meaning from physical activity. Reported elements of meaningful participation which also contributed to participants' motivation for physical activity in the current study included having fun, having an identity, learning, feeling successful and belonging (Willis et al., 2017). Our findings therefore indicate that fostering meaningful engagement in physical activity is a salient factor when developing physical literacy among children with CMCs.

Boys in this study had significantly higher total physical literacy scores in comparison to girls, with a small-to-medium effect. This contrasts with the negligible gender differences in physical literacy observed among the general population (Tremblay et al., 2018). Meanwhile, the only other recent examination of physical literacy outcomes among a diverse group of children with CMCs did not include gender nor sex in their analyses (Do et al., 2021). Although boys generally scored higher than girls on the CAPL-2 in our study, this was surprisingly not reflected by the score-based sampling method for the semi-structured interviews; an equal proportion of boys to girls were invited from each of the lower-scoring and higher-scoring groups to participate. Moreover, most of the participants in the higher-scoring interview cohort were girls. During the qualitative analysis, gender was consistently reviewed and considered as a contextual factor when interpreting the interview data, but overall gender differences were not evident nor examined in the formation of themes. This further emphasises the relevance of adopting an individualised approach when promoting physical activity to children with CMCs, as gender norms may be influencing their development in a way not highlighted by the current findings. Individualised approaches could also effectively support the physical literacy development of children who identify as non-binary, whose perspectives were not included in the interview data. One of the most notable differences between the high- and low-scoring cohorts was their involvement in school and extracurricular physical activities; 56% more interview participants with higher scores participated in extracurriculars compared to the lower-scoring group. Prior experiences influenced participants' desires to enrol in extracurriculars, meaning physical literacy could equally be considered an antecedent or consequence to participation in those physical activities (Edwards et al., 2017). Meanwhile, school-based opportunities for physical activity described by participants with CMCs were typically unstructured or deliberate play contexts. Although these opportunities are undoubtedly important for overall well-being in childhood (Lee et al., 2020), on their own they are perhaps insufficient to promote the required physical literacy to continue engagement in physical activity through adolescence and into adulthood, where unstructured, play-based activities (i.e., imaginative games) are much less common. Nevertheless, it was promising that most participants adopted a general definition of physical activity. When there is a change in health status (i.e., temporary exercise restriction, change in medication affective bleeding risk, etc.), it may be important to emphasize this general definition of movement, as it could encourage participation in safe physical activities and potentially mitigate the inclination to revert to sedentary activities (i.e., increased screen time, social media use). The implementation of generally flexible yet structured physical activity interventions targeting children with CMCs who require support with their physical literacy should therefore be considered.

Limitations

All data were collected between 2021 and 2022, following the onset of the COVID-19 pandemic when social distancing and subsequent changes to children's physical activity contexts were prominent (Paterson et al., 2021). While separate analyses of these data were conducted within the context of the COVID-19 pandemic (see Chapter 3, p. 49), it is important to acknowledge the potential impact the pandemic had on the results of this study. All interviewed participants were asked to describe their participation in physical activity before, during and after the lockdowns (when applicable), and informal discussions with participants and/or their parents during the CAPL-2 sessions provided additional context to their lived experiences. As well, since physical literacy is considered a journey that can change across the life course (Whitehead, 2010), we could not guarantee that individual scores were unchanged from when children with CMCs completed the CAPL-2 to when they participated in the interview. The physical literacy experiences of participants represented by the qualitative data are limited to those of boys and girls, as the two non-binary participants did not score in the top nor bottom quartile of their sampling group. Our results are also limited to the clinical groups that were approached as part of the recruitment strategy; children with CMCs followed in other pediatric outpatient clinics, such as rheumatology, gastroenterology, and nephrology, may have similar experiences with navigating physical activity but were not represented in this study. As with most clinical physical activity research, participants who were likely to enroll may have also been those who were already interested in being physically active. While this bias may have influenced the relatively high levels of motivation and confidence observed among participants, our findings illustrated that most children with CMCs would benefit from additional support in all domains of physical literacy to meet their embodied potential for engaging in an active lifestyle.

Conclusion

Physical literacy can and should be developed through diverse movement and learning experiences that are personally meaningful to individuals. The novel, comprehensive investigation of physical literacy development among children with CMCs in this study indicates that they can indeed achieve meaningful milestones in their physical literacy journeys, without meeting the physical competence standards of otherwise healthy children. However, our findings suggest that most children with CMCs would benefit from additional support in all domains to achieve their personal physical literacy potential. Overall, this study provides a more comprehensive illustration of physical literacy development among children with CMCs than what is currently available in the literature. Opportunities to practice physical self-regulation strategies and develop confidence in risk evaluation would be particularly useful for this population, as they learn how to safely maintain physical activity participation regardless of changes in their health. Findings should be applied to tailor the design of physical literacy-based interventions towards the specific needs of children who experience chronic disease.

References

Arbour-Nicitopoulos, K. P., Bremer, E., Leo, J., and Wright, F. V. (2023). A pragmatic approach to measuring physical literacy and behavioural outcomes in youth with and without disabilities. *Leisure*, *47*(3), 209–233. https://doi.org/10.1080/14927713.2022.2085157

Belanger, K., Barnes, J. D., Longmuir, P. E., Anderson, K. D., Bruner, B., Copeland, J. L., Gregg, M. J., Hall, N., Kolen, A. M., Lane, K. N., Law, B., MacDonald, D. J., Martin, L. J., Saunders, T. J., Sheehan, D., Stone, M., Woodruff, S. J., and Tremblay, M. S. (2018). The relationship between physical literacy scores and adherence to Canadian physical activity and sedentary behaviour guidelines. *BMC Public Health*, *18*(S2), 1042. https://doi.org/10.1186/s12889-018-5897-4

Bennett, E. V., Voss, C., Faulkner, G., and Harris, K. C. (2021). From 'it makes me feel free' to 'they won't let me play': the body and physical activity-related perceptions and experiences of children with congenital heart disease and their parents. *Qualitative Research in Sport, Exercise and Health*, *13*(2), 325–341. https://doi.org/10.1080/2159676X.2019.1710858

Boyer, C., Tremblay, M., Saunders, T. J., McFarlane, A., Borghese, M., Lloyd, M., and Longmuir, P. (2013). Feasibility, validity and reliability of the plank isometric hold as a field-based assessment of torso muscular endurance for children 8-12 years of age. *Pediatric Exercise Science*, *25*(3), 407–422. https://doi.org/10.1123/pes.25.3.407

Braun, V., and Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Brynjulfsen, T., Demmelmaier, I., Berntsen, S., Foyn, H., Andersen, K., Stang, J., Sigdestad, J. B., Stensrud, T., Tufte, K., Nielsen, A., and Westergren, T. (2021). Motivation for physical activity in adolescents with asthma. *Journal of Asthma*, *58*(9), 1247–1255. https://doi.org/10.1080/02770903.2020.1778025

Coleman, N., Nemeth, B. A., and Leblanc, C. M. A. (2018). Increasing Wellness Through Physical Activity in Children with Chronic Disease and Disability. *Current Sports Medicine Reports*, *17*(12), 425–432. https://doi.org/10.1249/JSR.0000000000000548

Constantinou, C., Payne, N., van den Akker, O., and Inusa, B. (2021). A qualitative exploration of health-related quality of life and health behaviours in children with sickle cell disease and healthy siblings. *Psychology and Health*, *38*(1), 125-146. https://doi.org/10.1080/08870446.2021.1955119

Cornish, K., Fox, G., Fyfe, T., Koopmans, E., Pousette, A., and Pelletier, C. A. (2020). Understanding physical literacy in the context of health: a rapid scoping review. *BMC Public Health*, *20*(1). https://doi.org/10.1186/s12889-020-09583-8

Deci, E. L., and Ryan, R. (1985). *Intrinsic motivation and self-determination in human behaviour*. New York: Plenum.

Delisle Nyström, C., Barnes, J. D., and Tremblay, M. S. (2018). An exploratory analysis of missing data from the Royal Bank of Canada (RBC) Learn to Play - Canadian

Assessment of Physical Literacy (CAPL) project. *BMC Public Health*, *18*(Suppl 2). https://doi.org/10.1186/s12889-018-5901-z

Do, J., Blais, A., Feldman, B., Brandão, L. R., Lougheed, J., Pohl, D., … Longmuir, P. E. (2021). Characterization of physical literacy in children with chronic medical conditions compared with healthy controls: A cross-sectional study. *Applied Physiology, Nutrition and Metabolism*, *46*(9), 1073–1082. https://doi.org/10.1139/apnm-2020-0957

Edwards, L., Bryant, A., Keegan, R., Morgan, K., and Jones, A. (2017). Definitions, Foundations and Associations of Physical Literacy: A Systematic Review. *Sports Medicine*, *47*(1), 113–126. https://doi.org/10.1007/s40279-016-0560-7

Francis, C. E., Longmuir, P. E., Boyer, C., Andersen, L. B., Barnes, J. D., Boiarskaia, E., … Shephard, R. J. (2016). The Canadian Assessment of Physical Literacy: Development of a Model of Children's Capacity for a Healthy, Active Lifestyle Through a Delphi Process. *Journal of Physical Activity and Health*, *13*(2), 214–222. https://doi.org/10.1123/jpah.2014-0597

Gauthier, N., Curran, T., O'Neill, J. A., Alexander, M. E., and Rhodes, J. (2020). Establishing a Comprehensive Pediatric Cardiac Fitness and Rehabilitation Program for Congenital Heart Disease. *Pediatric Cardiology*, *41*(8), 1569–1579. https://doi.org/10.1007/s00246-020-02413-z

Gunnell, K. E., Longmuir, P. E., Barnes, J. D., Belanger, K., and Tremblay, M. S. (2018). Refining the Canadian Assessment of Physical Literacy based on theory and factor analyses. *BMC Public Health*, *18*(Suppl 2), 1044. https://doi.org/10.1186/s12889-018-5899-2

Hay, J. A. (1992). Adequacy in and predilection for physical activity in children. *Clinical Journal of Sport Medicine*, *2*(3), 192–201. https://doi.org/10.1097/00042752-199207000-00007

Janssen, I., and Leblanc, A. G. (2010). Systematic review of the health benefits of physical activity and fitness in school-aged children and youth. *The International Journal of Behavioral Nutrition and Physical Activity*, *7*(1), 40. https://doi.org/10.1186/1479-5868-7-40

Lee, R. L. T., Lane, S., Brown, G., Leung, C., Kwok, S. W. H., and Chan, S. W. C. (2020). Systematic review of the impact of unstructured play interventions to improve young children's physical, social, and emotional wellbeing. *Nursing and Health Sciences*, *22*(2), 184–196. https://doi.org/10.1111/nhs.12732

Livny, R., Said, W., Shilo, S., Bar-Yoseph, R., Gal, S., Oren, M., Levy, M., Weiss, R., Shehadeh, N., Zuckerman-Levin, N., and Cohen, M. (2020). Identifying sources of support and barriers to physical activity in pediatric type 1 diabetes. *Pediatric Diabetes*, *21*(1), 128–134. https://doi.org/10.1111/PEDI.12938

Lobelo, F., Muth, N. D., Hanson, S., Nemeth, B. A., (2020). Physical activity assessment and counseling in pediatric clinical settings. *Pediatrics*, *145*(3). https://doi.org/10.1542/peds.2019-3992

Longmuir, P. E., Boyer, C., Lloyd, M., Borghese, M. M., Knight, E., Saunders, T. J., Boiarskaia, E., Zhu, W., and Tremblay, M. S. (2017). Canadian Agility and Movement Skill Assessment (CAMSA): Validity, objectivity, and reliability evidence for children 8–12 years of age. *Journal of Sport and Health Science*, *6*, 231–240. https://doi.org/10.1016/j.jshs.2015.11.004

Longmuir, P. E., Boyer, C., Lloyd, M., Yang, Y., Boiarskaia, E., Zhu, W., and Tremblay, M. S. (2015). The Canadian Assessment of Physical Literacy: methods for children in grades 4 to 6 (8 to 12 years). *BMC Public Health*, *15*(1), 767. https://doi.org/10.1186/s12889-015-2106-6

Longmuir, P. E., Gunnell, K. E., Barnes, J. D., Belanger, K., Leduc, G., Woodruff, S. J., and Tremblay, M. S. (2018). Canadian Assessment of Physical Literacy Second Edition: A streamlined assessment of the capacity for physical activity among children 8 to 12 years of age. *BMC Public Health*, *18*(Suppl 2), 1047. https://doi.org/10.1186/s12889-018-5902-y

Paterson, D. C., Ramage, K., Moore, S. A., Riazi, N., Tremblay, M. S., and Faulkner, G. (2021). Exploring the impact of COVID-19 on the movement behaviors of children and youth: A scoping review of evidence after the first year. *Journal of Sport and Health Science*, *10*(6), 675–689. https://doi.org/10.1016/J.JSHS.2021.07.001

Pohl, D., Alpous, A., Hamer, S., and Longmuir, P. E. (2019). Higher screen time, lower muscular endurance, and decreased agility limit the physical literacy of children with epilepsy. *Epilepsy and Behavior*, *90*, 260–265. https://doi.org/10.1016/j.yebeh.2018.05.010

Pot, N., Whitehead, M. E., and Durden-Myers, E. J. (2018). Physical Literacy From Philosophy to Practice. *Journal of Teaching in Physical Education*, *37*(3), 246–251. https://doi.org/10.1123/jtpe.2018-0133

Rhodes, R. E., and Nigg, C. R. (2011). Advancing physical activity theory: A review and future directions. *Exercise and Sport Sciences Reviews*, *39*(3), 113–119. https://doi.org/10.1097/JES.0b013e31821b94c8

Scott, S. N., Thompson, D. L., and Coe, D. P. (2013). The ability of the PACER to elicit peak exercise response in the youth. *Medicine and Science in Sports and Exercise*, *45*(6), 1139–1143. https://doi.org/10.1249/MSS.0b013e318281e4a8

Sebire, S. J., Jago, R., Fox, K. R., Edwards, M. J., and Thompson, J. L. (2013). Testing a self-determination theory model of children's physical activity motivation: a cross-sectional study. *International Journal of Behavioral Nutrition and Physical Activity*, *10*, 111. https://doi.org/10.1186/1479-5868-10-111

Shorey, S., and Ng, E. D. (2020). The lived experiences of children and adolescents with non-communicable disease: A systematic review of qualitative studies. *Journal of Pediatric Nursing*, *51*, 75–84. https://doi.org/10.1016/j.pedn.2019.12.013

Tang, Y., Algurén, B., Pelletier, C., Naylor, P. J., and Faulkner, G. (2023). Physical Literacy for Communities (PL4C): physical literacy, physical activity and associations with wellbeing. *BMC Public Health*, *23*(1), 1–16. https://doi.org/10.1186/S12889-023-16050-7/FIGURES/2

West, S. L., Banks, L., Schneiderman, J. E., Caterini, J. E., Stephens, S., White, G., Dogra, S., and Wells, G. D. (2019). Physical activity for children with chronic disease; A narrative review and practical applications. *BMC Pediatrics*, *19*, 12. https://doi.org/10.1186/s12887-018-1377-3

Whitehead, M. (2001). The concept of physical literacy. *European Journal of Physical Education*, *6*(2), 127–138. https://doi.org/10.1080/1740898010060205

Whitehead, M. (2010). *Physical Literacy: Throughout the life course.* New York: Routledge. https://doi.org/10.4324/9780203881903

Willis, C., Girdler, S., Thompson, M., Rosenberg, M., Reid, S., and Elliott, C. (2017). Elements contributing to meaningful participation for children and youth with disabilities: a scoping review. *Disability and Rehabilitation*, *39*(17), 1771–1784. https://doi.org/10.1080/09638288.2016.1207716

Article 3: "I Can Play Anything": A Community-Based Physical Literacy Program for Children with Chronic Medical Conditions

Abstract

Background: The physical literacy development of children with medical conditions can be compromised by physical and psychological limitations, unique from those living with visible disabilities. Community-based recreation settings have been suggested as ideally suited to support physical literacy development. Thus, the purpose of this study was to reflect on how children with medical conditions develop physical literacy within a community-based program setting.

Methods: A mini-ethnographic case study design incorporating multiple qualitative methods was applied to capture participants' experiences within the "I Can Play Anything", a physical literacy-based, multi-sport program. Nine children with medical conditions participated in the 8-week, physical literacy-based program. Weekly field notes during program participation and a post-program focus group or interview were completed. Open-ended questionnaires collected parent feedback at weeks 4 and 8 of the program.

Results: Data collected during the "I Can Play Anything" program highlighted the various expectations, applications, and implications of participation among children with medical conditions. Combined, those ideas were used to develop themes relating to physical literacy development in community-based settings, including: 1) learning to play ("there are many things that he can do, and [he] should be willing to look at new experiences", 2) inclusion supported by individualised variations, incorporating creativity and flexibility ("even if I can't do what I'm supposed to do I can still get through it my own way"), and 3) understanding one's need for rest and embodied self-awareness ("some kids might have a lot of energy and some kids might not have a lot of energy").

Conclusions: Community-based programs aiming to address principles of physical literacy can be meaningful contexts for children with medical conditions to participate in physical activity. Practitioners in these settings should be flexible and creative in their delivery of activity variations, as well as prompt for bodily self-awareness so that children become more comfortable recognising when they need rest.

Introduction

The concept of physical literacy has gained recent momentum in the field of sport and recreation pedagogy for its holistic approach, which considers the multidimensional and collective influence of physical, cognitive, and affective factors relevant to physical activity engagement. Physical literacy has since been applied to inform program design and relevant outcome measures for children and youth participating in recreational sport (Carl et al., 2022; Liu and Chen, 2020). Building from the philosophical assumptions of monism, existentialism and phenomenology, Whitehead (2010) posits that physical literacy is an individual journey, where the compass points towards one’s personal potential for participation. This perspective of physical literacy lends itself particularly well to the operationalization of inclusive physical activity programs (Pushkarenko et al., 2021).

Inclusion can be broadly defined as a process which mitigates barriers to participation (UNESCO, 2017). In recreational youth physical activity settings, the term is usually contextualized to the experiences of children living with physical or intellectual disabilities who encounter environmental and/or social barriers to participation. Children living with chronic medical conditions also face barriers which uniquely impact their overall participation in physical activity among typically healthy peers but are differentiated from those who experience disability (Goering, 2015). Typical barriers experienced by this population include the need to cease participation to address disease management (e.g. eating a snack to prevent hypoglycemia when living with type 1 diabetes; Jabbour et al., 2016), limitations in cardiorespiratory endurance (e.g. a child with a treated congenital heart defect who only has one functional ventricle; Moola et al., 2011), delays in motor development (Bolduc et al., 2020; David and MacAllister, 2022; Gruber et al., 2021), and experiencing negative stigma from peers or recreation leaders who misunderstand their capabilities (e.g. a child with epilepsy who sits out during tag games because their teacher is worried about the possibility they may experience a seizure while running; Fereday et al., 2009; Fried et al., 2021; Johnson et al., 2021; Moola et al., 2011).

Achieving a physically active lifestyle is a requisite for disease management and long-term well-being among this diverse population (Coleman et al., 2018). Currently, over one fifth of Canadian children are living with a chronic medical condition (Queenan et al., 2021), of which most are not participating in enough physical activity to achieve or maintain overall benefits (Elmesmari et al., 2022). Thus, there is a critical need to effectively promote physical activity to this population. While community-based physical activity settings have been suggested as ideal environments to address this need (Longmuir et al., 2013; MacMillan et al., 2016), previous studies have also described how children living with chronic medical conditions may be excluded from full participation in these settings (Moola, 2020; Nap-Van Der Vlist et al., 2021). Applying a physical literacy-based approach to recreational sport programs delivered to children living with chronic medical conditions therefore warrants study.

While there is an emerging body of literature on including children with disabilities in physical literacy programs (Arbour-Nicitopoulos, Boross-Harmer, et al., 2018; Pushkarenko et al., 2021), the experiences of children with chronic medical conditions are unique from those living with disabilities, and should be examined as such. This difference is not only evident in the barriers and potential risks they must navigate, but also in how they choose to disclose their needs in active settings, as many live with what might be considered an "invisible disability". Therefore, the purpose of this study was to reflect on how children with chronic medical conditions develop physical literacy in community-based program settings. The "I Can Play Anything" multi-sport program was the context of this research, designed as an inclusive community-based program informed by Whitehead's concept of physical literacy.

Methodology

Philosophical Assumptions

The concept of physical literacy was central to the design and delivery of the "I Can Play Anything" community-based program, and thus the interpretation of this study. Physical literacy assumes a) a monist perspective of the individual, where the body and mind work in tandem and are equally important in the participation of physical activity; and b) an existentialist perspective, where individuals develop through interactions with their environment (Pot, Whitehead, and Durden-Myers, 2018). In the current research context, these ontological assumptions posit that individual experiences within the community-based program were equally informed by physicality, affect and cognition. We are also situated epistemologically in constructivism, which acknowledges that the meanings and experiences throughout the community-based program were both individually and socially constructed.

Research Design

A mini-ethnographic case study design was applied to capture the experiences of a single group of children with chronic medical conditions participating in a community-based physical activity program. Case studies examine an individual or situation (i.e., children with medical conditions) within a specific context (i.e., the "I Can Play Anything" program) by using a variety of methods to capture the complexities of the case (Yin, 2014). Moreover, ethnographic methods were considered highly relevant to the research question, as we explored the various perceptions and meanings of participating in the community-based program with the added context of living with a chronic medical condition. Namely, an ethnography allowed our understanding of the program's design/delivery to be reflected upon alongside participants' unique experiences, using a physical literacy-based lens. Unfortunately, given the constraints of this research following the COVID-19 pandemic, there was not the time nor resources to commit to a more traditional, ethnographic approach. Instead, a mini-ethnographic case study was chosen as a blended design, which is recognized as ideal for studies which necessitate the use of traditionally ethnographic methods, but with limited time and contextual constraints more typical of a case study (Bayeck, 2023; Fusch et al., 2017).

Participants

Children living with chronic medical conditions between the ages of 8 to 12 years old, who had participated in a recent study of physical literacy development (Chapter 3, Article 2, p. 79), were recruited to participate. All participants had been recruited from outpatient cardiology, endocrinology, respirology/cystic fibrosis, haematology, and neurology clinics at our affiliated children's hospital. Participants were diagnosed with a chronic medical condition that was considered moderate to significant in severity by their responsible physician, had a stable health status and were medically cleared to participate in physical activity. Potential participants could speak and understand English, while none lived with any significant physical or intellectual disability.

There were several reasons why we recruited our sample of participants from an existing physical literacy study. Many participants had shared preliminary ideas about their ideal community-based program as part of the previous research, which were then applied to help inform the current study. We had also collected data on their physical literacy development and had established existing relationships with those participants and their families, both of which provided helpful context to reporting and interpreting their experiences throughout the program. Pseudonyms given to all participants are listed alongside contextual demographic and physical literacy information in Table 1. Finally, the logistic support of parents is instrumental in a child's involvement in extracurricular, community-based activities (Hutchens and Lee, 2018), therefore parents were also enrolled in the study (one parent for each child).

Table 1. *Participant pseudonyms, demographic and contextual information*

Pseudonym	Age	Gender	Diagnosis(es)	Number of ICPA sessions attended (% of all sessions)	Pre-determined level of PL
Khalid*	10	Boy	Type 1 diabetes	11 (69%)	Beginning
Harrison	10	Boy	Epilepsy	14 (88%)	Progressing
Taylor	11	Girl	Obesity, sleep apnea	13 (81%)	Beginning
Charlotte	9	Girl	Cystic fibrosis	2 (13%)	Achieving
Shreya*	11	Girl	Type 1 diabetes, unspecified bone condition	9 (56%)	Excelling
Ava	11	Girl	Type 1 diabetes	11 (69%)	Progressing
John	9	Boy	Congenital heart disease	13 (81%)	Beginning
Omar†	9	Boy	Type 1 diabetes	1 (6%)	Progressing
Caleb†	8	Boy	Sickle cell disease	1 (6%)	Beginning

*Note: PL = physical literacy; ICPA = "I Can Play Anything" multi-sport program; * Indicates a participant who participated in an interview instead of the post-program focus group; † Indicates participants who withdrew or were lost to follow-up during the study.*

Community-Based Physical Literacy Program: "I Can Play Anything"

All participants were enrolled in the 8-week "I Can Play Anything" (ICPA) multi-sport program, situated in a community-based recreational complex in Ottawa, Ontario. The ICPA program was designed using Whitehead's conceptualization of physical literacy (Whitehead, 2001, 2010) as a theoretical guide (Appendix F), while employing Lubans and colleagues' "SAAFE" teaching principles (i.e., Supportive, Active, Autonomous, Fair and Enjoyable) as a framework for program delivery (Lubans et al., 2017). Teaching principles within this framework were designed using relevant concepts from self-determination theory, achievement goal theory, Epstein's TARGET framework and competence motivation theory. When participants in the previous study were asked about the planned components of the ICPA program, their input on the importance of certain skills, coaching practices and games were implemented into the design and framework of the lesson plans (Appendix G). Over the 8-week session, participants were introduced to seven different sports: basketball, volleyball, archery, ultimate frisbee, curling, badminton, and pickleball. A new sport was played every week during two, one-hour lessons (2 hours of programming in total per week). Except for the last week, each lesson plan included: a warm-up with an instructional component (i.e., sport-specific terminology, activated muscle groups), an individual skill, an obstacle course applying at least one sport-specific skill, a cooperative skill, a competitive game, and a cool-down activity (Appendix H). The last week of the ICPA program was delivered as "player's choice", where participants had a wide variety of equipment to choose from to work on their sport-specific skills, to play sports, or create new games.

There were two leaders responsible for facilitating all lessons, two volunteer leaders to provide additional support to participants, and the first author, who oversaw the delivery of all lessons. Leaders of the ICPA program attended an educational training seminar with the first author, where they were briefed on the theoretical rationale of the program and how to facilitate physical literacy-based instructions through lesson plans (Appendix G). All leaders also received training on how to accommodate potential activity restrictions, including how to deliver prompts and adaptations to encourage breaks when needed, as well as common signs and symptoms indicating a child's need for rest or medical intervention. To ensure participant safety during the ICPA program, leaders were informed about enrolled participants' activity restrictions/considerations as well as their diagnoses (i.e., monitoring for hypoglycaemia in type 1 diabetes, dyspnoea in children with heart conditions, etc.).

Data Collection

The integration of various perspectives (children, parents, researcher) over the course of a weekly program warranted the use of multiple methods over the course of this research (Darbyshire et al., 2005; Markula and Sparkes, 2015). While there was some overlap in timing, the following methods were generally administered consecutively in the listed order below.

Field Notes

Field notes were recorded during and immediately following each lesson of the ICPA program. Descriptive, reflexive, and reflective field notes (Jeffrey, 2018) were written and collated each week (i.e., one set of field notes for each sport). Descriptive information that was commonly reported in the field notes included any disruptions or changes in the intended delivery of the lesson plans, how participants emotionally responded to the activities (i.e., excitement, frustration, etc.), how feedback was received and applied, collaborations or disputes between participants, observed or perceived skill development, and researcher perceptions of participants' physical exertion.

The first author wrote all field notes while consulting with one of the volunteer leaders, who had prior experience in coaching and was an undergraduate Human Kinetics student. There were also frequent check-ins and reflections with the other three leaders who were delivering the program, which provided additional breadth to the data. Finally, content recorded in the field notes were reviewed bi-weekly during check-ins with the supervising author, who did not attend the ICPA program but could provide an informed perspective given their extensive knowledge of children with chronic medical conditions and recreational sport.

Open-Ended Questionnaires

Parents were sent an open-ended questionnaire via e-mail at weeks 4 (halfway) and 8 of the ICPA program. The questions remained the same at both time points, which prompted parents to describe their child's eagerness to attend the weekly sessions, what they perceived their child had learned from participating, as well as general feedback of their experience, including perceived strengths and weaknesses of the program.

Focus Groups and Interviews

Four days after the final session of the ICPA program, a focus group was conducted with available participants. At the beginning of the focus group, participants were asked to create a comic strip or story board, illustrating a child's experience in the ICPA program (Appendix I). Participants were given a legend containing symbols and corresponding emotions, which they could incorporate into their stories to help them illustrate emotions experienced during the program (e.g.., excited, disappointed, fun, tired, supported, nervous, etc.). Unstructured questions prompted participants to describe their illustrations/stories to the group and in relation to their personal experience within the program. Once all stories were shared, participants were asked to provide feedback on what they enjoyed most about the ICPA program and how they thought the experience could have been improved. The first author facilitated the focus group discussion, having prior experience conducting focus groups with preadolescent children. This method of using comic book and story board templates to guide participants' reflections of their experiences was piloted by our research group during a previous intervention study among children with chronic medical conditions and disabilities.

Due to scheduling constraints, not all participants were available for the focus group session. Those who were unable to attend the focus group instead participated in an individual interview with the first author. The interview used the same format as the focus group. However, instead of questions prompting the group's perspective (i.e., "did anyone else feel that way?"), interview participants were asked to give their input on ideas that their peers had shared during the focus group. Focus groups and interviews were audio recorded and transcribed, with illustrations collected as reference materials for data analysis.

Data Analysis

All data were analysed using Braun and Clarke's reflexive thematic analysis (Braun and Clarke, 2019), applying an inductive, semantic approach to develop themes (Braun and Clarke, 2006). To ensure epistemological reflexivity in the analysis (Dowling, 2006), an iterative framework suggested by Srivastava and Hopwood (2009) was also applied throughout coding and analysis. This framework was comprised of three questions (What are the data telling me? What is it I want to know? What is the relationship between what the data are telling me and what I want to know?), which were consistently referred to throughout the analyses. All results were interpreted and reported from the perspective of the first author ("I"). During each week of the ICPA program, field notes were continuously reviewed and coded to ensure that I was adequately applying current contextual knowledge and reflexivity to the on-going analysis. Illustrations and written materials from participants were consulted alongside focus group transcripts and field notes to provide additional context to these data during the final analysis period.

Following the iterative framework during the first two stages of data analysis (familiarizing oneself with the data and generating codes), I decided to focus on three distinct ideas about how I wanted to move forward with the remaining analyses. These ideas were that: a) Children with chronic medical conditions hold certain expectations of community-based physical activity programs, based on prior experiences, personal desires, and their own capabilities ("expectations"); b) Since physical literacy is a holistic and individualized phenomenon, the community-based program should differ from a traditional intervention in that it is malleable for the changing needs and considerations of its participants ("applications"); and c) The perceived implications of the experience in the ICPA program will influence one's desire for similar experiences and, thus, on-going physical literacy development ("implications"). Once all data were collected and coded, codes were grouped, collated, and compared across those three ideas (i.e., expectations, applications, and implications) to develop main themes.

Self-Reflexivity

In addition to epistemological reflexivity, ensuring there is personal reflexivity allows for a more transparent and "bracketed" account of the research findings (Dowling, 2006). This is particularly important for ethnographic methodologies, where the researcher is intimately involved in the research context (Williamson, 2006). I have been conducting physical activity research at a local children's hospital for almost 8 years, where I have worked in multiple outpatient clinics and primarily with children who live with congenital heart disease. This experience has given me a relatively comprehensive understanding of where children living with chronic medical conditions need support to successfully participate in desirable physical activities. I have experienced for myself how living with a medical condition can inform participation in physical activity; when I was a child, I was diagnosed with a type of congenital heart disease that was considered mild to moderate in severity. I grew up with access to various activities and sports but throughout my youth I remained more interested in dance and the performing arts. I have been a dance instructor for 16 years and have several years' experience as a recreational, multi-sport coach. My personal preferences and expectations for physical activity instruction in recreational settings have evolved as I have continuously learned more about relevant psychological principles, child development, and physical literacy.

I wanted to, initially, dedicate a large portion of my doctoral research program to the design and implementation of the ICPA program among children with chronic medical conditions (including coach behaviours and perceptions). Unfortunately, I had to adjust my overall research so that it would be more feasible within the context of the pandemic. However, I was decidedly determined to include this project into my overall research program because I wanted to use my knowledge and resources to facilitate a successful (i.e., enjoyable, worthwhile) physical activity experience for children with chronic medical conditions. This study was a unique type of ethnography, such that I was creating a social environment that participants were interacting with, while also observing and reporting on those interactions. Having situated myself as an expert in the ICPA program environment, I would often take active responsibility for changes to the lesson plans and/or variations that I thought would be more appropriate for individual participants. Given my expertise and the existing relationships I had established with participating parents and children, I also felt responsible for ensuring the program was consistently delivered as intended. If I had taken a more passive role instead, I feared that I would lose participants' trust in the process. Although I have never done a full ethnography, I was interested in the opportunity to incorporate my own experiences into the data, given my passion for this project and population. These biases should be considered when interpreting these results.

Results

Nine children with chronic medical conditions were enrolled in this study (Table 1), however, two of those participants (Omar and Caleb) did not complete any of the study tasks (i.e., questionnaires, interview/focus group), and thus were only represented by a portion of the field note data. Omar withdrew from the study due to a decline in his health status while Caleb and his family were lost to follow-up. Shreya and Khalid were the only other participants who did not attend the focus group due to scheduling constraints, opting to participate in the interviews instead. Overall, participants were eager to attend the ICPA sessions and found them enjoyable. In the questionnaires, parents reflected on the value they perceived in the program, including how it gave their children more confidence in physical activities and the opportunity to try new sports.

Main themes represent the combined expectations, applications, and potential implications reported and observed among children with chronic medical conditions who participated in the physical literacy-based program.

Learning to Play

Children who participated in the ICPA program were given time to learn and refine basic skills from different sports each week. Focusing on basic, sport-specific skills (e.g., passing, serving, scoring) was considered an essential component of the curriculum for this population. The rationale for this was that children with CMCs may require additional support in developing their movement skills because of early developmental delays (Bjarnason-Wehrens et al., 2007; Reilly et al., 2015), prolonged periods of hospitalization

(Fereday et al., 2009; Moola et al., 2012) or a decline in physical function resulting from their disease progression (Moola et al., 2011; Omwanghe et al., 2017).

Since there was a wide variety of skill levels and prior sport experiences among participants in the ICPA program, the relative importance of learning and progressing in basic skills differed between each individual child. Some children appeared to understand the importance of specific skill objectives, whereas others would create their own objectives that were not similarly transferrable to game contexts (e.g., in badminton, getting the birdie over the net with as much force as possible instead of practicing a "rainbow" trajectory to better manipulate the timing of a rally). While this did not happen with every activity, it was a notable observation about the difference between simply learning how to execute versus apply basic skills. Overall, when participants valued and understood the objective of an activity, they remained engaged and were better equipped to apply learned skills to other active contexts.

Most participants understood, from their own prior experiences, that perfecting basic skills would allow them to be included amongst peers in similarly active settings ("I was scared to mess up [because] then I'd feel embarrassed" – Ava). When children with chronic medical conditions discussed their preferences for a community-based program, the importance of cooperative skills and working with others in practice game contexts were emphasised as particularly relevant skills to learn. Group-based practices may have also been helpful for children who were participating at an overall higher baseline skill level (i.e., those in the achieving/excelling levels of physical literacy), as they learned how to refine control over their movements to play with less skilled participants.

> *"She has learned patience and a better understanding that not all kids have the same physical abilities and level of energy"* – Ava's mother

Similarly, participants with lower skill levels, when given the supports necessary to succeed in executing and applying skills in a group-based context, may have had more positive experiences and variations to draw from when considering cooperative physical activities in the future.

Example: Learning to play among peers with different skill levels

> In volleyball, Shreya and Khalid were paired together to practice rallying over the net. One of the leaders noticed how Shreya looked frustrated and that Khalid kept making the same mistake (keeping his hands separated during a bump) which led to no successful rallies, despite Shreya's efforts to control her serves. After a leader gave specific feedback to Khalid, he was able to apply it right away and looked really excited about how successful he was at returning the ball over the net. Shreya also seemed relieved, and they both looked as though they were enjoying themselves as they continued to rally back and forth for the rest of the skill. While Khalid's skill level was still not as advanced as Shreya's (i.e., less control of the ball), they were at least able to successfully practice with one another by achieving the objective of getting the ball over the net.

Collaborative practice may have also been particularly important for children with chronic medical conditions who cannot reach or maintain high levels of activity intensity. As Moola (2020) explored, children with congenital heart disease desire capabilities which allow them to participate more effectively alongside their peers. When a child has lower cardiorespiratory fitness or medically necessary exercise intensity restrictions, learning how to strategically execute skills while conserving one's energy can be valuable. Aligning with an individualised concept of physical literacy, the ICPA program was strategically designed and delivered so participants could learn skills and game rules alongside others in a way that optimised their own capabilities. Lessons which supported individual, collaborative, and competitive skill development gave participants a broad toolkit to apply to game contexts.

Example: The importance of learning through practice

> The last session of the ICPA program was "player's choice", where equipment from multiple sports was available and participants could choose whichever sport they wanted to play. Most participants wanted to play soccer (which was not one of the ICPA lessons), but instead of going through the typical structure of the lesson plan, we played a game right away. One of the leaders noticed that John chose to play goalie and was almost hiding in the net more than he was playing the position. She then asked John if he wanted to practice passing, because she also noticed that when he would return the ball there would be uncertainties in his movements (i.e., hesitation and frequent repositioning during a kick). After a few minutes of passing and instructions (i.e., using the instep, how to stop the ball), they resumed play where John joined the field instead of staying behind the net. John later recalled this session as "chaotic", leading me to wonder if we had followed the lesson plan structure of all the other sports, perhaps he would have had more positive feelings about this session.

Finally, playing a different sport every week was highly valued by participants, as they learned to approach new sports with a positive mindset, identified more opportunities for physical activity and discovered new interests. For parents, the opportunity for their children to gain this perspective and experience within a safe learning environment was particularly valuable. ICPA was designed to focus on a different sport each week; children with chronic medical conditions need opportunities to develop skills in a wide variety of sports and/or physical activities, since their diagnostic history may limit their options (i.e., when medically necessary physical activity restrictions exist) or changes in their health status may cause fluctuations in their abilities over time. To promote long-term health, it is essential that children with chronic medical conditions realize there are indeed a wide variety of physical activities accessible to them.

> *"Although we have tried to focus him on what he can do, invariably there have been difficult discussions about what he can't do (i.e., driving a 4-wheeler, swimming alone). This program has helped him understand there are many things that he can do and should be willing to look at new experiences"* – Harrison's father.

Inclusion Supported by Individualised Variations

Children with chronic medical conditions interviewed ahead of the ICPA program agreed that coaches should know their diagnoses so they could participate safely, but also made a point to emphasize that this information should not be used to differentiate children from their peers. When children with chronic medical conditions are integrated into active settings (i.e., sports classes, clubs, etc.), they may experience unease towards the potential of being unnecessarily excluded from an activity if leaders misunderstand their capabilities (Fereday et al., 2009; Johnson et al., 2021; Moola et al., 2011). This uncertainty, combined with a strong desire to feel included (Shorey and Ng, 2020), has been cited as the reason why children will sometimes choose not to disclose their diagnosis in active settings (Svensson et al., 2020).

