The challenges of being physically active: A qualitative study of young people with type 1 diabetes and their parents

Fried, L¹, Chetty, T², Cross, D¹, Breen, L³, Davis, E², Roby, H², Jackiewicz, T¹, Nicholas, J², Jones, T²

¹ Telethon Kids Institute; Northern Entrance, Perth Children's Hospital, 15 Hospital Ave, Nedlands, Western Australia, 6009

² Perth Children's Hospital, 15 Hospital Ave, Nedlands, Western Australia, 6009

³ Curtin University, Kent St, Bentley, Western Australia, 6102.

Corresponding author: Leanne Fried - Telethon Kids Institute, Perth, Western Australia
Leanne.Fried@telethonkids.org.au

Abstract

Background: Benefits of physical activity are well recognized for youth with type 1 diabetes (T1DM), however being active is challenging. This study aimed to investigate the challenges experienced by adolescents, their parents and young adults with T1DM when they are physically active.

Methods: Six focus groups involving adolescents (13-18 years; n = 14) and young adults (19-25 years; n= 7) and four focus groups with parents (n = 14) of the adolescents (13-18 years) were conducted. Data were analysed using content analysis.

Results: Adolescents and young adults with T1DM identified challenges of unpredictability, knowledge, trust and stigma when they were physically active. Parent challenges were specifically unpredictability and trust.

Conclusions: Interventions are needed that provide AYA with T1DM and parents of adolescents with T1DM more in-depth information about managing physical activity in a manner that enhances their perceived competence and builds autonomy. Interventions can also target peer and community support.

Key words Adolescents; Focus Groups; Parents; Physical Activity; diabetes

Key messages

Physical activity is challenging for adolescents with T1DM. Interventions to build adolescent, parent, peer and community knowledge may support them to be active.

Adolescents with T1DM have a need for autonomy that their parents can struggle to provide. This can be addressed through specific physical activity interventions.

Introduction

Physical activity has many recognised physical and psychological benefits but remains challenging for adolescents and young adults with Type 1 Diabetes Mellitus (T1DM) [1]. In addition to cardio-vascular, weight loss and physical conditioning benefits, physical activity is also associated with positive mental well-being, improved self-esteem and quality of life for people with T1DM [2,3,4]. The challenges experienced by young people with T1DM can prevent them from being physically active [5,6]. They arise in part because maintaining stable blood glucose levels before, during and after exercise has been found to be affected by many factors and may not be predictable on repeated exercise occasions [7].

Guidance is available for children and adolescents with T1DM to assist them to participate safely in physical activity [8,9]. However, adolescents with T1DM are not meeting the physical activity recommendation of at least 60 min/day of moderate to vigorous activity [10]. They have also been found to be less physically active than their peers who do not have T1DM [11]. As paediatric diabetes is increasing globally, it is important to address perceived barriers to exercise specifically for children and adolescents [12].

While the barriers to physical activity experienced by non-T1DM youth are well understood [13] these may not be the same as experienced by the T1DM population. Several studies have investigated the challenges adults with T1DM experience when they are physically active but these may not be shared by adolescents and young adults (AYA) with T1DM [9, 14, 15]. While a small study of young people with T1DM identified diabetes-specific challenges to physical activity including poor community knowledge about T1DM and misunderstandings about the impact of diabetes on their life, further studies are needed [6]. In addition, although

peers become increasingly important to adolescents, parent support through adolescence can result in better T1DM outcomes [16]. Therefore, it is important to also understand the challenges parents face when supporting their adolescent to be physically active.

This study investigated the challenges experienced by AYA with T1DM when physically active and the challenges the parents of adolescents with T1DM experience when supporting their adolescent to be physically active. The study also provides guidance as to how these challenges can be overcome.

Method

Design

The research team was guided by an interpretivist research paradigm, underpinned by a constructivist epistemology [17]. A qualitative methodology allowed for exploration and interpretation of the ways in which young people with T1DM and their parents described their experiences of participating in physical activity and respected the right of young people to say what they think about matters that affect them [18]. Focus groups were chosen as a means of eliciting personal accounts and allowing ideas to be developed and articulated through discussion [19]. They can be particularly appropriate for adolescents who may feel more supported and confident in a group situation [20].

