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Parent and child perceptions of physical activity with type 1 diabetes

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ABSTRACT

Introduction Type 1 diabetes (T1D) is a lifelong illness that affects over 2500 children in Ireland. Management involves complex daily regimens including frequent blood glucose monitoring, pharmacotherapy, dietary management, and physical activity (PA). PA is an important modifiable lifestyle factor. Unfortunately, children with T1D remain physically inactive. Children with T1D face disease-specific barriers and facilitators to PA engagement. All aspects of T1D management for children are supported or supervised by parents. Thus, the purpose of this study was to examine parents' and children's perceptions of barriers and facilitators to PA engagement.

Research design and methods 43 parent and child dyads participated. Parents completed a self-report survey. Children completed a modified version of the Physical Activity Questionnaire for Children (PAQ-C) that explored habitual PA patterns, perceived facilitators and barriers to PA engagement.

Results 21 females, 22 males and their parents (36 mothers, 7 fathers) participated. 69% of males and 90% of females reported that having diabetes did affect their PA participation. 54% of males and 48% of females were insufficiently active based on their total PAQ-C score (<2.9 and <2.7). 53% of parents reported that their children participated in school physical education. 21% of parents reported that their child did not participate in PA outside of the school setting. 23% of parents reported that they did not feel comfortable with their child participating in strenuous PA. A further 30% of parents reported that they only felt comfortable with their child participating in strenuous PA if supervised. 66% of parents reported their child should be more physically active. 83% of parents reported that having T1D did impact their child's PA level.

Conclusions This study demonstrates the potential influence of parents' perceptions on PA engagement in children with T1D. Additional education is needed to support the promotion of PA for children with T1D.

INTRODUCTION

The goals of management of type 1 diabetes (T1D) in children include promoting healthy functioning and preventing or delaying negative health outcomes including cardiovascular disease, diabetic ketoacidosis, nephropathy, and neuropathy.¹ Management involves complex daily regimens including frequent blood glucose monitoring, pharmacotherapy, dietary management, and physical activity (PA). PA is an important modifiable lifestyle

WHAT IS ALREADY KNOWN ON THIS TOPIC

- ⇒ Physical activity (PA) is an important modifiable lifestyle factor that contributes to physical and psychological health during childhood.
- ⇒ Unfortunately, children and adolescents with type 1 diabetes (T1D) often do not meet the WHO-recommended PA targets.

WHAT THIS STUDY ADDS

- ⇒ This study explores both parent and child perceptions of PA and PA behaviors.
- ⇒ This study also explores the relationship between parents and child perceptions of PA.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

- ⇒ This study demonstrates the potential influence of parents' perceptions on PA engagement in children with T1D.
- ⇒ This study highlights key facilitators and barriers to PA that could be used in education to support the promotion of PA for children with T1D.

factor that contributes to physical and psychological health during childhood. The WHO recommends that children should achieve an average of 60 min of moderate to vigorous PA (MVPA) on most days of the week with limited sedentary time to maintain health. Unfortunately, children and adolescents with T1D often do not meet the WHO-recommended PA targets. For example, socioeconomic factors have been identified as a factor that influences opportunity and experience of engaging in PA outside of scheduled school activities.² Additionally, individuals living with chronic illness or disability have been identified as being at risk of not meeting PA recommendations due to limited safe, appropriate and supportive PA initiatives to meet their additional needs. Experiences of PA during childhood and adolescence can influence future behaviors and decisions made about PA later in life.²⁻⁷ PA markedly decreases during the transition from childhood to adolescents.²⁻⁷ Thus, early experiences of PA can have a long-term impact on health



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outcomes. Early intervention to promote PA engagement seems imperative in childhood.

