

“They don’t see it as priority if the kid’s not sporty”: Parents’ perceptions of clinic communication around physical activity to children with type 1 diabetes and their families

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Abstract

Background: The aim of the study was to understand parent’s perceptions of the way in which information about physical activity (PA) is communicated to families by healthcare professionals, and gather their views on the use of digital resources for physical activity promotion to inform the design of future supportive interventions.

Methods: Data were collected through semi-structured interviews with 11 parents (8 mothers, 3 fathers) who had a child with Type 1 diabetes (T1D). Interviews were recorded, transcribed verbatim and data were analysed using thematic analysis.

Results: Perceptions of PA, communication about PA, and the use of digital resources about PA were grouped into 8 overarching themes with 18 sub-themes: (1) Benefits and challenges of PA with T1D; (2) Parental need for more guidance around PA; (3) influence of individual differences on PA communication - relating to i) child’s ‘sportiness’ and ii) healthcare professional’s own PA level; (4) challenges of information-seeking; (5) importance of message pitching, framing and timing; (6) scarcity of digital resources around PA; (7) digital resources as facilitators to PA; (8) challenges for access to, and engagement with digital resources.

Conclusion: Parents perceive PA to be important for children with T1D, but raise challenges to managing PA alongside the condition. They report variation in the way in which PA is communicated according to prior activity level of the child, and healthcare professionals’ own interest in exercise. Parents would prefer to receive more information from clinical teams, provided earlier after diagnosis to reduce the burden of information seeking. They express positive views towards the potential of digital resources in diabetes care, although perceive there to be a lack of ‘trusted’ age-appropriate digital resources for PA promotion in children with T1D.

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Abbreviations

PA: Physical Activity; CYP: Children and Young People; T1D: Type 1 Diabetes

Introduction

In the UK, the 2015-16 National Diabetes Audit identified 27,115 children and young people (CYP) with type 1 diabetes (T1D) [1]. Regular physical activity (PA) is a key component of care for CYP

with T1D [2] with benefits for diabetes management [3]. CYP with T1D should be encouraged to be physically active to develop healthy lifestyle habits, control their weight and mitigate increased cardiovascular risk [4]. However, PA levels in children with chronic disease (including diabetes) are generally lower than the recommended 60 min/day and sedentary time is generally high [5]. Further, the national audit showed that over one quarter of these CYP with T1D aged 12 years and over had high blood pressure (26.3%), and the prevalence of overweight and obesity in CYP with T1D is rising; 16.4% of children aged 0-11 years were classified as overweight, and 16.5% as obese, rising to 18.1% and 20.8% respectively for those aged 12 years and above [1].

Parental concerns around hypoglycaemia can be a barrier to PA in CYP with T1D [6]. Professional support for young people is needed to communicate strategies for managing T1D during exercise [7], although healthcare professionals have reported a lack of availability of resources to help promote and manage everyday lifestyle physical activities [8]. CYP are often comfortable with, or even prefer, electronic media [9], and children with T1D commonly request web-based information and support [10].

To establish the need for digital clinical intervention, research is needed that helps us to understand more about the promotion of PA to children with T1D and their families, including how (and how much) information is communicated to families, and by whom. We need to understand more about the use of digital resources for PA promotion in T1D, and their perceived value to families.

Methods

Aims

The primary aim of the study was to understand the views of parents on how information about PA is communicated to children with T1D and their families. The secondary aim of the study was to understand parents' perceptions towards the use of digital resources to promote PA to children with T1D and their families.

The study employed qualitative research methods, collecting data through in-depth semi-structured

interviews (see Supplementary File 1). During design, data collection, and analysis, we adhered to the consolidated criteria for reporting qualitative research (COREQ) when possible (see Supplementary File 2). Parents were recruited between August 2015 and January 2016 using a purposeful sampling approach with snowball techniques [11]. Parents who had a child under the age of 16 years with a clinical diagnosis of T1D were eligible. This age range was targeted because it enables capture of the views of parents of a child with T1D at various stages of management, including parental management, the early years of child self-management and the transition between the two. An advertisement was placed on an online moderated tweet chat, on a website hosted by a not-for-profit social enterprise aimed at improving lives of people diagnosed with T1D. T1D parent support groups and networks across the UK were identified through professional networks and by using an online search engine, and support group leaders were emailed with request for an advertisement to be circulated amongst group members. Parents were provided with the opportunity to read about the study, and those wishing to take part were invited to contact a project researcher (LdS, HB) directly for more information. The researcher confirmed the parents' eligibility and sought informed consent prior to the interview.