Participants

Participants were recruited through the Princess Margaret Hospital diabetes clinic and database. The Princess Margaret Hospital Human Research Ethics Committee gave approval for the project and participants gave written informed consent. Potential participants were contacted by email based on age and whether they had given previous approval to be involved in research. AYA aged 13-25 years were eligible irrespective of level of physical

activity. Participants were grouped as follows: 13-15 years, 16-18 years and 19-25 years. The parents of the two younger age groups participated in one of two focus groups.

Materials

A semi-structured interview schedule, with prompts to facilitate discussion, was developed by the research team. Physical activity was defined as structured exercise and other activities involving movement including playing, working, using active transportation, household duties and recreational activities. Initial questions, designed to help participants feel relaxed, explored the types of physical activity in which participants were involved. Questions then targeted enablers and challenges to physical activity e.g. *What do you have to consider before, during and after physical activity? When a young person has diabetes what do they particularly need to consider when being physically active? Prior? During? After? What sorts of things make it challenging for a young person with diabetes to be physically active? Why is each one important? What can a person do to overcome each one?*

Procedure

The first and fourth authors conducted the focus groups. Neither was a member of the clinic team. Facilitators were experienced at managing groups and making sure that all individuals were brought into the conversation. Parents were asked to respond to questions from their own perspective and then from what they thought was their child's perspective. Each focus group discussion took approximately 60 minutes, at the end of which the facilitator summarized the main points covered from notes taken on the whiteboard and obtained feedback from participants as to the accuracy of the summary. The facilitator and co-facilitator met on completion of each focus group and made notes regarding initial impressions, interactions and processes.

Data analysis

Members of the research team transcribed the focus groups. The first author checked all transcripts for accuracy. Analysis of the data commenced shortly after the completion of the first focus group and continued concurrently until no new code categories emerged. Data were entered into NVivo software. Content analysis was used to generate codes within and across grouped data [21].

Trustworthiness of the analysis process was achieved through continual immersion in the data, keeping notes and diagrams on how the codes and themes were developed and having two researchers work in tandem to develop and check analysis processes [22]. Two focus group participants reviewed the codes and themes once analysis was complete. The data are reported in line with the consolidated criteria for reporting qualitative research guidelines [23].

Results

Twenty-one AYA participants had a mean duration of diabetes of 9 years with a range from 1.5 years to 19.4 years. Three participants were using multiple daily injections with the remainder using a pump to manage their T1DM. Fourteen parents of adolescents with T1DM participated. The gender distribution for all focus groups can be seen in Table 1. The AYA were generally active, participating in competitive and social sport, informal activities such as bushwalking and walking to school, regular exercise sessions, and work-related physical activity. They participated in planned and unplanned activities (see Figure 1). Figure 2 shows how often they participated in physical activity.

1 Insert Table 1 here

2 Insert Figure 1 and Figure 2 here

3 When asked about their main challenge when physically active, participants agreed that it
4 was maintaining a stable blood glucose level (BGL). Data were initially grouped in codes
5 that represented challenges related to managing food intake and equipment and psychosocial
6 issues that arose in the process of trying to maintain a stable BGL. Further analysis then
7 identified four main themes that were common across the codes. These were:
8 unpredictability, stigma, trust and knowledge.

9

10 Unpredictability

11 Participants described how predicting BGL during and after physical activity was difficult
12 due to various factors such as type and length of activity, intensity, emotional state and
13 whether they were having a growth spurt, weather conditions, time of day the activity was
14 taking place and what they had been doing previously. Swimming and cold water was a
15 specific challenge. A parent commented that maintaining stable BGLs was '*as much an art as*
16 *a science*'.