To support the development of tailored early interventions, a better understanding of factors that contribute to the adoption and maintenance of PA is needed. Psychosocial factors are reported to play an integral role in the development of PA behaviors. For example, parental support has been identified as a key factor associated with positive PA behavior in children and adolescents with T1D. Parental influence on PA behaviors within the general population is reportedly due to role modeling behaviors, supporting children's perceptions of competence and providing resources and opportunities for engagement.⁵ T1D presents additional disease-specific factors that may influence the relationship between parents' perceptions and children's participation in PA, for example, parents may be fearful of strenuous activity and risk of hypoglycemia and may in turn limit PA intensity or duration. All aspects of T1D management for children are supported or supervised by parents and guardians.^{6,7} Thus, the exploration of parents' perceptions of their children's PA is warranted to understand children's PA patterns. Previous research has examined either parent or child perceptions of PA independently; however, there is limited research that explores both parent and child perceptions of PA.⁵ Specifically within an Irish context, little is known about parents' perceptions of their children's PA participation with T1D. It is hoped that knowledge and understanding of parents' perceptions of PA in children with T1D could be used to inform future intervention and education for the promotion of PA for children and adolescents with T1D. Therefore, the purpose of this study is to explore both children's and parents' perceptions of PA with T1D and to examine the relationship between parents' perceptions of PA and children's habitual behaviors.

METHODS

This cross-sectional questionnaire-based study was conducted in the pediatric outpatient department (OPD) of a regional hospital. Inclusion criteria were patients aged between 8 and 16 years who had been diagnosed with T1D for greater than 12 months and their parents, attending routine clinical outpatient review. Data were collected during a 2-month period from June to July 2021. All parents (or legal guardians) of children attending outpatient clinics were invited to participate during routine clinic visits. Questionnaires were self-administered with assistance from the parents for younger patients as required. To ensure anonymity, the questionnaires were handed out on registration at the clinic reception and collected in a sealed envelope. Fifty parent and child dyads were given the opportunity to participate, 7 refused and 43 completed the questionnaire. Parent and child dyads (one parent per child) completed each of two questionnaires (one part completed by the child and one part completed by the parent).

Questionnaire design

Reflecting good practice in the design of qualitative instruments,^{8,9} the questions were reviewed by two specialists (a diabetes advanced nurse practitioner and a consultant pediatric endocrinologist). Feedback provided on content order, semantics and approach were used to refine the questionnaire protocol.

Questionnaire: parent

The parent section of the questionnaire was divided into two subsections; the first subsection gathered information about the home environment (including who was living at home, siblings) and information about current diabetes management (including years since diagnosis, management regimen). The second subsection gathered information about parents' perceptions of their child's PA engagement (eg, does diabetes impact your child's PA participation, what activities they undertake in school, outside of school, what helps them to be active, what challenges they experience, do they feel comfortable with their child taking part in strenuous PA, do they think their child should be more active). The final section of the parent questionnaire explored perceived factors that support PA participation and perceived future changes in their child's PA level.

Questionnaire: child

A modified and combined version of the Physical Activity Questionnaire for Children (PAQ-C) and the Physical Activity Questionnaire for Adolescents (PAQ-A) adapted from Crocker *et al*¹⁰ and Kowalski *et al*¹¹ was used to explore activity levels. An expert panel ranked the PAQ-C and PAQ-A as one of few self-report instruments that has acceptable validity, reliability and practicality for use in children and adolescents.¹² Both are self-administered with a 7-day recall tool to evaluate MVPA for school-going children and adolescents. The PAQ-C consists of 10 items and PAQ-A consists of 8 items, each scored on a 5-point scale with a higher score indicating higher PA level. In accordance with the PAQ-C scoring procedures, the last question of the PAQ-C (referring to typical week) did not contribute to the overall score calculation and was used to identify respondents who did not meet the inclusion criteria (ie, currently experiencing no contraindication to PA participation) and were subsequently excluded from the study. The PAQ-C and PAQ-A were amalgamated (hereafter PAQ-CA) and modified to include four questions relevant to children with T1D: (1) Do you think diabetes impacts your PA levels?; (2) Do you have any worries about taking part in activities?; (3) Is fear of low blood sugar likely to stop you from participating in PA?; (4) What helps you to be physically active? The four T1D specific questions were analyzed using thematic analysis and were not included in PAQ score analysis. Colloquial terms such as 'diabetes' and 'blood sugar' were used intentionally when communicating with children and their parents.