There was also an understanding among children with chronic medical conditions that an inclusive physical activity program should not simply be a setting where all children *can* participate, but one where all children *want* to participate and learn. In the focus group, participants reflected on why this made the ICPA program a good option for children with CMCs who need support to be more active:

Ava: *"[Because] you get a lot of energy out, and it's exciting, and fun, and like there's so many new people to meet, and all the coaches are super nice and encourage you to do more."*

Harrison: *"And because there's different sports!"*

While all participants shared the experience of living with a chronic medical condition, their physical abilities and prior experiences with sport differed from one another. Thus, variations were necessitated throughout the ICPA program. Variations are recognised as essential for physical literacy-based programs, as they allow opportunities for children of differing abilities to experience individualised success and challenge in the same activity context (Pot, Whitehead, and Durden-myers, 2018). Although variations have traditionally been classified as modifications or progressions, rather than presenting options as "easier" or "harder", leaders were instead encouraged to describe what the variation would allow participants to accomplish (i.e., "try bouncing the ball before serving it, so you have more time to hit it"). Not all variations were appropriate for each individual child, and so it was important that leaders were intentional with their suggested variations as to not indirectly exclude participants from the desired, activity-related experience.

Example: Individualized Variations

When symptoms of Shreya's bone condition began interfering with her participation in ultimate Frisbee, she reluctantly asked to sit out. In an effort to keep her involved in the activity, one of the leaders suggested she join Taylor as scorekeeper (score keeping was originally presented to leaders as a generally appropriate alternative for children who could not be physically involved in a competitive game). However, knowing Shreya was highly motivated to participate in competitive games, scorekeeping did not seem to be a suitable variation for her desired level of

> involvement. I suggested to the coaches that we instead change the rules of the game, such that one player stays in the end zone to receive passes for points. By creating a new role in the game, Shreya did not have to run around the field (which would further aggravate her symptoms) but could still be a more active participant in the game. As Shreya would go on to require more variations over the course of the program because of her symptoms, she later reflected on how these options allowed her to maintain a positive sense of self, saying "It [was] nice for me because it kind of reassures me, like even if I can't do what I'm supposed to do I can still get through it my own way, even with my bone condition" (Figure 1; Appendix J).

When coaches were able to thoughtfully and creatively select variations that participants knew were personalized to their individual needs, they became visibly more engaged in the activity.

Figure 1. *Shreya's recollection of how individualized variations contributed to her feeling engaged in the activities.*

Creativity and Flexibility as Cornerstones of Inclusion

An inclusive curriculum is one that is "based on the view that learning occurs when students are actively involved, taking the lead in making sense of their experiences" (UNESCO, 2017, p.18). Thus, it was important that lesson plans would engage participants by allowing them to maintain a sense of agency and find personal meaning in the ICPA experience. This was also emphasized in the pre-program interviews when children with chronic medical conditions described how they should be allowed to make choices about their involvement in the program based on personal preferences. Creativity was therefore regularly applied to promote autonomy wherever possible within the contextual and structural constraints of the program.

<u>Example: Using Creativity to Promote Autonomy</u>

> Khalid did not enjoy the serving skill in badminton – so much so, that he took himself out of the lesson and proceeded to watch the others for the duration of the skill. The leaders reminded him that he could join back whenever he was ready, to which he replied "I want to join for the obstacle course". When the same skill was incorporated into the obstacle course, the leaders created a different task for Khalid to do instead, encouraging him to remain engaged in the obstacle course (which he had wanted to participate in) without having to serve

Experiencing personal meaning in physical activity or sport is also a process which is highly individualised (Beni et al., 2017). In contrast, the ICPA program applied generally structured lessons so that coaches would be equipped with the tools and ideas to promote learning objectives. A conceptual tension therefore existed between the individualisation of the ICPA experience and the structured, group-based context of that same experience. This was particularly evident when there were only a couple of participants in attendance for some sessions, as reflected in the field notes:

> *" [We] noted that we tend to lose the structure of the lesson plan when delivering [the program] to these smaller groups, but at the same time it's more individualised instruction which is also important. I feel conflicted because the structure was compromised [today in pickleball], but I also can't say with confidence that the objectives of the lesson were or were not met."*

Ultimately, adopting a creative mindset was essential to be able to work around this tension; children were overall more engaged in activities where leaders created activity constraints which optimized individual participation in the group.

Understanding One's Need for Rest

Knowing how fatigue can impact the participation of children with chronic medical conditions in physical activity (Constantinou et al., 2021; Moola, 2020), one of the main considerations during the ICPA program was for breaks to be frequently prompted and encouraged by leaders. When group breaks are not frequently prompted, the onus of responsibility then extends to the child to decide for themselves when to take a break. This is not always an easy decision nor one that can be made simply based on somatic feelings; choosing to take a break also means choosing to end participation. With this in mind, we aimed to create a psychosocial environment within the ICPA program that would easily allow for breaks, without sacrificing participation. By doing so, the idea was that participants would experience less internal conflict when they wanted to keep playing but their bodies needed rest.

For the first week, it was difficult for leaders to remember to prompt for breaks as frequently as intended, because everyone was still familiarizing themselves with the structure of the lesson plans. By the second and third weeks however, leaders had begun to prompt for more breaks while encouraging participants to pay attention to their own bodily cues. Despite leaders being trained to monitor the class for signs of over-exertion and fatigue, children are capable and want to determine their own breaks (Bennett et al., 2021; Fereday et al., 2009). Leaders had to trust that participants would advocate for themselves when they needed a break, while simultaneously finding opportunities for group breaks when high levels of fatigue were observed. This balance between letting children determine their own breaks and prompting when necessary was described by John in his pre-program interview:

> *"For people like me? If they look like they're not doing as well as they were doing when they first got there, just don't tell them to take a break but give them the option to have breaks whenever they want. Or if they really look like they're having a lot of trouble breathing, then remind them."* – John.

> <u>*Example: Group Breaks for Individual Needs*</u>

> The coaches checked in with all participants after the obstacle course: "How is everyone feeling? Do we need a break? My arm is sore from throwing so much, I need a little break". They then encouraged a group stretch – this was a way for the leaders to provide the rest they figured Ava would need, without singling her out. After the stretch, Ava communicated on her own that she felt better and wanted to keep going.

Embodied Self-Awareness

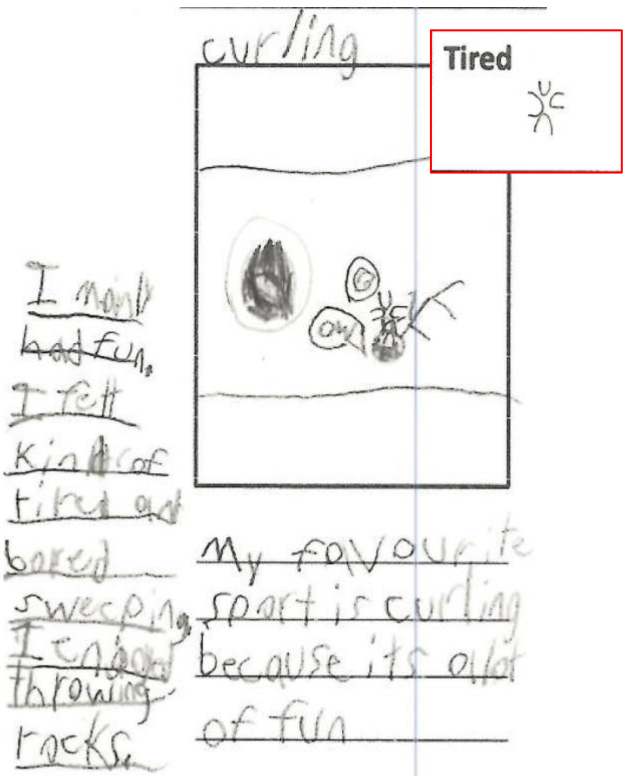
Creating opportunities for breaks and physical self-regulation were examples of how embodied self-awareness was considered in the delivery of the ICPA program. That an individual is embodied is a central concept within physical literacy theory; the mind and body are not differentiated from one another in thoughts or actions (Pot, Whitehead, and Durden-

Myers, 2018). Embodied self-awareness represents the conscious reflection of combined sensorimotor feedback, psychological emotions, and motivations (Fogel, 2011). By prompting for bodily cues and relating those to emotions and actions (i.e., rest, slower pace, etc.), there were opportunities for participants to build a stronger understanding of how their physical sensations and emotions related to one another during the sport skills and games. Developing embodied self-awareness may help children with chronic medical conditions more effectively navigate their participation in physical activity, as they learn how to self-regulate in active settings according to their signs and symptoms.

Example: Embodied Self-Awareness and Fatigue

When asked to describe their feelings during the ICPA program in the focus group, John and Harrison both described overall feeling "exhausted". This was noteworthy because they had not appeared to be over-exerted during the lessons and "tired" was already listed as a potential feeling to illustrate in the story boards, so I asked them to differentiate the terms. They both agreed that "exhausted" was one step before "tired"; feeling exhausted meant they felt they had minimal physical energy but were still emotionally engaged in the activity. John used "tired" in his story board when he described sweeping in curling as something that was physically draining, but also emotionally and mentally unmeaningful to him (Figure 2; Appendix K).

Figure 2. *John's description of conflicted feelings from being tired and bored during his favourite sport, which was curling.*



The variations embedded into the ICPA program also served as opportunities for participants to build embodied self-awareness by self-regulating their activity intensity. In their study among children with congenital heart disease, Bennett and colleagues (2021) also described how participants valued the opportunities to learn bodily self-regulation through physical activity. During the ICPA volleyball session, participants were given the choice to either practice bumps against the wall or on the court. Participants who chose the court were trying to add power to their bumps, and as such would frequently run around the court to line themselves up with where they had launched their volleyball. Meanwhile, those that chose to practice against the wall were more focused on maintaining control of the ball and therefore did not have to move their bodies as much to practice the skill. In this way, there were two intensity options for participants to choose from that were focusing on the same skill (low-to-moderate intensity against the wall and moderate-to-high intensity on the court). This is one example of many other skill variations throughout the ICPA program that allowed participants to choose how much energy they wanted to expend during a particular activity. Participants appreciated these opportunities to self-regulate their activity intensity during each skill, but in the focus group, expressed interest in having a similar opportunity during game play:

> *"You should have like a couple [of games going on] ... because some kids might have a lot of energy and some kids might not have a lot of energy. So, have two options; like have one game that doesn't have too much energy [except the] energy you need, and one game have a lot of energy"* – Ava

Having two levels of game play that participants can choose from, based on feedback from their embodied self-awareness, is something that could be feasibly incorporated into the design and delivery of an inclusive, recreational sport program.

Discussion

The reported experiences of children with chronic medical conditions in the ICPA program reflect the pragmatic, physical literacy-based approach that was adopted for its design and delivery. Developed themes highlight important considerations when delivering a community-based, physical literacy program to this population, encompassing shared expectations, dynamic observations, and potential implications for participants with chronic medical conditions. Learning different sports and practicing basic skills with individual and cooperative constraints was valuable to participants, as it created positive experiences and feedback to draw upon when transferring skills to new activities. Given the wide range of physical capabilities between participants, the ability of leaders to adopt a creative mindset in the design and delivery of sport-specific activities, in a way that also complimented teaching principles (i.e., creating a supportive environment, fostering autonomy, enjoyment, etc.), was an asset. Finally, implementing frequent breaks within the ICPA program created an environment where participants could develop an embodied self-awareness that would align with their medical needs.

The importance of learning how to participate in games and sports, both efficiently and effectively, is an idea that warrants particular focus among children living with chronic medical conditions. Within our results, we highlighted the ways in which learning a wide range of sports and movement competencies can help children with chronic medical conditions better conceptualize and navigate their participation in physical activity. This supports the suggested importance of sampling different sports during childhood for physical literacy development (Weissman et al., 2022), alongside other known benefits such as prolonged engagement in physical activity and positive psychosocial outcomes (Côté et al., 2009). From a chronic disease perspective, the theme of learning to play uniquely posits how this population may be overlooked by traditional modes of physical activity instruction when learning how to play alongside their otherwise healthy peers. Indeed, when children sit out from lessons or engage in an activity for a shorter duration, as is often the case for those experiencing on-going symptoms and/or disease management, they may not receive the same quality or quantity of practice that would allow them to participate equitably amongst their peers (Blanchard et al., 2022; Moola, 2020). In contrast, when children with chronic medical conditions are not bound to the constraints of a traditionally structured game context (i.e., deliberate play), there is more "space" for them to explore movement skills and patterns that will optimize their engagement (Côté et al., 2007), as evidenced within the current case study. However, children participating in the ICPA program still required – and desired – structured feedback from leaders who aimed to help them progress in their skill development (i.e., Learning to Play). Thus, applying deliberate preparation (MacNamara et al., 2015), in combination with deliberate play (Pesce et al., 2016), may be an effective method of instruction to consider in future interventions for children with chronic medical conditions.

The contrast experienced throughout the ICPA program, of trying to stay within the theoretically derived structure of the lesson plans while allowing for individual malleability in practice, should be expected within inclusive, structured recreation programs (Arbour-Nicitopoulos, Grassmann, et al., 2018; Weissman et al., 2022). Individual strategies that were creatively and thoughtfully applied to the delivery of the ICPA program ultimately aimed to facilitate personal meaning in participation. The importance of facilitating meaningful physical activity opportunities is emphasized in disability research (Bruno et al., 2022), but rarely acknowledged in the reporting of physical activity interventions for children with chronic disease. Experiencing a sense of meaning in physical activity or sport is also a critical component of the quality Parasport framework (Evans et al., 2018), which includes autonomy, belongingness, mastery, challenge, engagement, and meaning. Many of the components outlined by the quality participation framework were also observed throughout the ICPA program and cited as reasons why participants found their participation worthwhile. Although originally conceptualised to define optimal experiences in parasport (Evans et al., 2018), these findings suggest that many of the elements and underlying considerations of the quality participation framework are amenable to meet the needs of children living with chronic disease. Therefore, future research should consider the application of this framework among this population in community-based physical activity settings.

Researchers and practitioners who wish to interpret and apply these findings to the examination of their own contexts should acknowledge the underlying, physical literacy-based approach that guided the development and observation of the ICPA program. That is, an understanding that physical literacy objectives are not simply quantifiable milestones of physical competence or motivation (Carl et al., 2022) but extend to the general experiences and tools acquired to navigate participation in physical activity, regardless of one's embodied circumstance. This is particularly important for children living with chronic medical conditions, who need to determine their own breaks during physical activity, self-monitor their symptoms and learn to self-regulate their activity intensity (Bennett et al., 2021). Looking at embodiment as an outcome of physical literacy programs may, therefore, be more relevant for children with chronic medical conditions than simply reporting physical competence outcomes. The embodied self-awareness described in our results was primarily related to making decisions about energy expenditure and adjusting to changes in fatigue that would reasonably occur with symptoms and/or disease progression. Though challenging to measure (Fogel, 2011), embodied self-awareness should be considered a relevant outcome for children with chronic medical conditions following physical activity interventions, alongside traditional health outcomes (i.e., physical activity behaviour, cardiorespiratory health indicators, metabolic factors, etc.).

Limitations

There were limitations within this study that should be acknowledged. Main findings were contextualized by the small group of participants who enrolled in the study, among which most were boys and/or living with type 1 diabetes. Having few participants, as is typical in case study designs, raises concerns about the richness of the data (Small, 2009), which we aimed to address using methodological triangulation (Lambert and Loiselle, 2008). Multiple perspectives were captured throughout the program delivery using different modalities (i.e., interviews, focus groups, observations/field notes), creating a multi-faceted representation of the ICPA program's design and delivery. During the focus group, not all participants felt that they had been given enough time to complete their illustrations, leaving some feeling rushed for time. We allotted ninety minutes to complete the focus group, which comprised of one hour of drawing and a thirty-minute discussion, reflecting the time that would have previously been spent in the ICPA program. While there were no obvious tensions observed within the group dynamic, children may have had perceptions about their experience that they did not wish to disclose amongst other ICPA participants. For example, during her interview Shreya shared that she did not always feel challenged by the program activities and did not always try her “hardest” in competitive activities for fear of diminishing the confidence of the other participants; it is unlikely that Shreya would have shared this thought in the focus group, to protect the feelings of her peers. There were also variations in social meanings (i.e., exhausted versus tired) that became evident throughout the discussion and which were addressed with clarifying questions (Morgan et al., 2002). Furthermore, while ethnographic methods were used, it is important to acknowledge that I am not an experienced ethnographer and thus may have missed contextual data that a more experienced researcher might have included in field notes or reflective journals. While I continuously reviewed my biases throughout data collection and analysis, my deep understanding of the program’s rationale and design allowed me to critically observe how certain design elements were received by participants. Observations related to enjoyment, relatedness, and parental involvement were also noted throughout the analysis. However, these results were situated outside of the main findings due to the analytical decisions made when developing themes. Nonetheless, experiences related to enjoyment, relatedness and parental support/involvement are certainly relevant to the active experiences of children with chronic medical conditions (Moola et al., 2008; Shorey and Ng, 2020) and should continue to be considered in similar, future research.

Conclusion

Community-based programs can be a safe and meaningful context for children living with chronic medical conditions to participate in recreational sport. Having variations, both within and between activities, gives these children a wide range of experiences to draw from as they continue to navigate changes in their physical abilities or medical needs. Inclusive experiences that apply creative solutions to facilitate engagement in physical activity may also provide strategies for children to transfer to other contexts where they may have previously felt excluded. Finally, developing embodied self-awareness through participation in recreational activities may be a particularly meaningful physical literacy outcome for children with chronic medical conditions than physical competence alone.

References

Arbour-Nicitopoulos, K. P., Boross-Harmer, A., Leo, J., Allison, A., Bremner, R., Taverna, F., Sora, D., and Wright, F. V. (2018). Igniting Fitness Possibilities: a case study of an inclusive community-based physical literacy program for children and youth. *Leisure/Loisir: Journal of the Canadian Association for Leisure Studies*, *42*(1), 69–92. https://doi.org/10.1080/14927713.2017.1414627

Arbour-Nicitopoulos, K. P., Grassmann, V., Orr, K., McPherson, A. C., Faulkner, G. E., and Wright, F. V. (2018). A Scoping Review of Inclusive Out-of-School Time Physical Activity Programs for Children and Youth With Physical Disabilities. *Adapted Physical Activity Quarterly*, *35*(1), 111–138. https://doi.org/10.1123/apaq.2017-0012

Bayeck, R. Y. (2023). Is Microethnography an Ethnographic Case Study? and/or a mini-ethnographic case study? An analysis of the literature. *International Journal of Qualitative Methods*, *22*. https://doi.org/10.1177/16094069231172074

Beni, S., Fletcher, T., and Ní Chróinín, D. (2017a). Meaningful Experiences in Physical Education and Youth Sport: A Review of the Literature. *Quest*, *69*(3), 291–312. https://doi.org/10.1080/00336297.2016.1224192

Bennett, E. V., Voss, C., Faulkner, G., and Harris, K. C. (2021). From ‘it makes me feel free’ to ‘they won’t let me play’: the body and physical activity-related perceptions and experiences of children with congenital heart disease and their parents. *Qualitative Research in Sport, Exercise and Health*, *13*(2), 325–341. https://doi.org/10.1080/2159676X.2019.1710858

Bjarnason-Wehrens, B., Dordel, S., Schickendantz, S., Krumm, C., Bott, D., Sreeram, N., and Brockmeier, K. (2007). Motor development in children with congenital cardiac diseases compared to their healthy peers. *Cardiology in the Young*, *17*(5), 487–498. https://doi.org/10.1017/S1047951107001023

Blanchard, J., McCrindle, B. W., and Longmuir, P. E. (2022). The Impact of Physical Activity Restrictions on Health-Related Fitness in Children with Congenital Heart Disease. *International Journal of Environmental Research and Public Health*, *19*(8). https://doi.org/10.3390/ijerph19084426

Bolduc, M. E., Dionne, E., Gagnon, I., Rennick, J. E., Majnemer, A., and Brossard-Racine, M. (2020). Motor Impairment in Children With Congenital Heart Defects: A Systematic Review. *Pediatrics*, *146*(6). https://doi.org/10.1542/PEDS.2020-0083

Braun, V., and Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Braun, V., and Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, *11*(4), 589–597. https://doi.org/10.1080/2159676X.2019.1628806

Bruno, N., Richardson, A., Kauffeldt, K. D., Tomasone, J. R., Arbour-Nicitopoulos, K., and Latimer-Cheung, A. E. (2022). Exploring experiential elements, strategies and outcomes of quality participation for children with intellectual and developmental disabilities: A systematic scoping review. *Journal of Applied Research in Intellectual Disabilities*, *35*(3), 691–718. https://doi.org/10.1111/jar.12982

Carl, J., Barratt, J., Töpfer, C., Cairney, J., and Pfeifer, K. (2022). How are physical literacy interventions conceptualized? – A systematic review on intervention design and content: Design/Content of Physical Literacy Interventions. *Psychology of Sport and Exercise*, *58*, 102091. https://doi.org/10.1016/j.psychsport.2021.102091

Coleman, N., Nemeth, B. A., and Leblanc, C. M. A. (2018). Increasing Wellness Through Physical Activity in Children with Chronic Disease and Disability. *Current Sports Medicine Reports*, *17*(12), 425–432. https://doi.org/10.1249/JSR.0000000000000548

Constantinou, C., Payne, N., van den Akker, O., and Inusa, B. (2021). A qualitative exploration of health-related quality of life and health behaviours in children with sickle cell disease and healthy siblings. *Psychology and Health*, *38*(1), 125-146. https://doi.org/10.1080/08870446.2021.1955119

Côté, J., Baker, J., and Abernethy, B. (2007). Practice and Play in the Development of Sport Expertise. In G. Tenenbaum and R. C. Eklund (Eds.), *Handbook of Sport Psychology: Third Edition* (pp. 184–202). John Wiley and Sons.

Côté, J., Horton, S., MacDonald, D. J., and Wilkes, S. (2009). The Benefits of Sampling Sports During Childhood. *Physical and Health Education Journal*, *74*(4), 6–11.

Darbyshire, P., MacDougall, C., and Schiller, W. (2005). Multiple methods in qualitative research with children: more insight or just more? *Qualitative Research*, *5*(4), 417–436. https://doi.org/10.1177/1468794105056921

David, C. V., and MacAllister, W. S. (2022). Fine motor impairment in children with epilepsy: Relations with seizure severity and lateralizing value. *Epilepsy and Behavior*, *127*, 108518. https://doi.org/10.1016/j.yebeh.2021.108518

Dowling, M. (2006). Approaches to reflexivity in qualitative research. *Nurse Researcher*, *13*(3), 7–21. https://doi.org/10.7748/nr2006.04.13.3.7.c5975

Elmesmari, R. A., Reilly, J. J., and Paton, J. Y. (2022). 24-Hour Movement Behaviors in Children with Chronic Disease and Their Healthy Peers : A Case-Control Study. *International Journal of Environmental Research and Public Health*, *19*(5), 2912. https://doi.org/10.3390/ijerph19052912

Evans, M. B., Shirazipour, C. H., Allan, V., Zanhour, M., Sweet, S. N., Martin Ginis, K. A., and Latimer-Cheung, A. E. (2018). Integrating insights from the parasport community to understand optimal Experiences: The Quality Parasport Participation Framework. *Psychology of Sport and Exercise*, *37*, 79–90. https://doi.org/10.1016/j.psychsport.2018.04.009

Fereday, J., Macdougall, C., Spizzo, M., Darbyshire, P., and Schiller, W. (2009). "There's nothing I can't do – I just put my mind to anything and I can do it": a qualitative analysis of how children with chronic disease and their parents account for and manage physical activity. *BMC Pediatrics*, *9*(1). https://doi.org/10.1186/1471-2431-9-1

Fogel, A. (2011). Embodied awareness: Neither implicit nor explicit, and not necessarily nonverbal. *Child Development Perspectives*, *5*(3), 183–186. https://doi.org/10.1111/j.1750-8606.2011.00177.x

Fried, L., Chetty, T., Cross, D., Breen, L., Davis, E., Roby, H., Jackiewicz, T., Nicholas, J., and Jones, T. (2021). The Challenges of Being Physically Active: A Qualitative Study of Young People With Type 1 Diabetes and Their Parents. *Canadian Journal of Diabetes*, *45*, 421–427. https://doi.org/10.1016/j.jcjd.2020.09.010

Fusch, P. I., Fusch, G. E., and Ness, L. R. (2017). How to conduct a mini-ethnographic case study: A guide for novice researchers. *Qualitative Report*, *22*(3), 923–941. https://doi.org/10.46743/2160-3715/2017.2580

Goering, S. (2015). Rethinking disability: the social model of disability and chronic disease. *Current Reviews in Musculoskeletal Medicine*, *8*(2), 134–138. https://doi.org/10.1007/s12178-015-9273-z

Gruber, W., Welsner, M., Dillenhöfer, S., Olivier, M., Koerner-Rettberg, C., Sutharsan, S., Taube, C., Mellies, U., and Stehling, F. (2021). Health-Related and Motor Performance-Related Fitness and Physical Activity Among Youth With Cystic Fibrosis. *Perceptual and Motor Skills*, *128*(5), 2097–2116. https://doi.org/10.1177/00315125211036415

Hutchens, A., and Lee, R. E. (2018). Parenting Practices and Children's Physical Activity: An Integrative Review. *Journal of School Nursing*, *34*(1), 68–85. https://doi.org/10.1177/1059840517714852

Jabbour, G., Henderson, M., and Mathieu, M.-E. (2016). Barriers to Active Lifestyles in Children with Type 1 Diabetes. *Canadian Journal of Diabetes*, *40*(2), 170–172. https://doi.org/10.1016/j.jcjd.2015.12.001

Jeffrey, B. (2018). Ethnographic Writing. In D. Beach, C. Bagley, and S. Marques Da Silva (Eds.), *The Wiley Handbook of Ethnography of Education*. John Wiley and Sons, Incorporated.

Johnson, E., Atkinson, P., Muggeridge, A., Cross, H., and Reilly, C. (2021). Inclusion and participation of children with epilepsy in schools: Views of young people, school staff and parents. *Seizure: European Journal of Epilepsy*, *93*, 34–43. https://doi.org/10.1016/j.seizure.2021.10.007

Lambert, S. D., and Loiselle, C. G. (2008). Combining individual interviews and focus groups to enhance data richness. *Journal of Advanced Nursing*, *62*(2), 228–237. https://doi.org/10.1111/j.1365-2648.2007.04559.x

Liu, Y., and Chen, S. (2020). Physical literacy in children and adolescents: Definitions, assessments, and interventions. *European Physical Education Review*, *27*(1), 1–17. https://doi.org/10.1177/1356336X20925502

Longmuir, P. E., Brothers, J. a., de Ferranti, S. D., Hayman, L. L., Van Hare, G. F., Matherne, G. P., Davis, C. K., Joy, E. a., and McCrindle, B. W. (2013). Promotion of physical activity for children and adults with congenital heart disease: A scientific statement from the American Heart Association. *Circulation*, *127*(21), 2147–2159. https://doi.org/10.1161/CIR.0b013e318293688f

Lubans, D. R., Lonsdale, C., Cohen, K., Eather, N., Beauchamp, M. R., Morgan, P. J., Sylvester, B. D., and Smith, J. J. (2017). Framework for the design and delivery of organized physical activity sessions for children and adolescents: rationale and description of the 'SAAFE' teaching principles. *International Journal of Behavioral Nutrition and Physical Activity*, *14*(1), 24. https://doi.org/10.1186/s12966-017-0479-x

MacMillan, F., Kirk, A., Mutrie, N., Moola, F., and Robertson, K. (2016). Building physical activity and sedentary behavior support into care for youth with type 1 diabetes: patient, parent and diabetes professional perceptions. *Pediatric Diabetes*, *17*(2), 140–152. https://doi.org/10.1111/pedi.12247

MacNamara, Á., Collins, D., and Giblin, S. (2015). Just let them play? Deliberate preparation as the most appropriate foundation for lifelong physical activity. *Frontiers in Psychology*, *6*. https://doi.org/10.3389/fpsyg.2015.01548

Markula, P., and Sparkes, A. (2015). Part I Ethnography Methodological and theoretical considerations. In M. Gyozo and L. Purdy (Eds.), *Ethnographies in Sport and Exercise Research* (1st ed., pp. 27–74). Taylor and Francis Group.

Moola, F. J. (2020). Passive on the periphery: Exploring the experience of physical activity among children and youth with congenital heart disease using the draw-and-write technique. *The Arts in Psychotherapy*, *69*, 101662. https://doi.org/10.1016/j.aip.2020.101662

Moola, F., Faulkner, G. E. J., Kirsh, J.., and Kilburn, J. (2008). Physical activity and sport participation in youth with congenital heart disease: Perceptions of children and parents. *Adapted Physical Activity Quarterly*, *25*, 49–70. https://doi.org/10.1123/apaq.25.1.49

Moola, F., Fusco, C., and Kirsh, J. (2011). What I wish you knew: Social barriers toward physical activity in youth with congenital heart disease (CHD). *Adapted Physical Activity Quarterly*, *28*(1), 56–77. https://doi.org/10.1123/apaq.28.1.56

Moola, F. J., Faulkner, G. E. J., Kirsh, J. a., and Schneiderman, J. E. (2011). Developing physical activity interventions for youth with cystic fibrosis and congenital heart disease: Learning from their parents. *Psychology of Sport and Exercise*, *12*(6), 599–608. https://doi.org/10.1016/j.psychsport.2011.07.001

Moola, F. J., Faulkner, G. E. J., and Schneiderman, J. E. (2012). “No time to play”: Perceptions toward physical activity in youth with cystic fibrosis. *Adapted Physical Activity Quarterly*, *29*(1), 44–62. https://doi.org/10.1123/apaq.29.1.44

Morgan, M., Gibbs, S., Maxwell, K., and Britten, N. (2002). Hearing children’s voices: methodological issues in conducting focus groups with children aged 7–11 years. *Qualitative Research*, *2*(1), 5–20. https://doi.org/10.1177/1468794102002001636

Nap-Van Der Vlist, M. M., Berkelbach Van Der Sprenkel, E. E., Nijhof, L. N., Grootenhuis, M. A., Van Der Ent, C. K., Swart, J. F., Van Royen-Kerkhof, A., Van Grotel, M., Van De Putte, E. M., Nijhof, S. L., and Kars, M. C. (2021). Daily life participation in childhood chronic disease: a qualitative study on the child's and parent's perspective. *BMJ Pediatrics Open*, *5*, 1057. https://doi.org/10.1136/bmjpo-2021-001057

Omwanghe, O. A., Muntz, D. S., Kwon, S., Montgomery, S., Kemiki, O., Hsu, L. L., Thompson, A. A., and Liem, R. I. (2017). Self-reported physical activity and exercise patterns in children with sickle cell disease. *Pediatric Exercise Science*, *29*(3), 388–395. https://doi.org/10.1123/pes.2016-0276

Pesce, C., Masci, I., Marchetti, R., Vazou, S., Sääkslahti, A., and Tomporowski, P. D. (2016). Deliberate play and preparation jointly benefit motor and cognitive development: Mediated and moderated effects. *Frontiers in Psychology*, *7*, 349. https://doi.org/10.3389/fpsyg.2016.00349

Pot, N., Whitehead, M. E., and Durden-Myers, E. J. (2018). Physical Literacy From Philosophy to Practice. *Journal of Teaching in Physical Education*, *37*(3), 246–251. https://doi.org/10.1123/jtpe.2018-0133

Pushkarenko, K., Causgrove Dunn, J., and Wohlers, B. (2021). Physical literacy and inclusion: A scoping review of the physical literacy literature inclusive of individuals experiencing disability. *Prospects*, *50*(1–2), 107–126. https://doi.org/10.1007/s11125-020-09497-8

Queenan, J. A., Wong, S. T., Barber, D., Morkem, R., and Salman, A. (2021). *The Prevalence of Common Chronic Conditions Seen in Canadian Primary Care: Results from the Canadian Primary Care Sentinel Surveillance Network*. https://cpcssn.ca/wp-content/uploads/2021/05/cpcssn-chronic-conditions-report-2021.pdf

Reilly, C., Atkinson, P., Das, K. B., Chin, R. F., Aylett, S. E., Burch, V., Gillberg, C., Scott, R. C., and Neville, B. G. R. (2015). Features of developmental coordination disorder in active childhood epilepsy: A population-based study. *Developmental Medicine and Child Neurology*, *57*(9), 829–834. https://doi.org/10.1111/dmcn.12763

Shorey, S., and Ng, E. D. (2020). The lived experiences of children and adolescents with non-communicable disease: A systematic review of qualitative studies. *Journal of Pediatric Nursing*, *51*, 75–84. https://doi.org/10.1016/j.pedn.2019.12.013

Small, M. L. (2009). "How many cases do I need?": On science and the logic of case selection in field-based research. *Ethnography*, *10*(1), 5–38. https://doi.org/10.1177/1466138108099586

Srivastava, P., and Hopwood, N. (2009). A Practical Iterative Framework for Qualitative Data Analysis. *International Journal of Qualitative Methods*, *8*(1), 76-84. https://doi.org/10.1177/160940690900800107

Svensson, M. K., Wahlberg, A., and Gislason, G. H. (2020). Chronic Paradoxes: A Systematic Review of Qualitative Family Perspectives on Living With Congenital Heart Defects. *Qualitative Health Research*, *30*(1), 119–132. https://doi.org/10.1177/1049732319869909

UNESCO. (2017). *A Guide for ensuring inclusion and equity in education*. UNESCO. https://doi.org/10.54675/MHHZ2237

Weissman, S. E., Perinpanayagam, R., Wright, F. V., and Arbour-Nicitopoulos, K. P. (2022). Application of the behaviour change technique taxonomy (BCTTv1) to an inclusive physical literacy-based sport program for children and youth. *International Journal of Sports Science and Coaching*, *17*(1), 18–36. https://doi.org/10.1177/17479541211016580

Whitehead, M. (2001). The concept of physical literacy. *European Journal of Physical Education*, *6*(2), 127–138. https://doi.org/10.1080/1740898010060205

Whitehead, M. (2010). *Physical Literacy: Throughout the life course.*New York: Routledge. https://doi.org/10.4324/9780203881903

Williamson, K. (2006). Research in constructivist frameworks using ethnographic techniques. *Library Trends*, 55(1), 83–101. https://doi.org/10.1353/lib.2006.0054

Yin, R. K. (2014). *Case study research: Design and methods* (5th ed.). Sage.

Chapter Four - General Discussion

This final chapter of my dissertation will connect and discuss the salient information presented thus far, detailing the physical literacy development of children with CMCs. First, I begin this chapter with an overall summary and integration of findings from the articles in Chapter 3. Next, a discussion of how this research contributes to our broader, existing knowledge of physical literacy, as well as how children with CMCs navigate their participation in physical activity, follows. Finally, overall limitations of this research are described, followed by implications relevant to practitioners in both health and recreation sectors.

Knowledge Gained from Research Program

The overall purpose of this research was to deepen what has been to date a relatively superficial understanding of how children with CMCs develop physical literacy. This was accomplished by contextualising (Article 1), describing (Article 2), and reflecting (Article 3) on the physical literacy development of a diverse group of children with CMCs. Findings from each article are summarised below, followed by a discussion integrating results, to highlight potential areas of future inquiry and practical strategies for support.

Summary of Findings

At the time of this doctoral research, the physical literacy of children with CMCs could not be adequately described without first contextualising the influence of the COVID-19 pandemic on children's physical activity behaviours. This was accomplished in two parts: a comparison of participants with CMCs to pre-pandemic matched pairs in all domains of physical literacy; and an exploratory study to gather the experiences of participants with CMCs in physical activity during the pandemic. Total physical literacy scores were significantly lower in the pandemic group, driven by significantly lower physical competencies (i.e., movement skill and agility) and objectively measured participation in physical activity (i.e., daily step counts). Participants who were interviewed during the pandemic blamed physical distancing for lower levels of physical activity, namely the constraints it placed on active games and interpersonal relationships. Opportunities to explore new activities and spaces also changed for participants, but there were mixed perspectives on whether this was for the better (i.e., more time spent outdoors) or worse (i.e., closure of indoor facilities and sports). Re-learning how to be active or play certain games in a pandemic context was also challenging for most participants. As such, returning to pre-pandemic activities was not always perceived as worth the effort required to adjust to a drastically different, pandemic context (i.e., mask wearing, impending closures). A few participants experienced a decline in their health status during the pandemic, identifying an additional consideration unique to children with CMCs that may make returning to previous activities progressively more difficult.

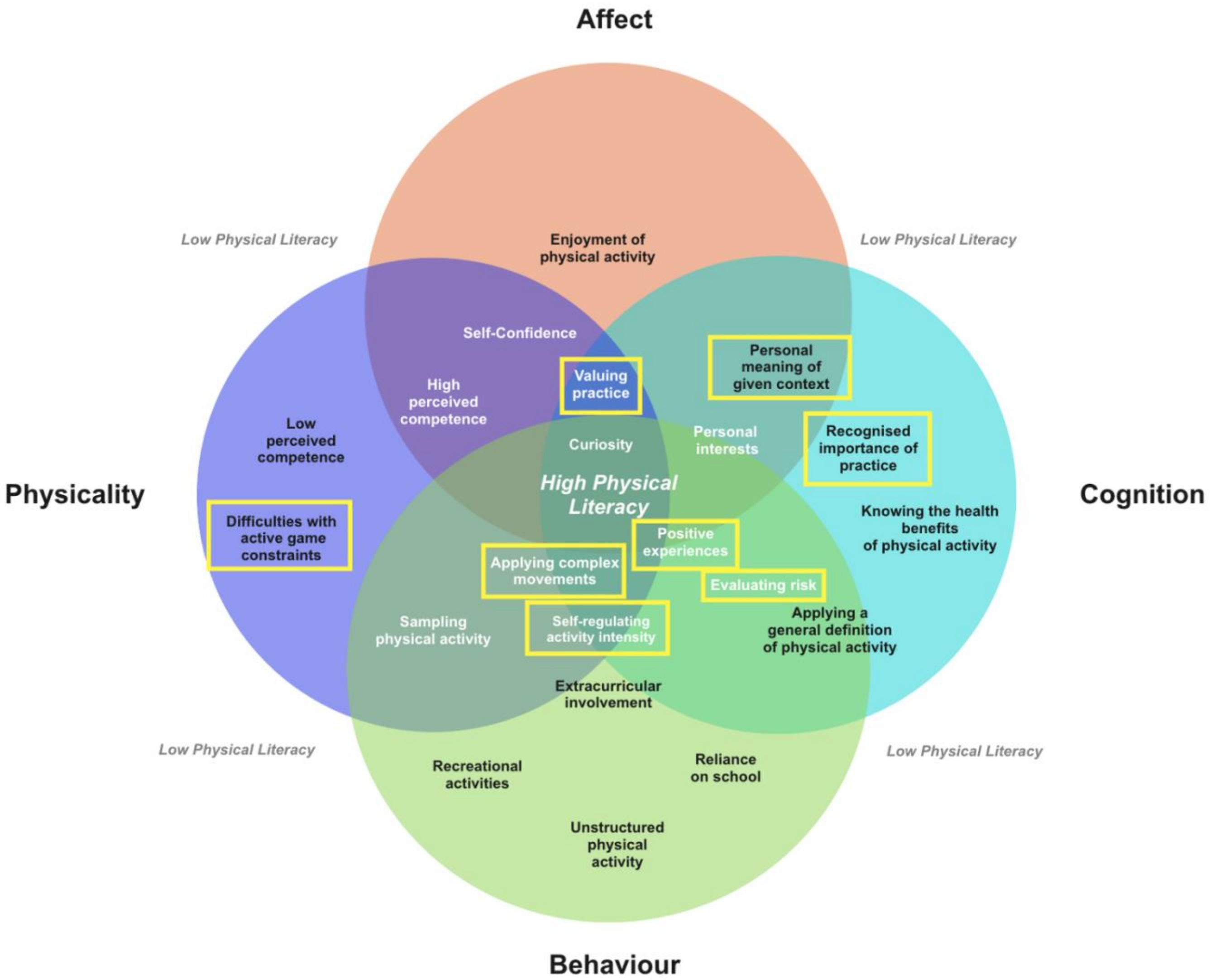
Once the underlying pandemic context was better understood, the purpose of the second article was to provide a comprehensive, balanced description of the diverse range of potential physical literacies among children with CMCs. Using an exploratory sequential design, physical literacy outcomes were assessed before interviewing children in the highest- and lowest-scoring quartiles. Boys scored significantly higher than girls in motivation/confidence, physical competence, and total physical literacy, with significantly different scores observed between endocrinology and hematology outpatients. Aligning with Whitehead's conceptualisation (Whitehead, 2010), total physical literacy levels appeared to contribute to a sense of self and how children with CMCs approached new experiences. In the affective domain, the importance of meaningful participation went beyond enjoyment for participants with CMCs, whose attitudes were generally informed by prior experiences in active settings. While most participants were in the beginning stages of physical competence by normative standards, there was a recognised importance attributed to practice for skill progression, which was believed to help sustain participation in active settings. Meanwhile, participants found it challenging to navigate bodily self-regulation, which was often medically necessary, alongside the complex movement patterns of sports and active games. Promisingly, children with CMCs adopted general definitions of physical activity, indicating a less limited view of active participation. They also recognised the benefits of physical activity for their health and well-being and were learning how to evaluate risks in active contexts. Finally, from a behavioural perspective, most children with CMCs were not meeting recommended levels of daily physical activity, and few spoke about participating in structured, extracurricular activities.