17

18 Unpredictability of BGLs when physically active caused various emotional responses such as
19 frustration, fear, worry and stress. Participants discussed being frustrated when beaten at a
20 competitive activity because their BGL was low and the fear they felt during the night of
21 going high or low after physical activity. Parents talked about being '*consumed*' by the fear
22 of their child's BGL going too high, or too low, especially when their child had been

1 physically active. This fear resulted in them continually checking their adolescent's BGL
2 during the night. One parent commented and others agreed:

3 *We try not to worry about hypos but the thought is there all the time.*

4 This fear also complicated their desire to transfer some of the responsibilities for diabetes
5 management to their adolescents.

6
7 Participants spoke about the worry they experienced making decisions when their BGL was
8 high or low and affecting the clarity of their thinking and the stress associated with constantly
9 monitoring their BGL if they wanted to be physically active. Differences in BGL responses
10 between 'training' days and 'game' days due to both the stress and intensity of competition
11 were also challenging. Participants discussed how stress could cause their BGL response to
12 physical activity to be unpredictable.

13 *The added stress of thinking of going low is added to the exercise and again it's the emotions*
14 *affecting your body.*

15
16 AYA also identified spontaneous activity (not routine) as challenging to manage BGLs. They
17 said they often chose not to participate in spontaneous physical activity given the preparation
18 required. This was a source of frustration to them as they then missed out on social activities.

19
20 Although there were many comments about the unpredictability of blood glucose responses
21 to physical activity, participants who were involved in high level competitive sport had come
22 to know themselves well:

1 *I find because I know myself I kind of know how my sugars are going to move around when*
2 *I'm doing sports. I sort of know how much it's going to go up and down – it's pretty*
3 *predictable.*

4 Discussion about patterns revealed how individualised they were with AYA expressing
5 surprise about the differences in their BGL responses to physical activity. While some
6 participants thought that understanding their individual patterns was the key to overcoming
7 unpredictable BGL responses, others commented that identifying patterns would mean they
8 would have to be too focused on BGL.

9

10 Getting the food '*right*' to maintain a stable BGL while physically active was identified by all
11 participants as challenging, but particularly by parents as the meal providers.

12 *My big challenge is trying to work out the right amount of food to give, because if they have*
13 *too much and they go high then that severely impacts on their performance as well. You know*
14 *they might not have to get out and rest but they won't be able to swim as fast...*

15 While participants described quite individualised foods that '*worked*' at various stages of
16 being physically active, many were interested in knowing more about nutrition and its
17 relationship with physical activity. Participants quizzed each other about the food they or
18 their adolescent ate at different times when physically active.

19 Trust

20 Participants identified trust as an issue for various reasons. Parents struggled with trusting
21 their adolescent, particularly when they were physically active, because of the unpredictable
22 BGL responses and because they felt their adolescent was not completely accepting of having
23 T1DM.

1 *My big thing is trust... trusting that they will do the common-sense things when you are not*
2 *around to keep themselves safe.*

3

4 Parents spoke about needing to know how to allow their adolescent autonomy when the risks
5 of poor management were so great, particularly when physically active, and how to deal with
6 the mismatch between their adolescents accepting responsibility for their T1DM and the
7 freedom they wanted.

8 *My biggest challenge is knowing when to step in, so when to give them that autonomy,*
9 *because they are right at that age [of wanting to be independent].*

10 Parents were keen to exchange experiences and asked each other questions during the focus
11 groups about how to “let go”. One solution they mentioned was learning from other parents
12 who had been through it.

13

14 AYA discussed the need for people they had daily contact with to trust them:

15 *...I think that it is better to have someone that trusts you than thinks they know what is*
16 *happening because if they think they know what is happening, they don't.*

17

18 Stigma

19 AYA were challenged by the equipment they needed to wear when physically active, not
20 only because of the awkwardness of being active while wearing equipment, knowing where
21 to put it, or the frustration of carrying ‘a whole lot of stuff to activities’ but also because they
22 couldn't hide it when physically active. The equipment identified them as different. AYA

1 reported it challenging to deal with other people's reactions to seeing them managing their
2 T1DM including people '*putting everything down to diabetes*' and giving them unwanted
3 special privileges or sympathy. They reported wanting to be treated as equals, like '*non-*
4 *diabetic normies*'. Participants talked with animation to each other, and with disbelief, about
5 other peoples' reactions to seeing them manage T1DM.