Analysis

PAQ-CA

PA composite score was calculated by the mean of six items from the PAQ-CA. The six items included (1) spare time activity, (2) physical education (PE) activity (school based), (3) lunch break activity, (4) weekend activity, (5) weekday activity, (6) activity statement. An average of the total item score was calculated as the total activity score in accordance with procedures reported elsewhere.^{10 11 13} PAQ-CA scores of more than 2.9 in boys and more than 2.7 in girls indicate 'sufficiently active' group, and scores below those thresholds were considered as 'low active' group.¹³

Quantitative data

SPSS V.25 for Mac was used for further quantitative analysis. Continuous variables were presented as mean±SD if normally distributed. Categorical variables were reported as the number and percentage of patients involved. The relationship between child and parent perceptions of PA was examined using Pearson's X^2 test to examine the relationship between children's anxiety about PA participation and parental anxiety about strenuous PA. Independent samples t-tests were used to examine the difference between child PA level for children with parents who reported anxiety about strenuous PA participation and those who did not report anxiety about strenuous PA participation.

Qualitative data

NVivo was used for qualitative data analysis. All questionnaires were examined at completion to minimize question misinterpretation and reduce the likelihood of missing data. A quasi-statistical approach was used to analyze qualitative data. Braun and Clarke's guidelines¹² were deployed for thematic analysis. Responses were read and reread for familiarity. From there, initial codes and themes were generated by the first author (SG) until saturation was established. A second independent researcher then reviewed and coded the data (ND). Where discrepancies existed, a third independent researcher was consulted.

RESULTS

Participant demographics

A total of 43 parent-child dyads were recruited. Children participants included 21 females, 22 males and their parent (36 mothers, 7 fathers). Thirty-three participants (76%) were from two-parent families with two or

more children, four participants (1%) were from single-parent families and six participants (14%) were from single-child families. The mean age for participants with T1D was 12.65±3.07 years (table 1). Mean duration since diabetes diagnosis was 5.41±3.49 years. Fifty-five per cent of participants were on multiple daily insulin injections (basal-bolus regimen), while 45% of participants were on continuous subcutaneous infusion insulin pump therapy. Mean HbA1c levels at the time of data collection were 66% mmol/mol (8.3%). Participant activity levels (PAQ scores) are reported in table 2.

Relationship between parent perceptions and child PA

A X^2 test showed no statistically significant difference between anxiety levels of children with parents who reported anxiety about strenuous PA participation compared with parents who did not report anxiety about strenuous PA participation ($X^2(1)=2.70$, $p<0.10$). Although statistical significance was not achieved with this sample dataset, frequency plot (figure 1) shows a higher rate of anxiety was reported by children whose parents' reported anxiety. Independent samples t-tests were used to examine the difference between child PA level for children with parents who reported anxiety about strenuous PA participation and those who did not report anxiety about strenuous PA participation. No significant differences between groups were found ($p=0.11$).

Child perception of PA

Sixty-nine per cent of males and 90% of females reported that having diabetes did affect their PA participation. Fifty-four per cent of males and 48% of females were insufficiently active based on their total PAQ-CA score (<2.9 and <2.7, respectively). Forty per cent of males and 48% of females reported that fear of hypoglycemia was likely to stop them from participating in PA (box 1). Differences between genders did not reach statistical significance ($p=0.09$). Thirty per cent of children reported having concerns or worries about participating in PA (figure 2).

Two main themes were identified for children's concerns about participating in PA (ie, diabetes management and peer comparison factors). Four codes were generated for diabetes management ((1) fear of low blood sugar, (2) fear of collapse, (3) anxiety checking blood sugar levels, (4) fear of high blood sugar) (box 1). Two codes were generated for peer factors ((1) letting

Table 1 Participant details (child)

Gender	Mean age (±SD)	HbA1c	Does having diabetes impact your activity?	Is fear of hypoglycemia likely to stop you from participating in PA?	Sufficiently active PAQ-C	Insufficiently active
22 male	12.62 (±2.09)	65 mmol/mol 9.1%	Yes 69% No 31%	Yes 40% No 60%	46%	54%
21 female	12.71 (±2.9)	68 mmol/mol 9.4%	Yes 90% No 10%	Yes 48% No 52%	58%	42%

PA, physical activity; PAQ-C, Physical Activity Questionnaire for Children.