Parents agreeing to participate were scheduled for an interview at a mutually convenient time with a project researcher (LdS=6, HB=5). Participants were given the choice of a telephone interview or, where geographically feasible, a face-to-face interview at the parent's home. The researcher obtained written, informed consent from the parents.

Interviewers were aged between 25-41 years, were female, and were trained in qualitative methods and interview techniques. LdS was a medical student and HB was a health psychologist. Interviews were recorded with the participant's consent using an Olympus Dictaphone.

The interviews were intended to be a free-flowing discussion, directed by the interviewee in an informal conversational style. An interview guide was used which comprised of open-ended questions. Parents were informed that the interview sought to explore parent's views on the way in which information about PA is communicated to

children and their families in the clinic setting, their perceptions of the availability of resources to support active lifestyles, and their views on the use of digital resources for PA promotion.

Interview length ranged from 18 to 54 minutes and the mean duration of interview was 38 minutes. No incentives were offered for participation. The number of parents recruited to this study was based on the number needed to achieve theoretical data saturation [12]. With each interview, the lead researcher (HB) judged whether any new data were emerging that would satisfy the purpose of the research. Fourteen parents expressed an interest in being interviewed and no new data emerged (and therefore data saturation was achieved) at the eleventh participant, at which point recruitment ceased.

The sample consisted of mothers (8/11) and fathers (3/11) and the majority of parents (9/11) had more than one child. Two parents had two children with T1D. The mean age of the child about whom the parent responded was 11.38 years (± 2.69 , range 9–16 years) and the mean length of diagnosis of T1DM was 6 years (± 3.3 years, range 6 months–11 years). All parents chose to be interviewed via telephone.

Data analysis

The majority of the audio recordings of the interviews were transcribed verbatim by the researcher who conducted the interview (7/11), which enabled early familiarisation with the data. Four of the interviews (4/11) were transcribed verbatim by an independent researcher (CL). Participant anonymity was maintained by allocating participants an identification number and using pseudonyms for participants' names within interview transcripts. The researchers made field notes following all the interviews. Field notes and interview transcripts were read three times to enhance familiarisation with the data prior to analysis.

Data analysis was an iterative process using a method of thematic analysis [13]. This involved identifying codes, patterns (themes) and common threads across all transcripts. Codes were meaningful groups of data that captured the essence of the data. NVivo version 10 [14] was used to facilitate the organisation of codes and themes, and has been used previously in similar research [6,15].

Codes were derived primarily from the data (inductive) but could also be theory-derived (deductive) [13]. Data analysis began with an inductive approach where codes were derived directly from the data, to ensure important aspects of the data were not missed. A deductive approach was then taken to allow for identification of a priori codes based on theoretical understanding from the literature. Analysis was iterative rather than a rigid linear process. Examples of a priori codes were: 'parental concerns around T1D', 'importance of physical activity' and 'lack of age-appropriate resources'.

Independent initial coding of four interviews (HB) established major themes derived from the data, which enabled development of a coding framework (HB, AP). A rigorous approach to establish the consistency and replicability of the themes was adhered to [16]. A codebook was developed which included a brief background to the study, a label for each theme, a theme and sub-theme description and example extracts that did and did not illustrate each theme [16]. Quotes belonging to each theme were given to a second coder (AP) to code blind using the codebook. It is recommended that the percentage agreement between two coders should be above 70% to demonstrate acceptable reliability [16]. The agreement was 82%, indicating that the themes were consistent and reliable to a recommended standard. Data saturation was assumed at the point where there was reiteration of earlier responses in later interviews, and no new data emerged.

A reflexive diary was kept by the researchers to acknowledge the potential influence of personal biases, values and judgements, prior to and during the research process [13]. This included their notes relating to their impressions of the interview and participant, and any emerging ideas or early thoughts about potential themes. These notes were utilised in the early stages of data analysis in the generation of themes, and in forming the rationale for any later reassignment of codes or themes.

Results

The purpose of this study was to understand parents' perceptions of PA, and the way in which information about PA is communicated to children in diabetes clinics, their perceptions of available resources around PA, and their views towards the

use of digital resources to promote PA in children with T1D.

Results are presented as eight major themes with 18 corresponding subthemes. Themes are supported by verbatim quotes from parents.