6
7 For some of the participants, the solution to the challenge of stigma was not to be part of
8 team sports: as '*when you do physical activity individually, nobody has to know that you are*
9 *a diabetic*' and they didn't want to let their team members down. Participants who were
10 involved in team games commented on the importance of being open and honest with team
11 members:

12 *You need to tell your team you have T1DM and give them information that may enable them*
13 *to help if necessary or not unfairly judge you.*

14
15 *I think it is important for others to know that if you're a diabetic you're just as good as the*
16 *person standing next to you for 99% of the time and for that one percent it is important for*
17 *people to know why you are not as good as them.*

18
19 Not all participants were concerned about feeling different. Two participants discussed how
20 they didn't care what others thought and even felt empowered by having T1DM:

21 *I love telling others that I have T1DM and educating them all about it.*

22 Parents discussed the problem of "normalisation" or as one parent put it:

1 *Striking the balance between making your child safe and looking normal is a challenge for*
2 *me. It can come down to your demeanour as to how you approach it so that no one else*
3 *realises that you are doing something additional for your child.*

4 Knowledge

5 Lack of knowledge of teachers, the general community and peers was identified as a
6 challenge for participants. While some parent participants spoke highly about the support
7 provided by school staff, others discussed their concerns about poor internal communication
8 and inadequate staff knowledge about T1DM when their children were physically active at
9 school. For example:

10 *... a while ago x was playing sport and he had a muesli bar and the teacher got cross with*
11 *him. One of the other kids said "No he has to have that" but the teacher still got x in trouble.*

13 AYA described challenges when involved in community sport that appeared to result from a
14 lack of knowledge or consultation. For example, rules in competitive sport such as not being
15 allowed to wear medical bands when playing netball or not being able to carry a lancet device
16 for finger prick checks in some sports made their T1DM management difficult. Many
17 examples were provided at community sports sessions when coaches or assistants treated
18 them inappropriately because of a lack of knowledge or did not listen or trust them.

20 Parents noted there is not a lot of T1DM and sport related education available to sporting
21 clubs and that they often needed to explain it to them and '*scare the hell out of them and*
22 *hopefully they take it on board*'. They commented that they didn't want to be the person
23 having to do this. One solution they identified was to instil confidence in their adolescents to
24 advocate for themselves in the community.

1

2 The need to have considerable personal knowledge was identified as both a challenge and a
 3 key to being physically active. Participants discussed the need to learn from trial and error but
 4 were challenged by the vigilance required to do this. Participants also said that they would
 5 like to be provided with more individualised information about physical activity and BGL
 6 and were keen to attend workshops or camps that focused on this. Participants also discussed
 7 how important it was for friends to have knowledge of T1DM:

8 *Some of my close friends can tell if I am going low... When I was diagnosed with T1DM I*
 9 *talked to them about it and they look out for things.*

10

Discussion

11 Four main themes, representing the main groups of challenges experienced by AYA with
 12 T1DM when physically active and parents of adolescents with T1DM, were developed when
 13 analysing the focus group data.

14

15 Unpredictability and stigma when young people with T1DM are physically active may be
 16 addressed through supporting the development of personal and community knowledge.

17 Studies acknowledge the importance that problem-solving skills play in improving personal
 18 knowledge and glycaemic control, particularly in relation to physical activity [24,25,26].

19 Trial and error is reported to be a good way for young people with T1DM to test professional
 20 advice and adapt it to suit personal needs [27] and is recommended by the American Diabetes
 21 Association [28] for physical activity. Improving knowledge of insulin pharmacokinetics has
 22 been identified as helping patients with T1DM engage in physical activity [14]. Personal
 23 knowledge may not only decrease the unpredictability of the disease but also help AYA
 24 manage feelings of stress related to uncertainty [29].

Enhancing perceived competence in managing T1DM through targeted interventions could improve the ability of AYA with T1DM to engage and persist with physical activity [30].

