Original Article

Understanding parent perceptions of healthy physical activity for their child with a chronic medical condition: A cross-sectional study

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Abstract

Objective: We sought to determine the prevalence of, and identify factors associated with, parent questions about physical activity for their child with a chronic cardiac, respiratory, or rheumatologic condition.

Methods: This cross-sectional study of 56 children (32 [57%] female), 3 to 18 years of age, with chronic cardiac (n=21), respiratory (n=18), or rheumatologic (n=17) conditions involved a parent questionnaire about their child's physical activity participation and measurement of the child's activity with an omni-directional accelerometer for 1 week.

Results: Parents of 20 (36%) children had at least one question about their child's physical activity participation, and the prevalence of questions did not vary by age (Wald chi square = 0.77, P=0.38), gender (Wald chi square = 0.11, P=0.74), or clinic (Wald chi square = 1.77, P=0.41). Parent questions were associated (P = 0.04) with lower levels of activity for boys (95% confidence interval [CI] for estimated marginal means: With questions: 197, 395; Without questions: 346, 500) and higher levels of activity for girls (95% CI for estimated marginal means: With questions: 268, 448; Without questions: 239, 369). A multivariable logistic regression model found that parents with questions had higher odds of having a child who was less well (odds ratio [OR]=19.9 for unwell, OR=5.6 for generally well with some symptoms versus well and asymptomatic) and had a history of cardiac arrhythmia (OR=7.6).

Conclusions: Over one-third of parents reported having questions about physical activity for their child with a chronic medical condition, suggesting substantial uncertainty even among children reported as active. Presence of parent uncertainty is associated with parent reports of the child being unwell or a history of cardiac arrhythmia. By asking parents if they have questions about their child's

activity, health care professionals may be better able to identify inactive boys and overprotective attitudes toward active girls.

Keywords: *Cardiology; Habitual physical activity; Parent perceptions; Respiriology; Rheumatology.*

Physical activity is important for children of all ages. A physically active lifestyle in childhood is associated with increased aerobic fitness, improved cardiovascular and musculoskeletal health and reduced symptoms of anxiety and depression (1). A sedentary lifestyle is associated with an increased risk of overweight and obesity and many other health risks (2). At the time that this study was conducted, a minimum of 60 minutes of moderate-to-vigorous physical activity (MVPA) daily was recommended for children and youth 5 to 17 years of age (3). Children with chronic medical conditions, such as congenital heart disease (CHD), asthma, or juvenile idiopathic arthritis, have low levels of physical activity (4–8), suggesting that they may not acquire the significant known physical and mental health benefits of physical activity (1,4,7,9,10).

Parents of healthy children report more barriers to supporting their child's physical activity in comparison to other health behaviours (11). Identified barriers to supporting physical activity were primarily environmental (e.g., weather, available programs or facilities) or parent level factors (e.g., lack of time, work schedule, cost). Parents of children with asthma have identified barriers unique to the child's medical condition. Challenges and lack of trust for asthma management, exacerbation of the condition due to a lack of the child's awareness of symptom onset, and nonadherence to required treatment or medications were of significant concern (12). It has also been reported that parents and health care providers have different perceptions regarding the physical activity restrictions appropriate for children with complex cardiac conditions (13).

In our experience, some parents of children with chronic medical conditions express a desire to ask their health care provider questions about exercise limitations and harms of exercise in the setting of chronic illness. However, the issue of parent uncertainty regarding physical activity for their child with a chronic medical condition has not been explored in detail. In this study, we sought to: (a) determine the prevalence of parent questions about physical activity for their child, (b) investigate the relationship between parent questions and child activity levels, and (c) identify other factors associated with parent uncertainty about their child's physical activity among a population of children with chronic cardiac, respiratory or rheumatologic conditions.

METHODS

This prospective, cross-sectional study examined parent perceptions of their children's physical activity and objectively

measured physical activity among children living with cardiac, respiratory or rheumatologic conditions. The primary outcome was whether parents had questions about their child's physical activity participation. The prevalence of parent questions was also considered in light of the children's medical condition, age, sex, and objectively measured physical activity.

Patients

Children were recruited to participate in this study if they were diagnosed with a chronic medical condition requiring ongoing follow-up in the cardiology, respiratory medicine or rheumatology clinics at The Hospital for Sick Children, a paediatric tertiary care teaching hospital affiliated with the University of Toronto in Toronto, Ontario, Canada. Inclusion criteria for study participation were: (a) 3 to 18 years of age, and (b) no medical condition or disability for which physical activity would be contraindicated.