Theme 1: Benefits and challenges of PA with T1D

Parents perceive benefits of physical activity

All of the parents recognised that being physically active was generally important for health. A small number of parents directly listed the chronic diseases that could be prevented through active lifestyles, and some reported on the knock-on effects for other health behaviours: ‘when she’s exercising, she tends to eat better’ (P08, Mother). Four of the parents interviewed recounted the specific benefits of PA for the management of T1D, although these parents had all indicated that they had a child who was particularly athletic or ‘sporty’: ‘It’s obviously important for any child to be active but I think with diabetes it can be an extra help’ (P06, Father). An awareness of the health benefits of PA and the link between active lifestyles and improved longer-term management of T1D, was demonstrated by four parents. For some, this specifically related to the impact that PA had on the condition, in particular, glycaemic control: ‘I notice...how she needs less insulin when she’s exercising’ (P08, Mother); ‘what we’ve learned is that physical activity keeps the spikes and the lows more moderate so you don’t fluctuate as much... the physical activity just makes that more stable’ (P04, Mother).

For others, it was related to an overall level of fitness that enabled the child to better manage T1D complications, or recover more quickly from general illness: ‘Just the fact that he’s got stronger, physically stronger and fitter it helped him out.... getting physically strong better reserves in terms of if he is hit by an illness, he’s not kind of down and out...he recovers a lot better’ (P06, Father).

The psychological benefits of being active were referred to, although this was not spoken about as an outcome of the PA per se, but was more commonly discussed with regards to the potential for improving the child’s self-confidence, and helping to generate feelings of autonomy and ‘mastery’ when the child successfully overcomes

the challenge of being active alongside T1D: ‘self-confidence and ... ability to manage different situations because the complexities of having to deal with the diabetes relating to exercise’ (P06, Father). However, six of the parents talked about PA in relation to general health only, and did not associate PA with diabetes management or outcomes.

Physical activity should be normalised for children with T1D

Parents were generally concerned that children with T1D are already ‘different’ to some extent, but that PA is part of normal life and something they should not be afraid of. A few of the parents referred to an avoidance of PA due to fear of hypoglycaemia, although there was a prevailing belief that PA should be normalised as far as possible and that children with T1D should not be excluded from physical activities because of their condition: ‘You know I think it’s important for everybody anyway but I think it’s really important that diabetics that are encouraged to keep up with it and not be frightened really’ (P03, Father). Physical activity was described as ‘business as usual’ (P03, Father) and managing PA: ‘like everything with type 1 diabetes, becomes your new normal’ (P03, Father).

Healthcare professional’s approaches were seen to be influential in normalising PA and reducing the anxiety for parents that was often apparent: She [nurse] made it seem like ‘well just have a go’ and it was kind of probably took the stress out of it by saying there’s no reason why not and helped us manage rather than saying it’s a really difficult and you’ve got to be careful which I think that would kind of put some kids off’ (P03, Father).

Physical activity generates specific challenges for the parent

Parents reported the difficulties associated with their child maintaining blood glucose levels during PA, and they reflected on the practical and emotional challenges it created for them as a parent. The high level of commitment involved in caring for a child with T1D was notable. This was manifest in reports of the effort and commitment involved in needing to continually monitor their child’s activities, and the need to: ‘make sure we’re testing at the right time while they’re doing physical activity’ (P04, Mother). ‘Parents described a ‘workload’ (P07; P09, Mother) involved in ensuring that blood glucose tests are undertaken before, during and after activity and throughout the

day in order to control blood glucose levels. A small number of parents described complex strategies used to avoid hypoglycaemia around physical exercise. One mother reported: ‘we set up a system where we give him free carbs ahead of time’ (P04, Mother) and this was described alongside changes to the administration of insulin at particular times to avoid hypoglycaemia. Parents generally reported that the additional effort involved in monitoring diabetes around PA increased the burden of diabetes management, and one parent described ‘sport’ as being ‘the icing on the cake’ and ‘just another thing on top of everything else that you’re trying to fine tune ... and to control’ (P03, Father). For most of the parents, this was something they accepted and ‘just get on with’ (P10, Mother) in order to normalise PA. However, a small number of parents admitted that they found managing fluctuations in blood glucose very challenging; for some it was a source of anxiety: ‘I find the whole sport and activity quite stressful’ (P01, Mother), which for some resulted in them avoiding advocating PA: ‘if she goes swimming then her sugars are all over the place and so being honest, I don’t encourage her to do it’ (P11, Mother). Three of the parents reported noticing marked variations in the way in which other families managed their diabetes, with some families being highly anxious about the diabetes and PA and/or engaging in ‘strict regimes to manage blood sugars’ (P11, Mother) around exercise, whereas others were seemingly unconcerned: ‘parents don’t really understand and the kids don’t really understand what’s going on and they’re kind of disengaged from it all ...’ (P04, Mother).