The overarching objective of the third article, within the scope of my dissertation, was to reflect upon my acquired knowledge of physical literacy among children with CMCs by examining how it could be applied to program design and delivery within a practical setting. This was accomplished through a mini-ethnographic case study reporting on the design and delivery of a community-based physical literacy program to participants with CMCs. Developed themes represented a combination of participant expectations, observed applications of program design/delivery decisions, and potential implications of the "I Can Play Anything" (ICPA) program for the physical activity and physical literacy of participants with CMCs. The first theme highlighted the importance of opportunities for learning to play. Such opportunities were valued by participants as offering transferrable skills and experiences while discovering new interests/capabilities. Learning how to play effectively with others while managing one's own capacities was important, albeit challenging with such a diverse group of participants of varying skill levels. The benefits of enabling an individualised approach, and the importance of creativity and flexibility in that process, were key to the successful inclusion of children with CMCs. How the constraints of the activities, skills and games were presented to and received by participants was just one example of the required flexibility and creativity among leaders. The implications of this approach were relevant to meaningful participation (i.e., supporting autonomy) and the inevitable necessity of creating variations to skills and/or games. Finally, prompting breaks and understanding one's need for rest was a particularly salient theme for children with CMCs. Breaks were appropriately normalised through the instructor-led implementation of the program design. That participants were taking greater responsibility for self-administering periods of rest towards the end of the program illustrates the important role of inclusive learning environments for the acquisition of this critically important skill. Opportunities to build embodied self-awareness were embedded within the variations that were offered to participants throughout the ICPA program.

Integration of Thesis Study Results

The adapted schema with findings from interview participants in the second article is an illustrative representation of experiences from low (i.e., outer edges of Venn diagram) to high (i.e., inner circles of Venn diagram) levels of physical literacy (**Figure** 1). Salient ideas within this schema were evidenced throughout the dissertation and warrant further discussion. These include recognising and valuing skill progressions developed through practice; the influence of meaningful experiences on active behaviours; self-regulating activity intensities in active contexts; and applying a general definition of embodied participation to physical activity.

Figure 1. *Schematic Representation of the CAPL-2 Model with Main Ideas from Developed Themes (Article 2) and Potential Areas of Intervention*



Note. Figure adapted from Longmuir et al., 2018. Text highlighted by a yellow square represents those ideas which should be considered for future interventions. Main ideas in the white text were more prominent among children with higher scores, whereas those in the black text were more prominent among children with lower scores.

Participants with CMCs recognised and valued movement skill progressions that were developed through practice (Article 2). More specifically, while children with lower physical literacy scores recognised the benefits of practice, those with higher scores appeared to attribute greater value to the concept of practicing to meet personal milestones. Participants demonstrated how they valued practice by recalling experiences in extracurricular settings where they realised the benefits of practice and applied that realisation to a future goal ("And then I could continue to learn. And then I had my first competition that spring" – Chapter 3, p.94). However, experiencing a shift from simply recognising to valuing the benefits of practice seemed less likely during the COVID-19 context, as there were fewer opportunities to develop and apply learned skills in extracurricular settings. While most interview participants had the physical and/or environmental resources to practice skills on their own (i.e., basketball soccer ball, nets, parks, etc.), few had opportunities to apply those skills to personally meaningful contexts (i.e., active games with friends, sports). This may be why children with CMCs appreciated the individual, collaborative, and offensive skills learned during the ICPA program. Similar opportunities to apply practiced skills to meaningful contexts might lead children with CMCs to attribute greater personal value to practice, which may promote ongoing physical literacy development.

Meaningful experiences in physical activity are typically those which involve social interaction, enjoyment, challenge, perceived competence, and personally relevant learning (Beni et al., 2017). The COVID-19 context, however, altered the social interactions expected within typical physical activity experiences of childhood. Nonetheless, affective domain scores were unchanged between the pandemic and pre-pandemic groups, despite qualitative reports of an opposite sentiment (i.e., less motivation) and significantly fewer active behaviours (i.e., daily step counts). Perhaps children with CMCs adapted to rely on other informants of meaningful participation to maintain measured levels of intrinsic motivation for physical activity (i.e., personal interests, challenges). For example, in the second article, a perceived enjoyment of physical activity was prevalent among almost all participants with CMCs. However, enjoyment, in comparison to the overall meaningfulness of physical activity, was seemingly not a salient factor on its own to facilitate active behaviours, thus providing some possible explanation for the lower step counts and perceived declines in motivation reported in the first article. Promoting a sense of meaningfulness for physical activity is therefore essential for children with CMCs and may be achieved through inclusive sport and physical activity opportunities, as evidenced by the findings of the third article.

Relatively lower levels of aerobic fitness were observed among children with CMCs in the pandemic context. However, interview participants perceived the rate of decline as being no different than their otherwise healthy peers, who also experienced significant declines in this capacity (Raine et al., 2023). Nevertheless, as discussed in the first article, children with CMCs may still face unique difficulties in post-pandemic active contexts, having further declined in already low levels of aerobic fitness. Even with targeted exercise training, the aerobic capacities required to keep up with otherwise healthy peers during highly active games may be physiologically incompatible, or unsafe, for children with CMCs (Bar-Or, 1986). This dissertation highlights the ways in which these cardiorespiratory limitations might be addressed within active contexts moving forward. The unique struggle of self-regulating physical activity intensities during active games was a salient theme in the physical domain of the second article. Children with CMCs described how overwhelming it could feel when trying to simultaneously develop skills, play the game(s), and maintain an appropriate level of exertion. This could sometimes lead to an inner conflict experienced by participants, when trying to decide whether to take a rest or maintain participation. Possible strategies to address this, which were incorporated into the ICPA program, were creating an environment where taking breaks would not come at the expense of participation/engagement in an activity, and teaching self-awareness to promote self-determined periods of rest. Implications of these results, relevant to both health and recreation practitioners, are discussed later in this chapter.

The World Health Organization defines participation as "a person's involvement in a life situation" (World Health Organization, 2011, p.307). Children with CMCs predominantly adopted this generalised definition of participation with regards to physical activity, as being physically engaged with their social and/or physical environment. Adopting this approach may have been especially relevant during the pandemic context, where typical opportunities (i.e., at school, extracurriculars, etc.) for physical activity were unavailable. Indeed, participants with CMCs spoke about broadening their scope of participation in physical activity through pursuing new interests and spending more time outside. Meanwhile, during the ICPA program, participation was not necessarily dependent on how skills were executed but rather how individuals were actively contributing to game play within their individualised constraints. Therefore, adopting a creative approach to instructing physical activities, as evidenced in the third article, aligns well with a general, less limited view of what constitutes physical activity. Furthermore, the creative approach applied to the ICPA program delivery accommodated children at varying levels of skill development. This may have been particularly beneficial for children with CMCs who anticipated an "adjustment period" following the pandemic, before being able to play at their full embodied potential.

Contributions to the Literature

This dissertation contributes methodological, theoretical, and practical knowledge to ongoing advancements in physical literacy research and the promotion of physical activity among children with CMCs. Methodologically, the ways in which pragmatism was applied throughout the research process were unique within physical literacy research and may help inform similar approaches in this field. Evidence from this dissertation also contributes to the theoretical relationship between self-concept and physical literacy (Whitehead, 2007; Fox, 2010), by extending research findings to the population of children with CMCs. This warrants further investigation into whether physical literacy interventions positively impact self-concept, which is of particular concern among children with CMCs (Ferro and Boyle, 2013b). Finally, the interweaving similarities and differences of this research population with both typically healthy and disabled children broadens the potential knowledge base from which to inform future physical activity interventions for children with CMCs. This also emphasises the importance of investigating the physical activity behaviours and perspectives of children with CMCs as distinct from otherwise healthy or disabled children. A more detailed discussion of these contributions is presented below.

Pragmatism in Physical Literacy Research and Application

The measurement or assessment of physical literacy is a common area of debate among researchers in this interdisciplinary field. Since assessment became a more relevant priority for the advancement of physical literacy research (Tremblay and Lloyd, 2010), two conflicting operationalisations have generally been adopted, informed by either idealistic or pragmatic perspectives (Edwards et al., 2018). The former contends that the domains of physical literacy (i.e., physical, cognitive, affective) cannot be separated if Whitehead's monist philosophical assumptions are to be followed. Thus, idealistic approaches tend to draw from qualitative sources of information and as such, often produce findings that are difficult to incorporate into clinical practice. The individualised findings generated by qualitative research are not seen as easily transferable to inform evidence-based practices and guidelines, which are relied upon in clinical care settings. Meanwhile, researchers who adopt a pragmatic perspective are looking to use measures that align with evidence-based practices and practical implications (Edwards et al., 2018). From a methodological perspective, my doctoral research addressed one of the main criticisms of how the pragmatic approach has been most often applied to date (Edwards et al., 2018), which maintains that isolated measures of domain-related outcomes cannot adequately represent the multifaceted and complex concept of physical literacy. Rather surprisingly, mixed methods are common in pragmatic methodologies but rarely used in the examination of physical literacy (Liu and Chen, 2020). Incorporating mixed and multiple methods into this research design allowed me to build a physical literacy narrative that considered relevant markers of development (i.e., task-based measures and validated questionnaires) alongside personal experiences.

The strengths of using this pragmatic approach to describe physical literacy were evidenced by this research in several ways. Firstly, a pragmatic approach allowed me to account for the heterogeneity of my research population, who may have experienced different chronic diseases but shared broader experiences of navigating their medical conditions in active contexts. In the first two articles, participants described the qualities of their physical activity experiences during the COVID-19 pandemic context and when living with a chronic disease. This experiential piece provided relevant information to inform measured physical literacy outcomes but may have been missing if solely quantitative methods were used. Further, the use of mixed and multiple methods in all three articles provided more information about the social influences of physical activity, which is often missing from physical literacy research (Edwards et al., 2018), and how those experiences may have influenced the behavioural and affective domains. For example, the emphasised lack of social interactions, which diminished participants' described motives for physical activity during the COVID-19 pandemic, prompted further questions about why the motivation/confidence scores were similar between pandemic and pre-pandemic matched pairs. Children with CMCs also described the perceived challenges of applying complex movements to active games where they had to play alongside and/or against peers; a competency that is not explicitly measured by the CAPL-2 or other physical literacy assessments. Finally, the use of multiple methods in the third article captured relevant findings about learning to play alongside peers in the ICPA program from multiple perspectives (i.e., researcher, parent, and child).

Another strength of employing this pragmatic approach was how the ontology consistently guided me to consider all components informing physical literacy. This helped mitigate the bias of physical competence in my results, which typically occurs in physical literacy research (Carl et al., 2022; Edwards et al., 2018) and is currently dominating the paradigms of health and recreation practitioners (Cornish et al., 2020; Lloyd, 2016). While focusing on physical competence is not necessarily wrong from a pragmatic perspective, physical literacy scholars would argue that it is only one piece of the much larger whole concept, and risks being interpreted as the entire concept itself (Young et al., 2020). My doctoral research addressed this concern by employing mixed methods to pragmatically capture the holistic conceptualisation of physical literacy, as opposed to focusing only on domain-related outcomes.

Regarding practical implications, the pragmatic approach of this research allowed the thoughts and perceptions of children with CMCs to be included in the design and delivery of the physical literacy based “I Can Play Anything” program (Article 3), so that it would more directly address individual needs and allow participants to meet personal milestones. By adopting a pragmatic approach throughout the entire research process, my general findings about children with CMCs were comprehensively interpreted in relation to a) other groups or populations and b) knowledge outside of the physical literacy literature (i.e., from other, related disciplines). Interview participants perceived self-reported declines in physical fitness as similar to their peers, but measured outcomes were further interpreted in a discussion of existing knowledge among otherwise healthy children, to fully capture the implications of these results. Findings related to self-concept, identity and perceived risks during play were all evident in these results, and the application of knowledge from these disciplines to children with CMCs will be discussed later in this chapter. Finally, observed and reported experiences during the ICPA program were aligned with the Quality Participation Framework (Evans et al., 2018) developed for populations of people with disabilities, suggesting that some aspects of work from the disability field could be useful to further inform future interventions among children with CMCs.

Self-Concept and Physical Literacy

The lived embodiment is central to the concept of physical literacy, wherein physical literacy is "the human potential that springs from our nature as embodied beings" (Whitehead, 2010, p.11). Whitehead's physical literacy conceptualisation therefore posits the self as central to all aspects of participation, highlighting the relevance of self-concept (Fox, 2010). Self-concept is a cognitive appraisal of one's lived embodiment, most often with regards to personality, roles, competencies, and features, among other perceptions of the self (Hattie, 1992). Self-concept has a direct influence on behaviour (Shavelson et al., 1976) and is a relevant indicator of psychological well-being among children and youth. Unfortunately, self-concept may be significantly compromised among children and youth with CMCs in comparison to typically healthy peers (Ferro and Boyle, 2013a), supporting the observed prevalence of negative psychological and psychosocial outcomes among this population (Geist et al., 2003; Lavigne and Faier-Routman, 1992). This dissertation suggests that the examination of physical literacy can provide additional insight into how self-concept is developed among children and youth with CMCs, supporting Whitehead's (2007) argument that the lived embodiment may influence the continuous formation of one's self-concept.

Physical aspects of self-concept have been associated with higher intensities of participation in physical activity among otherwise healthy children (Babic et al., 2014) and those living with chronic disease (Bedard et al., 2022). Nonetheless, empirical evidence of the relationship between physical literacy and self-concept is still emerging (Hastie and Wallhead, 2015). Among otherwise healthy 7- to 8-year-olds, physical self-concept (i.e., “are you athletic?”, “are you good in sports?”, “are you a good athlete?”) significantly mediates the relationship between motivation (intrinsic and extrinsic) and motor performance (Lohbeck et al., 2021). A significant relationship between the sum of outcomes relevant to physical literacy (i.e., motor competence, perceived competence, enjoyment, predilection) and self-concept, mediated by self-reported time spent in physical activity, was also found among preadolescent children (Clark et al., 2022). My research contributes to these findings as it presents more empirical evidence supporting a relationship between self-concept and physical literacy; participants with CMCs who had the highest physical literacy scores identified as “active kids”, a feeling that was not shared by those with the lowest scores.

There was an observed dichotomy in my findings between how participants with high levels of physical literacy remained motivated to participate in physical activity, despite their medical condition, whereas participants with lower levels of physical literacy felt uncomfortable in active contexts. These contrasting narratives are also evident in the broader literature among children with CMCs (Moola, 2020; Moola et al., 2012). While some authors report that children with CMCs reject disabling discourses to maintain participation in physical activity (“Their responses focused on what they ‘can do’… and in some instances made references to being more active than their peers”; Fereday et al., 2009, p.12), others assert how disease-related experiences make participating in physical activity undesirable (“…children could not imagine themselves without the limitations of [their disease] and expressed apprehension about doing new activities.”; Constantinou et al., 2021, p.8). In this way, physical literacy may help inform how children with CMCs protect their self-concept in active settings. For example, a child with high physical literacy may be able to confidently reject or cope with perceived competencies that conflict with their ideal, active self. This was evidenced when children with higher scores spoke of building strategic boundaries to protect themselves from feeling too self-conscious, or when speaking about the precedence of an "active" identity over one related to illness. Meanwhile, a child with low physical literacy may not be able to reject those perceived competencies that align with illness or disability, avoiding physical activity as a result. It is also possible that self-concept may drive physical literacy development, which is why future, experimental research investigating the directionality of this relationship is warranted.

Children who hesitated to return to physical activity during the pandemic may have also been protecting their sense of self by avoiding scenarios where they would experience disappointment (i.e., those that were worried activities would be cancelled with another lockdown) or their competencies would be diminished ("you get more tired easily [wearing a mask]" – Chapter 3, p.133). However, these concerns did not appear to be related to physical literacy levels, as they were discussed among both high- and low-scoring groups. Since the barriers to participation in physical activity during the pandemic were unexpected and novel to all children, perhaps the prior experiences and strategies that children with higher levels of physical literacy had previously leveraged to protect their self-concept were not sufficient to account for such unprecedented changes (i.e., the COVID-19 pandemic context). It should also be noted that not all children cited concerns about returning to physical activity. Future research would therefore benefit from longitudinal designs to examine how self-concept changes with varying levels of physical literacy across the life course.

While more research is certainly needed to examine how manipulating physical literacy may lead to positive developments in self-concept or vice versa, findings from the third article may give some insight on the potential of this relationship within an intervention context for children with CMCs. For example, building a wide range of physical competencies and learning to play numerous sports may help children understand that being restricted from some physical activities should not limit one's potential for an exciting, active lifestyle. This was acknowledged by one parent after the ICPA program, who stated "… invariably there have been difficult discussions about what he can't do… this program has helped him understand there are many things that he can do and should be willing to look at new experiences" (Chapter 3, p.133). Further, teaching children with CMCs how to adopt creative solutions to participate in physical activity (i.e., changing rules or adapting positions) may also encourage positive perceptions of competencies that align with existing interests and participation goals. These were examples reported in the third article, reflecting my growing recognition of the importance of the connection between self-concept and physical literacy among children with CMCs as this research progressed. Combined findings within this dissertation indicate that the potential to facilitate a positive self-concept among children with CMCs through physical literacy-based interventions should be explored further.

Points of Convergence and Divergence with Other Paediatric Populations

Children with CMCs are represented under the scope of the World Health Organization's definition of disability[1]. While themes relevant to disability are certainly evident in the literature encompassing physical activity experiences of children with CMCs (Moola, 2020; Moola et al., 2012), many have also reported "passing" as any other, typically

[1] The WHO defines disability as a concept that "results from the interaction between persons with impairments [i.e., problems in body function] and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others" (World Health Organization, 2011, p.4)

healthy child in active settings (Denford et al., 2020; Fereday et al., 2009; Shearer et al., 2013). My research contributes valuable, empirical evidence to this ongoing contrast, between disabled and able-bodied, that is uniquely situated throughout the lived experiences of children with CMCs. The purpose of this section of the discussion is to prompt the reader to critically appraise, and perhaps apply, existing knowledge/resources from other paediatric populations to children with CMCs. My findings are referenced throughout this section to highlight the similarities and differences between children with CMCs and other paediatric populations in physically active contexts, including for how physical literacy is operationalised, the active capacities and opportunities that were influenced by the COVID-19 pandemic, and the design of interventions to enhance physical activity experiences.

Physical literacy outcomes related to physical, cognitive, and affective domains can help characterise the general capacities of all children as they engage in active environments. However, the use of existing measures of physical literacy have been problematized for children with disabilities, as they risk being interpreted from an ableist lens (Pushkarenko et al., 2021). Children with disabilities may participate in specialised physical activity contexts (Martin Ginis et al., 2016) and/or employ unique movement patterns (Wiart and Darrah, 2002) that may impact assessments based on process rather than outcome measures. In contrast, children with CMCs *do* typically participate in the same contexts and engage in similar movement patterns as otherwise healthy peers, though the expectations of how they participate may vary depending on their physiological limitations. My results emphasise that the capacity for children with CMCs to navigate play alongside their symptoms is an aspect of physical literacy which should be uniquely considered among this population. This was particularly evidenced in the qualitative findings of the second and third articles, with themes relating to embodied self-awareness and bodily self-regulation in active games. Also given the potential floor effect observed in physical competence (Article 1) and the disproportional dominance of the affective domain (Article 2; Do et al., 2021), using physical literacy measures validated among typically healthy children should be interpreted cautiously if comparing children with CMCs to otherwise healthy peers, as their embodied potential may be misrepresented.

Although evidence is still emerging (Moss et al., 2023), the added context of participating in physical activity during the COVID-19 pandemic should also be compared between children with CMCs and typically healthy or disabled peers. Indeed, one might interpret the resulting themes from the first article of Chapter 3 to be applicable to most children who lived through this pandemic, which include: 1) physical distancing limited how children socially connected through physical activity; 2) pandemic-related prevention measures changed physical activity-based opportunities for development; and 3) even after restrictions are lifted, returning to physical activity is not simple. The only exception would perhaps be the third theme, where the added experience of living with a medical condition was more apparent. Comparable, pandemic-related declines in movement skill were observed among typically healthy children (Carcamo-Oyarzun et al., 2023; Pombo et al., 2021), children with intellectual disabilities (Sedaghati et al., 2022) and participants with CMCs in the current research. In contrast, significant declines in cardiorespiratory fitness, measured via graded exercise test (VO2 max), were found among otherwise healthy children (Raine et al., 2023). While this might seem promising for children with CMCs in the current study, who did not experience significant declines in the field-based PACER test, this does not necessarily suggest that their cardiorespiratory fitness levels are more like their otherwise healthy peers in a post-pandemic era. Since children with CMCs already demonstrated very low levels of cardiorespiratory fitness before the pandemic (Do, Blais, et al., 2021), the potential for a significant decline in this outcome was less likely. In the interviews, participant with CMCs commented that their physical competence would have declined no more or less than their peers. This supports the continued assumption that children with CMCs, without intervention, would also demonstrate lower levels of cardiorespiratory endurance in comparison to otherwise healthy peers during a post-pandemic context.

Measured outcomes relating to the affective domain suggested that children with CMCs maintained relatively high levels of motivation and confidence, even throughout the COVID-19 pandemic. While there are no statistical findings about how affective measures among otherwise healthy and disabled populations were influenced by the pandemic, qualitative research has illustrated various facilitators and barriers to physical activity during this time (Lindsay et al., 2021; Riazi et al., 2021; Richards et al., 2022; Roche et al., 2022). Notably, motivation for and perceived competence in physical activity during the pandemic is reported to have been impacted by a lack of access to structured activities, destinations for physical activity (Riazi et al., 2021) and, for children with disabilities, the cancellation of specialised services (Theis et al., 2021). Participants with CMCs did not emphasise facility closures as impacting their overall motivation, as much as they did the loss of social norms in these active settings. This also highlights a particular area of divergence from the population of children with disabilities, wherein a lack of specialised services during the pandemic was not relevant to the experiences of children with CMCs.

One of the ways in which participants with CMCs who demonstrated low levels of physical literacy were differentiated from those with relatively high levels was their reliance on school-based opportunities for physical activity. Within the COVID context, otherwise healthy adolescents and emerging adults experienced a decline in physical activity once incidental opportunities for physical activity were no longer required (i.e., walking to school, work, etc.) (Trask et al., 2023). Although this thesis included a different age demographic, it may be reasonable to consider that the reliance on incidental or habitual physical activities that traditionally occur at school (i.e., walking to class, recess, gym) is what partly characterises the low physical literacy group. When trying to contextualise these experiences, in comparison to otherwise healthy children who also rely on incidental physical activities at school, the differentiation may only be in the exclusion of children with CMCs from gym class (Fereday et al., 2009). Individuals with disabilities, on the other hand, experience more environmental and interpersonal barriers to habitual physical activities in school-based settings, such as a lack of appropriate equipment or time management issues (Carlon et al., 2013; McGarty and Melville, 2018). Children with disabilities also rely on routines for activities of daily living, the disruption of which had a profound impact during the pandemic context (Mete Yesil et al., 2022).These are experiences less likely to be shared among those with a CMC, highlighting how their needs may differ from peers upon their return to in-person learning, where much of their physical literacy development is expected to occur.

Meanwhile, many children with CMCs in the high physical literacy group, who had previously participated in extracurricular activities, used the COVID-19 context as an opportunity to focus on other pursuits. A similar shift in motivation occurred among otherwise healthy youth, as their determination to continue training in their extracurricular sport(s) also diminished during this time (Kalski et al., 2023). This shift may not have necessarily had a negative impact, since adapting to new circumstances/activities is argued to benefit overall physical literacy development (Trask et al., 2023). In contrast, children with disabilities may not have had the freedom or space to explore other opportunities in the same way as their peers, since they often rely on parental support to access physical activities (Moore et al., 2021). Thus, the temporary loss of extracurricular sport participation for children with CMCs may not have had the same impact as it appeared to have for children with disabilities, as participants described various circumstances where they were able to discover new contexts for play.

As pandemic-related restrictions have eased, the return to physical activity has been emphasised as a priority for all children (Kuzik et al., 2023). The complexities of returning to sport/physical activity, however, should not be underestimated. In this research, children with CMCs described various hesitancies for returning to physical activity/sport, which included a sense of nervousness that pre-pandemic activities would feel like trying something new for the first time, an expected period of low self-efficacy for various movement skills, and changes in health status that influenced their physical capabilities. Whether their peers would share these hesitancies is not yet known. While data from interventions addressing pandemic-related declines in physical activity are still emerging (Moss et al., 2023), it has been suggested that an enhanced focus on training community-based instructors/coaches as well as an intentional focus on quality physical activity programming would best support children with disabilities in a post-pandemic context (Arbour-Nicitopoulos et al., 2022). Therefore, in conjunction with my findings, enhancing the motivational/instructional climate of community-based physical activity settings may address the post-pandemic needs of both children with CMCs and those with disabilities. Future research may wish to examine intervention results alongside the contextual findings of this research, to evaluate the appropriateness of post-pandemic intervention techniques for children with CMCs.

The Quality Participation Framework[2] was created for individuals with disabilities to move beyond accessibility and towards quality physical activity participation (Evans et al., 2018). The elements of quality participation, which make up the core of the framework, include autonomy, challenge, engagement, belongingness, meaning and mastery (Martin Ginis et al., 2017). Given the parallel ideas of the framework with existing and well-established psychological theories (i.e., self-determination theory: Deci and Ryan, 1985;

[2] The Quality Participation Framework, developed by the Canadian Disability Participation Project, can be found here: https://cdpp.ca/resources-and-publications/blueprint-building-quality-participation-sport-children-youth-and-adults

competence motivation theory: Harter, 1978; positive youth development: Holt et al., 2017; etc.), Evans and colleagues (2018) emphasised that it is a structure within which existing theories might operate. As discussed in the third article, elements of the quality participation framework may also be appropriately applied to children with CMCs, including strategies to remain engaged in physical activities/sports, despite requiring a break or rest at any time, the implementation of safe sport tasks, and including children of varying abilities into programming while also providing opportunities for participants with similar abilities/capacities to play with each other at their desired level. In this way, the findings of my research warrant future investigations into the impact of intentionally designing interventions for children with CMCs within the Quality Participation Framework. The only aspects in which the framework's applicability to children with CMCs diverges from those with disabilities are some of the individualised conditions relevant to children with significant impairments in active settings (i.e., providing optimal sensory environments, physical accessibility; Bruno et al., 2022). Nonetheless, all remaining conditions and experiential elements informing the framework may be appropriately applied to children with CMCs. During the ICPA program, technical skills and sport-related knowledge from coaches were perceived as influencing participants' sense of mastery and personal meaning, as skills could apply to other play contexts. In another theme of the ICPA program, using creative ideas to facilitate an individualised level of challenge was helpful to support participants' autonomy. These examples demonstrate how conditions of the framework (i.e., coach knowledge, individual level of challenge) can influence various experiential elements of their participation (i.e., mastery, meaning, autonomy). The potential application of the Quality Participation Framework is just one example of how comparing the experiences of children with CMCs to other paediatric populations can broaden the scope of existing resources and appropriately leverage them t the benefit of children with CMCs.

Limitations

There were several limitations to this dissertation which should be considered when interpreting these findings, as well as addressed in future studies that may continue to build from this work. Many of these limitations were noted in the articles of Chapter 3, which include the enrolment bias of children who are already interested in physical activity, time constraints influencing the amount of data collected, potential changes in physical literacy perspectives between quantitative and qualitative data, and limited representations of the diverse group of children living with medical conditions due to the fixed inclusion criteria. The broader, overarching limitations influencing this dissertation include the precariousness of conducting in-person research during the COVID-19 pandemic, the representations of medical conditions within the data, and the lack of socioeconomic information available in the collected data.

Logistical Challenges and Limitations Related to the COVID-19 Pandemic

As with most studies conducted from 2020 through 2022, this research was limited by the unpredictable restrictions enforced to mitigate the spread of COVID-19. While almost all outpatient clinics adopted a hybrid approach to care (i.e., a mix of virtual and in-person appointments), the endocrinology, cystic fibrosis and hematology clinics only permitted an in-person recruitment strategy for research activities. Thus, potential participants would have been missed if they were followed virtually, or if prospective participant families were denied entry to the hospital based on the COVID-19 screening protocol. In some cases where I was denied entry to hospital grounds (due to close contact or the presentation of COVID-related symptoms), I was fortunate to have research team members who could recruit on my behalf, but this was not always a feasible alternative (i.e., varying schedules, incompatible workloads, etc.). Meanwhile, as opposed to pre-pandemic physical literacy data which were collected in group-based settings, almost all the data for this research were collected via individual sessions (or family sessions in the case of multiple eligible patients living in the same household). While this delayed the anticipated timeline for the completion of data collection, there were also unexpected benefits of an individual testing approach. For example, there were some participants who emphasised they would not have participated in this research if they were required to be active in front of others, due to social anxieties. Testing individual participants also allowed for more flexible timing to schedule physical literacy assessments, which potentially accommodated more participants than if data were collected in fixed, group-based sessions.

Securing physical space for data collection was the greatest logistical challenge related to COVID-19 that I faced throughout this process. There were no indoor spaces at the Children's Hospital of Eastern Ontario that were large enough to accommodate the full CAPL-2 protocol, which is why most data were collected during the spring/summer months (when the weather permitted the use of larger, outdoor spaces). Relying on an outdoor space also limited the data collection sessions that could occur during unfavourable climates (i.e., raining, too hot, too cold), which is why some participants were only able to complete a partial protocol (i.e., missing the movement skill and agility assessment). The use of the CAPL-2 was beneficial in this regard, as I was still able to compute the physical competence scores of participants who did not complete the full protocol for these reasons, by using the recommended statistical approach for missing data (Delisle Nyström et al., 2018). During the late fall, winter and early spring, data collection sessions had to take place indoors. While I was fortunate to be able to conduct these sessions at a local recreation centre (RA Centre), this was only permitted when the facility was allowed to be open and accessible to the public for sports participation. Furthermore in 2022, participant families who had not yet been vaccinated were limited from entering the RA Centre when vaccination requirements were in effect. While conducting virtual interviews was certainly feasible (and necessary) during the COVID-19 pandemic, the planned use of illustrations to enrich the qualitative data collected (Darbyshire et al., 2005) was not. In contrast to my prior experiences of being able to prompt follow-up questions from illustrations made in person (Blais, Lougheed, Yaraskavitch, et al., 2020), it proved much more difficult to use illustrations in a similar way online, when the virtual barrier prevented participants from sharing their drawings in real time. Finally, while pandemic-related societal challenges remained (i.e., different perspectives on vaccinations/masking, ongoing hesitations, and concerns about spreading the virus), almost all COVID-19 safety requirements (apart from masking in areas related to healthcare) and the uncertain provision of indoor recreational spaces had subsided by the time participants were enrolled in the ICPA program (mid Fall, 2022).

Representation of Medical Conditions

Although there was an expectation that participants would refer to their own experiences of living with a medical condition, this was rarely communicated explicitly. Only a few participants referred to their medical condition when discussing physical activity, but most had to be prompted to do so. In the semi-structured interviews, this was often following the question: “Some kids that go to CHEO [the children’s hospital] have told me that they feel nervous about doing physical activity. Is there anything that you might say to them? Do you sometimes feel this way?” (Appendix C). Even following this prompt, some participants would not relate or expand on their responses by comparing with their own experiences, as anticipated. In the ICPA program, the only participant to bring up their medical condition was Shreya, who participated in the individual interview instead of the focus group. Given the observed group dynamic and the discreetness that Shreya seemed to demonstrate throughout the study, it is unlikely that she would have referenced her medical conditions in the focus group context.

As I reflected on the lack of explicit data representing medical or disease-related experiences, I was prompted to think about what I might have done differently. If I had asked more direct questions probing children with CMCs to discuss their disease-related experiences during physical activity, I may have had richer expressions of this phenomenon in the data. However, I also did not want to inflate the importance of their disease on my findings. I was also aware of the dynamic between myself, a physical activity researcher at the children's hospital where participants received treatment and medical advice, and participating children with CMCs, who may have had unanswered questions about their disease-related, physiological limitations. By explicitly probing about their medical conditions in the context of physical activity, I feared I might elicit more uncertainties about safe participation, which could have prompted unnecessary, self-imposed physical activity restrictions among participants. This was ultimately why I decided to adopt a more implicit interview strategy, which may have impacted the relative importance of participants' medical conditions in their communicated experiences. However, one might also argue that *not* mentioning their medical conditions shows promise that children with CMCs prioritise other perceptions of physical activity (i.e., enjoyment, social interactions, goal setting, etc.) ahead of the disease-related barriers they may face.

Uncertain Socioeconomic Context

Socioeconomic status is a known, relevant factor influencing the physical activity behaviours of Canadian children (Brown et al., 2020), but investigating this aspect was considered outside of the scope of this research. Thus, my findings should be thoughtfully considered alongside existing knowledge of how socioeconomic status impacts physical activity behaviours (Sterdt et al., 2014; Westergren et al., 2017), sport participation (Fleming et al., 2023) and the psychosocial and health disparities of children during the COVID-19 context (Lachman, 2021). When interpreting the findings from the first article, it is possible that socioeconomic status may have mitigated observed declines in total physical literacy, physical competence, and daily step counts. However, my ability to consider the impact of socioeconomic status was limited because the retrospective data (pre-pandemic) did not provide this information. Within the context of the pandemic, children from low socioeconomic households may have been among the first to return to in-person schooling out of economic necessity (Green et al., 2021), which could have influenced findings about returning to physical activity. Opportunities to participate in physical activity during the lockdown periods may have also been drastically different between households with different socioeconomic statuses (Gu et al., 2022).

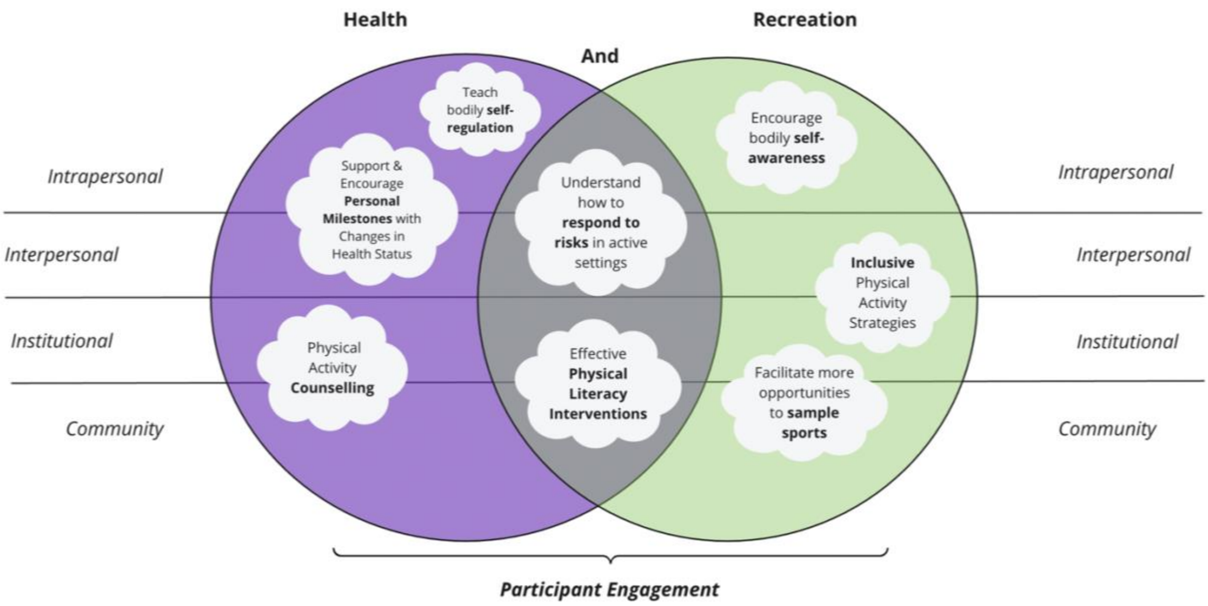
Themes presented in the second article which may have been reasonably influenced by socioeconomic status include those in the affective, physical, and behavioural domains, as well as total physical literacy. In the affective domain, attitudes towards physical activity were heavily drawn from prior experiences. Meanwhile, in the physical domain, practice was highlighted as essential for skill progression and valuable for on-going participation. Both themes may have been influenced by a greater number of physical activity opportunities afforded to children from high-income families, as they might have experienced and practiced more diverse movement skills in paid, extracurricular activities. In the behavioural domain, children from low socioeconomic households may have had to rely more on school programs for physical activity, meaning they primarily participated in unstructured, recreational games. The same socioeconomic disparity in extracurricular opportunities may have influenced the behavioural theme where physical activity was found to be driven by prior exposure to sport, accessibility and/or personal interests. Moreover, socioeconomic status may have a moderating role on gender differences in physical activity (Lee and Lim, 2022), which could have influenced physical literacy development. Finally, opportunities to try new physical activities which are afforded by greater socioeconomic privileges may have influenced how participants with CMCs approached new experiences in physically active settings (total physical literacy).

To address the potential bias of only assessing children whose families had access to reliable transportation for the CAPL-2 testing sessions, I conducted several remote sessions in outdoor spaces within walking distance of participants' homes. Likewise, all interview participants had the option of a phone or in-person interview (physical distancing restrictions permitting) if a virtual modality was unavailable, which was less common as interview participants had the resources required to access virtual school at the time. The potential bias of socioeconomic status was frequently recorded in my reflective notes during data collection and analyses. For example, during the interviews I noted that it would have been difficult to distinguish those participants who had not yet "found their sport", from those who simply would not have had the chance to do so through sampling. I also kept as flexible a schedule as possible to conduct data collection sessions at times that were considered the most convenient for participating families. While the ICPA program was free to attend, allowed for flexible attendance within a set schedule, had free on-site parking, and a nearby transit station, there was no remote option. Thus, families with higher socioeconomic statuses may have had more access to enroll in the program, which is a contextual factor that should be acknowledged.