While T1DM is one of the most common chronic diseases in childhood, community knowledge of this chronic disease seems variable, especially among teachers and other adults who spend time with young people with T1DM when physically active [31]. No specific training for coaches or assistants is currently required by Australian sports organisations to improve their knowledge about the impact of chronic health conditions on physical activity, and no training models appear to currently accredit sports coaches to support young people with chronic diseases like T1DM. Improved community knowledge, that's not left to parents to deliver, may help reduce disease unpredictability through appropriate provision of flexibility and support. However, as identified in this research, coaches and teachers need also to learn to trust that AYA with T1DM are generally experts on their disease management. Instructing coaches and teachers to have an autonomy supportive approach can in turn promote better self-management in AYA with T1DM [32].

Stigma is generally a challenge for people with T1DM [33] and can have several consequences including impaired psychological well-being, compromised self-care regimen, and sub-optimal clinical outcomes [34]. Improved knowledge of a condition is associated with less stigmatization, although the results from educational interventions have been mixed [35]. Increasing the level of personal contact between those living with stigmatized conditions and other people may also be beneficial in demystifying the condition, generating empathy, and reducing negative stereotyping [36]. Involving adolescents and young adults with T1DM in the development and implementation of training programs for peers and community members may help to reduce stigma.

Feeling stigmatised may prevent adolescents with T1DM from integrating fully into their peer group and may inhibit their involvement in team-based physical activity [37], as indicated by our participants. Social connection or relatedness has been found to influence the relationship between stigma and quality of life in adolescents with chronic diseases [38]. Participants reported the important role their peers played for them when they were physically active, advocating for them when needed and helping to reduce feelings of stigma. Peer support programs, although under-researched, have been found to have positive outcomes for adolescents with T1DM [39].

Although many participants discussed the stigma of having T1DM, other participants spoke strongly about not caring about what others thought, and even expressed feeling empowered. The Stigma Empowerment Model [40] suggests that those individuals who can identify highly with their group, despite the associated stigma, are more likely to feel empowered. Understanding individuals who are successful in overcoming stigma, through future research, may help us to alleviate the effects of stigma for others [41].

Parent participants were cognisant of the challenges their offspring faced when physically active and no discrepancies were found between the challenges identified by the adolescent participants and those their parents identified as their child's. However, the parents had challenges of their own. Parent participants struggled particularly with unpredictability and trust. Illness unpredictability can manifest as fear of hyperglycaemia (FOH) in parents of children with T1DM and is associated with negative psychosocial outcomes in AYA with various chronic illnesses [42]. Parental FOH is found to be a barrier to being active for

1 children with T1DM [27]. Closed-loop systems and sensor augmented pumps might help
2 reduce parental worry about hypoglycaemia [43] and improve adolescent confidence when
3 physically active [44]. In the meantime, interventions are necessary to help parents decrease
4 their FOH and improve their quality of life [45].

5
6 In addition, parents need assistance, perhaps through mentors, in determining an effective
7 threshold of parental involvement that is comfortable for both adolescents and parents
8 through the adolescent period [46]. Physical activity interventions for adolescents with
9 T1DM could include parents and focus on ways they can support the autonomy of their
10 offspring while physically active. Parents' concerns and fears about their teen's self-
11 management abilities, particularly when physically active, can heighten parental attachment
12 behaviour and affect the parents' ability to support autonomy development necessary for
13 effective self-care [47].

14
15 As has been found in other research, many parents felt they did not trust school staff for the
16 management of their child's T1DM, particularly when they are active [48]. A review
17 investigating the effects of T1DM on schooling found that teachers felt uninformed about
18 T1DM and were unable or unwilling to offer support [49]. Parent participants also
19 commented on the importance of empowering their children with T1DM with the advocacy
20 skills to respond to adults, at school and in the community, who lack knowledge about T1DM
21 and physical activity.