Potential study participants followed in the cardiology, respiratory medicine or rheumatology clinic were approached during the study enrolment period, June to August 2009. In this preliminary investigation of parent questions about physical activity, recruitment procedures varied by clinic as they were dictated by clinic preferences. In the cardiology clinic, potential study participants were randomly selected within four age groups (3–5 years, 6–10 years, 11–14 years, and 15–18 years) from children that met inclusion criteria, were deemed appropriate by their responsible cardiologist and had a scheduled clinic visit during the data collection timeframe. In the respiratory medicine and rheumatology clinics, potential study participants were approached on a consecutive basis during their clinic visit, following approval by their responsible physician and/or clinic nurse. Written informed consent of one parent and informed consent or verbal assent of the child were obtained.

Assessment

A parent questionnaire was utilized to obtain information about the child's age and gender, amount of physical activity on weekdays and weekends/holidays, fitness and coordination compared to other children of the same age, and parent perceptions of the importance of physical activity for the child, importance of the child increasing his or her physical activity level, and likelihood of the child achieving and maintaining a higher physical activity level if desired. The questionnaire was developed specifically for this study, and consisted of established questions from the research literature (14) combined with Likert scale ratings of

the importance of physical activity and probability of successful behaviour change. To identify parent questions about their child's current and future physical activity participation, the following questions were asked: "If you could ask your cardiologist/respirologist/rheumatologist or another expert for more information about your child's physical activity participation, what would you ask?" and "Do you have any questions or concerns regarding new activities that your child wishes to participate in?" For each question, parents could indicate that they did not have any questions or could provide the questions that they would ask.

The following additional data were extracted from each child's hospital chart: diagnosis, current physical activity restrictions, current use of antithrombotic medications, history of cardiac arrhythmia, presence of a learning disability, and postal code. Family income was estimated by postal code using 2006 census data (15). Reason for the clinic visit and the child's level of wellness at the time of the clinic visit were also abstracted from clinic letters written by the child's physician following the visit. Extraction of data from the medical charts was completed in December 2015.

Each child participant was provided with an omni-directional accelerometer (Actical 2.1, Respironics, Massachusetts) to measure MVPA in 15-second epochs. The child was instructed to wear the accelerometer at the iliac crest for 1 week, consisting of five weekdays and two weekend days.

Data analysis

Intervals of 15 seconds with activity counts between 400 and 1200 were considered to be periods of moderate physical activity and intervals of 15 seconds with counts >1,200 were considered to be vigorous physical activity (16). A minimum of three complete days of activity data with ≥ 8 hours per day were required for the participant to be included in the analysis. Nonwear time was calculated based on a parent-completed log sheet. Nine participants were excluded from the analyses due to missing accelerometer data.

Data from parent questionnaires, patient charts, and accelerometers were analyzed using SPSS software, Version 22. Prevalence of parent questions about physical activity were determined through frequency counts, with variation in prevalence by other variables (e.g., clinic) evaluated with chi-square statistics. The relationship between child activity levels (minutes of MVPA as measured by accelerometry) and the presence of parent questions about physical activity (yes/no) was evaluated by an ANOVA. Logistic regression analysis with backward variable selection, using variables that were statistically or marginally significant ($P \leq 0.1$) in single variable analyses with child age, gender and clinic as mandatory, was used to identify factors associated with the presence of parent questions (binary outcome = yes/no) about the physical activity participation of their child. A P -value of ≤ 0.05 was considered significant.

Ethics

This research was approved by The Hospital for Sick Children Research Ethics Board (Project #1000049376) prior to the commencement of the study. All study activities were conducted in accordance with the Helsinki Declaration.

RESULTS

Patients

A total of 65 children participated in the study, but only data for 56 children were included in the analyses. Nine children did not complete the accelerometer measures for the study (2 participants did not wear the accelerometer and 7 had fewer than three complete days of accelerometer data). Since we could not evaluate the relationship between parent questionnaire responses and the child's physical activity for these participants, they were excluded from the reported results. Less than one-third of participants (17/56 or 30%) achieved the recommended 60 minutes of MVPA per day (3), measured over an average of 6.4 ± 1.2 valid days (range 3 to 8 days) with at least 8 hours of accelerometer wear. Overall, parents of 3 (5%) children described their child as being unwell and 30 (54%) as being generally well with some symptoms. Descriptive information about participant age, gender, parent questions, and total, weekday and weekend MVPA is summarized by clinic in Table 1.