Implications

The first article of this dissertation suggested the use of a socioecological model to illustrate how policy decisions made during the COVID-19 pandemic influenced physical literacy outcomes on the inter- and intra-personal levels. Building on this idea, the resulting implications of this whole dissertation could also apply to both healthcare and recreation practitioners within a socioecological model (Figure 2). The rationale for encouraging a shared understanding of physical activity research implications across both sectors is to encourage collaboration (Martin Ginis et al., 2016) and an interdisciplinary system that would be particularly beneficial to children with CMCs (Lobelo et al., 2020; MacMillan et al., 2016). Ideally, collaboration would maximise the expertise and support that individuals with CMCs receive as they develop their full potential of physical literacy. This section contextualises the relevance of this dissertation within both sectors, followed by areas of future research that would benefit from a multidisciplinary approach between sectors.

Figure 2. *Implications for both healthcare and recreation practitioners within a socioecological model*



Relevance to Health Sector

Physical activity counseling is highly recommended for paediatric health specialists to implement into practice (Lobelo et al., 2020; Longmuir et al., 2013) and has recently become a more established component of clinical care at the Children’s Hospital of Eastern Ontario, where this research took place. Healthcare practitioners who play a role in supporting the physical activity behaviours of children with CMCs may not exclusively include doctors, but also specialised nurses, physiotherapists, occupational therapists, kinesiologists, psychologists, social workers, and child life specialists. Indeed, it is quite understandable that families of children with CMCs will look to their responsible healthcare practitioners for guidance on physical activity, yet many of those same practitioners do not feel equipped with adequate knowledge or counselling techniques to support them (Goff et al., 2010; Whooten et al., 2023). The knowledge gained from this research may support healthcare practitioners by providing insight to inform their physical activity counselling practices with patients, especially following the recent pandemic context. Understanding how children with CMCs develop physical literacy also gives some insight about how a healthcare practitioner should approach physical activity discussions in clinical settings. Namely, how children with CMCs adopt a general definition of physical activity, are continuously learning to self-regulate their physical activity intensities, and learn to value physical activities regardless of physical competencies, are all findings which have important implications for clinical physical activity counseling outcomes.

Adopting a general definition of physical activity is particularly beneficial for children with CMCs who experience symptoms or restrictions with higher intensity activities. While general perspectives provide children with more options for physical activity, they may also bias subjective reports of behaviour, which are often relied upon in clinical settings (Lobelo et al., 2020). Thus, it may be more relevant to prompt patients to describe the quality of their participation in physical activity (i.e., what they play at recess, their positions in sports, the skills they enjoy practicing) rather than the quantity (i.e., time spent in recess, sports enrolled in, number of hours spend in physical activity). When educating paediatric patients on the relative intensities of physical activity they should be pursuing, healthcare practitioners may also help children identify bodily cues and encourage strategies for embodied self-awareness, such as mindfulness (Perry-Parrish et al., 2016), ratings of perceived exertion, and the "talk" test (Bok et al., 2022).

One area where children with CMCs may need more specific, additional support is following a recent decline in health status. These children will likely perceive a difference in their physical competence when re-entering active contexts. Children with higher scores of physical literacies in my research were able to successfully draw from their personal experiences with success, as opposed to peer comparisons or current perceived competencies, to encourage continued participation. Valuing the relative benefits of practice may have also helped them maintain a sense of meaningfulness for physical activities during the pandemic, despite the absence of social influences/interactions. Thus, healthcare practitioners should help their patients cope with changes in physical competencies by encouraging them to reflect on previous experiences where they benefitted from practice. Then, perhaps clinicians could guide patients to visualise realistic milestones that can be achieved through practice or continued engagement in physical activity. A recommended strategy for paediatric physical activity counseling, which also aligns with this approach, is the use of SMART (specific, measurable, achievable, realistic, and timed) goals (Kris-Etherton et al., 2021). Findings from this dissertation suggest that personal milestones or metrics should be emphasised for the "measurable" aspect of these goals, rather than peer or normative comparisons.

Relevance to Recreation Sector

As previously suggested, the heterogeneous circumstances (i.e., different diagnoses, varying competencies) yet universal needs (i.e., autonomy, meaning, etc.) of children with CMCs support the implementation of the Quality Participation Framework in community-based recreation settings (Evans et al., 2018). Creating inclusive spaces for all children and youth, which promote meaningful participation will align with organisational goals of encouraging long-term engagement in physical activity. For children with CMCs specifically, the Venn diagram presented in the second article of this research (Figure 1 of this chapter) may be referenced to identify areas where recreation practitioners may provide additional support. Some of these areas which may be particularly applicable to recreation practitioners (i.e., coaches, instructors, program managers) include facilitating positive experiences with sport and physical activity, providing opportunities to sample physical activity, improving perceived competence, supporting students as they optimise their ability to self-regulate activity intensity, and teaching how to apply complex movements through creative modalities. The benefits of sampling physical activities are recognised (Côté et al., 2009), as well as the influence of building a mastery motivational climate to promote perceived competence in physical activity (Braithwaite et al., 2011). The ICPA study comments on the unique value of sampling sports, as well as the creative strategies used to facilitate competence and autonomy, calling attention to an ongoing need to incorporate these components more intentionally into recreation settings.

In addition to the factors which contribute to positive experiences in sport and physical activity for all children, such as experiencing appropriate levels of challenge, positive social interactions, and games which align with personal interests (Beni et al., 2017), how the unique needs of children with CMCs are addressed in community-based settings can also inform whether they associate more positive or negative feelings with the overall experience. For example, in the second article participants with low physical literacy described how not being able to physically keep up with their peers informed negative perceptions of physical activity. Meanwhile, participants in the ICPA program reflected on how being able to participate fully alongside peers, while also remaining within their own physical capacities, would inform (or did inform, when executed successfully) positive experiences with sport. This suggests that recreation practitioners, in addition to delivering relevant behaviour change and pedagogical strategies, should be trained to prompt for bodily self-awareness and teach bodily self-regulation techniques during their programs. Normalising self-determined periods of rest within active settings, as was demonstrated during the ICPA program, may also address the negative tension that some children with CMCs experience in this regard (Fereday et al., 2009; Moola et al., 2011; Winn et al., 2018). Finally, recreation settings are well suited to instruct children on how to execute complex movement patterns, which is something that many participants with CMCs struggled with in their prior experiences with sports. Including obstacle courses or pretend plays, which allowed participants to practice applying a combination of various movement patterns for a non-competitive goal during the ICPA program, are examples of components that recreation practitioners should consider when designing an inclusive sport or physical activity program.

Future Research Between Sectors

Due to the interdisciplinary nature of physical literacy research, there are numerous facets within the current findings that would benefit from further investigation by academics in human kinetics or kinesiology. These include the long-term effects of the COVID-19 pandemic on the physical literacy of children with CMCs, the relationship between self-concept and physical literacy, and the operationalisation of embodied self-awareness in active contexts. Moreover, specific attention should be directed towards two priority areas of research: a) the implementation and effectiveness of physical literacy-based interventions for children with CMCs, and b) interventions which support children with CMCs to effectively evaluate and respond appropriately to “risks” (real or perceived) in active settings.

Given their relative areas of expertise in supporting children with CMCs, both health and recreation sector practitioners should collaborate on the design and delivery of interventions that aim to address physical literacy outcomes in a safe, active environment.

The research conducted within this dissertation was largely descriptive and exploratory. Interventions designed to address physical literacy among children with CMCs should refer to these findings to determine valuable outcomes for this population. For example, results from the second article suggest that one's self-efficacy for self-regulating activity intensity during a competitive game is particularly relevant for children with CMCs, an idea which was expanded upon in the third article through a discussion of the importance of embodied self-awareness. Meanwhile, knowledge and confidence in applying complex movement patterns, evaluating risk, and trying new activities are also relevant for overall physical literacy development, suggesting the need for interventions that go beyond fitness training or motor skill development. Further, it is highly recommended that future studies employing physical literacy interventions also use a mixed methods approach; as evidenced by this dissertation, the experiences of children with CMCs are nuanced and may not be comprehensively represented by either qualitative or quantitative methods.

Like all children, those with CMCs face the risk of potential injury when participating in physical activity. However, unlike typically healthy children, those with CMCs have individual needs which make the associated risks of participating in physical activity highly variable. As presented in Chapter 1, some of these risks include the potential of greater injury with sports that may lead to hard bodily impacts or the enhanced physiological stress when participating in unfavourable environmental climates. For some children with CMCs, the risks of participating in certain modes or contexts of physical activity go beyond physical injury and may lead to more adverse events (Coleman et al., 2018). In the second article of this research, the ability of participants to evaluate relative risk of injury and understand how to play within their physiological limits was an aspect that differentiated those with high versus low physical literacy scores. Indeed, the ability to manage risks in active settings is a relevant facet of optimal child development (Brussoni et al., 2012). Unfortunately, healthcare practitioners often do not feel informed enough about the safety of community-based physical activity contexts to recommend them with confidence to their paediatric patients (Whooten et al., 2023). Meanwhile, recreation providers may take a more conservative approach to prevent potential adverse events, by excessively limiting the participation of children with CMCs out of an abundance of caution. A lack of collaboration and communication between sectors can therefore leave children with CMCs and their families with little guidance on which active contexts are safe enough for meaningful play. Supporting children with CMCs to effectively navigate the risks of play is therefore a unique research area where the relative expertise of both health and recreation sectors is desperately needed.

Finally, future research collaborations between health and recreation sectors within the field of physical literacy should also, undoubtedly, engage paediatric patients and their families in the research design, delivery, and interpretation. Patient and family engagement in health research, when done meaningfully (Black et al., 2018), can enhance the relevance of findings for stakeholders and build a sense of community among patient families and the research team (Vanderhout et al., 2022). Along the spectrum of what patient engagement can look like[3], this dissertation used strategies that aligned with "consulting" (i.e., obtaining interview data from participants for the first two articles) and "involving" (i.e., obtaining participant feedback on the ICPA design in pre-program interviews). The enthusiasm and thoughtfulness that participants demonstrated throughout data collection sessions confirmed that their input was essential to the success of this research. Conducting prospective, intervention-based research that engages patient partners further along this spectrum (i.e., involvement, collaboration, empowerment) will enhance the reach, applicability, and

[3] The International Association of Public Participation's Spectrum of Public Participation (IAP2) is a leading guide to define the public's role in any participation process. It is often referred to when defining the level of patient and family engagement in child health research. The IAP2 spectrum begins at a level of informing, to consulting and involving, followed by collaborating and empowering. More information about the IAP2 spectrum can be found here: https://iap2canada.ca/Pillars

sustainability of findings (Vanderhout et al., 2022) to support the ongoing physical literacy journey of children with CMCs from multiple levels of influence (i.e., family, community recreation, health).

Conclusion

The aim of this research was to contextualise, describe, and reflect on the physical literacy development of children living with CMCs. During the context of COVID-19, the lack of meaningful opportunities to participate in physical activity likely worsened existing deficits in physical literacy for children with CMCs. Thus, interventions leveraging the relative strengths of both recreation and medical experts should be designed to target combined physical, affective, cognitive, and/or behavioural outcomes relevant to children with CMCs. As physical activities resumed in a “post-pandemic” context, creativity and flexibility to promote inclusion, opportunities to sample various sports, and prompting for bodily self-awareness were all important, physical literacy-based strategies to promote the engagement of children with CMCs in a community-based sport setting. Overall, this dissertation provides a valuable, comprehensive contribution to the broader knowledge of how children living with medical conditions navigate their participation in physical activity and develop physical literacy.

References

Al Kitani, M., Thompson, D., and Stokes, K. (2014). Responses To Exercise in Omani Children With Sickle Cell Disease or Sickle Cell Trait, Compared With Healthy Controls. *International Journal of Sports Sciences and Fitness*, *4*(1), 39–52. https://doi.org/10.1001/archpedi.1982.03970470046013

Allemang, B., Sitter, K., and Dimitropoulos, G. (2022). Pragmatism as a paradigm for patient-oriented research. *Health Expectations*, *25*(1), p. 38–47 https://doi.org/10.1111/hex.13384

Allendorfer, J. B., and Arida, R. M. (2018). Role of Physical Activity and Exercise in Alleviating Cognitive Impairment in People With Epilepsy. *Clinical Therapeutics*, *40*(1), 26–34. https://doi.org/10.1016/j.clinthera.2017.12.004

Aman, J., Skinner, T. C., de Beaufort, C. E., Swift, P. G. F., Aanstoot, H.-J., and Cameron, F. (2009). Associations between physical activity, sedentary behavior, and glycemic control in a large cohort of adolescents with type 1 diabetes: the Hvidoere Study Group on Childhood Diabetes. *Pediatric Diabetes*, *10*(4), 234–239. https://doi.org/10.1111/j.1399-5448.2008.00495.x

Ameringer, S., Elswick, J. K., and Smith, W. (2014). Fatigue in Adolescents and Young Adults With Sickle Cell Disease: Biological and Behavioral Correlates and Health-Related Quality of Life. *Journal of Pediatric Oncology Nursing*, *31*(1), 6–17. https://doi.org/10.1177/1043454213514632

Ameringer, S., Elswick, R. K., Sisler, I., Smith, W., Lipato, T., and Acevedo, E. O. (2019). Exercise Testing of Adolescents and Young Adults With Sickle Cell Disease: Perceptual Responses and the Gas Exchange Threshold. *Journal of Pediatric Oncology Nursing*, *36(*5):310-320. https://doi.org/10.1177/1043454219844243

Anderson, C. A. J., Suna, J. M., Keating, S. E., Cordina, R., Tran, D. L., Ayer, J., and Coombes, J. S. (2022). Safety and efficacy of exercise training in children and adolescents with congenital heart disease: A systematic review and descriptive analysis, *American Heart Journal*, 253, p. 1–19. https://doi.org/10.1016/j.ahj.2022.06.006

Angell, C., Alexander, J., and Hunt, J. A. (2015). 'Draw, write and tell': A literature review and methodological development on the 'draw and write' research method. *Journal of Early Childhood Research*, *13*(1), 17–28. https://doi.org/10.1177/1476718X14538592

Arbour-Nicitopoulos, K. P., Boross-Harmer, A., Leo, J., Allison, A., Bremner, R., Taverna, F., Sora, D., and Wright, F. V. (2018). Igniting Fitness Possibilities: a case study of an inclusive community-based physical literacy program for children and youth. *Leisure/Loisir: Journal of the Canadian Association for Leisure Studies*, *42*(1), 69–92. https://doi.org/10.1080/14927713.2017.1414627

Arbour-Nicitopoulos, K. P., Bremer, E., Leo, J., and Wright, F. V. (2023). A pragmatic approach to measuring physical literacy and behavioural outcomes in youth with and without disabilities. *Leisure*, *47*(3), 209–233. https://doi.org/10.1080/14927713.2022.2085157

Arbour-Nicitopoulos, K. P., Grassmann, V., Orr, K., McPherson, A. C., Faulkner, G. E., and Wright, F. V. (2018). A Scoping Review of Inclusive Out-of-School Time Physical Activity Programs for Children and Youth With Physical Disabilities. *Adapted Physical Activity Quarterly*, *35*(1), 111–138. https://doi.org/10.1123/apaq.2017-0012

Arbour-Nicitopoulos, K. P., James, M. E., Moore, S. A., Sharma, R., and Ginis, K. A. M. (2022). Movement behaviours and health of children and youth with disabilities: Impact of the 2020 COVID-19 pandemic. *Paediatrics and Child Health (Canada)*, *27*, S66–S71. https://doi.org/10.1093/pch/pxac007

Arigliani, M., and Gupta, A. (2020). Management of chronic respiratory complications in children and adolescents with sickle cell disease. *European Respiratory Review*, *29*(157), 1–9. https://doi.org/10.1183/16000617.0054-2020

Arikan, H., Yatar, I., Calik-Kutukcu, E., Aribas, Z., Saglam, M., Vardar-Yagli, N., Savci, S., Inal-Ince, D., Ozcelik, U., and Kiper, N. (2015). A comparison of respiratory and peripheral muscle strength, functional exercise capacity, activities of daily living and physical fitness in patients with cystic fibrosis and healthy subjects. *Research in Developmental Disabilities*, *45–46*, 147–156. https://doi.org/10.1016/j.ridd.2015.07.020

Ash, G. I., Joiner, K. L., Savoye, M., Baker, J. S., Gerosa, J., Kleck, E., Patel, N. S., Sadler, L. S., Stults-Kolehmainen, M., Weinzimer, S. A., and Grey, M. (2019). Feasibility and safety of a group physical activity program for youth with type 1 diabetes. *Pediatric Diabetes*, *20*(4), 450–459. https://doi.org/10.1111/pedi.12841

Atay, C., Kaya Mutlu, E., Taskiran, H., and Ozgen, I. T. (2018). Comparison of Hand Function Between Children With Type 1 Diabetes Mellitus and Children Without Type 1 Diabetes Mellitus. *Pediatric Physical Therapy : The Official Publication of the Section on Pediatrics of the American Physical Therapy Association*, *30*(1), 58–65. https://doi.org/10.1097/pep.0000000000000465

Atkin, A. J., Sharp, S. J., Harrison, F., Brage, Sø., and Van Sluijs, E. M. F. (2016). Seasonal Variation in Children's Physical Activity and Sedentary Time. *Medicine and Science in Sports and Exercise*, *48*(3), 449–456. https://doi.org/10.1249/MSS.0000000000000786

Babic, M. J., Morgan, P. J., Plotnikoff, R. C., Lonsdale, C., White, R. L., and Lubans, D. R. (2014). Physical Activity and Physical Self-Concept in Youth: Systematic Review and Meta-Analysis. *Sports Medicine*, *44*(11), 1589–1601. https://doi.org/10.1007/s40279-014-0229-z

Bai, G., Herten, M. H. Van, Landgraf, J. M., Korfage, I. J., and Raat, H. (2017). Childhood chronic conditions and health- related quality of life: Findings from a large population-based study. *PloS One*, *12*(6), e0178539. https://doi.org/10.1371/journal.pone.0178539

Bandura, A. (1986). *Social Foundations of thought and action: A social cognitive theory*. Prentice-Hall.

Banks, L., Lin, Y. T., Chahal, N., Manlhiot, C., Yeung, R. S. M., and McCrindle, B. W. (2012). Factors associated with low moderate-to-vigorous physical activity levels in pediatric patients with Kawasaki Disease. *Clinical Pediatrics*, *51*(9), 828–834. https://doi.org/10.1177/0009922812441664

Bar-mor, G., Bar-tal, Y., Krulik, T., and Zeevi, B. (2000). Self-efficacy and physical activity in adolescents with trivial, mild, or moderate congenital cardiac malformations. *Cardiology in the Young*, *10*(6), 561–566. https://doi.org/10.1017/s1047951100008829

Barnett, L. M., Jerebine, A., Keegan, R., Watson-Mackie, K., Arundell, L., Ridgers, N. D., Salmon, J., and Dudley, D. (2023). Validity, Reliability, and Feasibility of Physical Literacy Assessments Designed for School Children: A Systematic Review. In *Sports Medicine*. Springer Science and Business Media Deutschland GmbH. https://doi.org/10.1007/s40279-023-01867-4

Bar-Or, O. (1986). Pathophysiological factors which limit the exercise capacity of the sick child. *Medicine and Science in Sports and Exercise*, *18*(3), 276–282. https://doi.org/10.1249/00005768-198606000-00004

Bar-Or, O., Hay, J. A., Ward, D. S., Blimkie, C. J. R., MacDougall, J. D., and Wilson, W. M. (1992). Voluntary dehydration and heat intolerance in cystic fibrosis. *The Lancet*, *339*(8795), 696–699. https://doi.org/10.1016/0140-6736(92)90597-V

Basterfield, L., Burn, N. L., Galna, B., Batten, H., Goffe, L., Karoblyte, G., Lawn, M., and Weston, K. L. (2022). Changes in children's physical fitness, BMI and health-related quality of life after the first 2020 COVID-19 lockdown in England: A longitudinal study. *Journal of Sports Sciences*, *40*(10), 1088–1096. https://doi.org/10.1080/02640414.2022.2047504

Bayeck, R. Y. (2023). Is Microethnography an Ethnographic Case Study? and/or a mini-ethnographic case study? An analysis of the literature. *International Journal of Qualitative Methods*, *22*. https://doi.org/10.1177/16094069231172074

Bedard, C., King-Dowling, S., Obeid, J., Timmons, B. W., and Ferro, M. A. (2022). Correlates of Moderate-to-Vigorous Physical Activity in Children With Physical Illness and Physical–Mental Multimorbidity. *Health Education and Behavior*, *49*(5), 780–788. https://doi.org/10.1177/10901981221100697

Belanger, K., Barnes, J. D., Longmuir, P. E., Anderson, K. D., Bruner, B., Copeland, J. L., Gregg, M. J., Hall, N., Kolen, A. M., Lane, K. N., Law, B., MacDonald, D. J., Martin, L. J., Saunders, T. J., Sheehan, D., Stone, M., Woodruff, S. J., and Tremblay, M. S. (2018). The relationship between physical literacy scores and adherence to Canadian physical activity and sedentary behaviour guidelines. *BMC Public Health*, *18*(S2), 1042. https://doi.org/10.1186/s12889-018-5897-4

Beni, S., Fletcher, T., and Ní Chróinín, D. (2017a). Meaningful Experiences in Physical Education and Youth Sport: A Review of the Literature. *Quest*, *69*(3), 291–312. https://doi.org/10.1080/00336297.2016.1224192

Beni, S., Fletcher, T., and Ní Chróinín, D. (2017b). Meaningful Experiences in Physical Education and Youth Sport: A Review of the Literature. *Quest*, *69*(3), 291–312. https://doi.org/10.1080/00336297.2016.1224192

Bennett, E. V., Voss, C., Faulkner, G., and Harris, K. C. (2021). From ‘it makes me feel free’ to ‘they won’t let me play’: the body and physical activity-related perceptions and experiences of children with congenital heart disease and their parents. *Qualitative Research in Sport, Exercise and Health*, *13*(2), 325–341. https://doi.org/10.1080/2159676X.2019.1710858

Benson, A., Lambert, V., Gallagher, P., Shahwan, A., and Austin, J. K. (2015). “I don’t want them to look at me and think of my illness, I just want them to look at me and see me”: Child perspectives on the challenges associated with disclosing an epilepsy diagnosis to others. *Epilepsy and Behavior*, *53*, 83–91. https://doi.org/10.1016/j.yebeh.2015.09.026

Beraki, Å., Magnuson, A., Särnblad, S., Åman, J., and Samuelsson, U. (2014). Increase in physical activity is associated with lower HbA1c levels in children and adolescents with type 1 diabetes: Results from a cross-sectional study based on the Swedish pediatric diabetes quality registry (SWEDIABKIDS). *Diabetes Research and Clinical Practice*, *105*(1), 119–125. https://doi.org/10.1016/j.diabres.2014.01.029

Berger, R. (2015). Now I see it, now I don’t: researcher’s position and reflexivity in qualitative research. *Qualitative Research*, *15*(2), 219–234. https://doi.org/10.1177/1468794112468475

Biesta, G. (2010). Pragmatism and the Philosophical Foundations of Mixed Methods Research. In *SAGE Handbook of Mixed Methods in Social and Behavioral Research* (pp. 95–118). SAGE Publications, Inc. https://doi.org/10.4135/9781506335193

Bjarnason-Wehrens, B., Dordel, S., Schickendantz, S., Krumm, C., Bott, D., Sreeram, N., and Brockmeier, K. (2007). Motor development in children with congenital cardiac diseases compared to their healthy peers. *Cardiology in the Young*, *17*(5), 487–498. https://doi.org/10.1017/S1047951107001023

Black, A., Strain, K., Wallsworth, C., Charlton, S. G., Chang, W., McNamee, K., and Hamilton, C. (2018). What constitutes meaningful engagement for patients and families as partners on research teams? *Journal of Health Services Research and Policy*, *23*(3), 158–167. https://doi.org/10.1177/1355819618762960

Blais, A. Z., Lougheed, J., Adamo, K. B., and Longmuir, P. E. (2020). Participation in a Community-Based Sport Program is Feasible for Children with Congenital Heart Disease and May Benefit Physical Literacy Development: A Pilot Study. *Exercise Medicine*, *4*, 8. https://doi.org/10.26644/em.2020.008

Blais, A. Z., Lougheed, J., Yaraskavitch, J., Adamo, K. B., and Longmuir, P. E. (2020). " I really like playing games together " : Understanding what influences children with congenital heart disease to participate in physical activity. *Child: Care, Health and Development*, *46*(4), 457-467. https://doi.org/10.1111/cch.12754

Blanchard, J., McCrindle, B. W., and Longmuir, P. E. (2022). The Impact of Physical Activity Restrictions on Health-Related Fitness in Children with Congenital Heart Disease. *International Journal of Environmental Research and Public Health*, *19*(8). https://doi.org/10.3390/ijerph19084426

Bok, D., Rakovac, M., and Foster, C. (2022). An Examination and Critique of Subjective Methods to Determine Exercise Intensity: The Talk Test, Feeling Scale, and Rating of Perceived Exertion. *Sports Medicine*, *52*(9), 2085–2109 https://doi.org/10.1007/s40279-022-01690-3

Bolduc, M. E., Dionne, E., Gagnon, I., Rennick, J. E., Majnemer, A., and Brossard-Racine, M. (2020). Motor Impairment in Children With Congenital Heart Defects: A Systematic Review. *Pediatrics*, *146*(6). https://doi.org/10.1542/PEDS.2020-0083

Bopp, T., Stellefson, M., Weatherall, B., and Spratt, S. (2019). Promoting Physical Literacy for Disadvantaged Youth Living With Chronic Disease. *American Journal of Health Education*, *50*(3), 153–158. https://doi.org/10.1080/19325037.2019.1590263

Boyer, C., Tremblay, M., Saunders, T. J., McFarlane, A., Borghese, M., Lloyd, M., and Longmuir, P. (2013). Feasibility, validity and reliability of the plank isometric hold as a field-based assessment of torso muscular endurance for children 8-12 years of age. *Pediatric Exercise Science*, *25*(3), 407–422. https://doi.org/10.1123/pes.25.3.407

Boyes, N. G., Stickland, M. K., Fusnik, S., Hogeweide, E., Fries, J. T. J., Haykowsky, M. J., Baril, C. L., Runalls, S., Kakadekar, A., Pharis, S., Pockett, C., Bradley, T. J., Wright, K. D., Erlandson, M., and Tomczak, C. R. (2018). Physical activity modulates arterial stiffness in children with congenital heart disease: A CHAMPS cohort study. *Congenital Heart Disease*, *13*(4), 578–583. https://doi.org/10.1111/chd.12614

Braithwaite, R., Spray, C. M., and Warburton, V. E. (2011). Motivational climate interventions in physical education: A meta-analysis. *Psychology of Sport and Exercise*, *12*(6), 628–638. https://doi.org/10.1016/j.psychsport.2011.06.005

Braun, V., and Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Braun, V., and Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, *11*(4), 589–597. https://doi.org/10.1080/2159676X.2019.1628806

Brief, F., Guimber, D., Baudelet, J. B., Houeijeh, A., Piéchaud, J. F., Richard, A., Vaksmann, G., Godart, F., and Domanski, O. (2022). Prevalence and Associated Factors of Long-term Growth Failure in Infants with Congenital Heart Disease Who Underwent Cardiac Surgery Before the Age of One. *Pediatric Cardiology*, *43*(8), 1681-87. https://doi.org/10.1007/S00246-022-02933-W

Brna, P. M., Gordon, K. E., Woolridge, E., Dooley, J. M., and Wood, E. (2017). Perceived need for restrictions on activity for children with epilepsy. *Epilepsy and Behavior*, *73*, 236–239. https://doi.org/10.1016/j.yebeh.2017.05.012

Broderick, C. R., Latimer, J., Mathieu, E., Curtin, J. A., Herbert, R. D., Barnes, C., Monagle, P., and Brown, S. A. (2012). Association between physical activity and risk of bleeding in children with hemophilia. *JAMA - Journal of the American Medical Association*, *308*(14), 1452–1459. https://doi.org/10.1001/jama.2012.12727

Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design.* Harvard University Press.

Brousse, V., Pondarre, C., Arnaud, C., Kamden, A., de Montalembert, M., Boutonnat-Faucher, B., Bourdeau, H., Charlot, K., Grévent, D., Verlhac, S., da Costa, L., and Connes, P. (2020). One-fifth of children with sickle cell anemia show exercise-induced hemoglobin desaturation: Rate of perceived exertion and role of blood rheology. *Journal of Clinical Medicine*, *9*(1), 133. https://doi.org/10.3390/jcm9010133

Brown, D. M. Y., Dudley, D. A., and Cairney, J. (2020). Physical literacy profiles are associated with differences in children's physical activity participation: A latent profile analysis approach. *Journal of Science and Medicine in Sport*, *23*(11), 1062–1067. https://doi.org/10.1016/j.jsams.2020.05.007

Brown, D. M. Y., and Ronen, G. M. (2021). Associations between 24-hour movement guideline adherence and mental health disorders among young people with active and inactive epilepsy. *Epilepsy and Behavior*, *125*, 108386. https://doi.org/10.1016/j.yebeh.2021.108386

Brown, H. E., Atkin, A. J., Panter, J., Wong, G., Chinapaw, M. J. M., and van Sluijs, E. M. F. (2016). Family-based interventions to increase physical activity in children: A systematic review, meta-analysis and realist synthesis. *Obesity Reviews*, *17*(4), 345–360. https://doi.org/10.1111/obr.12362

Brudy, L., Meyer, M., Oberhoffer, R., Ewert, P., and Müller, J. (2021). Move more – be happier? physical activity and health-related quality of life in children with congenital heart disease. *American Heart Journal*, *241*, 68–73. https://doi.org/10.1016/j.ahj.2021.07.004

Bruno, N., Richardson, A., Kauffeldt, K. D., Tomasone, J. R., Arbour-Nicitopoulos, K., and Latimer-Cheung, A. E. (2022). Exploring experiential elements, strategies and outcomes of quality participation for children with intellectual and developmental disabilities: A systematic scoping review. *Journal of Applied Research in Intellectual Disabilities*, *35*(3), 691–718. https://doi.org/10.1111/jar.12982

Brussoni, M., Olsen, L. L., Pike, I., and Sleet, D. A. (2012). Risky play and children's safety: Balancing priorities for optimal child development. *International Journal of Environmental Research and Public Health*, *9*(9), 3134–3148. https://doi.org/10.3390/ijerph9093134

Brynjulfsen, T., Demmelmaier, I., Berntsen, S., Foyn, H., Andersen, K., Stang, J., Sigdestad, J. B., Stensrud, T., Tufte, K., Nielsen, A., and Westergren, T. (2021). Motivation for physical activity in adolescents with asthma. *Journal of Asthma*, *58*(9), 1247–1255. https://doi.org/10.1080/02770903.2020.1778025

Burke, S. (2016). Rethinking "Validity" and "Trustworthiness" in Qualitative Inquiry: How might we judge the quality of qualitative research in sport and exercise sciences? In B. Smith and A. S. Sparkes (Eds.), *Routledge Handbook of Qualitative Research in Sport and Exercise* (pp. 330–339). Routledge.

Burstein, D. S., Edelson, J., O'Malley, S., McBride, M. G., Stephens, P., Paridon, S., and Brothers, J. A. (2022). Cardiopulmonary Exercise Performance in the Pediatric and Young

Adult Population Before and During the COVID-19 Pandemic. *Pediatric Cardiology*, *43*, 832–1837. https://doi.org/10.1007/s00246-022-02920-1

Cahal, M., Amirav, I., Diamant, N., Be'er, M., Besor, O., and Lavie, M. (2021). Real-time effects of COVID-19 pandemic lockdown on pediatric respiratory patients. *Pediatric Pulmonology*, *56*(6), 1401–1408. https://doi.org/10.1002/ppul.25310

Carcamo-Oyarzun, J., Salvo-Garrido, S., and Estevan, I. (2023). Actual and Perceived Motor Competence in Chilean Schoolchildren before and after COVID-19 Lockdowns: A Cohort Comparison. *Behavioral Sciences*, *13*(4). https://doi.org/10.3390/bs13040306

Carl, J., Barratt, J., Töpfer, C., Cairney, J., and Pfeifer, K. (2022). How are physical literacy interventions conceptualized? – A systematic review on intervention design and content: Design/Content of Physical Literacy Interventions. *Psychology of Sport and Exercise*, *58*, 102091. https://doi.org/10.1016/j.psychsport.2021.102091

Carlon, S. L., Taylor, N. F., Dodd, K. J., and Shields, N. (2013). Differences in habitual physical activity levels of young people with cerebral palsy and their typically developing peers: A systematic review. *Disability and Rehabilitation*, *35*(8) 647–655. https://doi.org/10.3109/09638288.2012.715721

Caveney, B., Halterman, J. S., Fagnano, M., Stern, J., and Frey, S. M. (2022). Caregiver Experiences Managing Persistent Childhood Asthma During the COVID-19 Pandemic. *Clinical Pediatrics*, *61*(4), 313–319. https://doi.org/10.1177/00099228211070659

Chaddock-Heyman, L., Hillman, C. H., Cohen, N. J., and Kramer, A. F. (2014). The Importance of Physical Activity and Aerobic Fitness for Cognitive Control and Memory in Children. *Monographs of the Society for Research in Child Development*, *79*(4), 25–50. https://doi.org/10.1111/MONO.12129

Cheung, C. C., Laksman, Z. W. M., Mellor, G., Sanatani, S., and Krahn, A. D. (2016). Exercise and Inherited Arrhythmias. *Canadian Journal of Cardiology*, *32*(4), 452–458. https://doi.org/10.1016/j.cjca.2016.01.007

Christian, S., Somerville, M., Giuffre, M., and Atallah, J. (2018). Physical activity restriction for children and adolescents diagnosed with an inherited arrhythmia or cardiomyopathy and its impact on body mass index. *Journal of Cardiovascular Electrophysiology*, *29*(12), 1648–1653. https://doi.org/10.1111/jce.13713

Clark, H. J., Dudley, D., Barratt, J., and Cairney, J. (2022). Physical literacy predicts the physical activity and sedentary behaviours of youth. *Journal of Science and Medicine in Sport*, *25*(9), 750–754. https://doi.org/10.1016/j.jsams.2022.04.008

Cleland, V., Dwyer, T., and Venn, A. (2012). Which domains of childhood physical activity predict physical activity in adulthood? A 20-year prospective tracking study. *British Journal of Sports Medicine*, *46*(8), 595–602. https://doi.org/10.1136/bjsports-2011-090508

Cocca, A., Greier, K., Drenowatz, C., and Ruedl, G. (2021). Relationship between objectively and subjectively measured physical activity in adolescents during and after COVID-19 restrictions. *Behavioral Sciences*, *11*(12), 177. https://doi.org/10.3390/bs11120177

Coleman, N., Nemeth, B. A., and Leblanc, C. M. A. (2018). Increasing Wellness Through Physical Activity in Children with Chronic Disease and Disability. *Current Sports Medicine Reports*, *17*(12), 425–432. https://doi.org/10.1249/JSR.0000000000000548

Connes, P., MacHado, R., Hue, O., and Reid, H. (2011). Exercise limitation, exercise testing and exercise recommendations in sickle cell anemia. *Clinical Hemorheology and Microcirculation*, *49*(1–4), 151–163. https://doi.org/10.3233/CH-2011-1465

Constantinou, C., Payne, N., van den Akker, O., and Inusa, B. (2021). A qualitative exploration of health-related quality of life and health behaviours in children with sickle cell disease and healthy siblings. *Psychology and Health*, *38*(1), 125-146. https://doi.org/10.1080/08870446.2021.1955119

Cooper, D. M., and Liem, R. I. (2019). Translating exercise benefits in sickle cell disease. *Blood*, *134*(25), 2227–2229. https://doi.org/10.1182/blood.2019003651

Corbin, C. B. (2016). Implications of Physical Literacy for Research and Practice: A Commentary. *Research Quarterly for Exercise and Sport*, *87*(1), 14–27. https://doi.org/10.1080/02701367.2016.1124722

Cornish, K., Fox, G., Fyfe, T., Koopmans, E., Pousette, A., and Pelletier, C. A. (2020). Understanding physical literacy in the context of health: a rapid scoping review. *BMC Public Health*, *20*(1). https://doi.org/10.1186/s12889-020-09583-8

Corten, L., and Morrow, B. M. (2019). Motor Performance in South African Children with Cystic Fibrosis. *Physical and Occupational Therapy In Pediatrics*, *40*(2), 1–9. https://doi.org/10.1080/01942638.2019.1647329

Côté, J., Baker, J., and Abernethy, B. (2007). Practice and Play in the Development of Sport Expertise. In G. Tenenbaum and R. C. Eklund (Eds.), *Handbook of Sport Psychology: Third Edition* (pp. 184–202). John Wiley and Sons.

Côté, J., and Fraser-Thomas, J. (2007). Youth Involvement in Sport. In P. Crocker (Ed.), *Sport Psychology: A Canadian Perspective* (pp. 270–298). Pearson.

Côté, J., Horton, S., MacDonald, D. J., and Wilkes, S. (2009). The Benefits of Sampling Sports During Childhood. *Physical & Health Education Journal*, *74*(4), 6–11.

https://www.proquest.com/scholarly-journals/benefits-sampling-sports-during-childhood/docview/214331960/se-2

Craggs, C., Corder, K., Van Sluijs, E. M. F., and Griffin, S. J. (2011). Determinants of change in physical activity in children and adolescents: A systematic review. *American Journal of Preventive Medicine*, *40*(6), 645–658. https://doi.org/10.1016/j.amepre.2011.02.025

Creswell, J., and Plano Clark, V. (2018). *Designing and conducting mixed methods research* (3rd ed.). SAGE publications.

Darbyshire, P., MacDougall, C., and Schiller, W. (2005). Multiple methods in qualitative research with children: more insight or just more? *Qualitative Research*, *5*(4), 417–436. https://doi.org/10.1177/1468794105056921

David, C. V., and MacAllister, W. S. (2022). Fine motor impairment in children with epilepsy: Relations with seizure severity and lateralizing value. *Epilepsy and Behavior*, *127*, 108518. https://doi.org/10.1016/j.yebeh.2021.108518

De Almeida Thomazinho, P., De Miranda Chaves, C. R. M., Pássaro, C. P., and Meio, M. D. B. (2011). Motor delay in cystic fibrosis infants: An observational study. *Early Human Development*, *87*(12), 769–773. https://doi.org/10.1016/j.earlhumdev.2011.05.012

Deci, E. L., and Ryan, R. (1985). *Intrinsic motivation and self-determination in human behaviour*. Plenum.