Table 2 Participant PAQ-CA activity levels

Spare time activity	Activity during physical education classes	Lunchtime activity	After school activity	Weekend activity	Weekday activity	Total activity score	Total PAQ score
2.00 (±0.48)	3.97 (±0.82)	2.74 (±0.95)	3.13 (±1.23)	2.79 (±1.02)	3.32 (±0.82)	2.76 (±0.74)	2.96 (±2.96)

PAQ, Physical Activity Questionnaire; PAQ-A, Physical Activity Questionnaire for Adolescents; PAQ-C, Physical Activity Questionnaire for Children; PAQ-CA, amalgamated PAQ-C and PAQ-A.

teammates down, (2) fear of continuous glucose monitor falling off or being seen) (box 1).

For factors that helped children to be physically active, three main themes were identified ((1) social factors, (2) psychological factors, (3) diabetes management) (box 2). Six codes were generated. A stable diabetes routine (diabetes management) and enjoyment of PA (psychological factor) were the two most frequently reported codes (box 2).

Parent perception of PA

The majority of parents reported that their children participated in school PE (53%) or PE and another activity or sport in school (41%). Twenty-one per cent of parents reported that their child did not participate in PA outside of the school setting. Twenty-three per cent of parents reported that they did not feel comfortable with their child participating in strenuous PA: 'I am very anxious about high level activity...', 'I worry about hypos a lot...', '...it is very stressful'. A further 30% of parents reported that they only felt comfortable with their child participating in strenuous PA if supervised: '...not really, only if the teacher or coach is aware of the diabetes and is keeping an eye on them'. '...not really, I am always on standby' (figure 3). Sixty-six per cent of parents reported that they believed their child should be more physically active. Eighty-three per cent of parents reported that having T1D did impact their child's PA level. The most frequently reported examples of how T1D impacts their child's PA level were difficulty maintaining their T1D management routine, anxiety about regular blood

glucose level monitoring and hypoglycemia. Similarly, the most frequently perceived challenges experienced with PA in T1D were: checking blood glucose levels regularly, fear of hypoglycemia and match and competition preparation anxiety.

DISCUSSION

The purpose of this study was to examine parents' and children's perceptions about PA with T1D. The research provides a detailed look at the challenges that parents of children with T1D may face when their child is participating in PA. Additionally, self-report activity levels were assessed to explore the relationship between both child and parent perceptions of participation and habitual PA engagement. Notably, the majority of participants, both parents (83%) and children (females 90%, males 69%) reported that having diabetes did impact PA participation. The majority of parents (66%) believed that their child should be more physically active. Furthermore, children were reported as 'insufficiently active' according to PAQ-CA scores (54% males and 42% females).

Parental anxiety about participation in strenuous PA was related to children's reported anxiety with a higher proportion of anxiety reported by children of parents who reported discomfort with children participating in strenuous PA, although the relationship did not reach statistically significant levels. Similarly, children of parents who reported anxiety about participation in strenuous PA did have lower PAQ-CA scores compared with parents who did not report anxiety about strenuous PA participation, although the differences did not reach statistical significance.

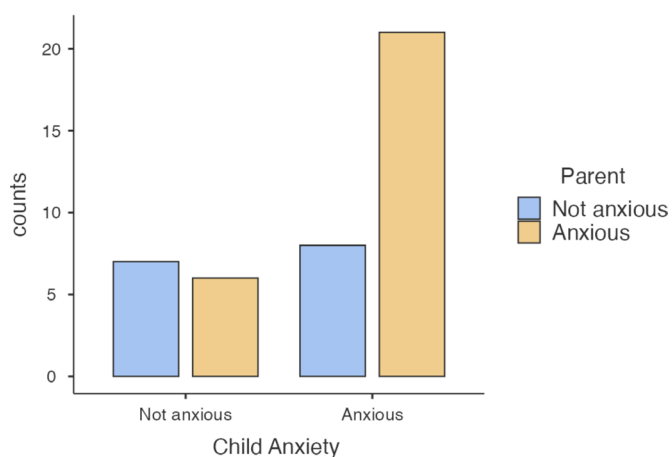


Figure 1 Child anxiety and parental anxiety frequency bar plot ($p=0.11$).

Box 1 Main themes identified: diabetes management (four codes) and peer factors (two codes)

Diabetes management

1. Fear of low blood sugars (f=9/13)
2. Fear of collapsing (f=3/13)
3. Anxiety checking levels (f=2/13)
4. Fear of high blood sugar (f=1/13)

Peer factors

5. Fear of letting teammates down (f=2/13)
 6. Fear of continuous glucose monitor falling off or being seen (f=1/13)
- f, frequency reported.