22
23 This study provides further insight about the specific challenges adolescents, young adults,
24 and their parents may face when the adolescent or young adult with T1DM is participating in
25 physical activity. The findings will help to inform practical guidance to support AYA with

T1DM to exercise safely and be physically active. Most of the AYA participating in the focus groups were partaking in at least 3 to 4 physical activity sessions per week, so the findings may not reflect the experiences of those with low levels of activity. Also, differences may exist between the way mothers and fathers interact with their child about being physically active. Fathers were under-represented in this research. Males, who may experience different challenges when physically active, were also under-represented. Additionally, due to self-selected recruitment, the study may have involved more motivated parents who actively seek assistance and information about physical activity and who were very involved with their child's T1DM management.

Conclusion

Being physically active presents many disease specific challenges for AYA with T1DM and their parents. Interventions are needed that provide AYA with T1DM and parents of adolescents with T1DM more in-depth information about managing physical activity in a manner that enhances their perceived competence and builds autonomy. However, supporting AYA to be physically active requires an approach that focuses also on peers, schools and the general community. The findings from this study require additional research and education in specific settings to develop supportive programs and policies.

Acknowledgements

The authors thank the adolescents, young adults and parent participants for their time and contribution to the focus groups.

References

- [1] MacMillan F, Kirk A, Mutrie N, Matthews L, Robertson K, Saunders DH. A systematic review of physical activity and sedentary behavior intervention studies in youth with type 1 diabetes: study characteristics, intervention design, and efficacy. *Pediatr Diabetes* 2014;15:175-89.
- [2] Chimen M., Kennedy A, Nirantharakumar K, Pang T, Andrews R, Narendran P. What are the health benefits of physical activity in type 1 diabetes mellitus? A literature review. *Diabetologia* 2012;55:542-51.
- [3] Ekland E, Heian F, Hagen KB, Abbott JM, Nordheim L. Exercise to improve self-esteem in children and young people. *The Cochrane Library* 2004.
- [4] Zoppini G, Carlini M, Muggeo M. Self-reported exercise and quality of life in young type 1 diabetic subjects. *Diabetes Nutr Metab* 2003;16:77-80.
- [5] Mulvaney SA, Hood KK, Schlundt DG, Osborn CY, Johnson, KB, Rothman RL et al. Development and initial validation of the barriers to diabetes adherence measure for adolescents. *Diabetes Res Clin Pract* 2011;94:77-83.
- [6] Ryninks K, Sutton E, Thomas E, Jago R, Shield JP, Burren CP. Attitudes to exercise and diabetes in young people with type 1 diabetes mellitus: a qualitative analysis. *PloS One* 2015;10(10):e0137562.
- [7] Rabasa-Lhoret R, Bourque J, Ducros F, Chiasson JL. Guidelines for premeal insulin dose reduction for postprandial exercise of different intensities and durations in type 1 diabetic subjects treated intensively with a basal-bolus insulin regimen (ul-tralente-lispro). *Diabetes Care* 2001;24:625-30.

- 1 [8] ISPAD Clinical Practice Consensus Guidelines 2018 compendium exercise in children
2 and adolescents with diabetes. *Pediatr Diabetes*. (suppl 27). 206-25. 2018
- 3 [9] Riddell MC, Gallen IW, Smart CE, Taplin CE, Adolfsson P, Lumb AN et al. Exercise
4 management in type 1 diabetes: a consensus statement. *Lancet Diabetes Endocrinol*
5 2018;5:377-90.
- 6 [10] Michaliszyn SF, Faulkner MS. Physical activity and sedentary behavior in adolescents
7 with type 1 diabetes. *Res Nurs Health* 2010;33:441-9.
- 8 [11] Maggio, AB, Hofer MF, Martin XE, Marchand LM, Beghetti M, Farpour-Lambert NJ.
9 Reduced physical activity level and cardiorespiratory fitness in children with chronic
10 diseases. *Eur J Pediatr* 2010;169:1187-93.
- 11 [12] Pivovarov JA, Taplin CE, Riddell MC. Current perspectives on physical activity and
12 exercise for youth with diabetes. *Pediatr Diabetes* 2015;16:242-55.
- 13 [13] Martins J, Marques A, Sarmento H, Carreiro da Costa F. Adolescents' perspectives on
14 the barriers and facilitators of physical activity: a systematic review of qualitative studies.
15 *Health Educ Res* 2015;30:742-55.
- 16 [14] Brazeau AS, Rabasa-Lhoret R, Strychar I, Mircescu H. Barriers to physical activity
17 among patients with type 1 diabetes. *Diabetes Care* 2008;31:2108-9.
- 18 [15] Lascar N, Kennedy A, Hancock B, Jenkins D, Andrews RC, Greenfield S et al. Attitudes
19 and barriers to exercise in adults with type 1 diabetes (T1DMM) and how best to address
20 them: a qualitative study. *PloS One* 2014;9:e108019.
- 21 [16] Wysocki T, Taylor A, Hough BS, Linscheid TR, Yeates KO, Naglieri JA. Deviation
22 from developmentally appropriate self-care autonomy: association with diabetes outcomes.
23 *Diabetes Care* 1996;19:119-25.