Decramer, M., Lacquet, L., Fagard, R., and Rogiers, P. (1994). Corticosteroids contribute to muscle weakness in chronic airflow obstruction. *Am J Respir Crit Care Med*, *150*(1), 11–16. https://doi.org/10.1164/ajrccm.150.1.8025735

Delisle Nyström, C., Barnes, J. D., and Tremblay, M. S. (2018). An exploratory analysis of missing data from the Royal Bank of Canada (RBC) Learn to Play - Canadian Assessment of

Physical Literacy (CAPL) project. *BMC Public Health*, *18*(Suppl 2). https://doi.org/10.1186/s12889-018-5901-z

Denford, S., Hill, D. M., Mackintosh, K. A., McNarry, M. A., Barker, A. R., Williams, C. A. (2019). Using photo-elicitation to explore perceptions of physical activity among young people with cystic fibrosis. *BMC Pulmonary Medicine*, *19*(1), 1–13. https://doi.org/10.1186/s12890-019-0985-5

Denford, S., Mackintosh, K. A., Mcnarry, M. A., Barker, A. R., and Williams, C. A. (2019). Enhancing intrinsic motivation for physical activity among adolescents with cystic fibrosis: A qualitative study of the views of healthcare professionals. *BMJ Open*, *9*(6), 1–10. https://doi.org/10.1136/bmjopen-2019-028996

Denford, S., Van Beurden, S., O'halloran, P., and Williams, C. A. (2020). Barriers and facilitators to physical activity among children, adolescents, and young adults with cystic fibrosis: a systematic review and thematic synthesis of qualitative research. *BMJ Open*, *10*, 35261. https://doi.org/10.1136/bmjopen-2019-035261

Diaw, M., Samb, A., Diop, S., Sall, N. D., Ba, A., Cissé, F., and Connes, P. (2014). Effects of hydration and water deprivation on blood viscosity during a soccer game in sickle cell trait carriers. *British Journal of Sports Medicine*, *48*(4), 326–331. https://doi.org/10.1136/bjsports-2012-091038

Dimitri, P., Joshi, K., and Jones, N. (2020). Moving more: physical activity and its positive effects on long term conditions in children and young people. *Archives of Disease in Childhood*, *105*(11), 1035–1040. https://doi.org/10.1136/archdischild-2019-318017

Do, J., Blais, A., Feldman, B., Brandão, L. R., Lougheed, J., Pohl, D., Klaassen, R. J., Johnston, D. L., De Laat, D., Roth, J., Katz, S. L., McCormick, A., Wright, F. V., Macartney, G., McMillan, H. J., Venkateswaran, S., Sell, E., Doja, A., Matheson, K., … Longmuir, P. E.

(2021). Characterization of physical literacy in children with chronic medical conditions compared with healthy controls: A cross-sectional study. *Applied Physiology, Nutrition and Metabolism*, *46*(9), 1073–1082. https://doi.org/10.1139/apnm-2020-0957

Do, J., Webster, R. J., Longmuir, P. E., Reddy, D., and Pohl, D. (2021). Poor adherence to sleep and physical activity guidelines among children with epilepsy. *Epilepsy and Behavior*, *115*, 107722. https://doi.org/10.1016/j.yebeh.2020.107722

Dougherty, K. A., Schall, J. I., Rovner, A. J., Stallings, V. A., and Zemel, B. S. (2011). Attenuated Maximal Muscle Strength and Peak Power in Children with Sickle Cell Disease. *J Pediatr Hematol Oncol*, *33*(2), 93–97. https://doi.org/10.1097/MPH.0b013e318200ef49

Dowling, M. (2006). Approaches to reflexivity in qualitative research. *Nurse Researcher*, *13*(3), 7–21. https://doi.org/10.7748/nr2006.04.13.3.7.c5975

Driscoll, K. A., Corbin, K. D., Maahs, D. M., Pratley, R., Bishop, F. K., Kahkoska, A., Hood, K. K., Mayer-Davis, E., Bishop, F., Driscoll, K., Maahs, D., Hood, K., Ekhlaspour, L., Bock, C., Corbin, K., Davis, C., Pratley, R., Smith, S. R., Whitaker, K., … Riddell, M. (2017). Biopsychosocial Aspects of Weight Management in Type 1 Diabetes: a Review and Next Steps. *Current Diabetes Reports*, *17*(8). https://doi.org/10.1007/s11892-017-0892-1

Duarte, V., Mota, B., Ferreira, S., Costa, C., and Correia, C. C. (2022). Impact of COVID-19 lockdown on glycemic control in type 1 diabetes. *Archives de Pediatrie*, *29*(1), 27–29. https://doi.org/10.1016/j.arcped.2021.11.008

Dubow, J. S., and Kelly, J. P. (2003). Epilepsy in sports and recreation. *Sports Medicine*, *33*(7), 499–516. https://doi.org/10.2165/00007256-200333070-00003

Dulfer, K., Duppen, N., Kuipers, I. M., Schokking, M., van Domburg, R. T., Verhulst, F. C., Helbing, W. A., and Utens, E. M. W. J. (2014). Aerobic Exercise Influences Quality of Life of Children and Youngsters With Congenital Heart Disease: A Randomized Controlled Trial. *Journal of Adolescent Health*, *55*(1), 65–72. https://doi.org/10.1016/j.jadohealth.2013.12.010

Duppen, N., Kapusta, L., De Rijke, Y. B., Snoeren, M., Kuipers, I. M., Koopman, L. P., Blank, A. C., Blom, N. A., Dulfer, K., Utens, E. M. W. J., Hopman, M. T. E., and Helbing, W. A. (2015). The effect of exercise training on cardiac remodelling in children and young adults with corrected tetralogy of Fallot or Fontan circulation: A randomized controlled trial. *International Journal of Cardiology*, *179*. https://doi.org/10.1016/j.ijcard.2014.10.031

Duppen, N., Takken, T., Hopman, M. T. E., ten Harkel, a. D. J., Dulfer, K., Utens, E. M. W. J., and Helbing, W. a. (2013). Systematic review of the effects of physical exercise training programmes in children and young adults with congenital heart disease. *International Journal of Cardiology*, *168*(3), 1779–1787. https://doi.org/10.1016/j.ijcard.2013.05.086

Eccles, J. (2007). Subjective task value and the Eccles et al. model of achievement-related choices. In A. J. Eliot and C. S. Dweck (Eds.), *Handbook of competence and motivation* (pp. 105–121). Guilford.

Eccles, J., Adler, T. F., Futterman, R., Goff, S. B., Kaczala, C. M., Meecce, J. L., and Midgley, C. (1983). Expectations, values and academic behaviors. In J. T. Spence (Ed.), *Achievement and achievement motivation* (pp. 75–146). W.H. Freeman.

Edwards, L., Bryant, A., Keegan, R., Morgan, K., and Jones, A. (2017). Definitions, Foundations and Associations of Physical Literacy: A Systematic Review. *Sports Medicine*, *47*(1), 113–126. https://doi.org/10.1007/s40279-016-0560-7

Edwards, L. C., Bryant, A. S., Keegan, R. J., Morgan, K., Cooper, S.-M., and Jones, A. M. (2018). 'Measuring' Physical Literacy and Related Constructs: A Systematic Review of Empirical Findings. *Sports Medicine*, *48*(3), 659–682. https://doi.org/10.1007/s40279-017-0817-9

Eime, R. M., Young, J. A., Harvey, J. T., Charity, M. J., and Payne, W. R. (2013). A systematic review of the psychological and social benefits of participation in sport for children and adolescents: informing development of a conceptual model of health through sport. *International Journal of Behavioral Nutrition and Physical Activity*, *10*(1), 98. https://doi.org/10.1186/1479-5868-10-98

Elmesmari, R. A., Reilly, J. J., and Paton, J. Y. (2022). 24-Hour Movement Behaviors in Children with Chronic Disease and Their Healthy Peers : A Case-Control Study. *International Journal of Environmental Research and Public Health*, *19*(5), 2912. https://doi.org/10.3390/ijerph19052912

Elmesmari, R., Reilly, J. J., Martin, A., and Paton, J. Y. (2017). Accelerometer measured levels of moderate-to-vigorous intensity physical activity and sedentary time in children and adolescents with chronic disease: A systematic review and meta-analysis. *PLOS ONE*, *12*(6), e0179429. https://doi.org/10.1371/journal.pone.0179429

Elnaggar, R. K., Alqahtani, B. A., Mahmoud, W. S., and Elfakharany, M. S. (2022). Prospective analysis of physical activity levels and associated fitness factors amid COVID-19 pandemic and social-distancing rules. A special focus on adolescents. *Science and Sports*, *37*(2), 131–138. https://doi.org/10.1016/j.scispo.2021.07.002

Epstein, J. (1989). Family Structures and Student Motivation: A Developmental Perspective, in Research on Motivation in Education. In C. Ames and R. Ames (Eds.), *Goals and Cognitions* (Vol. 3, pp. 259–295). Academic Press.

Evans, M. B., Shirazipour, C. H., Allan, V., Zanhour, M., Sweet, S. N., Martin Ginis, K. A., and Latimer-Cheung, A. E. (2018). Integrating insights from the parasport community to understand optimal Experiences: The Quality Parasport Participation Framework. *Psychology of Sport and Exercise*, *37*, 79–90. https://doi.org/10.1016/j.psychsport.2018.04.009

Fairweather, N., and Jones, F. W. (2022). Facilitators and barriers to empowerment in children and young people with cystic fibrosis: a meta-synthesis of the qualitative literature. *Disability and Rehabilitation*, *44*(25), 7767–7780. https://doi.org/10.1080/09638288.2021.2003876

Fereday, J., Macdougall, C., Spizzo, M., Darbyshire, P., and Schiller, W. (2009). "There's nothing I can't do – I just put my mind to anything and I can do it": a qualitative analysis of how children with chronic disease and their parents account for and manage physical activity. *BMC Pediatrics*, *9*(1). https://doi.org/10.1186/1471-2431-9-1

Ferguson, K., Moore, H., Kaidbey, J. H., Khattak, S., Saeed, A., Cogen, F. R., Streisand, R., and Sylvetsky, A. C. (2022). Impacts of the COVID-19 Pandemic on Pediatric Type 1 Diabetes Management: A Qualitative Study. *The Science of Diabetes Self-Management and Care*, *48*(6), 523–532. https://doi.org/10.1177/26350106221125701

Ferraro, V. A., Zanconato, S., and Carraro, S. (2022). Impact of COVID-19 in Children with Chronic Lung Diseases. *International Journal of Environmental Research and Public Health*, *19*(18), 11483. https://doi.org/10.3390/ijerph191811483

Ferro, M. A., and Boyle, M. H. (2013a). Longitudinal Invariance of Measurement and Structure of Global Self-Concept: A Population-Based Study Examining Trajectories Among Adolescents With and Without Chronic Illness. *Journal of Pediatric Psychology*, *38*(4), 425–437. https://doi.org/10.1093/jpepsy/jss112

Ferro, M. A., and Boyle, M. H. (2013b). Self-concept among youth with a chronic illness: A meta-analytic review. *Health Psychology*, *32*(8), 839–848. https://doi.org/10.1037/a0031861

Fetters, M. D., Curry, L. A., and Creswell, J. W. (2013). Achieving integration in mixed methods designs - Principles and practices. *Health Services Research*, *48*(6), 2134–2156. https://doi.org/10.1111/1475-6773.12117

Fleming, D. J. M., Dorsch, T. E., Serang, S., Hardiman, A. L., Blazo, J. A., Farrey, T., Lerner, J. B., and Solomon, J. (2023). The association of families' socioeconomic and demographic characteristics with parents' perceived barriers to returning to youth sport following the COVID-19 pandemic. *Psychology of Sport and Exercise*, *65*. https://doi.org/10.1016/j.psychsport.2022.102348

Flick, U. (2018). Methodological Triangulation in Qualitative Research. In *Doing Triangulation and Mixed Methods*. SAGE Publications Ltd. https://doi.org/10.4135/9781529716634

Florczak, K. L. (2014). Purists Need Not Apply: The Case for Pragmatism in Mixed Methods Research. *Nursing Science Quarterly*, *27*(4), 278–282. https://doi.org/10.1177/0894318414546419

Fogel, A. (2011). Embodied awareness: Neither implicit nor explicit, and not necessarily nonverbal. *Child Development Perspectives*, *5*(3), 183–186. https://doi.org/10.1111/j.1750-8606.2011.00177.x

Fortnum, K., Furzer, B., Reid, S., Jackson, B., and Elliott, C. (2018). The physical literacy of children with behavioural and emotional mental health disorders: A scoping review. *Mental Health and Physical Activity*, *15*(June), 95–131. https://doi.org/10.1016/j.mhpa.2018.10.001

Fox, K. (2010). The Physical Self and Physical Literacy. In *Physical Literacy: Throughout the Lifecourse* (pp. 71–82).

Francis, C. E., Longmuir, P. E., Boyer, C., Andersen, L. B., Barnes, J. D., Boiarskaia, E., Cairney, J., Faigenbaum, A. D., Faulkner, G., Hands, B. P., Hay, J. A., Janssen, I., Katzmarzyk, P. T., Kemper, H. C. G., Knudson, D., Lloyd, M., McKenzie, T. L., Olds, T. S., Sacheck, J. M., and Shephard, R. J. (2016). The Canadian Assessment of Physical Literacy: Development of a Model of Children's Capacity for a Healthy, Active Lifestyle Through a Delphi Process.

Journal of Physical Activity and Health, *13*(2), 214–222. https://doi.org/10.1123/jpah.2014-0597

Fried, L., Chetty, T., Cross, D., Breen, L., Davis, E., Roby, H., Jackiewicz, T., Nicholas, J., and Jones, T. (2021). The Challenges of Being Physically Active: A Qualitative Study of Young People With Type 1 Diabetes and Their Parents. *Canadian Journal of Diabetes*, *45*, 421–427. https://doi.org/10.1016/j.jcjd.2020.09.010

Fusch, P. I., Fusch, G. E., and Ness, L. R. (2017). How to conduct a mini-ethnographic case study: A guide for novice researchers. *Qualitative Report*, *22*(3), 923–941. https://doi.org/10.46743/2160-3715/2017.2580

Gauthier, N., Curran, T., O'Neill, J. A., Alexander, M. E., and Rhodes, J. (2020). Establishing a Comprehensive Pediatric Cardiac Fitness and Rehabilitation Program for Congenital Heart Disease. *Pediatric Cardiology*, *41*(8), 1569–1579. https://doi.org/10.1007/s00246-020-02413-z

Geist, R., Grdisa, V., and Otley, A. (2003). Psychosocial issues in the child with chronic conditions. *Bailliere's Best Practice and Research in Clinical Gastroenterology*, *17*(2), 141–152. https://doi.org/10.1016/S1521-6918(02)00142-7

Giacobbi, P. R., Poczwardowski, A., and Hager, P. (2005). A Pragmatic Research Philosophy for Applied Sport Psychology. *The Sport Psychologist*, *19*(1), 18-31. https://doi.org/10.1123/tsp.19.1.18

Giblin, S., Collins, D., and Button, C. (2014). Physical Literacy: Importance, Assessment and Future Directions. *Sports Medicine*, *44*(9), 1177–1184. https://doi.org/10.1007/s40279-014-0205-7

Goering, S. (2015). Rethinking disability: the social model of disability and chronic disease. *Current Reviews in Musculoskeletal Medicine*, *8*(2), 134–138. https://doi.org/10.1007/s12178-015-9273-z

Goff, S. L., Holboe, E. S., and Concato, J. (2010). Pediatricians and Physical Activity Counseling: How Does Residency Prepare Them for This Task? *Teaching and Learning in Medicine*, *22*(2), 107–111. https://doi.org/10.1080/10401331003656512

Gomes-Neto, M., Saquetto, M. B., da Silva e Silva, C. M., Conceição, C. S., and Carvalho, V. O. (2016). Impact of Exercise Training in Aerobic Capacity and Pulmonary Function in Children and Adolescents After Congenital Heart Disease Surgery: A Systematic Review with Meta-analysis. *Pediatric Cardiology*, *37*(2), 217–224. https://doi.org/10.1007/s00246-015-1270-x

Gomis, M., Querol, F., Gallach, J. E., González, L. M., and Aznar, J. A. (2009). Exercise and sport in the treatment of haemophilic patients: A systematic review. *Haemophilia*, *15*(1), 43–54. https://doi.org/10.1111/j.1365-2516.2008.01867.x

Goto, M., Takedani, H., Yokota, K., and Haga, N. (2016). Strategies to encourage physical activity in patients with hemophilia to improve quality of life. *Journal of Blood Medicine*, *7*, 85–98. https://doi.org/10.2147/JBM.S84848

Green, D. A., Karimirad, A., Simard-Duplain, G., and Siu, H. E. (2021). COVID-19 and the economic importance of in-person K-12 schooling. *Canadian Public Policy*, *47*(2), 265-280. https://doi.org/10.3138/CPP.2021-002

Gruber, W., Welsner, M., Dillenhöfer, S., Olivier, M., Koerner-Rettberg, C., Sutharsan, S., Taube, C., Mellies, U., and Stehling, F. (2021). Health-Related and Motor Performance-Related Fitness and Physical Activity Among Youth With Cystic Fibrosis. *Perceptual and Motor Skills*, *128*(5), 2097–2116. https://doi.org/10.1177/00315125211036415

Gu, X., Keller, J., Zhang, T., Dempsey, D. R., Roberts, H., Jeans, K. A., Stevens, W., Borchard, J., VanPelt, J., and Tulchin-Francis, K. (2022). Disparity in Built Environment and Its Impacts on Youths' Physical Activity Behaviors During COVID-19 Pandemic Restrictions. *Journal of Racial and Ethnic Health Disparities*, *10*, 1549–1559. https://doi.org/10.1007/s40615-022-01341-3

Gualano, B., Bonfa, E., Pereira, R. M. R., and Silva, C. A. (2017). Physical activity for paediatric rheumatic diseases: standing up against old paradigms. *Nature Reviews. Rheumatology*, *13*(6), 368–379. https://doi.org/10.1038/nrrheum.2017.75

Gunnell, K. E., Longmuir, P. E., Barnes, J. D., Belanger, K., and Tremblay, M. S. (2018). Refining the Canadian Assessment of Physical Literacy based on theory and factor analyses. *BMC Public Health*, *18*(Suppl 2), 1044. https://doi.org/10.1186/s12889-018-5899-2

Gunnell, K. E., Longmuir, P. E., Woodruff, S. J., Barnes, J. D., Belanger, K., and Tremblay, M. S. (2018). Revising the motivation and confidence domain of the Canadian assessment of physical literacy. *BMC Public Health*, *18*(Suppl 2), 1045. https://doi.org/10.1186/s12889-018-5900-0

Hanssen-Doose, A., Jaeschke, R., Niessner, C., Oriwol, D., and Worth, A. (2021). Physical fitness of children and youth with asthma in comparison to the reference population: Cross-sectional results of the population-based MoMo study in Germany. *BMC Sports Science, Medicine and Rehabilitation*, *13*(1), 1–10. https://doi.org/10.1186/s13102-021-00359-0

Harris, K. C., Voss, C., Rankin, K., Aminzadah, B., Gardner, R., and Mackie, A. S. (2018). Modifiable cardiovascular risk factors in adolescents and adults with congenital heart disease. *Congenital Heart Disease*, *13*(4), 563–570. https://doi.org/10.1111/chd.12612

Harter, S. (1978). Effectance motivation reconsidered: Toward a developmental model. *Human Development*, *21*, 34–64.

Hastie, P. A., and Wallhead, T. L. (2015). Operationalizing physical literacy through sport education. *Journal of Sport and Health Science*, *4*(2), 132–138. https://doi.org/10.1016/j.jshs.2015.04.001

Hattie, J. (1992). *Self-Concept*. Psychology Press.

Hatziagorou, E., Toulia, I., Avramidou, V., Kampouras, A., Tsara, V., and Tsanakas, J. (2021). Change in CF care during COVID-19 pandemic: Single-center experience in a middle-income setting. *Pediatric Pulmonology*, *56*(9), 3065–3067. https://doi.org/10.1002/ppul.25560

Hay, J. A. (1992). Adequacy in and predilection for physical activity in children. *Clinical Journal of Sport Medicine*, *2*(3), 192–201. https://doi.org/10.1097/00042752-199207000-00007

Hemphill, N. M., Kuan, M. T., and Harris, K. C. (2020). Reduced Physical Activity During COVID-19 Pandemic in Children with Congenital Heart Disease. *The Canadian Journal of Cardiology*, *36*(7), 1130–1134. https://doi.org/10.1016/j.cjca.2020.04.038

Higgs, C., Way, R., Vicki Harber, M., Jurbala, P., Balyi, I., Carey, A., Trono, C., Mitchell, D., Grove, J., Laing, T., Special Olympics Canada, Norris, S., and Cardinal, C. (2019). *Long-Term Development in Sport and Physical Activity*. Sport for Life . https://sportforlife.ca/wp-content/uploads/2019/06/Long-Term-Development-in-Sport-and-Physical-Activity-3.0.pdf

Hock, J., Reiner, B., Neidenbach, R. C., Oberhoffer, R., Hager, A., Ewert, P., and Müller, J. (2018). Functional outcome in contemporary children with total cavopulmonary connection – Health-related physical fitness, exercise capacity and health-related quality of life. *International Journal of Cardiology*, *255*, 50–54. https://doi.org/10.1016/j.ijcard.2017.11.092

Holmes, A. G. D. (2020). Researcher Positionality - A Consideration of Its Influence and Place in Qualitative Research - A New Researcher Guide. *Shanlax International Journal of Education*, *8*(4), 1–10. https://doi.org/10.34293/education.v8i4.3232

Holt, N. L., Neely, K. C., Slater, L. G., Camiré, M., Côté, J., Fraser-Thomas, J., Macdonald, D., Strachan, L., and Tamminen, K. A. (2017). A grounded theory of positive youth development through sport based on results from a qualitative meta-study. *International Review of Sport and Exercise Psychology*, *10*(1), 1–49. https://doi.org/10.1080/1750984X.2016.1180704

Howell, C., Scott, K., and Patel, D. R. (2017). Sports participation recommendations for patients with bleeding disorders. *Translational Pediatrics*, *6*(3), 174–180. https://doi.org/10.21037/tp.2017.04.07

Hutchens, A., and Lee, R. E. (2018). Parenting Practices and Children's Physical Activity: An Integrative Review. *Journal of School Nursing*, *34*(1), 68–85. https://doi.org/10.1177/1059840517714852

Hutzal, C. E., Wright, F. V., Stephens, S., Schneiderman-Walker, J., and Feldman, B. M. (2009). A qualitative study of fitness instructors' experiences leading an exercise program for children with Juvenile idiopathic arthritis. *Physical and Occupational Therapy in Pediatrics*, *29*(4), 409–425. https://doi.org/10.3109/01942630903245309

Ilkowitz, J. R., Wu, F., Chen, Y., and Gallagher, M. P. (2019). Perspectives on the Role of Exercise in the Treatment of Pediatric Type 1 Diabetes. *Pediatric Diabetes*, *December 2019*, 1–7. https://doi.org/10.1111/pedi.12965

International Physical Literacy Association. (2015). *Canada's Physical Literacy Consensus Statement*. https://physicalliteracy.ca/wp-content/uploads/2016/08/Consensus-Handout-EN-WEB_1.pdf

Jabbour, G., Henderson, M., and Mathieu, M.-E. (2016). Barriers to Active Lifestyles in Children with Type 1 Diabetes. *Canadian Journal of Diabetes*, *40*(2), 170–172. https://doi.org/10.1016/j.jcjd.2015.12.001

Jago, R., Searle, A., Henderson, A. J., and Turner, K. M. (2017). Designing a physical activity intervention for children with asthma: a qualitative study of the views of healthcare professionals, parents and children with asthma. *BMJ Open*, *7*(3), e014020. https://doi.org/10.1136/bmjopen-2016-014020

Janssen, I., and Leblanc, A. G. (2010). Systematic review of the health benefits of physical activity and fitness in school-aged children and youth. *The International Journal of Behavioral Nutrition and Physical Activity*, *7*(1), 40. https://doi.org/10.1186/1479-5868-7-40

Janssen, I., and LeBlanc, A. G. (2010). Systematic review of the health benefits of physical activity and fitness in school-aged children and youth. *International Journal of Behavioral Nutrition and Physical Activity*, *7*(1), 40. https://doi.org/10.1186/1479-5868-7-40

Jarnig, G., Kerbl, R., and van Poppel, M. N. M. (2022). The Impact of COVID-19-Related Mitigation Measures on the Health and Fitness Status of Primary School Children in Austria: A Longitudinal Study with Data from 708 Children Measured before and during the Ongoing COVID-19 Pandemic. *Sports*, *10*(3), 43. https://doi.org/10.3390/sports10030043

Jeffrey, B. (2018). Ethnographic Writing. In D. Beach, C. Bagley, and S. Marques Da Silva (Eds.), *The Wiley Handbook of Ethnography of Education* . John Wiley and Sons, Incorporated.

Johnson, E., Atkinson, P., Muggeridge, A., Cross, H., and Reilly, C. (2021). Inclusion and participation of children with epilepsy in schools: Views of young people, school staff and parents. *Seizure: European Journal of Epilepsy*, *93*, 34–43. https://doi.org/10.1016/j.seizure.2021.10.007

Johnson, E. C., Helen Cross, J., and Reilly, C. (2020). Physical activity in people with epilepsy: A systematic review. *Epilepsia*, *61*(6), 1062–1081. https://doi.org/10.1111/epi.16517

Joschtel, B., Gomersall, S. R., Tweedy, S., Petsky, H., Chang, A. B., and Trost, S. G. (2018). Effects of exercise training on physical and psychosocial health in children with chronic respiratory disease: a systematic review and meta-analysis. *BMJ Open Sport and Exercise Medicine*, *4*(1), e000409. https://doi.org/10.1136/bmjsem-2018-000409

Joschtel, B., Gomersall, S. R., Tweedy, S., Petsky, H., Chang, A. B., and Trost, S. G. (2021). Fundamental movement skill proficiency and objectively measured physical activity in children with bronchiectasis: a cross-sectional study. *BMC Pulmonary Medicine*, *21*(1). https://doi.org/10.1186/s12890-021-01637-w

Kacperski, J., Green, A., and Qaiser, S. (2020). Management of Chronic Migraine in Children and Adolescents: A Brief Discussion on Preventive Therapies. *Pediatric Drugs, 22*(6), 635–643. https://doi.org/10.1007/s40272-020-00418-y

Kalski, L., Bauerecker, I. L., Jarius, L., Hafermann, L., and Wolfarth, B. (2023). The Impact of the COVID-19 Pandemic on Training and Motivational Behavior: A Survey of Children and Adolescents. *Deutsche Zeitschrift Fur Sportmedizin*, *74*(3), 61–66. https://doi.org/10.5960/dzsm.2023.561

Kavey, R.-E. W., Allada, V., Daniels, S. R., Hayman, L. L., McCrindle, B. W., Newburger, J. W., Parekh, R. S., and Steinberger, J. (2006). Cardiovascular risk reduction in high-risk pediatric patients: a scientific statement from the American Heart Association Expert Panel on Population and Prevention Science; the Councils on Cardiovascular Disease in the Young, Epidemiology and Prevention. *Circulation*, *114*(24), 2710–2738. https://doi.org/10.1161/CIRCULATIONAHA.106.179568

Kendall, L., Parsons, J. M., Sloper, P., and Lewin, R. J. P. (2007). A simple screening method for determining knowledge of the appropriate levels of activity and risk behaviour in young people with congenital cardiac conditions. *Cardiology in the Young*, *17*(2), 151–157. https://doi.org/10.1017/S1047951107000285

Kennedy, A., Nirantharakumar, K., Chimen, M., Pang, T. T., Hemming, K., Andrews, R. C., and Narendran, P. (2013). Does exercise improve glycaemic control in type 1 diabetes? A systematic review and meta-analysis. *PloS One*, *8*(3), e58861. https://doi.org/10.1371/journal.pone.0058861

Kennedy, M., O'Gorman, P., Monaghan, A., Lavin, M., O'Mahony, B., O'Connell, N. M., O' Donnell, J. S., Turecek, P. L., and Gormley, J. (2021). A systematic review of physical activity in people with haemophilia and its relationship with bleeding phenotype and treatment regimen. *Haemophilia*, *27*(4), 544–562. https://doi.org/10.1111/hae.14282

Keshawarz, A., Piropato, A. R., Brown, T. L., Duca, L. M., Sippl, R. M., Wadwa, R. P., and Snell-Bergeon, J. K. (2018). Lower objectively measured physical activity is linked with perceived risk of hypoglycemia in type 1 diabetes. *Journal of Diabetes and Its Complications*, *32*(11), 975–981. https://doi.org/10.1016/j.jdiacomp.2018.05.020

Khair, K., Holland, M., Bladen, M., Griffioen, A., McLaughlin, P., von Mackensen, S., Wilkinson, M., Basingstoke, A. W., Charles, L., Bingham, G., Harvey, A., Harbridge, H., Emmitt, S., Stephensen, D., Ward, J., Hook, S., Reid, J., Preston, S., Flannery, T., … Garland, D. (2017). Study of physical function in adolescents with haemophilia: The SO-FIT study. *Haemophilia*, *23*(6), 918–925. https://doi.org/10.1111/hae.13323

Khair, K., Littley, A., Will, A., and von Mackensen, S. (2012). The impact of sport on children with haemophilia. *Haemophilia*, *18*(6), 898–905. https://doi.org/10.1111/j.1365-2516.2012.02857.x

Kirk, S. (2007). Methodological and ethical issues in conducting qualitative research with children and young people: A literature review. *International Journal of Nursing Studies*, *44*(7), 1250–1260. https://doi.org/10.1016/J.IJNURSTU.2006.08.015

Kitsantas, A., and Zimmerman, B. J. (2000). Self-efficacy, activity participation, and physical fitness of asthmatic and non asthmatic adolescent girls. *Journal of Asthma*, *37*(2), 163–174. https://doi.org/10.3109/02770900009055439

Köiter, J., Van Genderen, F. R., Brons, P. P. T., and Nijhuis-van Der Sanden, M. W. G. (2009). Participation and risk-taking behaviour in sports in children with haemophilia. *Haemophilia*, *15*(3), 686–694. https://doi.org/10.1111/j.1365-2516.2009.02006.x

Kornblit, A., Cain, A., Bauman, L. J., Brown, N. M., and Reznik, M. (2018). Parental Perspectives of Barriers to Physical Activity in Urban Schoolchildren with Asthma. *Academic Pediatrics*, *18*(3), 310–316. https://doi.org/10.1016/j.acap.2017.12.011

Kris-Etherton, P. M., Petersen, K. S., Després, J. P., Braun, L., De Ferranti, S. D., Furie, K. L., Lear, S. A., Lobelo, F., Morris, P. B., and Sacks, F. M. (2021). Special Considerations for Healthy Lifestyle Promotion Across the Life Span in Clinical Settings: A Science Advisory from the American Heart Association, *Circulation*, *144*(24), E515–E532. https://doi.org/10.1161/CIR.0000000000001014

Kuzik, N., Cameron, C., Carson, V., Chaput, J. P., Colley, R., Doiron, J., Faulkner, G., Janssen, I., Saunders, T., Spence, J. C., Tucker, P., Vanderloo, L. M., and Tremblay, M. S. (2023). The 2022 ParticipACTION Report Card on Physical Activity for Children and Youth: Focus on the COVID-19 pandemic impact and equity-deserving groups. *Frontiers in Public Health*, *11*, 1172168. https://doi.org/10.3389/fpubh.2023.1172168

Kwak, L., Kremers, S. P. J., Bergman, P., Ruiz, J. R., Rizzo, N. S., and Sjöström, M. (2009). Associations between physical activity, fitness, and academic achievement. *Journal of Pediatrics*, *155*(6). https://doi.org/10.1016/j.jpeds.2009.06.019

Lachman, P. (2021). Where to make a difference: research and the social determinants in pediatrics and child health in the COVID-19 era. *Pediatric Research*, *89*(2), 259–262. https://doi.org/10.1038/s41390-020-01253-0

Lambert, S. D., and Loiselle, C. G. (2008). Combining individual interviews and focus groups to enhance data richness. *Journal of Advanced Nursing*, *62*(2), 228–237. https://doi.org/10.1111/j.1365-2648.2007.04559.x

Lankhorst, K., Takken, T., Zwinkels, M., van Gaalen, L., Velde, S. te, Backx, F., Verschuren, O., Wittink, H., and de Groot, J. (2019). Sports Participation, Physical Activity, and Health-Related Fitness in Youth With Chronic Diseases or Physical Disabilities. *Journal of Strength and Conditioning Research*, *35*(8), 2327-2337. https://doi.org/10.1519/jsc.0000000000003098

Lattuca, L. (2001). *Creating Interdisciplinarity: Interdisciplinary research and teaching among college and university faculty.* Vanderbilt University Press. https://doi.org/10.2307/j.ctv167563f

Lavigne, J. V, and Faier-Routman, J. (1992). Psychological Adjustment to Pediatric Physical Disorders: A Meta-Analytic Review. *Journal of Pediatric Psychology*, *17*(2), 133–157. https://doi.org/10.1093/jpepsy/17.2.133

Lee, E. J., Phoenix, D., Brown, W., and Jackson, B. S. (1997). A comparison study of children with sickle cell disease and their non-diseased siblings on hopelessness, depression, and perceived competence. *Journal of Advanced Nursing*, *25*(1), 79–86. https://doi.org/10.1046/j.1365-2648.1997.1997025079.x

Lee, R. L. T., Lane, S., Brown, G., Leung, C., Kwok, S. W. H., and Chan, S. W. C. (2020). Systematic review of the impact of unstructured play interventions to improve young children's physical, social, and emotional wellbeing. *Nursing and Health Sciences*, *22*(2), 184–196. https://doi.org/10.1111/nhs.12732

Lee, S., and Lim, Y. (2022). The gendered playing field: Family socioeconomic status and national gender inequality in adolescents; out of school physical activity. *Social Science and Medicine*, *305*, 115062. https://doi.org/10.1016/j.socscimed.2022.115062

Liem, R. I. (2018). Balancing exercise risk and benefits: Lessons learned from sickle cell trait and sickle cell anemia. *Hematology*, *1*, 418–425. https://doi.org/10.1182/asheducation-2018.1.418

Liem, R. I., Onyejekwe, K., Olszewski, M., Nchekwube, C., Zaldivar, F. P., Radom-Aizik, S., Rodeghier, M. J., and Thompson, A. A. (2015). The acute phase inflammatory response to maximal exercise testing in children and young adults with sickle cell anaemia. *British Journal of Haematology*, *171*(5), 854–861. https://doi.org/10.1111/bjh.13782

Lincoln, Y. S., and Guba, E. G. (1985). *Naturalistic Inquiry*. Sage.

Lindsay, S., Ahmed, H., and Apostolopoulos, D. (2021). Facilitators for coping with the COVID-19 pandemic: Online qualitative interviews comparing youth with and without disabilities. *Disability and Health Journal*, *14*(4). https://doi.org/10.1016/j.dhjo.2021.101113

Liu, Y., and Chen, S. (2020). Physical literacy in children and adolescents: Definitions, assessments, and interventions. *European Physical Education Review*, *27*(1), 1–17. https://doi.org/10.1177/1356336X20925502

Livny, R., Said, W., Shilo, S., Bar-Yoseph, R., Gal, S., Oren, M., Levy, M., Weiss, R., Shehadeh, N., Zuckerman-Levin, N., and Cohen, M. (2020). Identifying sources of support and barriers to physical activity in pediatric type 1 diabetes. *Pediatric Diabetes*, *21*(1), 128–134. https://doi.org/10.1111/PEDI.12938

Lloyd, R. J. (2016). Becoming physically literate for life: Embracing the functions, forms, feelings and flows of alternative and mainstream physical activity. *Journal of Teaching in Physical Education*, *35*(2), 107–116. https://doi.org/10.1123/jtpe.2015-0068

Lobelo, F., Muth, N. D., Hanson, S., Nemeth, B. A., (2020). Physical activity assessment and counseling in pediatric clinical settings. *Pediatrics*, *145*(3). https://doi.org/10.1542/peds.2019-3992

Lohbeck, A., von Keitz, P., Hohmann, A., and Daseking, M. (2021). Children's Physical Self-Concept, Motivation, and Physical Performance: Does Physical Self-Concept or Motivation Play a Mediating Role? *Frontiers in Psychology*, *12*. https://doi.org/10.3389/fpsyg.2021.669936

Longmuir, P., Corey, M., Faulkner, G., Russell, J. L., and McCrindle, B. W. (2015). Children After Fontan have Strength and Body Composition Similar to Healthy Peers and Can Successfully Participate in Daily Moderate-to-Vigorous Physical Activity. *Pediatric Cardiology*, *36*(4), 759–767. https://doi.org/10.1007/s00246-014-1080-6

Longmuir, P. E., Boyer, C., Lloyd, M., Borghese, M. M., Knight, E., Saunders, T. J., Boiarskaia, E., Zhu, W., and Tremblay, M. S. (2017). Canadian Agility and Movement Skill Assessment (CAMSA): Validity, objectivity, and reliability evidence for children 8–12 years of age. *Journal of Sport and Health Science*, *6*, 231–240. https://doi.org/10.1016/j.jshs.2015.11.004

Longmuir, P. E., Boyer, C., Lloyd, M., Yang, Y., Boiarskaia, E., Zhu, W., and Tremblay, M. S. (2015). The Canadian Assessment of Physical Literacy: methods for children in grades 4 to 6 (8 to 12 years). *BMC Public Health*, *15*(1), 767. https://doi.org/10.1186/s12889-015-2106-6

Longmuir, P. E., Brothers, J. a., de Ferranti, S. D., Hayman, L. L., Van Hare, G. F., Matherne, G. P., Davis, C. K., Joy, E. a., and McCrindle, B. W. (2013). Promotion of physical activity for children and adults with congenital heart disease: A scientific statement from the American

Heart Association. *Circulation*, *127*(21), 2147–2159. https://doi.org/10.1161/CIR.0b013e318293688f

Longmuir, P. E., Gunnell, K. E., Barnes, J. D., Belanger, K., Leduc, G., Woodruff, S. J., and Tremblay, M. S. (2018). Canadian Assessment of Physical Literacy Second Edition: A streamlined assessment of the capacity for physical activity among children 8 to 12 years of age. *BMC Public Health*, *18*(Suppl 2), 1047. https://doi.org/10.1186/s12889-018-5902-y

Longmuir, P. E., and McCrindle, B. W. (2009). Physical activity restrictions for children after the Fontan operation: Disagreement between parent, cardiologist, and medical record reports. *American Heart Journal*, *157*(5), 853–859. https://doi.org/10.1016/j.ahj.2009.02.014

Longmuir, P. E., Wang, S., Timmons, B. W., Mondal, T., Cinanni, N. L., Di Cristofaro, N. A., Dillenburg, R., Adamo, K., Tremblay, M. S., and Lee, S. (2022). Inactive Lifestyles Among Young Children With Innocent Murmurs or Congenital Heart Disease, Regardless of Disease Severity or Treatment. *Canadian Journal of Cardiology*, *38*(1), 59–67. https://doi.org/10.1016/j.cjca.2021.09.014

Lubans, D. R., Lonsdale, C., Cohen, K., Eather, N., Beauchamp, M. R., Morgan, P. J., Sylvester, B. D., and Smith, J. J. (2017). Framework for the design and delivery of organized physical activity sessions for children and adolescents: rationale and description of the 'SAAFE' teaching principles. *International Journal of Behavioral Nutrition and Physical Activity*, *14*(1), 24. https://doi.org/10.1186/s12966-017-0479-x

Lukács, A., Mayer, K., Juhász, E., Varga, B., Fodor, B., and Barkai, L. (2012). Reduced physical fitness in children and adolescents with type 1 diabetes. *Pediatric Diabetes*, *13*(5), 426–431. https://doi.org/10.1111/j.1399-5448.2012.00848.x

MacMillan, F., Kirk, A., Mutrie, N., Moola, F., and Robertson, K. (2016). Building physical activity and sedentary behavior support into care for youth with type 1 diabetes: patient, parent and diabetes professional perceptions. *Pediatric Diabetes*, *17*(2), 140–152. https://doi.org/10.1111/pedi.12247

MacNamara, Á., Collins, D., and Giblin, S. (2015). Just let them play? Deliberate preparation as the most appropriate foundation for lifelong physical activity. *Frontiers in Psychology*, *6*. https://doi.org/10.3389/fpsyg.2015.01548

Majnemer, A., Limperopoulos, C., Shevell, M., Rosenblatt, B., Rohlicek, C., and Tchervenkov, C. (2006). Long-term neuromotor outcome at school entry of infants with congenital heart defects requiring open-heart surgery. *Journal of Pediatrics*, *148*(1), 72–77. https://doi.org/10.1016/j.jpeds.2005.08.036

Marchese, V., Rock, K., Harpold, A., Salazar, A., Williams, M., and Shipper, A. G. (2021). Physical Impairment and Function in Children and Adolescents With Sickle Cell Disease: A Systematic Review. *Archives of Physical Medicine and Rehabilitation*, *103*(6), 1144-1167.e2. https://doi.org/10.1016/j.apmr.2021.08.022

Marino, B. S., Lipkin, P. H., Newburger, J. W., Peacock, G., Gerdes, M., Gaynor, J. W., Mussatto, K. A., Uzark, K., Goldberg, C. S., Johnson, W. H., Li, J., Smith, S. E., Bellinger, D. C., and Mahle, W. T. (2012). Neurodevelopmental outcomes in children with congenital heart disease: evaluation and management: A scientific statement from the American Heart Association. *Circulation*, *126*(9), 1143–1172. https://doi.org/10.1161/CIR.0b013e318265ee8a

Markula, P., and Sparkes, A. (2015). Part I Ethnography Methodological and theoretical considerations. In M. Gyozo and L. Purdy (Eds.), *Ethnographies in Sport and Exercise Research* (1st ed., pp. 27–74). Taylor and Francis Group.