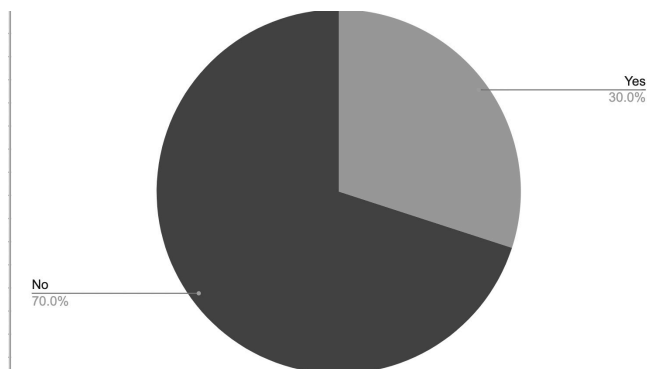


Figure 2 Do you have any worries about participating in physical activity?

Supportive personnel and appropriate supervision were valued and reported by parents as contributing to helping their children participate in PA. Well-controlled T1D, T1D knowledge and understanding and stable T1D management routine were reported as helping children to participate in PA by both parents and children. This finding is in keeping with previous research; parents of children with chronic conditions (including T1D) reported that having management plans as part of daily routine were perceived as fundamental to children leading a physically active lifestyle (reference). Parents expressed concerns about the possible adverse side-effects of PA and spoke specifically about hypoglycemia. Anxiety about checking blood glucose levels, fear of hypoglycemia and fear of collapse were reported by both parents and children as causing difficulty in PA participation. Previous research has found that parents commonly report fear of hypoglycemia.^{6,7} This study findings demonstrate that parents' anxiety may be heightened particularly during strenuous PA. Thus, ongoing education about how to manage the side-effects of PA and designing interventions to support parents in managing the hypoglycemic response to PA are important.

In keeping with Bandura's self-efficacy theory¹⁴ and social cognitive theory,¹⁵ active peers and active role

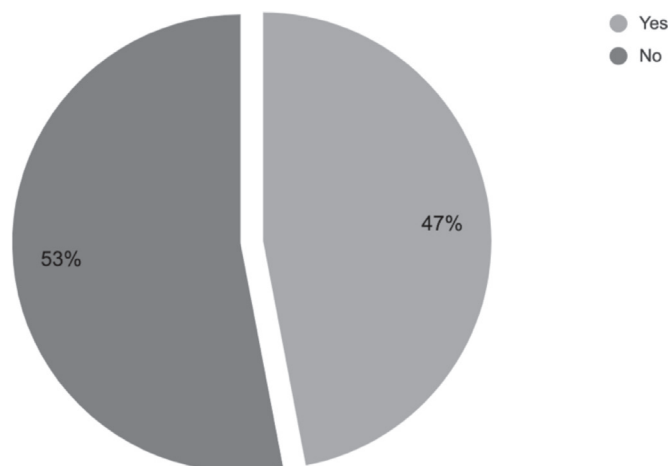


Figure 3 Do you feel comfortable about your child participating in strenuous physical activity?

models were reported as being supportive of PA engagement for children with T1D. Confidence and enjoyment were consistently reported as important factors that help children with T1D to remain physically active. Conversely, low confidence, anxiety and lack of active peers were reported as factors that contribute to low PA engagement. Parents also reported that competitive sport caused specific difficulty for their children. Fear of match performance decreases due to T1D; fear of telling the sports coach about T1D, fear of letting teammates down and difficulty checking levels and adjusting meals around match preparation were reported as factors that some children find particularly difficult. Education and support for sports clubs, coaches and schools were identified as factors that could help children to be more physically active.