- 1 [17] Charmaz K. Constructing Grounded Theory: A Practical Guide through Qualitative
2 Analysis. Sage; 2006.
- 3 [18] Patton M. Qualitative Research and Evaluation Methods. Thousand Oaks Sage; 2002.
- 4 [19] Krueger RA, Casey MA. Focus Groups: A Practical Guide for Applied Research.
5 California: Sage publications; 2014.
- 6 [20] Vaughn S, Shay Schumm J, Sinagub JM. Focus Group Interviews in Education and
7 Psychology. California: Sage Publications; 1996.
- 8 [21] Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. Qual Health
9 Res 2005;15:1277-1288.
- 10 [22] Krefting L. Rigor in qualitative research: The assessment of trustworthiness. Am J
11 Occup Ther 1991;45:214-22.
- 12 [23] Tong A, Sainsbury P, Craig, J. Consolidated criteria for reporting qualitative research
13 (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care
14 2004;19:349-57.
- 15 [24] Naranjo D, Mulvaney S, McGrath M, Garnero T, Hood K. Predictors of self-
16 management in pediatric type 1 diabetes: Individual, family, systemic, and technologic
17 influences. Current Diabetes Reports 2014;14:1-8.
- 18 [25] Hill-Briggs F, Gemmell L. Problem solving in diabetes self-management and control.
19 Diabetes Educator 2007;33:1032-50.
- 20 [26] Majumder E, Cogen FR, Monaghan M. Self-management strategies in emerging adults
21 with type 1 diabetes. Journal of Pediatric Health Care 2017;31:29-36.

- 1 [27] Quirk H, Blake H, Tennyson R, Randell TL, Glazebrook C. Physical activity
2 interventions in children and young people with type 1 diabetes mellitus: A systematic review
3 with meta-analysis. *Diabetic Medicine* 2014;31:1163-73.
- 4 [28] American Diabetes Association. "Physical activity/exercise and diabetes". *Diabetes*
5 *Care*. 27(suppl 1). 58-62. Jan 2004.
- 6 [29] Lundman B, Jansson L. The meaning of living with a long-term disease. To revalue and
7 be revalued. *J Clin Nurs* 2007;16:109-15.
- 8 [30] Haslem L, Wilkinson C, Prusak KA, Christensen WF, Pennington T. Relationships
9 between health-related fitness knowledge, perceived competence, self-determination, and
10 physical activity behaviors of high school students. *J Teach Phys Ed*. 2016 Jan 1;35(1):27-37
- 11 [31] Nurmi MA, Stieber-Roger K. Parenting children living with type 1 diabetes: a
12 qualitative study. *Diabetes Educ* 2012;38:530-6.
- 13 [32] Hill E, Sibthorp J. Autonomy support at diabetes camp: a self determination theory
14 approach to therapeutic recreation. *Ther Rec J*. 2006 Apr 1;40(2):107.
- 15 [33] Freeborn D, Dyches T, Roper SO, Mandelco B. Identifying challenges of liv-ing with
16 type 1 diabetes: child and youth perspectives. *J Clin Nurs* 2013;22:1890-8.
- 17 [34] Schabert J, Browne JL, Mosely K, Speight J. Social stigma in diabetes: A framework to
18 understand a growing problem for an increasing epidemic. *The Patient* 2013;6:1-10
- 19 [35] Heijnders M, Van Der Meij S. The fight against stigma: an overview of stig-ma-
20 reduction strategies and interventions. *Psychol, Health Med* 2006;11:353-63.
- 21 [36] Pettigrew TF, Tropp LR. A meta-analytic test of intergroup contact theory. *J Pers Soc*
22 *Psychol* 2006;90:751-83.