Maron, B. J. (2004). Recommendations for Physical Activity and Recreational Sports Participation for Young Patients With Genetic Cardiovascular Diseases. *Circulation*, *109*(22), 2807–2816. https://doi.org/10.1161/01.CIR.0000128363.85581.E1

Maron, B. J. and Zipes, D. P. (2005). 36th Bethesda Conference: Eligibility Recommendations for Competitive Athletes with Cardiovascular Abnormalities. *Journal of the American College of Cardiology*, *45*(8), 1312–1375. https://doi.org/10.1016/j.jacc.2005.02.004

Martin, C., Pialoux, V., Faes, C., Charrin, E., Skinner, S., and Connes, P. (2018). Does physical activity increase or decrease the risk of sickle cell disease complications? *British Journal of Sports Medicine*, *52*(4), 214–218. https://doi.org/10.1136/bjsports-2015-095317

Martin Ginis, K. A., Evans, M. B., Mortenson, W. Ben, and Noreau, L. (2017). Broadening the Conceptualization of Participation of Persons With Physical Disabilities: A Configurative Review and Recommendations. *Archives of Physical Medicine and Rehabilitation*, *98*(2), 395–402. https://doi.org/10.1016/j.apmr.2016.04.017

Martin Ginis, K. A., Ma, J. K., Latimer-Cheung, A. E., and Rimmer, J. (2016). A Systematic Review of Review Articles Addressing Factors Related to Physical Activity Participation Among Children and Adults with Physical Disabilities. *Health Psychology Review*, *10*(4), 478–494. https://doi.org/10.1080/17437199.2016.1198240

Martins, J., Onofre, M., Mota, J., Murphy, C., Repond, R.-M., Vost, H., Cremosini, B., Svrdlim, A., Markovic, M., and Dudley, D. (2020). International approaches to the definition, philosophical tenets, and core elements of physical literacy: A scoping review. *Prospects*, *50*, 13–30. https://doi.org/10.1007/s11125-020-09466-1

Masood, I. R., Detterich, J., Cerrone, D., Lewinter, K., Shah, P., Kato, R., and Sabati, A. (2022). Reduced Forced Vital Capacity and the Number of Chest Wall Surgeries are Associated with

Decreased Exercise Capacity in Children with Congenital Heart Disease. *Pediatric Cardiology*, *43*(1), 54–61. https://doi.org/10.1007/s00246-021-02692-0

Mazzella, A. J., Gehi, A. K., Lampert, R., Buck, S., and Rosman, L. (2022). Effects of COVID-19 pandemic on physical activity in children and young adults with implanted devices. *Heart Rhythm*, *19*(1), 165–166. https://doi.org/10.1016/j.hrthm.2021.09.037

McGarty, A. M., and Melville, C. A. (2018). Parental perceptions of facilitators and barriers to physical activity for children with intellectual disabilities: A mixed methods systematic review. *Research in Developmental Disabilities*, *73*, 40–57. https://doi.org/10.1016/j.ridd.2017.12.007

McMullen, J. A., McCrindle, B. W., Dell, S. D., Feldman, B. M., and Longmuir, P. E. (2019). Understanding parent perceptions of healthy physical activity for their child with a chronic medical condition: A cross-sectional study. *Paediatrics and Child Health (Canada)*, *24*(3), E135–E141. https://doi.org/10.1093/pch/pxy122

Melby, P. S., Elsborg, P., Nielsen, G., Lima, R. A., Bentsen, P., and Andersen, L. B. (2021). Exploring the importance of diversified physical activities in early childhood for later motor competence and physical activity level: a seven-year longitudinal study. *BMC Public Health*, *21*(1), 1492. https://doi.org/10.1186/s12889-021-11343-1

Mendes, F. A. R., Gonçalves, R. C., Nunes, M. P. T., Saraiva-Romanholo, B. M., Cukier, A., Stelmach, R., Jacob-Filho, W., Martins, M. A., and Carvalho, C. R. F. (2010). Effects of aerobic training on psychosocial morbidity and symptoms in patients with asthma: A randomized clinical trial. *Chest*, *138*(2), 331–337. https://doi.org/10.1378/chest.09-2389

Merlet, A. N., Chatel, B., Hourdé, C., Ravelojaona, M., Bendahan, D., Féasson, L., and Messonnier, L. A. (2019). How Sickle Cell Disease Impairs Skeletal Muscle Function:

Implications in Daily Life. *Medicine and Science in Sports and Exercise*, *51*(1), 4–11. https://doi.org/10.1249/MSS.0000000000001757

Mete Yesil, A., Sencan, B., Omercioglu, E., and Ozmert, E. N. (2022). The Impact of the COVID-19 Pandemic on Children With Special Needs: A Descriptive Study. *Clinical Pediatrics*, *61*(2), 141–149. https://doi.org/10.1177/00099228211050223

Michalak, A., Gawrecki, A., Galczynski, S., Nowaczyk, J., Mianowska, B., Zozulinska-Ziolkiewicz, D., and Szadkowska, A. (2019). Assessment of Exercise Capacity in Children with Type 1 Diabetes in the Cooper Running Test. *International Journal of Sports Medicine*, *40*(2), 110–115. https://doi.org/10.1055/a-0805-1326

Mitra, R., Moore, S. A., Gillespie, M., Faulkner, G., Vanderloo, L. M., Chulak-Bozzer, T., Rhodes, R. E., Brussoni, M., and Tremblay, M. S. (2020). Healthy movement behaviours in children and youth during the COVID-19 pandemic: Exploring the role of the neighbourhood environment. *Health and Place*, *65*, 102418. https://doi.org/10.1016/j.healthplace.2020.102418

Moola, F. J. (2020). Passive on the periphery: Exploring the experience of physical activity among children and youth with congenital heart disease using the draw-and-write technique. *The Arts in Psychotherapy*, *69*, 101662. https://doi.org/10.1016/j.aip.2020.101662

Moola, F., Buliung, R., Vance, C., Consunji-Araneta, R., and Naganathan, M. (2022). Parenting Between the Rules: How the Parents of Young People with Cystic Fibrosis in Canada Navigate Cross-Contamination Restrictions. *Child and Youth Care Forum*, *51*, 683–703. https://doi.org/10.1007/s10566-021-09648-8

Moola, F., Faulkner, G. E. J., Kirsh, J.., and Kilburn, J. (2008). Physical activity and sport participation in youth with congenital heart disease: Perceptions of children and parents. *Adapted Physical Activity Quarterly*, *25*, 49–70. https://doi.org/10.1123/apaq.25.1.49

Moola, F., Fusco, C., and Kirsh, J. (2011). What I wish you knew: Social barriers toward physical activity in youth with congenital heart disease (CHD). *Adapted Physical Activity Quarterly*, *28*(1), 56–77. https://doi.org/10.1123/apaq.28.1.56

Moola, F. J. (2020). Passive on the periphery: Exploring the experience of physical activity among children and youth with congenital heart disease using the draw-and-write technique. *The Arts in Psychotherapy*, *69*, 101662. https://doi.org/10.1016/J.AIP.2020.101662

Moola, F. J., Faulkner, G. E. J., Kirsh, J. a., and Schneiderman, J. E. (2011). Developing physical activity interventions for youth with cystic fibrosis and congenital heart disease: Learning from their parents. *Psychology of Sport and Exercise*, *12*(6), 599–608. https://doi.org/10.1016/j.psychsport.2011.07.001

Moola, F. J., Faulkner, G. E. J., and Schneiderman, J. E. (2012). "No time to play": Perceptions toward physical activity in youth with cystic fibrosis. *Adapted Physical Activity Quarterly*, *29*(1), 44–62. https://doi.org/10.1123/apaq.29.1.44

Moola, F. J., Garcia, E., Huynh, E., Henry, L., Penfound, S., Consunji-Araneta, R., and Faulkner, G. E. (2017). Physical Activity Counseling for Children With Cystic Fibrosis. *Respiratory Care*, *62*(11), 1466–1473. https://doi.org/10.4187/respcare.05009

Moola, F., McCrindle, B. W., and Longmuir, P. E. (2009). Physical activity participation in youth with surgically corrected congenital heart disease: Devising guidelines so Johnny can participate. *Paediatrics and Child Health*, *14*(3), 167–170. https://doi.org/10.1093/pch/14.3.167

Moore, S. A., Sharma, R., Martin Ginis, K. A., and Arbour-Nicitopoulos, K. P. (2021). Adverse effects of the COVID-19 pandemic on movement and play behaviours of children and youth living with disabilities: Findings from the national physical activity measurement (NPAM) study. *International Journal of Environmental Research and Public Health*, *18*(24), 12950. https://doi.org/10.3390/ijerph182412950

Morgan, D. L. (2007). Paradigms Lost and Pragmatism Regained: Methodological Implications of Combining Qualitative and Quantitative Methods. *Journal of Mixed Methods Research*, *1*(1), 48–76. https://doi.org/10.1177/2345678906292462

Morgan, D. L. (2014). Pragmatism as a Paradigm for Social Research. *Qualitative Inquiry*, *20*(8), 1045–1053. https://doi.org/10.1177/1077800413513733

Morgan, M., Gibbs, S., Maxwell, K., and Britten, N. (2002). Hearing children's voices: methodological issues in conducting focus groups with children aged 7–11 years. *Qualitative Research*, *2*(1), 5–20. https://doi.org/10.1177/1468794102002001636

Moschovi, D., Kapetanakis, E. I., Sfyridis, P. G., Rammos, S., and Mavrikaki, E. (2019). Physical activity levels and self-efficacy of Greek children with congenital heart disease compared to their healthy peers. *Hellenic Journal of Cardiology*, *61*(3), 180-186. https://doi.org/10.1016/j.hjc.2019.01.002

Moss, S. J., Mizen, S. J., Stelfox, M., Mather, R. B., FitzGerald, E. A., Tutelman, P., Racine, N., Birnie, K. A., Fiest, K. M., Stelfox, H. T., and Parsons Leigh, J. (2023). Interventions to improve well-being among children and youth aged 6-17 years during the COVID-19 pandemic: a systematic review. *BMC Medicine*, *21*(1), 131. https://doi.org/10.1186/s12916-023-02828-4

Müller, J., Böhm, B., Semsch, S., Oberhoffer, R., Hess, J., and Hager, A. (2013). Currently, children with congenital heart disease are not limited in their submaximal exercise performance. *European Journal of Cardio-Thoracic Surgery*, *43*(6), 1096–1100. https://doi.org/10.1093/ejcts/ezs712

Nadella, S., Indyk, J. A., and Kamboj, M. K. (2017). Management of diabetes mellitus in children and adolescents: Engaging in physical activity. *Translational Pediatrics*, *6*(3), 215–224. https://doi.org/10.21037/tp.2017.05.01

Naef, N., Liamlahi, R., Beck, I., Bernet, V., Dave, H., Knirsch, W., and Latal, B. (2017). Neurodevelopmental Profiles of Children with Congenital Heart Disease at School Age. *Journal of Pediatrics*, *188*, 75–81. https://doi.org/10.1016/j.jpeds.2017.05.073

Nap-Van Der Vlist, M. M., Berkelbach Van Der Sprenkel, E. E., Nijhof, L. N., Grootenhuis, M. A., Van Der Ent, C. K., Swart, J. F., Van Royen-Kerkhof, A., Van Grotel, M., Van De Putte, E. M., Nijhof, S. L., and Kars, M. C. (2021). Daily life participation in childhood chronic disease: a qualitative study on the child's and parent's perspective. *BMJ Pediatrics Open*, *5*, 1057. https://doi.org/10.1136/bmjpo-2021-001057

Nap-Van Der Vlist, M. M., Dalmeijer, G. W., Grootenhuis, M. A., Van Der Ent, K., Van Den Heuvel-Eibrink, M. M., Swart, J. F., Van De Putte, E. M., and Nijhof, S. L. (2021). Fatigue among children with a chronic disease: a cross-sectional study. *BMJ Paediatrics Open*, *5*, e000958. https://doi.org/10.1136/bmjpo-2020-000958

Nguyen, T., Obeid, J., Walker, R. G., Krause, M. P., Hawke, T. J., Mcassey, K., Vandermeulen, J., and Timmons, B. W. (2015). Fitness and physical activity in youth with type 1 diabetes mellitus in good or poor glycemic control. *Pediatric Diabetes*, *16*(1), 48–57. https://doi.org/10.1111/pedi.12117

Nicholas, D. B., Zulla, R. T., Conlon, O., Dimitropoulos, G., Urschel, S., Rapoport, A., Katz, S. L., Bruce, A., West, L. J., Belletrutti, M., Cullen, E., and Zwaigenbaum, L. (2022). Mental health impacts of the COVID-19 pandemic on children with underlying health and disability issues, and their families and health care providers. *Paediatrics and Child Health*, *27*(S1), S33–S39. https://doi.org/10.1093/PCH/PXAB103

Noonan, R. J., Boddy, L. M., Fairclough, S. J., and Knowles, Z. R. (2016). Write, draw, show, and tell: a child-centred dual methodology to explore perceptions of out-of-school physical activity. *BMC Public Health*, *16*(1), 326. https://doi.org/10.1186/s12889-016-3005-1

Nyenhuis, S. M., Kahwash, B., Cooke, A., Gregory, K. L., Greiwe, J., and Nanda, A. (2022). Recommendations for Physical Activity in Asthma: A Work Group Report of the AAAAI Sports, Exercise, and Fitness Committee. *Journal of Allergy and Clinical Immunology: In Practice*, *10*(2), 433–443. https://doi.org/10.1016/j.jaip.2021.10.056

Olorunyomi, O. O., Liem, R. I., and Hsu, L. L. (2022). Motivators and Barriers to Physical Activity among Youth with Sickle Cell Disease : Brief Review. *Children, 9*(4), 572. https://doi.org/10.3390/children9040572

Omwanghe, O. A., Muntz, D. S., Kwon, S., Montgomery, S., Kemiki, O., Hsu, L. L., Thompson, A. A., and Liem, R. I. (2017). Self-reported physical activity and exercise patterns in children with sickle cell disease. *Pediatric Exercise Science*, *29*(3), 388–395. https://doi.org/10.1123/pes.2016-0276

Omwanghe, O. A., Muntz, D. S., Kwon, S., Montgomery, S., Kemiki, O., Hsu, L. L., Thompsonand, A. A., and Liem, R. I. (2017). Self-Reported Physical Activity and Exercise Patterns in Children With Sickle Cell Disease. *Pediatric Exercise Science*, *29*(3), 388–395. https://doi.org/10.1123/pes.2016-0276

Ostman, C., Jewiss, D., King, N., and Smart, N. A. (2018). Clinical outcomes to exercise training in type 1 diabetes: A systematic review and meta-analysis. *Diabetes Research and Clinical Practice*, *139*, 380–391. https://doi.org/10.1016/j.diabres.2017.11.036

Padilla-Medina, J. A., Prado-Olivarez, J., Amador-Licona, N., Cardona-Torres, L. M., Galicia-Resendiz, D., and Diaz-Carmona, J. (2013). Study on simple reaction and choice times in patients with type I diabetes. *Computers in Biology and Medicine*, *43*(4), 368–376. https://doi.org/10.1016/j.compbiomed.2013.01.010

Paterson, D. C., Ramage, K., Moore, S. A., Riazi, N., Tremblay, M. S., and Faulkner, G. (2021). Exploring the impact of COVID-19 on the movement behaviors of children and youth: A scoping review of evidence after the first year. *Journal of Sport and Health Science*, *10*(6), 675–689. https://doi.org/10.1016/J.JSHS.2021.07.001

Peck, B., Bray, L., Dickinson, A., Blamires, J., Terry, D., and Carter, B. (2023). Health literacy among children living with a long-term condition: “What I know and who I tell.” *Health Education Journal*, *82*(5), 487–504. https://doi.org/10.1177/00178969231168210

Peltier, S., Kellum, A., Brewer, J., Duncan, A., Cooper, D. L., and Saad, H. (2020). Psychosocial Impact and Disease Management in Patients with Congenital Factor VII Deficiency. *Journal of Blood Medicine*, *11*, 297–303. https://doi.org/10.2147/JBM.S259909

Perry-Parrish, C., Copeland-Linder, N., Webb, L., and Sibinga, E. M. S. (2016). Mindfulness-based approaches for children and youth. *Current Problems in Pediatric and Adolescent Health Care*, *46*(6), 172–178. https://doi.org/10.1016/j.cppeds.2015.12.006

Pesce, C., Masci, I., Marchetti, R., Vazou, S., Sääkslahti, A., and Tomporowski, P. D. (2016). Deliberate play and preparation jointly benefit motor and cognitive development: Mediated and moderated effects. *Frontiers in Psychology*, *7*, 349. https://doi.org/10.3389/fpsyg.2016.00349

Philpott, J. F., Houghton, K., and Luke, A. (2010). Physical activity recommendations for children with specific chronic health conditions: juvenile idiopathic arthritis, hemophilia, asthma, and cystic fibrosis. *Clin.J.Sport.Med.*, *20*(3), 167–172. https://doi.org/10.1097/jsm.0b013e3181d2eddd

Pianosi, P. T., and Davis, H. S. (2004). Determinants of physical fitness in children with asthma. *Pediatrics*, *113*(3), e225–e229. https://doi.org/10.1542/peds.113.3.e225

Pittman, D. D., Hines, P. C., Beidler, D., Rybin, D., Frelinger, A. L., Michelson, A. D., Liu, K., Gao, X., White, J., Zaidi, A. U., Charnigo, R. J., and Callaghan, M. U. (2021). Evaluation of Longitudinal Pain Study in Sickle Cell Disease (ELIPSIS) by patient-reported outcomes, actigraphy, and biomarkers. *Blood*, *137*(15), 2010–2020. https://doi.org/10.1182/blood.2020006020

Pluye, P., and Hong, Q. N. (2014). Combining the power of stories and the power of numbers: Mixed methods research and mixed studies reviews. *Annual Review of Public Health*, *35*, 29–45. https://doi.org/10.1146/annurev-publhealth-032013-182440

Pohl, D., Alpous, A., Hamer, S., and Longmuir, P. E. (2019). Higher screen time, lower muscular endurance, and decreased agility limit the physical literacy of children with epilepsy. *Epilepsy and Behavior*, *90*, 260–265. https://doi.org/10.1016/j.yebeh.2018.05.010

Poitras, V. J., Gray, C. E., Borghese, M. M., Carson, V., Chaput, J.-P., Janssen, I., Katzmarzyk, P. T., Pate, R. R., Gorber, S. C., Kho, M. E., Sampson, M., and Tremblay, M. S. (2016). Systematic review of the relationships between physical activity and health indicators in the early years (0-4 years). *Applied Physiology, Nutrition and Metabolism*, *41*, S197–S239. https://doi.org/10.1186/s12889-017-4860-0

Pombo, A., Luz, C., de Sá, C., Rodrigues, L. P., and Cordovil, R. (2021). Effects of the COVID-19 lockdown on portuguese children's motor competence. *Children*, *8*(3), 199. https://doi.org/10.3390/children8030199

Pot, N., Whitehead, M. E., and Durden-Myers, E. J. (2018). Physical Literacy From Philosophy to Practice. *Journal of Teaching in Physical Education*, *37*(3), 246–251. https://doi.org/10.1123/jtpe.2018-0133

Pushkarenko, K., Causgrove Dunn, J., and Wohlers, B. (2021). Physical literacy and inclusion: A scoping review of the physical literacy literature inclusive of individuals experiencing disability. *Prospects*, *50*(1–2), 107–126. https://doi.org/10.1007/s11125-020-09497-8

Queenan, J. A., Wong, S. T., Barber, D., Morkem, R., and Salman, A. (2021). *The Prevalence of Common Chronic Conditions Seen in Canadian Primary Care: Results from the Canadian Primary Care Sentinel Surveillance Network*. https://cpcssn.ca/wp-content/uploads/2021/05/cpcssn-chronic-conditions-report-2021.pdf

Quirk, H., Blake, H., Dee, B., and Glazebrook, C. (2015). “Having diabetes shouldn’t stop them”: healthcare professionals’ perceptions of physical activity in children with Type 1 diabetes. *BMC Pediatrics*, *15*, 68. https://doi.org/10.1186/s12887-015-0389-5

Quirk, H., Blake, H., Tennyson, R., Randell, T. L., and Glazebrook, C. (2014). Physical activity interventions in children and young people with Type 1 diabetes mellitus: A systematic review with meta-analysis. *Diabetic Medicine*, *31*(10), 1163–1173. https://doi.org/10.1111/dme.12531

Quirk, H., Glazebrook, C., and Blake, H. (2016). “We don’t worry about diabetes that much”: A qualitative study exploring perceptions of physical activity among children with Type 1 Diabetes. *Advances in Pediatric Research*, *37*(6), 934-44. https://doi.org/10.1111/dme.14299

Quirk, H., Glazebrook, C., and Blake, H. (2018). A physical activity intervention for children with type 1 diabetes- steps to active kids with diabetes (STAK-D): A feasibility study. *BMC Pediatrics*, *18*(1), 37. https://doi.org/10.1186/s12887-018-1036-8

Radtke, T., Nevitt, S. J., Hebestreit, H., and Kriemler, S. (2017). Physical exercise training for cystic fibrosis. *The Cochrane Database of Systematic Reviews*, *8*(8), CD002768. https://doi.org/10.1002/14651858.cd002768.pub5

Raine, L. B., Erickson, K. I., Grove, G., H Watrous, J. N., McDonald, K., Kang, C., Jakicic, J. M., Forman, D. E., Kramer, A. F., Burns, J. M., Vidoni, E. D., McAuley, E., and Hillman, C. H. (2023). Cardiorespiratory fitness levels and body mass index of pre-adolescent children and older adults during the COVID-19 pandemic. *Frontiers in Public Health*, *10*, 1052389. https://doi.org/10.3389/fpubh.2022.1052389

Raudsepp, L., and Päll, P. (2006). The relationship between fundamental motor skills and outside-school physical activity of elementary school children. *Pediatric Exercise Science*, *18*(4), 426–435. https://doi.org/10.1123/pes.18.4.426

Ray, T. D., and Henry, K. (2011). Self-efficacy and physical activity in children with congenital heart disease: is there a relationship? *Journal for Specialists in Pediatric Nursing*, *16*(2), 105–112. https://doi.org/10.1111/j.1744-6155.2011.00282.x

Reddigan, J. I., Riddell, M. C., and Kuk, J. L. (2012). The joint association of physical activity and glycaemic control in predicting cardiovascular death and all-cause mortality in the US population. *Diabetologia*, *55*(3), 632–635. https://doi.org/10.1007/s00125-011-2374-3

Reilly, C., Atkinson, P., Das, K. B., Chin, R. F., Aylett, S. E., Burch, V., Gillberg, C., Scott, R. C., and Neville, B. G. R. (2015). Features of developmental coordination disorder in active childhood epilepsy: A population-based study. *Developmental Medicine and Child Neurology*, *57*(9), 829–834. https://doi.org/10.1111/dmcn.12763

Reilly, C., Muggeridge, A., and Cross, J. H. (2021). The perceived impact of COVID-19 and associated restrictions on young people with epilepsy in the UK: Young people and caregiver survey. *Seizure*, *85*, 111–114. https://doi.org/10.1016/j.seizure.2020.12.024

Rhodes, R. E., and Nigg, C. R. (2011). Advancing physical activity theory: A review and future directions. *Exercise and Sport Sciences Reviews*, *39*(3), 113–119. https://doi.org/10.1097/JES.0b013e31821b94c8

Riazi, N. A., Wunderlich, K., Gierc, M., Brussoni, M., Moore, S. A., Tremblay, M. S., and Faulkner, G. (2021). "You Can't Go to the Park , You Can't Go Here , You Can't Go There": Exploring Parental Experiences of COVID-19 and Its Impact on Their Children's Movement Behaviours. *Children*, *8*(3), 219. https://doi.org/10.3390/children8030219

Richards, A. B., Minou, M., Sheldrick, M. P., Swindell, N., Griffiths, L. J., Hudson, J., and Stratton, G. (2022). A Socioecological Perspective of How Physical Activity and Sedentary Behaviour at Home Changed during the First Lockdown of COVID-19 Restrictions: The HomeSPACE Project. *International Journal of Environmental Research and Public Health*, *19*(9), 5070. https://doi.org/10.3390/ijerph19095070

Roberts, A. J., Yi-Frazier, J. P., Aitken, K. E., Mitrovich, C. A., Pascual, M. F., and Taplin, C. E. (2017). Do youth with type 1 diabetes exercise safely? A focus on patient practices and glycemic outcomes. *Pediatric Diabetes*, *18*(5), 367–375. https://doi.org/10.1111/pedi.12402

Robinson, D. B., and Randall, L. (2017). Marking Physical Literacy or Missing the Mark on Physical Literacy? A Conceptual Critique of Canada's Physical Literacy Assessment Instruments. *Measurement in Physical Education and Exercise Science*, *21*(1), 40–55. https://doi.org/10.1080/1091367X.2016.1249793

Roche, C., Fisher, A., Fancourt, D., and Burton, A. (2022). Exploring Barriers and Facilitators to Physical Activity during the COVID-19 Pandemic: A Qualitative Study. *International Journal of Environmental Research and Public Health*, *19*(15), 9169. https://doi.org/10.3390/ijerph19159169

Rodriguez-Merchan, E. C. (2010). Musculoskeletal complications of hemophilia. *HSS Journal*, *6*(1), 37–42. https://doi.org/10.1007/s11420-009-9140-9

Rosenblum, O., Katz, U., Reuveny, R., Williams, C. A., and Dubnov-Raz, G. (2015). Exercise Performance in Children and Young Adults After Complete and Incomplete Repair of

Congenital Heart Disease. *Pediatric Cardiology*, *36*(8), 1573–1581. https://doi.org/10.1007/s00246-015-1198-1

Rosenthal, T. M., Leung, S. T., Ahmad, R., Young, T., Lavie, C. J., Moodie, D. S., and Shah, S. (2016). Lifestyle modification for the prevention of morbidity and mortality in adult congenital heart disease. *Congenital Heart Disease*, *11*(2), 189–198. https://doi.org/10.1111/chd.12341

Rothacker, K. M., Armstrong, S., Smith, G. J., Benjanuvatra, N., Lay, B., Adolfsson, P., Jones, T. W., Fournier, P. A., and Davis, E. A. (2021). Acute hyperglycaemia does not have a consistent adverse effect on exercise performance in recreationally active young people with type 1 diabetes: a randomised crossover in-clinic study. *Diabetologia*, *64*(8), 1737–1748. https://doi.org/10.1007/s00125-021-05465-9

Ryninks, K., Sutton, E., Thomas, E., Jago, R., Shield, J. P. H., and Burren, C. P. (2015). Attitudes to Exercise and Diabetes in Young People with Type 1 Diabetes Mellitus: A Qualitative Analysis. *PloS One*, *10*(10), e0137562. https://doi.org/10.1371/journal.pone.0137562

Santuz, P., Baraldi, E., Filippone, M., and Zacchello, F. (1997). Exercise performance in children with asthma: Is it different from that of healthy controls? *European Respiratory Journal*, *10*(6), 1254–1260. https://doi.org/10.1183/09031936.97.10061254

Sanz-Santiago, V., Diez-Vega, I., Donadio, M. V. F., Schiwe, D., Lopez-Nuevo, C., Vendrusculo, F. M., Santana-Sosa, E., Burgos, S., Escribano-Ceruelo, E., Villa-Asensi, J. R., and Perez-Ruiz, M. (2021). Comparison of physical fitness between healthy and mild-to-moderate asthmatic children with exercise symptoms: A cross-sectional study. *Pediatric Pulmonology*, *56*(8), 2512–2521. https://doi.org/10.1002/ppul.25506

Schaan, C. W., de Macedo, A. C. P., Sbruzzi, G., Umpierre, D., Schaan, B. D., and Pellanda, L. C. (2017). Functional Capacity in Congenital Heart Disease: A Systematic Review and Meta-

Analysis. *Arquivos Brasileiros de Cardiologia*, *109*(4), 357–367. https://doi.org/10.5935/abc.20170125

Schary, D. P., and Cardinal, B. J. (2015). Interdisciplinary and Intradisciplinary Research and Teaching in Kinesiology: Continuing the Conversation. *Quest*, *67*(2), 173–184. https://doi.org/10.1080/00336297.2015.1017586

Schelbe, L., Chanmugam, A., Moses, T., Saltzburg, S., Williams, L. R., and Letendre, J. (2015). Youth participation in qualitative research: Challenges and possibilities. *Qualitative Social Work*, *14*(4), 504–521. https://doi.org/10.1177/1473325014556792

Schneiderman, J. E., Wilkes, D. L., Atenafu, E. G., Nguyen, T., Wells, G. D., Alarie, N., Tullis, E., Lands, L. C., Coates, A. L., Corey, M., and Ratjen, F. (2014). Longitudinal relationship between physical activity and lung health in patients with cystic fibrosis. *European Respiratory Journal*, *43*(3), 817–823. https://doi.org/10.1183/09031936.00055513

Scott, S. N., Thompson, D. L., and Coe, D. P. (2013). The ability of the PACER to elicit peak exercise response in the youth. *Medicine and Science in Sports and Exercise*, *45*(6), 1139–1143. https://doi.org/10.1249/MSS.0b013e318281e4a8

Sebire, S. J., Jago, R., Fox, K. R., Edwards, M. J., and Thompson, J. L. (2013). Testing a self-determination theory model of children's physical activity motivation: a cross-sectional study. *International Journal of Behavioral Nutrition and Physical Activity*, *10*, 111. https://doi.org/10.1186/1479-5868-10-111

Sedaghati, P., Balayi, E., and Ahmadabadi, S. (2022). Effects of COVID-19 related physical inactivity on motor skills in children with intellectual disability. *BMC Public Health*, *22*(1), 2381. https://doi.org/10.1186/s12889-022-14887-y

Shearer, C., Goss, H. R., Edwards, L. C., Keegan, R. J., Knowles, Z. R., Boddy, L. M., Durden-Myers, E. J., and Foweather, L. (2018). How Is Physical Literacy Defined? A Contemporary Update. *Journal of Teaching in Physical Education*, *37*(3), 237–245. https://doi.org/10.1123/jtpe.2018-0136

Shearer, K., Rempel, G. R., Norris, C. M., and Magill-Evans, J. (2013). "It's No Big Deal": Adolescents with congenital heart disease. *Journal of Pediatric Nursing*, *28*(1), 28–36. https://doi.org/10.1016/j.pedn.2012.03.031

Shei, R. J., Mackintosh, K. A., Peabody Lever, J. E., McNarry, M. A., and Krick, S. (2019). Exercise Physiology Across the Lifespan in Cystic Fibrosis. *Frontiers in Physiology*, *10*, 1382. https://doi.org/10.3389/fphys.2019.01382

Shorey, S., and Ng, E. D. (2020). The lived experiences of children and adolescents with non-communicable disease: A systematic review of qualitative studies. *Journal of Pediatric Nursing*, *51*, 75–84. https://doi.org/10.1016/j.pedn.2019.12.013

Sırtbaş, G., Yalnızoğlu, D., and Livanelioğlu, A. (2021). Comparison of physical fitness, activity, and quality of life of the children with epilepsy and their healthy peers. *Epilepsy Research*, *178*, 106795. https://doi.org/10.1016/j.eplepsyres.2021.106795

Small, M. L. (2009). "How many cases do I need?": On science and the logic of case selection in field-based research. *Ethnography*, *10*(1), 5–38. https://doi.org/10.1177/1466138108099586

Sousa, A. W., Cabral, A. L. B., Silva, R. A., Fonseca, A. J., Grindler, J., Martins, M. A., and Carvalho, C. R. F. (2021). Physical fitness and quality of life in adolescents with asthma and fixed airflow obstruction. *Pediatric Pulmonology*, *56*(1), 65–73. https://doi.org/10.1002/ppul.25160

Sparacino, P. S., Tong, E. M., H Messias, D. K., Foote, D., Chesla, C. A., Gilliss, C. L., and Francisco, S. (1997). The dilemmas of parents of adolescents and young adults with congenital heart disease. *Heart and Lung*, *26*(3), 187-195. https://doi.org/10.1016/s0147-9563(97)90055-8

Sparkes, A. C., and Smith, B. (2009). Judging the quality of qualitative inquiry: Criteriology and relativism in action. . *Psychology of Sport and Exercise*, *10*, 491–497.

Srivastava, P., and Hopwood, N. (2009). A Practical Iterative Framework for Qualitative Data Analysis. *International Journal of Qualitative Methods*, *8*(1), 76-84. https://doi.org/10.1177/160940690900800107

Steele, J. M., Preminger, T. J., Erenberg, F. G., Wang, L., Dell, K., Alsaied, T., and Zahka, K. G. (2019). Obesity trends in children, adolescents, and young adults with congenital heart disease. *Congenital Heart Disease*, *14*(4), 517–524. https://doi.org/10.1111/chd.12754

Stephens, S. L., Tremblay, M. S., Faulkner, G., Beyene, J., Nguyen, T. H., Koohsari, S., Limenis, E., and Feldman, B. M. (2016). Validity of the stage of exercise scale in children with rheumatologic conditions. *Journal of Rheumatology*, *43*(12), 2189–2198. https://doi.org/10.3899/jrheum.151377

Sterdt, E., Liersch, S., and Walter, U. (2014). Correlates of physical activity of children and adolescents: A systematic review of reviews. *Health Education Journal*, *73*(1), 72–89. https://doi.org/10.1177/0017896912469578

Stodden, D. F., Langendorfer, S. J., Goodway, J. D., Roberton, M. A., Rudisill, M. E., Garcia, C., and Garcia, L. E. (2008). A developmental perspective on the role of motor skill competence in physical activity: An emergent relationship. *Quest*, *60*(2), 290–306. https://doi.org/10.1080/00336297.2008.10483582

Stössel, S., Neu, M. A., Oschwald, V., Söntgerath, R., Däggelmann, J., Eckert, K., Hamacher, V., Baumann, F. T., Bloch, W., and Faber, J. (2020). Physical activity behaviour in children and adolescents before, during and after cancer treatment. *Sport Sciences for Health*, *16*(2), 347–353. https://doi.org/10.1007/s11332-019-00612-7

Strack, R. W., Magill, C., and McDonagh, K. (2004). Engaging youth through photovoice. *Health Promotion Practice*, *5*(1), 49–58. https://doi.org/10.1177/1524839903258015

Strike, K., Mulder, K., and Michael, R. (2016). Exercise for haemophilia (Review). *Cochrane Library*, *1*(12), 1–55. https://doi.org/10.1002/14651858.CD011180.pub2

Svensson, M. K., Wahlberg, A., and Gislason, G. H. (2020). Chronic Paradoxes: A Systematic Review of Qualitative Family Perspectives on Living With Congenital Heart Defects. *Qualitative Health Research*, *30*(1), 119–132. https://doi.org/10.1177/1049732319869909

Swisher, A. K., and Erickson, M. (2008). Perceptions of Physical Activity in a Group of Adolescents with Cystic Fibrosis. *Cardiopulmonary Physical Therapy Journal*, *19*(4), 107–114. https://doi.org/10.1097/01823246-200819040-00002

Tagougui, S., Leclair, E., Fontaine, P., Matran, R., Marais, G., Aucouturier, J., Descatoire, A., Vambergue, A., Oussaidene, K., Baquet, G., and Heyman, E. (2015). Muscle oxygen supply impairment during exercise in poorly controlled type 1 diabetes. *Medicine and Science in Sports and Exercise*, *47*(2), 231–239. https://doi.org/10.1249/mss.0000000000000424

te Velde, S. J., Lankhorst, K., Zwinkels, M., Verschuren, O., Takken, T., and de Groot, J. (2018). Associations of sport participation with self-perception, exercise self-efficacy and quality of life among children and adolescents with a physical disability or chronic disease—a cross-sectional study. *Sports Medicine - Open*, *4*(1), 38. https://doi.org/10.1186/s40798-018-0152-1

Teach, S. J., and St. Geme, J. W. (2021). The indirect effects of COVID-19 on pediatric research. *Pediatric Research*, *90*(2), 246–247. https://doi.org/10.1038/s41390-021-01563-x

Theis, N., Campbell, N., De Leeuw, J., Owen, M., and Schenke, K. C. (2021). The effects of COVID-19 restrictions on physical activity and mental health of children and young adults with physical and/or intellectual disabilities. *Disability and Health Journal*, *14*(3), 101064. https://doi.org/10.1016/j.dhjo.2021.101064

Thelen, E., and Smith, L. B. (2006). Dynamic Systems Theories. In R. M. Lerner and W. Damon (Eds.), *Handbook of Child Psychology* (Sixth, Vol. 1, pp. 258–312). John Wiley and Sons.

Thurman, D. J., Logroscino, G., Beghi, E., Hauser, W. A., Hesdorffer, D. C., Newton, C. R., Scorza, F. A., Sander, J. W., and Tomson, T. (2017). The burden of premature mortality of epilepsy in high-income countries: A systematic review from the Mortality Task Force of the International League Against Epilepsy. *Epilepsia*, *58*(1), 17–26. https://doi.org/10.1111/epi.13604

Torres-Castro, R., Vasconcello-Castillo, L., Acosta-Dighero, R., Sepúlveda-Cáceres, N., Barros-Poblete, M., Puppo, H., Vera-Uribe, R., Vilaró, J., and Herrera-Romero, M. (2021). Physical Activity in Children and Adolescents With Chronic Respiratory Diseases: A Systematic Review and Meta-Analysis. *Journal of Physical Activity and Health*, *18*(2), 219-229. https://doi.org/10.1123/jpah.2020-0641

Tracy, S. J. (2010). Qualitative quality: Eight “Big Tent” criteria for excellent qualitative research. *Qualitative Inquiry*, *16*, 837–851.