Prevalence of parent questions

Parents of 20 (36%) children had at least one question about their child's physical activity participation (Figure 1). Most parent questions addressed the following themes: physical activity limitations imposed by chronic illness, harms of exercise in the setting of chronic illness, increasing physical activity in the setting of chronic illness, and benefits of exercise and harms of not exercising. The prevalence of parent questions did not differ significantly by age (Wald chi square = 0.77, $P=0.38$), gender (Wald chi square = 0.11, $P=0.74$), or clinic (Wald chi square = 1.77, $P=0.41$).

Parent questions and child physical activity level

Presence/absence of parent questions about the child's physical activity participation was not associated with the child's weekday ($F=0.4$, $P=0.55$), weekend ($F=0.4$, $P=0.52$), or total ($F=0.5$, $P=0.49$) minutes of MVPA as measured by accelerometry, when accounting for age, clinic and gender. The relationship between presence/absence of parent questions and total minutes of MVPA did not vary significantly by clinic ($F=1.6$, $P=0.22$). There was a significant interaction between parent questions and gender ($P=0.037$). For boys, parent questions were associated with lower levels of MVPA (95% confidence interval [CI] for estimated marginal means: With questions:

Table 1. Characteristics of the study population by clinic

Variable	Cardiac (CHD)	Respiratory	Rheumatology (JIA)
Total, n (% of total)	21 (38)	18 (32)	17 (30)
Diagnoses, n (% of clinic total)	Simple: 6 (29) Valve/obstruction: 8 (38) Repaired complex: 7 (33)	Asthma: 14 (78) ILD: 2 (11) PCD: 2 (11)	Oligoarthritis: 10 (59) Polyarthritis (RF negative): 3 (17) ERA: 2 (12) Psoriatic arthritis: 2 (12)
Age, mean (SD) (range), years	10.2 (4.9) (3–17)	9.5 (3.4) (4–16)	10.5 (3.7) (5–17)
Gender			
Female, n (% of clinic total)	10 (48)	9 (50)	13 (76)
Male, n (% of clinic total)	11 (52)	9 (50)	4 (24)
Parent question(s)			
Yes, n (% of clinic total)	6 (29)	9 (50)	5 (29)
No, n (% of clinic total)	15 (71)	9 (50)	12 (71)
Total MVPA, mean (SD) (range), minutes/week	325 (175) (35–785)	377 (208) (79–730)	336 (156) (41–654)
Weekday MVPA, mean (SD) (range), minutes/day	47 (24) (5–87)	56 (31) (14–112)	48 (24) (7–97)
Weekend MVPA, mean (SD) (range), minutes/day	44 (35) (5–176)	49 (32) (5–115)	48 (24) (3–90)

CHD Congenital heart disease; ERA Enthesitis-related arthritis; ILD Interstitial lung disease; JIA Juvenile idiopathic arthritis; MVPA Moderate-to-vigorous physical activity; PCD Primary ciliary dyskinesia; RF Rheumatoid factor.

Figure 1. Number of children with parent questions did not differ by clinic.

197, 395; Without questions: 346, 500). For girls, parent questions were associated with higher levels of MVPA (95% CI for estimated marginal means: With questions: 268, 448; Without questions: 239, 369). MVPA (total minutes per week) for boys and girls with and without parent questions is illustrated in Figure 2. MVPA (minutes/week) was lower by 22 ± 5 minutes per year for each 1-year increase in age (95% CI of beta: $-32, -12$; $P < 0.001$; partial $\eta^2 = 0.28$).

Other factors associated with parent questions

Factors associated with the presence or absence of parent questions about the child's physical activity (binomial variable)

Figure 2. Moderate-to-vigorous physical activity minutes per week by gender with and without parent questions.

were evaluated (Table 2). The final multivariable model contained five variables: child gender, age and clinic, which were mandatory variables in the model, along with history of arrhythmia and parent-reported child wellness. Parents with questions about their child's physical activity participation were seven to eight times more likely to have a child with a history of cardiac arrhythmia (odds ratio [OR]=7.6, $P=0.03$) and were much more likely to report that their child was unwell (OR=19.9, $P=0.05$) or generally well with some symptoms (OR=5.6, $P=0.05$), compared with parents who reported their

Table 2. Factors associated with presence of parent questions about their child's physical activity participation