- 1 [37] Sentenac M, Arnaud C, Gavin A, Molcho M, Gabhainn SN, Godeau E. Peer
2 victimization among school-aged children with chronic conditions. *Epidemiol Rev*
3 2011;34:120-8.
- 4 [38] Earnshaw VA, Quinn DM, Kalichman SC, Park CL. Development and psychometric
5 evaluation of the chronic illness anticipated stigma scale. *J Behav Med.* 2013 Jun
6 1;36(3):270-82.
- 7 [39] La Greca AM. Peer influences in pediatric chronic illness: An update. *J Pediatr Psychol*
8 1992;17:775-84
- 9 [40] Oyserman D, Swim JK. Stigma: An insider's view. *J Soc Iss* 2001;57:1-14.
- 10 [41] Shih M. Positive stigma: Examining resilience and empowerment in over-coming
11 stigma. *Ann Am Acad Pol Soc Sc* 2004;591:175-85.
- 12 [42] Padilla GV, Mishel MH, Grant MM. Uncertainty, appraisal and quality of life. *Qual Life*
13 *Res* 1992;1:155-65.
- 14 [43] Lawton J, Waugh N, Noyes K, Barnard K, Harden J, Bath L et al. Improving
15 communication and recall of information in paediatric diabetes consultations: a qualitative
16 study of parents' experiences and views. *BMC Pediatr* 2015;15:67.
- 17 [44] Nicholas JA, Gill FJ, Elliott L et al. Sensor-augmented pump therapy in the management
18 of type 1 diabetes: lived experiences of children, adolescents and parents. *Aust Diabetes Educ*
19 2017; 2:30-8.
- 20 [45] Pate T, Klemenčič S, Battelino T, Bratina N. Fear of hypoglycemia, anxiety, and
21 subjective well-being in parents of children and adolescents with type 1 diabetes. *J Health*
22 *Psychol* 2019;24:209-18.

- [46] Monaghan M, Hilliard ME, Cogen FR, Streisand R. Supporting parents of very young children with type 1 diabetes: Results from a pilot study. Patient Educ Couns 2011;82:271-4.
- [47] Dashiff C, Vance D, Abdullatif H, Wallander J. Parenting, autonomy and self-care of adolescents with type 1 diabetes. Child: care, health devel. 2009 Jan;35(1):79-88.
- [48] Särnblad S, Berg L, Detlofsson I, Jönsson Å, Forsander G. Diabetes management in Swedish schools: a national survey of attitudes of parents, children, and diabetes teams. Pediatr Diabetes 2014;15:550-6
- [49] Wodrich DL, Hasan K, Parent KB. Type 1 diabetes mellitus and school: a review. Pediatr Diabetes 2011;12:63-70.

Funding

This research was supported by the JDRF Australian Type 1 Diabetes Clinical Research Network (4-SRA-2015-157-M-B), a special initiative of the Australian Research Council (ARC). Additional support was received from the Centre of Research Excellence grant funded by the JDRF and National Health and Medical Research Council of Australia. One of the authors is supported by an NHMRC Research Fellowship (GNT 1119339).

The authors declare that they have no conflicts of interest to disclose.

Age group (years)	Males	Females
13 – 15	3	4
16 – 18	3	4
19 – 25	2	5
Parents (13 – 15 yr adol.)	1	6
Parents (16 – 18 yr adol.)	2	5
Total	11	24

Table 1. Focus group participants

Figure 1. AYA activity type.

Figure 2. AYA frequency of activity