Trask, S., Lockyer, P., Hildreth, J., D’Souza, E., Buklijas, T., Menzies, R., Vickers, M., and Bay, J. L. (2023). Sustaining youth physical activity in times of challenge and change: lessons from COVID-19. *Health Promotion International*, *38*(3). https://doi.org/10.1093/heapro/daad038

Tremblay, M., and Lloyd, M. (2010). Physical Literacy Measurement: The Missing Piece. *Physical and Health Education Journal*, *76*(1), 26–30. https://www.proquest.com/docview/894858510

Tremblay, M. S., Carson, V., and Chaput, J.-P. (2016). Introduction to the Canadian 24-Hour Movement Guidelines for Children and Youth: An Integration of Physical Activity, Sedentary Behaviour, and Sleep [1]. *Applied Physiology, Nutrition, and Metabolism*, *41*(6 (Suppl. 3)), iii–iv. https://doi.org/10.1139/apnm-2016-0203

Tremblay, M. S., Costas-Bradstreet, C., Barnes, J. D., Bartlett, B., Dampier, D., Lalonde, C., Leidl, R., Longmuir, P., McKee, M., Patton, R., Way, R., and Yessis, J. (2018). Canada's Physical Literacy Consensus Statement: process and outcome. *BMC Public Health*, *18*(Suppl 2), 1034. https://doi.org/10.1186/s12889-018-5903-x

Tremblay, M. S., and Longmuir, P. E. (2017). Conceptual Critique of Canada's Physical Literacy Assessment Instruments Also Misses the Mark. *Measurement in Physical Education and Exercise Science*, *21*(3), 174–176. https://doi.org/10.1080/1091367X.2017.1333002

Tremblay, M. S., Longmuir, P. E., Barnes, J. D., Belanger, K., Anderson, K. D., Bruner, B., Copeland, J. L., Delisle Nyström, C., Gregg, M. J., Hall, N., Kolen, A. M., Lane, K. N., Law, B., MacDonald, D. J., Martin, L. J., Saunders, T. J., Sheehan, D., Stone, M. R., and Woodruff, S. J. (2018). Physical literacy levels of Canadian children aged 8-12 years: Descriptive and normative results from the RBC Learn to Play-CAPL project. *BMC Public Health*, *18*(Suppl 2), 1036. https://doi.org/10.1186/s12889-018-5891-x

Tully, C., Aronow, L., Mackey, E., and Streisand, R. (2016). Physical Activity in Youth With Type 1 Diabetes: a Review. *Current Diabetes Reports*, *16*(9), 85. https://doi.org/10.1007/s11892-016-0779-6

UNESCO. (2017). *A Guide for ensuring inclusion and equity in education*. UNESCO. https://doi.org/10.54675/MHHZ2237

Vahlkvist, S., and Pedersen, S. (2009). Fitness, daily activity and body composition in children with newly diagnosed, untreated asthma. *Allergy: European Journal of Allergy and Clinical Immunology*, *64*(11), 1649–1655. https://doi.org/10.1111/j.1398-9995.2009.02081.x

van Deutekom, A. W., and Lewandowski, A. J. (2021). Physical activity modification in youth with congenital heart disease: a comprehensive narrative review. *Pediatric Research*, *89*(7), 1650–1658. https://doi.org/10.1038/s41390-020-01194-8

Van Ryckeghem, L., Franssen, W. M. A., Verbaanderd, E., Indesteege, J., De Vriendt, F., Verwerft, J., Dendale, P., Bito, V., and Hansen, D. (2021). Cardiac Function is Preserved in Adolescents With Well-Controlled Type 1 Diabetes and a Normal Physical Fitness: A Cross-Sectional Study. *Canadian Journal of Diabetes*, *45*(8), 718-724.e1. https://doi.org/10.1016/j.jcjd.2021.01.010

Vanderhout, S. M., Bhalla, M., Van, A., Fergusson, D. A., Potter, B. K., Karoly, A., Ly, V., and Macarthur, C. (2022). The impact of patient and family engagement in child health research: A scoping review. *Journal of Pediatrics, 253,* 115-128. https://doi.org/10.1016/j.jpeds.2022.09.030

Vasconcello-Castillo, L., Torres-Castro, R., Sepúlveda-Cáceres, N., Acosta-Dighero, R., Miranda-Aguilera, S., Puppo, H., Rodríguez-Borges, J., and Vilaró, J. (2021). Levels of physical activity in children and adolescents with asthma: A systematic review and meta-analysis. *Pediatric Pulmonology*, *56*(6), 1307–1323. https://doi.org/10.1002/PPUL.25293

Vilhjalmsson, R., and Kristjansdottir, G. (2003). Gender differences in physical activity in older children and adolescents: the central role of organized sport. *Social Science and Medicine*, *56*(2), 363–374. https://doi.org/10.1016/S0277-9536(02)00042-4

Villaseca-Rojas, Y., Varela-Melo, J., Torres-Castro, R., Vasconcello-Castillo, L., Mazzucco, G., Vilaró, J., and Blanco, I. (2022). Exercise Capacity in Children and Adolescents With Congenital Heart Disease: A Systematic Review and Meta-Analysis. *Frontiers in Cardiovascular Medicine*, *9*, 874700. https://doi.org/10.3389/fcvm.2022.874700

Voskuil, V. R., and Robbins, L. B. (2015). Youth physical activity self-efficacy: A concept analysis. *Journal of Advanced Nursing*, *71*(9), 2002–2019. https://doi.org/10.1111/jan.12658

Walker, T. J., and Reznik, M. (2014). In-school asthma management and physical activity: Children's perspectives. *Journal of Asthma*, *51*(8), 808–813. https://doi.org/10.3109/02770903.2014.920875

Waltz, X., Romana, M., Hardy-Dessources, M. D., Lamarre, Y., Divialle-Doumdo, L., Petras, M., Tarer, V., Hierso, R., Baltyde, K. C., Tressières, B., Lalanne-Mistrih, M. L., Maillard, F., Hue, O., Etienne-Julan, M., and Connes, P. (2013). Hematological and hemorheological Determinants of the Six-Minute Walk Test Performance in Children with Sickle Cell Anemia. *PLoS ONE*, *8*(10), 6–10. https://doi.org/10.1371/journal.pone.0077830

Wanrooij, V. H. M., Willeboordse, M., Dompeling, E., and Van De Kant, K. D. G. (2014). Exercise training in children with asthma: A systematic review. *British Journal of Sports Medicine*, *48*(13), 1024–1031. https://doi.org/10.1136/bjsports-2012-091347

Warburton, D. E. R., Nicol, C. W., Bredin, S. S. D. (2006). Health benefits of physical activity: the evidence. *Canadian Medical Association Journal*, *174*(6), 801–809. https://doi.org/10.1503%2Fcmaj.051351

Warburton, D. E. R., Gledhill, N., Jamnik, V. K., Bredin, S. S. D., McKenzie, D. C., Stone, J., Charlesworth, S., and Shephard, R. J. (2011). Evidence-based risk assessment and recommendations for physical activity clearance: Consensus Document 2011 1 This paper is one of a selection of papers published in this Special Issue, entitled Evidence-based risk assessment and recommendations for phys. *Applied Physiology, Nutrition, and Metabolism*, *36*(S1), S266–S298. https://doi.org/10.1139/h11-062

Weissman, S. E., Perinpanayagam, R., Wright, F. V., and Arbour-Nicitopoulos, K. P. (2022). Application of the behaviour change technique taxonomy (BCTTv1) to an inclusive physical literacy-based sport program for children and youth. *International Journal of Sports Science and Coaching*, *17*(1), 18–36. https://doi.org/10.1177/17479541211016580

Welsh, L., Roberts, R. G. D., and Kemp, J. G. (2004). Fitness and physical activity in children with asthma. *Sports Med*, *34*(13), 861–870. https://doi.org/10.2165/00007256-200434130-00001

West, S. L., Banks, L., Schneiderman, J. E., Caterini, J. E., Stephens, S., White, G., Dogra, S., and Wells, G. D. (2019). Physical activity for children with chronic disease; A narrative review and practical applications. *BMC Pediatrics*, *19*, 12. https://doi.org/10.1186/s12887-018-1377-3

Westergren, T., Berntsen, S., Ludvigsen, M. S., Aagaard, H., Hall, E. O. C., Ommundsen, Y., Uhrenfeldt, L., and Fegran, L. (2017). Relationship between physical activity level and psychosocial and socioeconomic factors and issues in children and adolescents with asthma. *JBI Database of Systematic Reviews and Implementation Reports*, *15*(8), 2182–2222. https://doi.org/10.11124/JBISRIR-2016-003308

Whitehead, M. (2001). The concept of physical literacy. *European Journal of Physical Education*, *6*(2), 127–138. https://doi.org/10.1080/1740898010060205

Whitehead, M. (2007). Physical Literacy: Philosophical Considerations in Relation to Developing a Sense of Self, Universality and Propositional Knowledge. *Sport, Ethics and Philosophy*, *1*(3), 281–298. https://doi.org/10.1080/17511320701676916

Whitehead, M. (2010). *Physical Literacy: Throughout the life course.* New York: Routledge. https://doi.org/10.4324/9780203881903

Whitehead, M. (2019). Physical Literacy Moving Forward. In M. Whitehead (Ed.), *Physical Literacy Across the World*. Routledge. https://doi.org/10.4324/9780203702697

Whooten, R., Horan, C., Aguirre, A., Dartley, A. N., and Taveras, E. (2023). Parent and Pediatrician Perspectives on Physical Activity Promotion in Pediatric Primary Care: A Preliminary Mixed Methods Study. *American Journal of Health Promotion*, *37*(1), 65–76. https://doi.org/10.1177/08901171221113317

Wiart, L., and Darrah, J. (2002). Changing philosophical perspectives on the management of children with physical disabilities - Their effect on the use of powered mobility. *Disability and Rehabilitation*, *24*(9), 492–498. https://doi.org/10.1080/09638280110105240

Wilfred, A. M., Humphreys, C., Patterson, S., Brown, D. M., Pohl, D., Moyes, C., Rosenbaum, P. L., and Ronen, G. M. (2022). Being physically active with epilepsy: Insights from young people and their parents. *Epilepsy Research*, *188,* 107035. https://doi.org/10.1016/j.eplepsyres.2022.107035

Williams, B. K., Guelfi, K. J., Jones, T. W., and Davis, E. A. (2011). Lower cardiorespiratory fitness in children with Type 1 diabetes. *Diabetic Medicine : A Journal of the British Diabetic Association*, *28*(8), 1005–1007. https://doi.org/10.1111/j.1464-5491.2011.03271.x

Williams, C. A., and Stevens, D. (2013). Physical activity and exercise training in young people with cystic fibrosis: Current recommendations and evidence. *Journal of Sport and Health Science*, *2*(1), 39–46. https://doi.org/10.1016/j.jshs.2012.11.002

Williams, C. A., Wadey, C., Pieles, G., Stuart, G., Taylor, R. S., and Long, L. (2020). Physical activity interventions for people with congenital heart disease. *Cochrane Database of Systematic Reviews*, *1*(10), 1–77, https://doi.org/10.1002/14651858.CD013400.pub2

Williamson, K. (2006). Research in constructivist frameworks using ethnographic techniques. *Library Trends*, 55(1), 83–101. https://doi.org/10.1353/lib.2006.0054

Willis, C., Girdler, S., Thompson, M., Rosenberg, M., Reid, S., and Elliott, C. (2017). Elements contributing to meaningful participation for children and youth with disabilities: a scoping review. *Disability and Rehabilitation*, *39*(17), 1771–1784. https://doi.org/10.1080/09638288.2016.1207716

Winn, C. O. N., Mackintosh, K. A., Eddolls, W. T. B., and Stratton, G. (2018). Perceptions of asthma and exercise in adolescents with and without asthma. *Journal of Asthma*, *55*(8), 868–876. https://doi.org/10.1080/02770903.2017.1369992

World Health Organization. (2011). *World Report on Disability*. https://www.who.int/publications/i/item/9789241564182

Yang, P.-Y., Lou, M.-F., Lien, A. S.-Y., and Gau, B.-S. (2018). Adolescent Perceptions of Peer Responses to Diabetes Self-Management: A Qualitative Study. *The Journal of Nursing Research : JNR*, *26*(2), 104–111. https://doi.org/10.1097/jnr.0000000000000234

Young, L., O'Connor, J., and Alfrey, L. (2020). Physical literacy: a concept analysis. *Sport, Education and Society*, *25*(8), 946–959. https://doi.org/10.1080/13573322.2019.1677586

Zetterberg, E., Ljungkvist, M., and Salim, M. (2018). Impact of Exercise on Hemophilia. *Seminars in Thrombosis and Hemostasis*, *44*(8), 787–795. https://doi.org/10.1055/s-0038-1675381

Zwinkels, M., Verschuren, O., Balemans, A., Lankhorst, K., Te Velde, S., van Gaalen, L., de Groot, J., Visser-Meily, A., and Takken, T. (2018). Effects of a School-Based Sports Program on Physical Fitness, Physical Activity, and Cardiometabolic Health in Youth With Physical Disabilities: Data From the Sport-2-Stay-Fit Study. *Frontiers in Pediatrics*, *6*, 75. https://doi.org/10.3389/fped.2018.00075

Appendices

Appendix A: CAPL and CAPL-2 Conceptual Models

Original CAPL Model

Figure Used with Permission from:

Original: Longmuir PE, Boyer C, Lloyd M et al. (2015) The Canadian Assessment of Physical Literacy: methods for children in grades 4 to 6 (8 to 12 years). *BMC Public Health, 15,* 767.

<u>*Revised CAPL-2 Model*</u>

Figure Used with Permission from:

Revised: Longmuir PE, Gunnell KE, Barnes JD, et al. (2018) Canadian Assessment of Physical Literacy Second Edition: A streamlined assessment of the capacity for physical activity among children 8 to 12 years of age. *BMC Public Health; 18*(Suppl 2), 1047.

Appendix B: Research Ethics Board Approval Letters

CHEO Research Institute Ethics Board Approval

10/28/2020 REB Protocol No 20/108X - Final Approval - Delegated Review

Reply all | Delete Junk | ...

REB Protocol No 20/108X - Final Approval - Delegated Review

vbourada@cheo.on.ca
Wed 2020-10-28 10:20 AM
To: Blais, Angelica; Longmuir, Patricia
Cc: DiGasparro, Miranda; Yaraskavitch, Jenna; Bourada, Valerie

Reply all |

Inbox

EXTERNAL MAIL*

CHEO

CHEO Research Ethics Board Approval - Delegated Review

REB Protocol No: 20/108X
ROMEO File No: 20200461
Principal Investigator: Dr. Patricia Longmuir
Project Title: CHEOREB# 20/108X - Investigating the physical literacy of children with chronic medical conditions and how it has changed due to the COVID-19 pandemic.

Protocol Status: Active

Approval Date*: October 28, 2020
Approval Expiry Date:** October 15, 2021

Documents Reviewed & Approved:

Document Name	Comments	Version Date
Other Document	End of Study Letter	2020/09/11
Case Report Form	Case Report Form	2020/09/11
Other Document	Pedometer Log Sheet	2020/09/11
Questionnaire/Survey	Interview Guide	2020/09/11
Questionnaire/Survey	CAPL2 Questionnaire	2020/09/11
Protocol	Protocol - Version 1	2020/10/26
Assent Form	Assent Form	2020/09/11
Recruitment Materials	Study Introduction Letter	2020/09/11

https://webmail.cheo.on.ca/owa/projection.aspx 1/3

Reply all | Delete Junk | •••

Recruitment Materials	Recruitment Telephone Script	2020/09/11
Recruitment Materials	Study Information Letter	2020/09/11
Other Document	Study Eligibility Form	2020/10/22
Consent Form	Clean Revised Mature Minor Consent Form	2020/10/23
Consent Form	clean - parent informed consent form	2020/10/23

Documents Reviewed & Acknowledged:

Document Name	Comments	Version Date
Investigator Response	Itemized response letter - October 27, 2020	2020/10/27
Investigator Response	Itemized Response Letter - October 2020	2020/10/25

This is to notify you that the Children's Hospital of Eastern Ontario Research Ethics Board has granted approval to the above named research study on the date noted above. Your project was reviewed within the delegated stream, which is reserved for projects that involve no more than minimal risk to human participants.

Final approval is granted for the above noted study, with the understanding that the investigator agrees to comply with the following requirements:

1. The investigator must conduct the study in compliance with the protocol and any additional conditions set out by the Board.
2. The investigator is responsible for complying with all applicable guidelines and regulations regarding the ethical conduct of research with humans, as applicable to the research project.
3. Investigators must obtain annual renewal approval prior to the expiry date stated above.
4. The investigator must not implement any deviation from, or changes to, the protocol without the approval of the REB except where necessary to eliminate an immediate hazard to the research subject, or when the change involves only logistical or administrative aspects of the study (e.g., change of telephone number or research staff). As soon as possible, however, the implemented deviation or change, the reasons for it and, if appropriate, the proposed protocol amendment(s) should be submitted to the Board for review and approval.
5. The investigator must, prior to use, obtain approval from the Board for changes to the study documentation, e.g., changes to the informed consent letters, recruitment materials.
6. Investigators must obtain approval from the Board of French version(s) of the consent/assent form(s), unless a waiver has been granted. An interpreter should be offered to participants as required or at the request of the participant throughout the course of research.
7. For clinical drug or device trials, investigators must promptly report to the REB all adverse events that are both serious and unexpected (SAEs) or unexpected and untoward occurrences (including the loss or theft of study data and other such privacy breaches.
8. For SAE reports on clinical drug trials, the investigator must also comply with the hospital-wide Policy regarding, Procedures for Considering Medical Error in the Differential Diagnosis of Severe Adverse Events (SAE) Associated with the Drugs Administered in a Clinical Trial.
9. Investigators must promptly report to the REB any new information regarding the safety of research subjects (e.g., changes to the product monograph or investigator's brochure of drug trials). Where

Reply all | Delete Junk | •••

10. Investigators must notify the REB of any change in study status (closed to accrual, temporary, premature or permanent).
11. Investigators must submit a study closure event form at the conclusion of the study.

If you have any questions, pertaining to this letter, please contact the Research Ethics Board Office.

Regards,

Cécile Bensimon, MA, PhD
Chair, Research Ethics Board
Président, Comité d'éthique de la recherche

* The final approval date for initial delegated study applications approved with or without modifications will be the date the REB has determined that the conditions of approval have been satisfied.

** The expiry date of REB approval for initial study applications will be as follows:
- If the date of approval was **on or before** the 15th of the month, the expiry date will be the 15th of the month prior to the date of review and approval by the Chair and/or delegate *in the following year*,
- If the date of review and approval was **after** the 15th of the month, the expiry date will be the 15th of the month in which the date of review and approval by the REB *in the following year*.

University of Ottawa Research Ethics Board Approval

16/09/2021

Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

University of Ottawa
Office of Research Ethics and Integrity

CERTIFICAT D'APPROBATION ÉTHIQUE I CERTIFICATE OF ETHICS APPROVAL

Numéro du dossier / Ethics File Number	H-03-21-6711
Titre du projet / Project Title	Investigating the physical literacy of children with chronic medical conditions and changes due to the COVID-19 pandemic.
Type de projet / Project Type	Thèse de doctorat / Doctoral thesis
Statut du projet / Project Status	Approuvé / Approved
Date d'approbation (jj/mm/aaaa) / Approval Date (dd/mm/yyyy)	15/04/2021
Date d'expiration (jj/mm/aaaa) / Expiry Date (dd/mm/yyyy)	15/10/2021

Équipe de recherche / Research Team

Chercheur / Researcher	Affiliation	Role
Angelica BLAIS	École des sciences de l'activité physique / School of Human Kinetics	Chercheur Principal / Principal Investigator
Patricia LONGMUIR	Département de pédiatrie / Department of Pediatrics	Superviseur / Supervisor
Olubusola DEHINBO	École interdisciplinaire des sciences de la santé / Interdisciplinary School of Health Sciences	Étudiant-chercheur / Student-researcher
Javier PORRAS GIL	École des sciences de l'activité physique / School of Human Kinetics	Étudiant-chercheur / Student-researcher

Conditions spéciales ou commentaires / Special conditions or comments

CHEO REB # 20/108X

550, rue Cumberland, pièce 154
Ottawa (Ontario) K1N 6N5 Canada

550 Cumberland Street, Room 154
Ottawa, Ontario K1N 6N5 Canada

613-562-5387 • 613-562-5338 • ethique@uOttawa.ca / ethics@uOttawa.ca
www.recherche.uottawa.ca/deontologie I www.recherche.uottawa.ca/ethics

16/09/2021

Université d'Ottawa

Bureau d'éthique et d'intégrité de la recherche

University of Ottawa

Office of Research Ethics and Integrity

Le Comité d'éthique de la recherche (CÉR) de l'Université d'Ottawa, opérant conformément à l'*Énoncé de politique des Trois conseils* (2014) et toutes autres lois et tous règlements applicables, a examiné et approuvé la demande d'éthique du projet de recherche ci-nommé.

L'approbation est valide pour la durée indiquée plus haut et est sujette aux conditions énumérées dans la section intitulée "Conditions Spéciales ou Commentaires". Le formulaire « Renouvellement ou Fermeture de Projet » doit être complété quatre semaines avant la date d'échéance indiquée ci-haut afin de demander un renouvellement de cette approbation éthique ou afin de fermer le dossier.

Toutes modifications apportées au projet doivent être approuvées par le CÉR avant leur mise en place, sauf si le participant doit être retiré en raison d'un danger immédiat ou s'il s'agit d'un changement ayant trait à des éléments administratifs ou logistiques du projet. Les chercheurs doivent aviser le CÉR dans les plus brefs délais de tout changement pouvant augmenter le niveau de risque aux participants ou pouvant affecter considérablement le déroulement du projet, rapporter tout évènement imprévu ou indésirable et soumettre toute nouvelle information pouvant nuire à la conduite du projet ou à la sécurité des participants.

The University of Ottawa Research Ethics Board, which operates in accordance with the *Tri-Council Policy Statement* (2014) and other applicable laws and regulations, has examined and approved the ethics application for the above-named research project.

Ethics approval is valid for the period indicated above and is subject to the conditions listed in the section entitled "Special Conditions or Comments". The "Renewal/Project Closure" form must be completedfour weeks before the above-referenced expiry date to request a renewal of this ethics approval or closure of the file.

Any changes made to the project must be approved by the REB before being implemented, except when necessary to remove participants from immediate endangerment or when the modification(s) only pertain to administrative or logistical components of the project. Investigators must also promptly alert the REB of any changes that increase the risk to participant(s), any changes that considerably affect the conduct of the project, all unanticipated and harmful events that occur, and new information that may negatively affect the conduct of the project or the safety of the participant(s).

Catherine PAQUET
Directeur / Director
Pour/For **Daniel LAGAREC** Président(e) du/ Chair of the **Comité d'éthique de la recherche en sciences de la santé et sciences / Health Sciences and Sciences Research Ethics Board**

550, rue Cumberland, pièce 154 550 Cumberland Street, Room 154
Ottawa (Ontario) K1N 6N5 Canada Ottawa, Ontario K1N 6N5 Canada

613-562-5387 • 613-562-5338 • ethique@uOttawa.ca / ethics@uOttawa.ca
www.recherche.uottawa.ca/deontologie I www.recherche.uottawa.ca/ethics

Appendix C: Semi-Structured Interview Guides

If physical literacy scores were in the low (bottom 25%) or high (top 25%) quartiles:

Icebreaker: Do you have a favourite game that you like to play with family or friends?

Question #1: When I say the words "physical activity", what do you think that means?

- *What does that mean for you? Can you draw an example?*
- *How do you think physical activity is different from other activities, like watching a movie or reading a book?*
- *Do you think that physical activity is different from exercise? If yes, why? If no, why not?*
- *What about sport? How is that different from physical activity or exercise?*

Question #2: Do you like physical activity? What about sports?

- ***If yes**, why? What about physical activity do you like the most?*
- ***If no**, why not? What about physical activity do you not like?*

Question #3: Has anyone ever told you how much physical activity children should do each day?

- *If so, what did they tell you?*
- *If not, how much physical activity do you think children should do each day?*
- *Do you think that you should do that much physical activity?*

Question #4: What types of physical activity did you do before COVID19 and what types of physical activity do you do now?

- *Do you remember why you started [activities]? Why do you do them now?*
- *What do you like about those activities?*
- *Are you good at those activities?*

Question #5: Do you remember how you felt when you first learned [activities]?

- *Can you draw a face to show what you were feeling?*
- *Right now, do you think it's easy or hard to do those activities? Why?*

Question #6: Do you feel motivated to do [activities]?

- *Why? Why not?*

Question #7: Is there any physical activity that you do or have tried, but don't like?

- *If yes, why? What don't you like about it?*
- *What about any sports? Or gym class?*
- *Is there anything about the activities you do now that you don't like?*

Question #8: Is there any physical activity that you haven't tried, but would like to?

- *Is there anything that your friends do that you would like to try?*
- ***If yes**, why haven't you tried?*
- ***If yes**, What makes you think you will like it?*

Question #9 (or 10, see below): Some kids that go to CHEO have told me that they feel nervous about doing physical activity. Is there anything that you might say to them?

- *Do you sometimes feel this way?*

If enrolled and interviewed **before** June 21, 2022:

Question #9: If you could design a sports club or class, what would it look like?

- *If this program was just for kids like you, what would you want to learn? What would you do? What would the teachers/coaches be like?*

If enrolled **after** June 21, 2022, *or* had not previously participated in an interview, participants were invited to participate in a separate interview, which expanded on what children with CMCs would like to experience in a multi-sport program.

Introduction: Thank you so much for meeting with me again for another interview. We are doing this interview because we are trying to make a sport/physical activity program for kids like you who go to CHEO. We're calling it the "I Can Play Anything" program. Before we start the program, we want to know what kinds of things would be important for kids like you. The questions I'm going to ask today are for you to share your ideas, whether they are big or small, so that we can make sure the "I Can Play Anything" program is fun but also helpful.

Question #1: What would you want to learn in the program? Or play in the program if there's some that you've already learned?

- *What types of skills?*
- *Why would you like to learn that/those game(s)?*
- *How often should we play those games?*
- *What if we had two options available at the same time?*

Question #2: What would make everyone want to participate?

- *Would that work for you?*
- *What helps keep you motivated in gym class? In an after-school club?*

Question #3: We were thinking of changing the games or sports every two weeks. Do you think that's a good idea?

- *If yes, why?*
- *If no, how often do you think the sports/activities should change?*

Question #4: What would the coaches be like?

- *How can the coaches help everyone improve their skills?*
- *How can the coaches help everyone have fun?*
- *Have you ever had a favourite coach or gym teacher? What did they do that made them your favourite?*

Question #5: What would be important for the coaches of the program to know?

- *Since all the kids will be from CHEO, is there something specific about their medical conditions that coaches should know?*

Question #6: The "I Can Play Anything" program will have 5 sections: a warm-up, an individual skill, an obstacle course, a partner skill, and a competitive game.

- *What do you think about these sections? Why?*

[using visual below] From "not much" to "a lot", how much time do you think we should spend on each section?

- *Did you choose the _____ section as the most time because you think it's the most important? Why?*

Question #7: Is there anything else that we should consider for the "I Can Play Anything" program?

Appendix D: Deductive Coding Framework

List of All Possible Codes Derived from Whitehead's (2010) Conceptualisation of Physical Literacy.

Cognitive Codes	Affective Codes	Physical Codes
appreciation of skill development	willingness, eagerness	movement within specific context
sense of self/identity	persistence	simple movement capacity
self-awareness/self-consciousness	positive attitude	combined movement capacity
exercise as means of self-improvement	self-esteem	complex movement capacity
comparison to others	curiosity	innate movement
empathy/understanding towards others	engagement	refined movement
grasping essential principles of movement	sharing common interests/belongingness	specifying movement patterns
vocabulary	value of PA	progression of skills
defining a "successful" movement	independence	individual capability
performance evaluation	"joy of movement"	selecting activities to match strengths
understanding how to improve skills	desire to improve skills	selecting activities to match experiences/interests
value of exercise	enjoy challenge	overspecialization
self-evaluation	positive influence of previous experience	broad experience of activities
understanding 24-hr movement	intrinsic motivation	wide range of skills
attention to health	extrinsic motivation	life demands/expectations
understanding of PL interactions	self-respect	successful interaction w/ environment
appreciation of general movement	achievement feeling	intuitive actions
uncertainty	meaningful movement	understand how to respond
lack of self-awareness	emotions with movement	practice
exercise as fatigue	anticipating success vs. failure	"operative meaning"
non-active identity	self-affirming	imagination
self-consciousness	body image	movement modification

difficult to illustrate/define movement	lack of willingness	opportunities for action
limited vocabulary	lack of persistence	"intelligent action"
"successful" movement isn't the same as others	lack of confidence	"reading the game"
not understanding how to improve skills	negative attitude	conscious attention to movement
not all PA is valuable	low self-esteem	exercise is not innate
evaluation from others	boredom	difficult to learn movement
prioritizing sedentary behaviours	lack of engagement	unspecified movement patterns
attention to weight	lack of belongingness	avoiding activities that are difficult
not understanding 24-hr movement	embarrassment	avoiding activities that don't align with interests
lack of appreciation for skill development	self-doubt / prefer individual activity	narrow experience of activities
	dislike PA	only necessary skills
	doesn't enjoy challenge	difficult to interact w/ environment
	negative influence of previous experience	actions are learned
	inconsistent motivation	does not understand how to respond
	losing feeling	lack of practice
	unmeaningful movement	rules/structure interfere
	validation from others	games are unmodifiable
	indifference to PA	not enough time for action
		lack of intelligent action
		lack of control over movement

Appendix E: Results of Sensitivity Analyses (Articles 1 and 2)

Table 1. *Sensitivity Analyses including and excluding non-binary (NB) participants in Article 1.*

	Δ mean	**F-value**	**P-value**	**η^2**
Total Score				
Including NB	7.99	8.91	.004	.081
Excluding NB	7.00	8.76	.004	.081
Affective Domain				
Including NB	1.03	1.24	.268	.012
Excluding NB	0.77	.832	.364	.008
Physical Domain				
Including NB	3.36	9.43	.003	.086
Excluding NB	3.05	9.16	.003	.085
Cognitive Domain				
Including NB	0.24	.208	.649	.002
Excluding NB	0.05	.120	.729	.001
Behavioural Domain				
Including NB	3.53	4.68	.033	.048
Excluding NB	3.96	5.16	.026	.054
Motor Skill (CAMSA)				
Including NB	3.37	10.74	.001	.100
Excluding NB	3.47	10.11	.002	.096
Daily Step Counts				
Including NB	1717	5.45	.022	.060
Excluding NB	2006	6.15	.015	.068

Table 2. Sensitivity Analyses including and excluding non-binary (NB) participants in Article 2.

	Factors included in model	F-value	P-value	η^2
Total Score				
Including NB	Season	2.09	.107	.065
	Clinic	2.58	.043	.103
	Gender	4.64	.034	.049
Excluding NB	Season	2.13	.102	.068
	Clinic	2.61	.041	.106
	Gender	4.64	.034	.050
Affective Domain				
Including NB	Season*Clinic	2.22	.009	.347
	Age	1.38	.248	.069
	Gender	5.79	.019	.072
Excluding NB	Season*Clinic	2.12	.013	.343
	Age	1.49	.215	.075
	Gender	5.44	.022	.069
Physical Domain				
Including NB	Age	2.29	.066	.094
	Season	3.32	.023	.102
	Gender	3.99	.049**	.043
Excluding NB	Age	2.38	.057	.100
	Season	3.43	.021	.107
	Gender	3.82	.054**	.043

Cognitive Domain

Including NB	Season	4.93	.003	.143
	Age	5.28	.000	.192
	Gender	2.80	.098	.030
Excluding NB	Season	4.94	.003	.146
	Age	5.30	.000	.196
	Gender	2.60	.111	.029
Behavioural Domain				
Including NB	Age	3.00	.023	.130
Excluding NB	Age	3.09	.020	.135

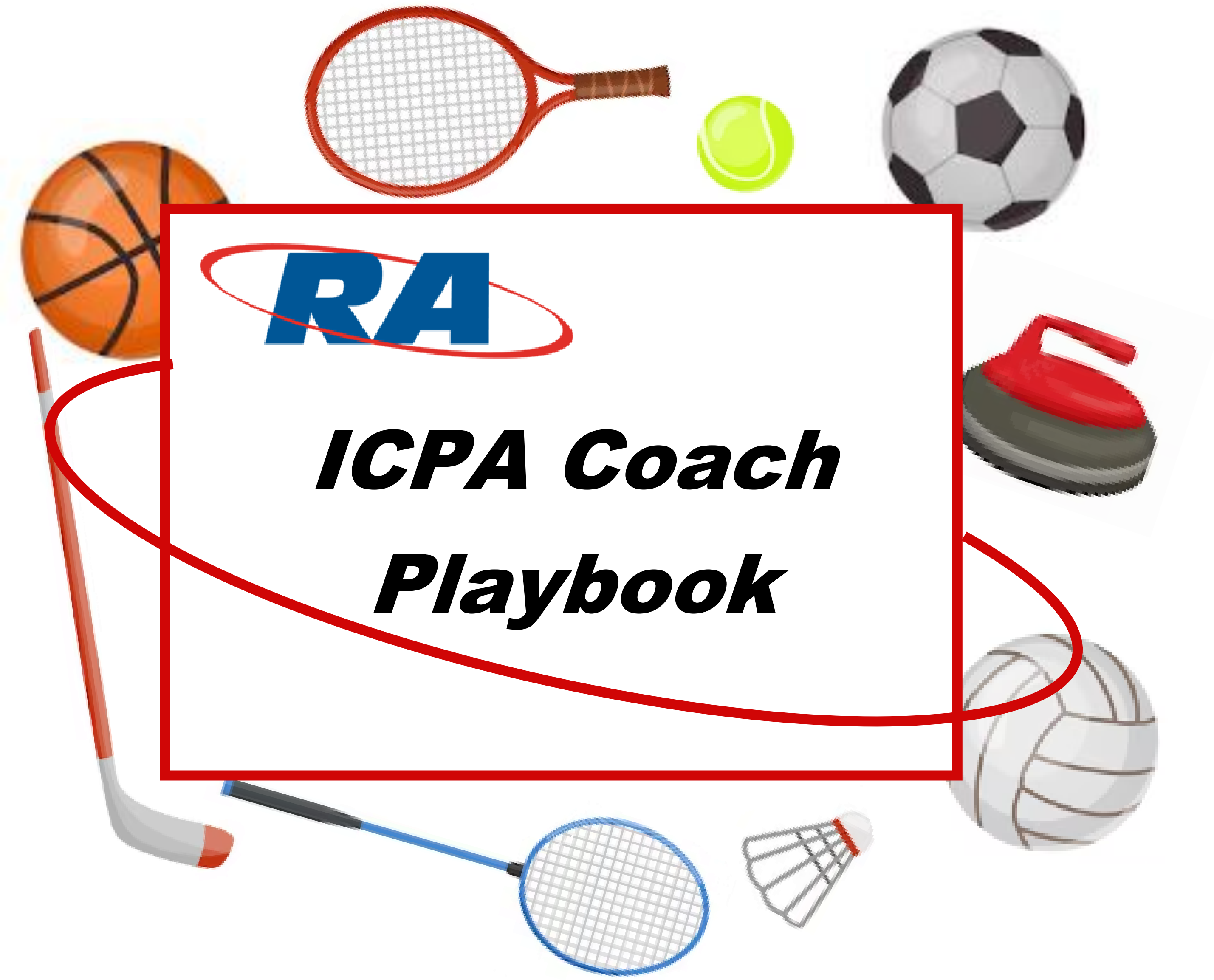
Note: ** Indicates a change in level of significance that would influence the interpretation of results.

Appendix F: "I Can Play Anything" Physical Literacy-Based Design and Delivery

*It should be noted that per the monist philosophy that informs the concept of physical literacy (Whitehead, 2010), while one domain may be *predominant* in any component of the program, all domains are still influencing the lived embodiment.

ICPA Design Component	ICPA Delivery	Physical Literacy Domain(s)*
Warm-Up	The instructor engages all participants as a group in the warmup by being energetic, welcoming, enthusiastic, and encouraging	Affective
	The warm-up is appropriate for the sport/activity	Physical
	There is an educational component to the warm-up and/or fitness-specific terminology is consistently used	Cognitive
Independent Skill/Goal	All levels of variation are described and demonstrated	Cognitive
	Participants receive individual, skill specific feedback that is constructive and appropriate	Physical & Affective
	Progressions are encouraged where appropriate	Affective & Physical
Obstacle Course	All skills and variations are described and demonstrated	Cognitive
	Coaches provide consistent praise for participant effort and improvements	Affective
	The course contains movement skills that are relevant and transferable to the sport of that lesson, as well as appropriate for the developmental level of participants	Physical & Cognitive
Cooperative Skill	Participants are appropriately paired/grouped based on skill level	Affective & Physical
	The importance of collaboration to achieve a common goal is emphasised	Affective & Cognitive
	Coaches clearly explain what needs to be done at each level, as well as possible variations	Physical & Cognitive
	Participant effort is emphasised over points gained	Affective
	Constructive and appropriate feedback is given	Physical & Cognitive
Competitive Game	Groups and teams are evenly distributed by skill level	Affective
	Variations are provided where appropriate	Physical
	Key rules of the sport (at least 1 to 3) are emphasised during the game, as well as potential strategies	Cognitive
	Consistent encouragement is delivered to participants	Affective
Cool-Down Activity	Participants have options in how they want to cool-down/stretch	Cognitive & Physical
	Positive feedback about the group's progression throughout the lesson is delivered	Affective
	Coaches deliver a "re-cap" of which skills were worked on in the lesson and how they apply to the sport.	Cognitive

Appendix G: "I Can Play Anything" Coach Training Manual



ICPA Coach Playbook

Prepared in collaboration with the

CHEO RESEARCH INSTITUTE
INSTITUT DE RECHERCHE

Index

About this Document

This resource was created through a research partnership between the Children's Hospital of Eastern Ontario Research Institute and the RA Centre in Ottawa, Ontario. This document is meant to guide coaches and volunteers as they deliver the "I Can Play Anything" program to children with various lived experiences.

Authors:
Angelica Blais, MSc, PhD(c)
Kyleigh Forth, BSc
Patricia E. Longmuir, PhD, RKin

What is Physical Literacy?

"Physical literacy is the motivation, confidence, physical competence, knowledge, and understanding to value and take responsibility for engagement in physical activities for life."

– The International Physical Literacy Association, May 2014

Physical literacy has 4 main components:

- **Affective**: Motivation and confidence to participate in general physical activities.
- **Physical**: Physical competence to develop movement skills and patterns, as well as to participate in a wide range of physical activities and settings.
- **Cognitive**: Knowledge and understanding of how to identify and express the essential qualities that influence movement, health benefits and safety when participating in physical activity.
- **Behavioural**: Taking personal responsibility for physical literacy by freely choosing to be active on a regular basis.

What is the "I-Can-Play-Anything" (ICPA) program?

ICPA → An inclusive, multi-sport program at the RA Centre which aims to promote the physical literacy of children by teaching them skills and strategies relevant to a wide variety of sports.

NOTE: ICPA isn't exclusively for children who lack physical literacy. It aims meet and support children anywhere in their physical literacy journey (beginner or advanced)

Variations made to the activities can be done in such a way that increases difficulty for more advanced players, or decreases difficulty for beginners.

Why a "Multi-sport" Program?

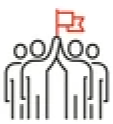
Children can discover personal interests and strengths by sampling different sports and applying movement skills to new contexts. Children who participate in multi-sport are…

a) Provided the opportunity to participate and experience all types of sports
b) Building a wide base of fundamental movement skills with a physical literacy focus
c) Enhancing their physical literacy skills, motivation and knowledge of physical activity
d) Exposed to the primary rules and skills associated with variety of sports to help them become **confident** and develop **competency**.