Fifty-three per cent of parents reported that they are not comfortable with their children taking part in strenuous activity with some parents reported that they only feel comfortable with their child taking part in strenuous activity if they are present to supervise. This may have implications for children with T1D not achieving the recommended intensity of activity. There is a large body of epidemiological evidence to suggest that MVPA is associated with more favorable glycaemic control profiles and less variation in HbA1c profiles.²⁻⁷ Furthermore, there is evidence to suggest that the association between HbA1c levels and MVPA⁶ is present regardless of gender, age, pubertal status, body composition, insulin dose and insulin regimen. Higher levels of MVPA are required to achieve an improvement in aerobic capacity, and higher aerobic capacity reduces the increase of insulin resistance risk factors in adolescents with T1D.⁶ Given the importance of PA for T1D management, exercise and activity are topics discussed in the outpatient clinic setting as part of multidisciplinary care. Advanced nurse practitioners, doctors and dieticians address the importance of activity and barriers to participation of children, adolescents and parents at each clinic visit. We are currently undertaking research to examine the skills and experiences of

Box 2 What helps you to be physically active? Main themes identified: social factors (one code), psychological factors (two codes) and diabetes management (three codes)

Social factors

1. Being social (f=9/43)

Psychological factors

2. Enjoyment of physical activity (f=11/43)
3. Motivation to be healthy (f=6/43)

Diabetes management

4. Stable diabetes routine (f=14/43)
 5. School support (f=2/43)
 6. Technology (f=3/43)
- f, frequency reported.

multidisciplinary healthcare team members with a view to standardizing and optimizing the delivery of individualized, evidence-based exercise prescription in the pediatric outpatient clinic setting.

Furthermore, parents reported that PE was the main source of PA for their children (53%) and 21% of their children did not participate in PA outside of structured PE in school. Previous research has reported that although participation in structured activity contributes to overall PA, MVPA levels in children were found to be significantly higher during free play than during structured activity.¹⁴ Interventions that educate and support children, parents and supervision personnel (teachers, coaches, etc) to confidently pursue both structured and unstructured strenuous leisure activities (eg, chasing, skipping, trampolining) may aid in increasing MVPA and support children to meet the recommended MVPA requirements to confer protective health benefits.^{16 17}

Strengths and limitations

The higher representation of mothers (n=36) compared with fathers (n=7) may prevent the generalizability of findings from this study. Previous studies have shown that parental influence on PA differs between mothers and fathers.^{1 2} The purposeful nature of selection for this study may have resulted in a higher proportion of motivated and dedicated parents and children with active family support for their T1D and thus the findings may not represent families who fail to attend OPD services for their T1D care regularly. This study deployed a quasi-qualitative questionnaire approach. Additional qualitative research using in-depth reflexive interview methodology may be beneficial to provide more detailed information that could be extrapolated into clinical implications for the support and education of parents by healthcare professionals in OPD diabetes settings.

The assessment of PA used in this study is subject to bias. While the PAQ-C has demonstrated validity and reliability, subjectivity, social desirability bias, and variable recall ability particularly in younger people are considerable limitations of self-report instruments. The assessment of PA is an essential part of understanding patterns and influences of behavior, designing interventions, and undertaking monitoring of PA.⁸ Additional quantitative measures of PA that triangulate qualitative self-report may be beneficial in future research.

This study focused on the parent–child relationship and the potential relationship between parents' perceptions of PA participation and PA levels in children with T1D. To expand our knowledge and understanding of antecedents to PA promotion, management and support for children with T1D, research that examines healthcare professionals, peers and sibling influence on PA engagement may be beneficial. Furthermore, the study did not explore parents' self-rated activity levels. In keeping with social cognitive theory, active role models are likely to have an influential effect on children's activity levels.

CONCLUSIONS

This study explored parent and child perceptions of participating in PA with T1D. In addition, the relationships between parents' perceptions of PA and children's perceptions and children's activity behaviors were examined. In accordance with other studies,^{2–7} children with T1D were found to be insufficiently active. A number of diabetes-specific challenges to PA participation were identified (eg, fear of hypoglycemia, fear of monitoring blood glucose levels). Parental anxiety about participation in strenuous PA was related to children's reported anxiety with a higher proportion of anxiety reported by children of parents who reported discomfort with children participating in strenuous PA, although the relationship did not reach statistically significant levels. Similarly, children of parents who reported anxiety about participation in strenuous PA did have lower PAQ-CA scores compared with parents who did not report anxiety about strenuous PA participation, although the differences did not reach statistical significance.

The perceived challenges and perceived facilitators to PA provide insight into the support that may be required to interventions that are targeted at sustainably increased PA in children with T1D. It is hoped that the findings may be used to extrapolate practical implications for care of children with T1D and support for their parents.

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Patient consent for publication Not required.

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Data availability statement Data are available upon reasonable request.

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