Factor	n	Univariable model		Multivariable model			
		Wald X ^{2a}	P-value	Odds ratio ^b	Wald X ²	95% CI of Wald X ²	P-value
Female gender	Male = 24 Female = 32	1.11	0.74	0.7	0.32	–1.7, 1.0	0.57
Child age, years	56	0.77	0.38	1.0	0.06	–0.2, 0.2	0.82
Clinic: respiratory compared to cardiac	Resp = 18	1.77	0.41	2.7	0.95	–1.0, 3.0	0.33
Clinic: rheumatology compared to cardiac	Rheum = 17 Cardiac = 21			1.6	0.18	–1.8, 2.7	0.67
Parent report of child's activity compared to peers		4.42	0.11	--	--	--	--
History of arrhythmia	Yes = 17 No = 39	4.70	0.03	7.6	4.80	0.2, 3.9	0.03
Parent report of child as unwell ^c	Unwell = 3	7.77	0.02	19.9	3.80	–0.01, 6.0	0.05
Parent report of child as generally well with some symptoms ^c	Symptoms = 30 Asymptomatic = 23			5.6	3.92	0.02, 3.4	0.05

Hosmer and Lemeshow Goodness of Fit Chi-Square = 2.74 (P=0.91).

CI Confidence interval

^aDependent variable was presence of parent questions. Age, gender, and clinic were in the initial model. Other variables were added in isolation to the initial model to complete the univariate analyses.

^bOdds of having parents who have questions about their child's physical activity participation for each associated factor.

^cAbstracted from clinic letter as (1) well and asymptomatic, (2) generally well with some symptoms, or (3) unwell.

child as well and asymptomatic. Parent questions about their child's physical activity were not associated with child gender (P=0.57) or age (P=0.82).

DISCUSSION

Over a third of parents of children with chronic medical conditions have questions that they would like to ask their child's physician about physical activity participation for their child. This suggests substantial uncertainty among these parents about physical activity as it relates to their child's medical condition. Previous research has identified significant parent uncertainty about their child's physical activity restrictions in a population of children with complex CHD who have undergone the Fontan procedure (13). The present study suggests additional parent uncertainty about physical activity more generally in these populations. Given the frequency of parent questions about physical activity for their child with a chronic medical condition, it is crucial that physicians and other health care professionals who care for children with chronic medical conditions be aware of and actively solicit, encourage, and address parent questions and concerns about activity participation.

Data for healthy children indicate that children and adolescents have lower levels of physical activity when a parent

accompanies them to the park in comparison to when they are at the park without a parent being present (17). We hypothesized that if parents had questions about their child's physical activity, they may be more likely to be present during times when their child could be active or may restrict some activities due to uncertainty about the impact of physical activity on their child's medical condition. We hypothesized that both of these scenarios would lead to a lower level of physical activity for the child, and therefore asking if parents had questions about their child's physical activity might be an appropriate screening tool to identify children who are less active and require more physical activity counselling. The results of this study suggest that the impact of parent questions on MVPA differs between boys and girls. For boys, our hypothesis was supported; parent questions were associated with lower levels of physical activity. However, for girls in our study, the opposite was true; parent questions were associated with higher levels of MVPA. Clearly, different mechanisms are at play. One potential explanation of our study results is that boys decrease their physical activity when accompanied by their parents (as found in healthy children), but that, when girls with chronic medical conditions are more active, it prompts more questions of concern from their parents. The type of questions posed by parents suggests that societal expectations that differ

by sex regarding physical activity participation may also have influenced these results. Questions from parents of boys suggested they recognized limited participation compared to peers and were seeking information about how activity could change. For example, “How do they become more active when they tire more easily?”, “How much does he need to control his weight gain?”, “Will there be changes during the teenage years?” or “How long is reasonable for his body to recover or gain stamina?”. Questions from parents of girls were focused on whether activity was appropriate. For example, “Should I take some prevention measures regarding activity?”, “Why does she breathe hard sometimes?”, “Does the flushed look on her face mean anything?” or “Can she do physical activity?”. There is a strong body of evidence that, in healthy children, boys are more active than girls (18). Given the different topics of questions from parents of boys versus girls, we believe that societal expectations regarding physical activity participation may have contributed to our results. If the expectation is that boys will be active, then parents who believe their sons are not active will ask questions about how to encourage more activity. By contrast, girls are less likely to participate in physical activity. Therefore, parents may feel it more socially acceptable for girls to withdraw from or limit their activity, leading to questions about how activity should be limited in light of the child’s medical condition. It is important for health care providers to be mindful of the possibility of parent uncertainty about physical activity for their child regardless of the child’s level of activity. This applies for all children with CHD, respiratory disease or juvenile idiopathic arthritis.