General Coaching Guidelines

"SAAFE" Teaching Principles

S → Supportive: create an environment where the instructor is facilitative (not demanding)

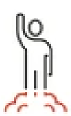


- Skill-specific feedback
- Consistent praise for effort and improvement
- Demonstrate empathy towards participants who are frustrated
- Support feelings of autonomy, competence and social connection
- Demonstrate empathy toward students who appear frustrated

A → Active: high levels of physical activity and minimal transition time

- Games with "elimination" should have an active component to keep eliminated kids moving/involved
- Include high intensity "burst" of energy between transitions
- Reduce transitions by setting up while participants are being active

A → Autonomous: allow participants to make choices about what they are doing



- Opportunities for choice/selection
- Free play at start of sessions
- Involve participants in creating rules for creative games
- Provide meaningful explanations for different activities

F→ Fair: providing all students with opportunity to experience success in the sport

- Should be evenly matched by skill level during group activities
- Modify activities to maximize success
- Encourage self-compassion instead of peer compassion
- De-emphasize competition
- Regularly change teams/partners

E → Enjoyable

- Activities that help children exhibit choice, feel competent and interact with others
- Sessions that involve a wide variety of tasks/activities
- Do not use exercise as punishment

"SAAFE" Framework by Lubans and colleagues (2017)

Making Sport Inclusive

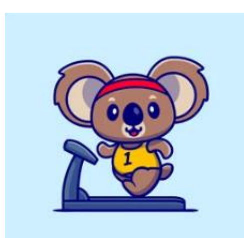
Consider the needs, likes, dislikes, sensitivities and abilities of the participants.

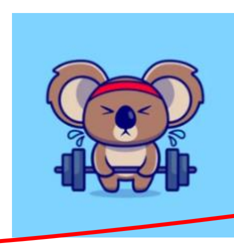
What to ask (parents & participants)→ Ask for suggestions and discuss strategies to improve the experience.

- Ask what specific skills they would like to focus on (i.e. focus, attention, personal space, making friends, sportsmanship, etc.).
- Ask about the level of support needed.

Applying the "TREE" Method for Inclusive Physical Activity

Teaching Method: **The use of different communication and delivery strategies**	**Rules & Regulation:** **Simplify or modify rules, later to be reintroduced as skill levels are developed**	**Equipment:** **Vary the equipment used: sizes, shapes, colours, weights, etc.**	**Environment:** **Modify the "play area": length, height, zones, etc.**
• Present directions using a multisensory approach (combination of visual and verbal auditory) to facilitate group learning. • Teach in a consistent way and allow practice time. • Be aware of the speed, clarity, and volume of voice (limit the number of words used)	• Rules can be modified mid-game if needed. • Emphasize safety. • Give plenty of warning before changing/ending an activity (transitions can be difficult for children)	• Consider adapting the movements to make equipment more accessible. • Use colour coordination for games/skills.	• Create a designated "break" space where children can direct themselves any time they need to rest. • Decrease audio distractions or warn children of loud noises beforehand. • Ask for consent before making physical contact with children.




ICPA Lesson Framework

Start the first 5 minutes of every session with free-play. Have a variety of equipment (hula hoops, jump rope, balls, Frisbees, etc.) available for participants to play with before the session starts.

Type of activity	Warm-up	Individual Skill	Obstacle Course	Cooperative skill (or Individual w/team goal)	Competitive game	Cool down / stretch
Approximate duration	10min	2min of instruction + 8min practice	5-10min	15min	10min	5min
	Dynamic stretches	Skills should have options with variations (avoid labelling levels, tiers, difficulties, etc. as to avoid *hurting feelings*)	Begin assembly while children are working on skill #1 (if possible)	As a pair or small team they are trying to achieve a common goal (ex: a certain number of points or progression of instructed skill).	Group according to skill level and known preferences of participants. If you have the space, include options for multiple games with different energy levels (high energy, low energy games)	Introduce a cool-down game or ask the kids to choose something.
	Sport-specific conditioning	Introduce variations during the instructions so participants know all their options.	Incorporate fundamental movement skills with a (or multiple) sport-specific movement(s) or themes	Each individual is to be given the opportunity to perform the skill and contribute to the group's goal.	Modify the game based on observations made in the rest of the session about participant skill level (ex: bigger ball, smaller court, etc.)	This is a good opportunity to ask the participants for feedback about that days' session (the activities, personal successes, etc.) to inform future sessions
	Include an instructional component (learning about positions of the field/court, anatomical names, etc.)	Make progressions accessible (children should be able to complete 2 "levels")	Can be team-based, partner-based, circuit format, etc.	Results are not compared to those of other teams (this is not a competition amongst teams). Coach instruction should emphasize working together for the shared goal.	Try not to highlight winners over losers. If you do establish a winning team, highlight strengths of the opposing team, too.	Include static stretches.
		Give specific feedback at an individual level (both corrective and reaffirming feedback)	Coaches should emphasize positive feedback so everyone is a part of the activity.	For kids who want competition, make the goal to beat their previous group results/points.	Explain rules that work on respect for others and/or ethics of that particular sport (i.e. no pushing when guarding in basketball).	

Type of activity	Warm-up	Individual Skill	Obstacle Course	Cooperative skill (or Individual w/team goal)	Competitive game	Cool down / stretch
Approximate duration	10min	2min of instruction + 8min practice	5-10min	15min	10min	5min
		Variations should be introduced in the individual skill and encouraged throughout the rest of the session if needed. • Different equipment (ball/bigger ball, different racket sizes, etc.) • Changes to the distance from and/or size of the target • Change game goal (ex: number of points needed) *See the "General Variations" section for more suggestions.*	Avoid stationary "wait-times". If kids are not going through the obstacle course keep them engaged→ *encourage their peers, sideline movement (ex: yoga pose, balance a ball, etc.), etc.*	Pair participants together according to skill level, as much as possible (teams can be rearranged if needed)	Not everyone wants to engage in competition in the same ways (direct/indirect), in this case create different roles for them so that they can still actively engage or modify the rules to be more inclusive. • Could be due to lack of confidence, intimidating opponents, lack of skill proficiency, tiredness, etc. • *Examples*: Scorekeeper, goalie, change ball size, rules that every team member, must touch the ball, etc. *See the "ICPA program delivery: possible scenarios and how to respond" section*	
		When introducing progressions/modifications avoid language with negative connotations (i.e. "if you can't/unable/etc.").	Fundamental skills can be reflected on afterwards ("jumping in this course can be transferred because XYZ sports require this skill")	Pairs/groups can modify their task/goal (can change mid-practice) to better fit their skill level	During the game, give quick suggestions and feedback on possible strategies/plays that anyone can use	
		Use words like "If you want" or "you can try it like this"	Sport specific skills are explained and demonstrated before beginning.	Incorporate ethical rules when needed (i.e. no pushing)		

Feedback → How and When to Give It

Feedback serves as a tool to validate participants' experiences and help develop their skills. To support that development, we must be mindful about when we choose to give feedback, how we deliver our feedback and what we say.

***Consider the participants' self-perception* (especially in regards to the skills of the group)**

- ➔ Why we give feedback: To encourage a child's continued learning/development.
  - Being harsh, critical, or offensive does not effectively contribute to this goal.
  - Validating or encouraging the participant's self-perception in active spaces will help motivate them to continue trying.

Remember the skill level of the child you are speaking to. Feedback should be based on the appropriate expectations and skill level of each child.

Types of Feedback

Positive

- ➔ Praise. Highlights the success of the participant. Amplifies the results.
  - Helps participants believe in their success
  - Applied to "good" performance
  - *"Great shot!"*

Constructive

- ➔ Encouraging. Linking the correction to the expected result.
  - *Observation. Correction. Expected outcome.*
  - Applied to "poor" performance, without the impact of negative feedback
  - *"I like how you flicked your wrist when throwing the Frisbee. Next time point your hand towards your target and the Frisbee will go in that direction."*

Negative

- ➔ Critiques the performance of the participant without suggesting corrections.
  - Pits the coach against the participant
  - **NOT** to be used in ICPA
  - *"Don't throw the ball like that."*

When to give Feedback

- **Be timely**: It is easier to correct something that someone has been doing for 5 minutes, than it is to correct something that has been done for 30 minutes. (habits are hard to break)
    - If the feedback is applied, we could avoid a frustrated kid
    - If a kid is emotional (frustrated, upset, etc.) give them a moment to calm down before engaging in feedback (they will be more receptive to it this way)
- **Public vs Private:**
    - Individual feedback (especially constructive feedback) is better delivered in private, as to avoid hurting their confidence, drawing unwanted attention, or causing defensiveness and embarrassment.
    - Public feedback is great for when it is information or praise that could apply to a large part of the group.
        - Avoid using people's names in these instances
- **Follow up**: You give feedback in order to validate or improve performance. Make sure you circle back around to see if the feedback is being applied.
- **Progress**: Feedback can help a participant progress. If they look "stuck" consider the type of feedback that will help bring them to the "next level"
    - Be mindful of their skill level.
    - Keeping a kid's confidence is more important than succeeding at the task.

How to give feedback

- **Be authentic:** No matter what feedback you're delivering, it's important to be authentic.
    - Pickup on cues
- **Be specific:**
    - Be clear about what you're praising
    - Tell them how/what to do to improve or adjust the skill
- **Limit your focus:** Feedback should only address 1-2 issues at a time. Too much information could overwhelm the participant.
    - They may not retain all the information, or it could hurt their confidence.
- **Talk about positives:** When providing feedback starting with a positive statement will…
    - **a)** Put the person at ease
    - **b)** Allow them to "see" what success looks like and that they are capable of it
    - **c)** Keep them encouraged
- **Highlight individual progress:**
    - When in groups we tend to compare ourselves to others. This can be especially harmful for low confidence kids who are struggling at the skill.
    - Reminds kids that there are multiple forms of success. Keeps focus on themselves, and their ability to succeed.

TAKING BREAKS

Taking breaks is important for all kids, no matter what their skill level, endurance or physical ability is. It's your job to make sure that everybody gets the breaks that they need, so you will have to prompt for group breaks from time to time. At the beginning of the season talk to kids about why we take breaks: to recharge your body. Everyone has a different battery level, and it's not a competition to go the longest without a break. Remind kids that the coaches will also encourage breaks every session.

Why would a kid need a break?

- Weather
- Terrain
- High energy activity
- Emotional stimulation
- Medical reasons

How do we know when to give breaks?

- Lethargic or slower movements
- Irritability
- Decrease in performance
- Where applicable be knowledgeable/aware of the kids medical history and possible symptoms

Encourage unprompted breaks

- Have a dedicated break space
- By actively encouraging participants to take a break it will lower stigmatization
- Connect with kids while they're taking their break, and encourage them with positive feedback

General Variations Table

Here's some ideas for general adjustments you can make to your activities. This is not an extensive list, you may come up with other variations that work better for your program

- Some variations will be *modifications* and some will be *progressions*. Coaches should know the degree of difficulty with each variation and be able to apply them accordingly to each of their students.

Balls	Rackets *Racket choice can be based on:*	Play area	Targets	Distances
Smaller/bigger	Weight (heavier/lighter)	Smaller/bigger playing area (use other lines in the gym)	Size (smaller/larger)	Closer/farther to the target
Lighter/heavier	Shaft length	Type of surface (gym floor, turf, grass, playcourt, etc.)	Height of target (low/high)	
More/less bouncy	Surface area of head			

REMINDER!

We want to try and target FMS throughout the lesson plans

Fundamental Movement Skills (Canadian sport for life)

- Body Control: agility, balance, coordination (ABC), speed,.
- Locomotor: running, jumping, shuffling, skipping
- Object Control: sending, receiving, dribbling,.

ICPA program delivery:

Possible Scenarios and How to Respond

We want to emphasize making sport accessible to everyone! There are many reasons why an activity or skill may be difficult or inaccessible for someone. Remember that every skill/activity has possible variations. Consider the following reasons and the ways to respond:

- Variations being applied should be tailored to the individual child's preferences and personality. Not everyone wants to participate in the same way, but everyone can still be involved in the group activity.

Scenario 1 → *We are playing ultimate Frisbee. One of the kids has a sore ankle. They are allowed to participate, but can't run.*

Teaching point → Injury: injuries that do not put the child at risk can be worked around. Often injuries lead to a lack of mobility, limitation of movement, and other general physical restrictions.

- **Questions to ask yourself before responding to this scenario:**
  - Does the activity have a position or can you create an alternative task/position where the child doesn't have to put any strain on their injury?
  - How actively does this player want to participate in the game?

Response → *At first the coach thinks that the participant would be happy scorekeeping from the sidelines. However, this participant wants to be in the action of the game. The coach then decides to change the rules so that there's someone in the end zone ("goalkeeper") in our version of the game. This way she doesn't have to run around the field, but is still actively participating.*

Scenario 2* → *We are playing a game of basketball. We know that one of the kids has anxiety, and does not like participating in big group activities.

Teaching Point → Anxious/lack of confidence: not everyone is prepared to participate at the same level as the rest of the group. This shouldn't be reprimanded, instead we need to work with the participant to determine their level of comfort.

- **Strategies to incorporate and questions to ask yourself before responding to this scenario:**
  - What do they need? Ask them.
  - Check in with them frequently, but privately.
  - Give them choices
  - Would they want to participate away from the group (to the side/on a different court or with a coach 1-on-1)?
  - Keeping them engaged is most important. They don't have to actively be doing the skill to still be engaged in the activity. Consider other ways they can participate.

Response → Ask them what they need; give choices. Check in with them frequently, but privately. *Instead of making them sit on the sidelines, we ask them to be the scorekeeper to keep them engaged in the game.* Knowing this moving forwards in the program, find ways to promote that child's confidence, so that by the end of the sessions they progress their participation into a role that is more active. (Score-keeper to player)

Scenario 3* → *The kids are practicing an individual skill. They have a timed goal (ex: hit as many targets as you can in 3min). You notice that some of the kids are getting really tired and other kids are frustrated with them for not keeping up.

Teaching Point → Tired or Low Energy: not every participant will have the same energy levels or endurance throughout the session.

- **Strategies to incorporate and questions to ask yourself before responding to this scenario:**
  - If group numbers allow it, have multiple games running based on energy levels (high intensity vs low intensity games)
  - Encourage breaks!
  - Give options for variations to the sport that change the intensity or duration (ex: rounds of 3min instead of 5min)

- In group settings, pivot from group goals (ex: being able to meet a certain target and time as a collective), to the group working towards a target but individuals working towards their own goal (ex: individual time).

Response → *You decide to change the goal of the game: throw at the target 3 times (group goal), pick your pace (individual goal), see how many times you hit it. This way they still get to play the game without being rushed by time, thus letting them go at their own pace.*

Scenario 4 → *There are two groups playing a competitive game against each other. You notice that one team is getting upset. They don't like losing and are less interested in playing the game now.*

Teaching Point → Recreation vs competition: competition can be daunting for many people, and it isn't always what people seek in sports.

- **Strategies to incorporate before responding to this scenario:**
  - Give individual goals instead of group goals in sport
  - Have multiple games running, divide teams based on levels of competitiveness
  - There can be competition without scorekeeping

Response → *You decide to split up the group. The team that was losing is going to play a small game between themselves, without keeping score. The team that was winning will play a game while keeping score.*

Warm-up Activities

Here is a list of different Warm-up activities that can be used by the coaches. For Warm-ups consider if the group has played this sport before. If not, <u>using an activity that introduces the court and sport specific movements should be used.</u> When possible, Warm-ups should have an endurance and dynamic component. Here is a non-exhaustive list of activity ideas:

<table>
<tr>
<td>“Follow the Leader”
Play “follow the leader” from each end of the court: pick a new leader each time to run, skip, slide, lunge, high knees or a creative movement to the other side</td>
<td>Circle Stretches
In a circle, do the following stretches and introduce muscle groups for each (lower body):
Squats
Mountain climbers
Spiderman lunges
“superman” stretch (back)
Pulsing lunges</td>
<td>“Burpee Relay”
Everyone starts on their stomach in the “ready” position. On the whistle, have them get up and jump to high-5 the coach before going back down. Once they’ve completed one or two in a row, the next person starts and so on.</td>
</tr>
<tr>
<td>“Court Awareness”
Sport specific
The coach will start by pointing out key locations on the court (ex: basketball→ baseline, midline, midcourt line).

Coach will call out a line on the court for the kids to run to (coach can point if needed) and an exercise for participants to do while going there:
Jog
Butt kick
Arm circles (both directions)
High knees
Repeat multiple times</td>
<td>“Have you ever”
Start with participants running around the room/playing area at a steady pace.

The coach will direct which movements/stretches the participants will do by saying: “Have you ever…” and the participants will do 5 repetitions

For example: “have you ever done a jumping jack?” – kids would then have to stop where they are and do 5 jumping jacks.</td>
<td>“Coach Calls”
All participants start by touching one of the side walls. On the coach’s demand, they have to do one of the following to get to the other wall as quickly as possible:
Running
Crawling (knees stay up. off the ground)
High knees
Lunges
Sliding/shuffling
Silly walk (i.e. cross over steps)</td>
</tr>
</table>

“Tour de Court”	“Simon Says”	“Mr. Wolf”
1 – 2 laps around the court, with various movements along the sidelines (i.e. skipping, sliding, sprinting, etc).	Start at “end line” and play a game of Simon says. Each round have the kids suggest a movement (ie lunge, squats, arm circles, etc) as they approach ‘Simon’ If they fail to do as “Simon says” they become Simon (or the coach can remain Simon the whole time)	Play “what time is it mr. wolf?” starting in the end zone. Pick a new movement for them to do each round (i.e., skip, slides, lunges, high knees or a silly walk!) as they approach ‘Mr. Wolf’
“Athletic Stance” ***Sport Specific*** Introduce the “athletic stance” to participants. Show them how to jump from this stance with their arms pushing up away from them, and shuffle side to side. On the coach’s command, players have to either shuffle left, right, forwards or backwards maintaining a low, athletic position. Once the coach yells “jump”, players have to jump as quickly as they can. After doing this for a few rounds and correcting players on their athletic stance, can do some stretches for their legs and arms.	**“Octopus”** Play “octopus”. Kids start at one side of the court and have to run to the other side without being tagged by the person in the center of the court who is “it”. This player can move around. When players are tagged, they have to stay standing (not sitting) where they were tagged (allow them pivot or take one step from their spot) The round is repeated and the remaining kids have to avoid being tagged by every octopus in the middle.	**“Rock the boat”** ***Sport specific*** Start at the “baseline” and pretend the court is a boat; participants have to run, skip, slide, lunge and balance on the plank along the different edges of the boat. Use the sport relevant court terminology to direct participants to different areas. Integrate activities with more arm range of motion and/or mobility and footwork and use fitness specific terminology.

Cool-down Activities

Here is a list of some fun cool-down activities. Feel free to use your own if you have other activities in mind!

"Memory game" Coach shows a stretch to the group, and they have to repeat it back. Keep adding stretches to the sequence and have the kids remember the order. Explain what muscles are being stretched when a new movement is introduced. Don't rush through the movements, make sure they hold the stretch for the appropriate amount of time.	**"Bean bag freeze"** Give each student a bean bag to balance. Coaches will instruct where the bean bag needs to balance (i.e. head, shoulder, elbow, knee), while kids travel around space; when the whistle blows, the kids have to "freeze" keeping the bean bag in place.	**"Night at the museum"** One person is the "security guard" and all other players are the statues. Statues are holding a stretch and trying to change stretches when the security guard isn't looking. If the security guard catches them moving, they become the guard. Start with a coach as the security guard. Give example stretches that would be most beneficial following today's lesson plan.
"Electricity" Divide into 2 equal teams. Each team will make a shoulder to shoulder line facing the opposing team while holding hands. At one end of the line you will have team 1 holding the hand of a member of team 2 and at the other end of the line no one will be holding hands. There will be an object of your choosing at the end of the line where team 1 and 2 are not holding hands. A coach will be positioned at the end of the line where both teams are holding hands. The object of the game is to squeeze the hands of both teams who will then squeeze the hand of the person next to them until they reach the end of their line. Once the current reaches the end of	**"Clap it and catch it"** Standing in a circle, have the kids underhand a small ball to each other. Before being caught, whoever is receiving the ball must clap and then catch. If the ball drops, then kids have to sit down (but are still in play). If they clap & catch while seated, they can stand back up.	**"Freeze dance"** Every time the music stops, participants have to freeze. If they're the last to freeze they have to suggest the next dance move.

the line, they are to grab the object placed at the end of the line. Rotate players each round. **Variation:** Use a soft ball (ex: foam) and pass it along the line as the "current". The goal is to make it to the last person before the other team		
"Broken Telephone" 2 ways to play: either stretching in circle OR traveling to different corners of the court to deliver message. Same rules as traditional broken telephone, but with active or stretching component added. Stand in a circle, one person starts with the ball and bounces it to someone else. The person who catches the ball has to suggest an stretch, or a muscle group/area to stretch (coach or other students can help identify a stretch that corresponds)	**"A Bone to Pick"** Ask students to pick a muscle on their body that they would like to stretch. (Demonstrate one example first – i.e. back of the legs would be a toe touch, hamstring stretch). Demonstrate the stretch for that muscle group and hold 20 secs. Can also ask children to demonstrate a stretch and ask them to identify the muscle group being stretched.	**"X Marks the Spot"** Every student places an item (disc, bean bag, hoop, etc.) on the floor. This marks their spot. When the coach says, everyone needs to find a new marker to stand "on". Last person to find a marker has to decide the stretch.

Lesson Plans included in the ICPA Curriculum

1. Badminton
2. Basketball
3. Curling
4. Pickleball
5. Soccer
6. Squash
7. Ultimate Frisbee
8. Volleyball

Resources

- **Playsport (skills/games/activity database):** For more game ideas visit https://www.playsport.net/
- **Playtool (physical literacy screening tests)**: To access the screening tests visit https://physicalliteracy.ca/portfolio_category/physical-literacy-assessment-for-youth-play/
- **TREE Method**: https://www.sportaus.gov.au/sports_ability/using_tree
- **Types of feedback**:
    - https://acecoach.com/feedback-series-part-6-positive-feedback/#:~:text=Positive%20feedback%20is%20a%20communication,when%20a%20player%20performs%20correctly.
    - https://www.mindtools.com/a18a0wu/giving-feedback
- **Physical Literacy:** https://physicalliteracy.ca/physical-literacy/

Appendix H: "I Can Play Anything" Example Lesson Plan

Ultimate Frisbee

Equipment Required
- Multipurpose balls - Bean bags - Frisbees/discs - Hula hoops - Pylons/wose markers - Tape - Pinnies

Lesson 1: Backhand throw & Wrist snaps

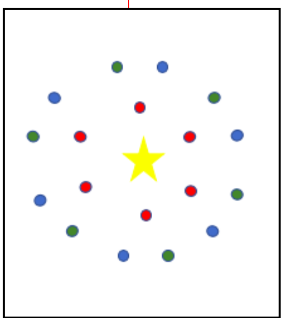
Activity	Skill	Time	Description & Progression
Free Play	N/A	First 5 mins of class	Have multi-purpose balls & hoops available
Warm Up	Endurance	5 mins	
Skill #1: ***Backhand Throw & Wrist Snap***	*Individual Skill*	2 mins instruction + 8-10 mins pratice	***Demonstrate how to execute a backhand toss:*** Hold the disc: thumb on top, index finger along the side edge, three fingers grasp the bottom edge. 1. Point the shoulder of your throwing hand towards where you want your Frisbee to go 2. With the same foot as your dominant hand, take a step to the side making sure your toes are facing the direction of your target. 3. Bend your elbow, bringing the disc to your abdomen (or wherever is most comfortable) and keeping your elbow level with the Frisbee. Your arm should be in an "L" shape 4. Keep the disc as flat as possible when you release *5.* Quickly release by extending your elbow and *flicking your wrist** 6. After the Frisbee is released, your fingers should be pointed towards the target

			Instruct participants to practice a few times on the line without a disc, emphasizing a flick of the wrist (pretend like they're "casting a spell")* **<u>Goal: To hit the target with your disc</u> **Level 1 =** hitting the wall **Level 2 =** hitting a large, high target (i.e. taping a hula hoop to the wall) **Level 3 =** hitting a lower target (i.e. pylons in a "goal" orientation against the wall. ***<u>Safety</u>: should always be throwing their discs in the same direction! Try to all keep them facing a wall when throwing, with at least 2m between participants.*** ***Variations:*** - Instead of manipulating a disc, try completing the toss with a bean bag instead. - Stand at different distances to the target. - Step immediately before toss (making one smooth motion forward)
Obstacle Course	*Motor Skill & Agility*	2 min instructions + 5 min movement	**Course Suggestions:** - Balance Frisbee on head - Quick steps through hula hoops - Throw bean bags at target - Shuffle from one line to another - End: take Frisbee off head and throw it at target (or to next person in the relay) *Find a way to keep kids engaged while on sidelines. Balancing Frisbee on head on sidelines?*
Skill #2 **How to catch a Frisbee**	*Cooperative Skill*	2 min of instructions + 5 mins of practice	Explain the most common types of catches in Frisbee: - Pancake (alligator) catch - Two handed rim catch (used when the disc is low near the ankles, or high above your head)

			Have kids paired up and lightly toss the Frisbee to one another. The focus is on catching the Frisbee. Issue a team goal to make as many consecutive catches as possible. If kids have gotten a hang of doing this stationary, have the partner who doesn't have the Frisbee move a couple steps in a different direction before the Frisbee is tossed to them. Continue doing this while moving around the gym. **Variations** - Vary the distance between kids (closer/farther) - Focus on using only one catching method.
Skill #3: "Passing & Receiving"	*Competitive Game*	2 min of instruction + 10 mins of play	*Pair participants (one high with one low skill)***.** *Each pair gets one bean bag.* **Activity goal:** Introduce a structure at the beginning that the kids have to replicate using different objects, proceed with the race with the objective being the first team to replicate the structure, wins. Starting in the end zone, one partner has to toss the bean bag to the other. Once that toss has been received (even if it isn't caught), the partner that threw the bean bag can run further along the field before the next pass. The player who received the pass cannot move until they complete the next pass…. *Why?* Tell participants this is one of the main rules of the game. **Once a team make it to the end zone they collect an item for the structure. They continue until all items are collected.** **<u>Variations</u>**: - Use different objects as the projectile: Frisbee, woose marker, bean bag, etc.

			- Complete a specified number of passes before the end zone.
Cooldown Activity	*Cool-down*	1 min instruction + 4 min of play	

Lesson 2: Moving around the field/court

Activity	Skill	Time	Description & Progression
Free Play	N/A	First 5 mins of class	Have multi-purpose balls & hoops available
Warm Up	Endurance + Dynamic Stretches	5 min	
Skill #1 **"Tip Tap Top"**	*Individual Skill :* Lateral movement on the field  *The star represents the coach, who is surrounded by the players in their own respective triangles* *If you don't have different coloured cones, that is OK.*	10 mins (2 min instruction + 8 of play)	Each participant is in the middle of three cones: a blue one to his left, a green one to his right and a red one in front of him **The coach is directing this skill by saying either "tip, tap, or top". The goal is to do the action as fast as possible.** The blue one (back left) corresponds to ***tip.*** Participants use the "tip" of their finger following a lateral step to press this pylon on the coach's instruction. The green one (back right) corresponds to ***tap.*** Use the palm of their hand after doing a lateral step on coach's instruction. The red one is ***top***. Participants use a "fist bump" to touch this pylon after doing a lunge on the coach's instruction. ***Variations:*** - Make the individual playing area smaller. Give more time in between directions so that participants can rest after burst. - Just focus on touching the right cone, not the way it's touched - Give multiple directions at one time, and ask participants to remember the pattern (i.e. tap tip top).

			- Change the distance to the cones (closer/farther)
Obstacle course	*Motor Skill and Agility*	2 mins instruction + 5 mins movement	**Course Suggestion: Two person obstacle course⑦** Students are paired into groups of 2. After one partner completes a section of the course their partner throws the Frisbee (or bean bag to them). The partner who threw the bag goes through the course. And they continue to take turns and tossing the bean bag
Skill #2: **Disc Toss with a Partner**	*Cooperative Skill*	2 mins instruction + 10 mins practice	*Pair participants (**similar** skill levels). Each pair will get one pylon/marker and one disc. <u>Review backhand toss and catching from last week!</u>* Place the pylon approx. 3 steps in front of the goal line. One partner stands at the goal line while the other stands at the marker, facing each other. They must pass the disc back and forth successfully before moving the pylon 1 step back. Continue to see how far you can get as a pair. **Emphasize that they are not just working on aim, but power as well – they have to adjust appropriately in order to meet a shorter vs. longer target.** <u>**Variation**</u>*:* - Have partners both stand in front of the goal line – objective is to *both* make their disc cross the goal line before taking a step back together.
Skill #3: **"Ultimate Frisbee!"** *Taken from Playsport Games*	*Competitive Game*	2 mins instruction + 5 mins play	*Divide participants into 2 teams by skill level. Explain where the end zone is for each team and applicable rules.* **Goal =** to catch the disc in the other team's end zone to score a point ***NOT a contact sport. Encourage participants to communicate with their team members!**

			Once a participant catches a disc, they cannot move. They have 10 seconds to throw to another player on their team. ***Variations:*** - use a ball instead of a disc (if participants are not strong at throwing). - put additional balls and/or discs in play as necessary
Cooldown Activity	*Cool-down*	5 mins	

Lesson 3: Quick movements: In ultimate Frisbee you want to be able to move quickly. This lesson will work on moving around the field and passing the Frisbee 'quickly'. It isn't about having the quickest time, but doing things as efficiently as we can.

Activity	Skill	Time (approximate)	Description
Free-play	*n/a*	5min	Have an assortment of gym equipment available
Warm-up	*Warm-up*	5min	
Skill #1	*Individual Skill*	10min	Find a drill that practices moving quickly release of the Frisbee (ex: have multiple Frisbees lined up, and have a kid grab them one at a time and throw them towards the wall as quick as possible).
Obstacle Course	*Motor Skill + Agility*	5min	Use this obstacle course as an opportunity to practice multiple sport specific skills.
Skill #2	*Cooperative Skill*	10min	The focus of this skill should be on the individual to complete a task/goal, which counts towards a greater group goal. Find a game that works on moving around the court with a teammate. Consider how teammates should communicate during this drill (calling for the Frisbee "*mine*" or "I got it")
Skill #3	*Competitive Game*	10min	Play a game of ultimate Frisbee! Modify game rules as needed.
Cool Down	*Cool-down*	5min	

Lesson 4: Combination of skills ⑦ Work on as many skills as you can in this lesson plan! This plan is just a suggested outline as to what skills can be practiced in each section.

Activity	Skill	Time (approximate)	Description
Free-play	*n/a*	5min	Have an assortment of gym equipment available

Warm-up	*Warm-up*	5min	
Skill #1	*Individual*	10min	Find a drill that works on target practice.
Obstacle Course	*Motor Skill + Agility*	5min	Use this obstacle course as an opportunity to practice multiple sport specific skills.
Skill #2	*Cooperative Skill*	10min	The focus of this skill should be on the individual to complete a task/goal, which counts towards a greater group goal. Find a game that works on passing the Frisbee (catch and throw) with a teammate.
Skill #3	*Competitive Game*	10min	Play a game of Ultimate Frisbee! Modify game rules as needed.
Cool Down	*Cool-down*	5min	

Appendix I: Focus Group Comic Strip / Story Board Template (Article 3)

"A Day in the I Can Play Anything Program"….

Use either the story board (page 1) or the comic strip (page 2), to create a short story about the ICP program.

- Your story can be about yourself or a made up character. You **cannot** include another kid from the class in your story, but you **can** include the leaders.
- We want you to include activities that you liked, activities that you didn't like, or both in your story.
- When we're done, we'll share our stories with each other.
- Try using the following symbols to represent different feelings in your story:

Excited	**Scared**	**Motivated**
Nervous	**Confident**	**Disappointed**
Energetic	**Tired**	**Surprised**
Sad	**Supported**	**Fun**

“A Day in the I Can Play Anything Program”….

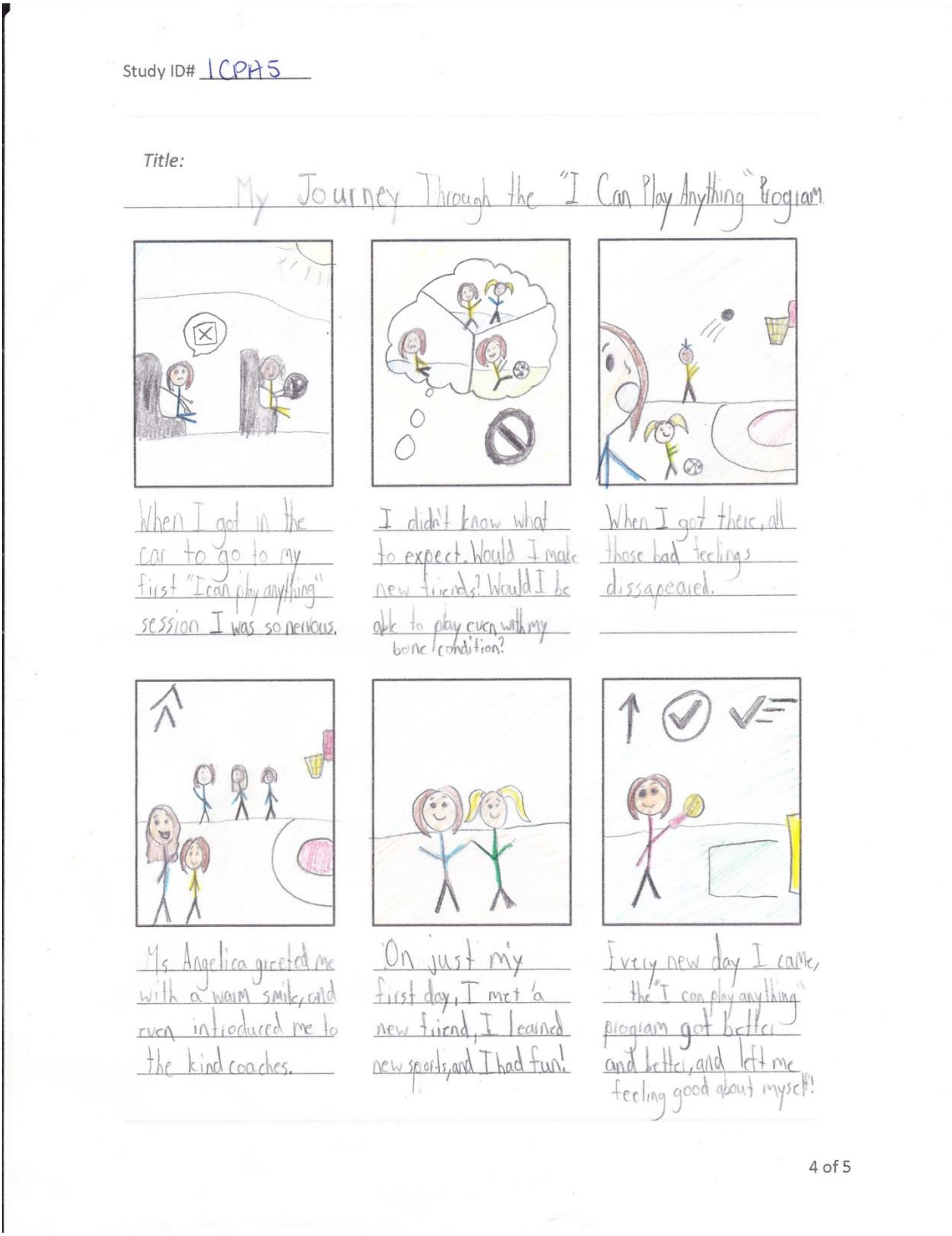
Use either the story board (page 1) or the comic strip (page 2), to create a short story about the ICP program.

- Your story can be <u>about yourself or a made up character</u>. You **cannot** include another kid from the class in your story, but you **can** include the leaders.
- We want you to include activities that you liked, activities that you didn’t like, or both in your story.
- When we’re done, we’ll share our stories with each other.
- Make up symbols to represent different kinds of emotions in your story:

Excited	**Scared**	**Motivated**
Nervous	**Confident**	**Disappointed**
Energetic	**Tired**	**Surprised**
Sad	**Supported**	**Fun**

Title:

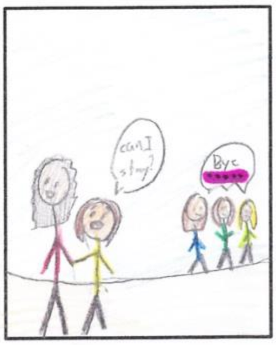
Appendix J: Shreya's Illustration (Interview)



Study ID# 1CPA5

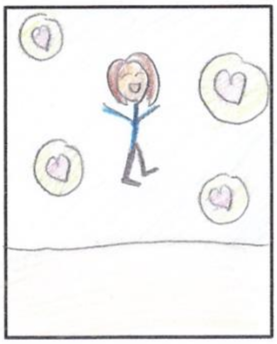
Title:

On days that my bone condition limited my abilities, the coaches found fun things that I could do.



The last day of the program, I didn't want to leave. The people there felt like family to me.

Even though I was leaving, I was happy. I had made friends for life, and had a blast at the "I can play anything" program.



I had a blast. (especially during soccer and pickle ball) and I would do it all again. It was amazing!

Appendix K: John's Illustration (Focus Group

Study ID# ICPA11

"A Day in the I Can Play Anything Program"....

Use either the story board (page 1) or the comic strip (page 2), to create a short story about the ICP program.

- Your story can be about yourself or a made up character. You **cannot** include another kid from the class in your story, but you **can** include the leaders.
- We want you to include activities that you liked, activities that you didn't like, or both in your story.
- When we're done, we'll share our stories with each other.
- Make up symbols to represent different kinds of emotions in your story:

Excited	**Scared**	**Motivated**
Nervous	**Confident**	**Disappointed**
Energetic	**Tired**	**Surprised**
Sad	**Supported**	**Fun**

3 of 5

Study ID# 1CPA11

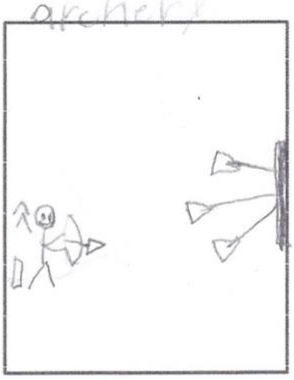
Title: ??? (im bad at coming up with titles)

curling

My favourite sport is curling because its alot of fun

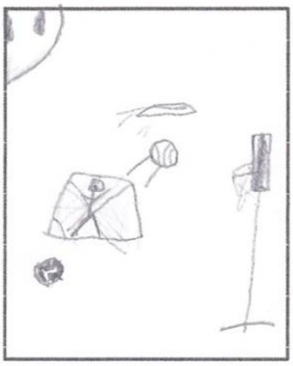
I mainly had fun. I felt kind of tired and bored sweeping. I enjoyed throwing rocks.

archery

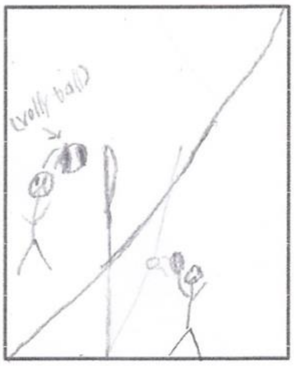


I had alot of fun at archery. Shooting arrows was my favorite part.

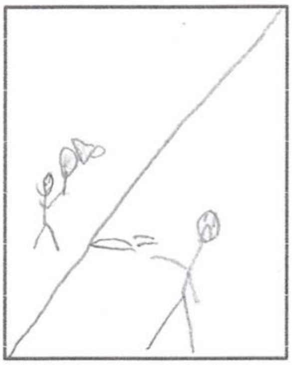
Basket ball, I had mixed feelings.



The mix was confusing and chaotic. I didnt Reallyenjoy it



Vollyball and pickleball was fun but got boring after a while.



Frisbee and badminton I found the least fun.