Parents who had questions about their child’s physical activity participation more often identified their child as less well in both univariable and multivariable models. Parents who perceive their child to be unwell may naturally be concerned about the impact of the increased demands of physical activity on what they perceive to be an already physically poor state of their child. These results suggest that clinicians must be aware of parent perceptions of their child’s wellness and offer additional support and physical activity counselling to those who perceive their child to be unwell.

Children with parents who had questions about their physical activity participation were also more likely to have a history of cardiac arrhythmia in a multivariable model accounting for gender, age, and wellness, though the association was not significant in univariable analysis. It is understandable that parents with a child who has had a possibly life-threatening cardiac rhythm disturbance in the past may be concerned about physical activity participation for their child, as physical activity can provoke certain types of arrhythmias in susceptible individuals. It is thus important that health care professionals offer additional physical activity counselling for parents whose child has a history of arrhythmia. It is unknown whether the hospital charts of

children seen in the respirology and rheumatology clinics are as comprehensive about reporting cardiac arrhythmias as charts from the cardiology clinic. However, since there was no statistical interaction between history of cardiac arrhythmia and hospital clinic ($P=0.98$), our data suggest that all three clinics were similar in their reporting of this variable.

Presence of parent questions was not related to the child’s age, gender, family income, presence of a learning disability, use of antithrombotic medications, or parent-reported physical activity level, importance of physical activity for the child, importance of the child increasing their physical activity level, or likelihood of the child achieving and maintaining a higher activity level if desired. Health care professionals must recognize that questions about physical activity may occur at any age, and among families who report low and high activity participation or ratings of activity importance. It is important that clinicians do not assume that parents do not have questions about their child’s physical activity participation, even if the child is reported as active.

Canadian physical activity guidelines published at the time of this research study recommended a minimum of 60 minutes of MVPA daily for children and youth 5 to 17 years of age (3). In this study, on average, children with chronic medical conditions did not meet the minimum recommendation for daily physical activity. The 30% of study participants who met the current physical activity guidelines is similar to, but slightly lower than recent data indicating that 36% of Canadian children and youth are achieving the physical activity recommended for optimal health outcomes (19). The observed decrease in physical activity with increasing age (22 minutes/week for each year) among our study participants is consistent with the pattern observed in healthy children (19), but the decline in activity occurs at a much more rapid rate. Data for Canadian children and youth indicate that children 6 to 11 years of age perform, on average, an additional 12 minutes/day of physical activity compared to adolescents 12 to 17 years of age (19). More recent guidelines provide targets for a healthy, 24-hour day, including reducing inactivity, increasing light physical activity and achieving good sleep quality (20). Future research should evaluate parent questions about all aspects of a healthy day, including sleep, screen time, and light physical activity.

Interpretation of these results must consider the limitations of this study. First, though most study data were collected prospectively, certain patient characteristics, such as child wellness, were captured retrospectively, resulting in data that is less rich than the elements captured specifically for the study. In addition, accelerometer results are dependent on participant compliance, which, when incomplete, may limit the accuracy of the data. To minimize this limitation, a minimum of three complete days of activity data with ≥ 8 hours per day were required for the participant to be included in the analysis. In addition, while potential study

participants were randomly selected in the cardiology clinic, recruitment in the respiratory medicine and rheumatology clinics was done on a serial basis due to clinic preferences, limiting the ability to determine true prevalence of parent questions in these populations. Finally, the results must be interpreted in light of the cross-sectional study design and relatively small sample size. The questionnaire used in the study was comprised of items from published instruments, but the authors did not undertake additional validity or reliability testing of the combined instrument.

Additional studies are needed to identify factors associated with parent questions about their child's physical activity participation in other populations of children with chronic medical conditions. The development of screening tools that can identify less physically active children in need of additional physical activity counselling, suitable for use in a paediatric clinic setting, should also be developed.

CONCLUSION

Over one-third of parents reported having questions about physical activity for their child with a chronic medical condition, suggesting substantial uncertainty even among children reported as active. Presence of parent uncertainty is associated with parent reports of a reduced level of child wellness and a history of cardiac arrhythmia. Boys whose parents do not have questions are more active, while parent questions occur more frequently among more active girls. Asking parents if they have questions about their child's physical activity or if they perceive their child as unwell may help to identify children and families for whom increased physical activity counselling may be beneficial.

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