Theme 2: Parental need for guidance around physical activity with T1D

Feeling uninformed about physical activity

It was common for parents to feel uncertain about PA and they reported lacking information from the clinics about how to manage everyday PA. One parent reported that nurses had a ‘limp attitude’ (P03, Father) towards PA, and stated: ‘our nurse just said ‘just have a go and see what happens’ and I was thinking well what am I supposed to do with that, what does that mean?’ (P03, Father). Uncertainty was evident in relation to the types of activity a child with T1D could engage in, and parents felt unprepared for the effects of exercise on

glycaemic control: ‘So I personally had no idea how, two hours later how it [the exercise] would catch up with him. No idea about different types of sport, what that could do, you know, aerobic and anaerobic’ (P03, Father). This translated for some into an expressed need for more information: ‘Need something I can look at later but you’re not really given anything’ (P10, Mother). This was often coupled with a hesitancy to contact clinical teams with what they perceived to be small queries about everyday activities such as swimming, or walking to school: ‘I’ve felt a bit lost with it all and something to take away and look at home would have helped but we didn’t get anything, they said we can call but you’re not going to call a hospital just to ask that, are you?’ (P10, Mother). Many of the parents indicated that they needed more guidance about PA and T1D, with specific strategies to try: ‘what we got the first year was conceptual information. I receive information better when it is clearly stated, when it is more directive, more prescriptive’ (P08, Mother).

Limited discussion about physical activity in routine clinic appointments

Only two of eleven parents indicated that there was discussion about PA during clinic appointments, and both of them proposed that PA was discussed at only one appointment per year: ‘It gets discussed in your annual review because there’s lots of things to cover in that checklist thing as part of the things they talk about, again that she understands the importance of a healthy lifestyle, we don’t normally talk about it as far as the other three appointments’ (P05, Mother).

Nine parents reported that they had not received any information from the clinic that was specifically relating to PA with T1D: ‘I don’t feel that we have had much information’ (P01, Mother). The rationale for this from two of the parents was that their child was not particularly sporty: ‘probably because she doesn’t do like organised swimming or anything like that’ (P05, Mother). Some of the parents attributed the lack of clinic discussion about PA to the limited time available within clinic appointments: ‘Because we only have 20 minutes so we focus on the basics’ (P02, Father). A few of the parents suggested that the volume of information being discussed in clinic early after diagnosis meant that exercise was not the focus of attention at the outset, as the family

adjusted to the condition: ‘Exercise isn’t something you’re necessarily thinking about when you’re in clinic, especially earlier on when you’re trying to get to grips with it’ (P09, Mother). Whilst parents felt that they were adequately provided for in terms of access to qualified healthcare professionals to answer their questions, many of them felt they were left to lead topics for discussion: ‘they don’t tend to give us information without us asking for it’ (P01, Mother). Several parents indicated that they were not likely to initiate discussion themselves about PA during the clinic appointment, if the healthcare professional did not raise it: ‘I’m sure they’d tell you if you asked, but there’s so much to take in you don’t always ask do you?’ (P11, Mother); ‘I’ve not raised it as an issue so they probably thought ‘well we don’t need to talk about that, we’ll talk about other things’’ (P05, Mother).

For some of the parents, the lack of discussion about general physical activities resulted in feelings of frustration that they were ill-equipped at the point of decision: ‘if they don’t bring it up then you don’t, and then you have no idea what to do really when it comes round to him saying ‘mum, can I do football on Saturday?’ (P10, Mother). Several parents reported that they would have liked to have been given information about general PA to take home, and that the lack of discussion about PA in clinic appointments resulted in them seeking information themselves at a later date, albeit with some concern regarding the trustworthiness of the information they accessed: ‘...I don’t have anything I can look at outside of the clinic except what other mums have given me, though I don’t always know where that’s from’ (P09, Mother). The prevailing view was that PA was not discussed in clinic appointments as much as families would like: ‘I don’t think it is discussed enough and I don’t think it is discussed in the level of detail that a parent or a child needs to be able to do something about it’ (P08, Mother); ‘clinics should be offering a little bit more’ (P01, Mother). However, there was recognition that healthcare professionals were aware that parents need more support around PA: ‘I think they are aware that there is a gap there and they’re trying to fill it’ (P01, Mother).

Theme 3: Influence of individual differences on physical activity communication

Physical activity is more likely to be raised with families of sporty children

There was a general consensus that PA was more likely to be discussed in clinic if the children were particularly athletic or engaging in competitive sport, and: ‘if they’re not, well it’s probably not seen as an issue, and it doesn’t really come up in clinics...they don’t see it as priority if the kid’s not sporty’ (P09, Mother).

Clinical teams were perceived to be sympathetic towards those parents with athletic children, and parents reported compassionate responses from their clinic consultant: ‘he said...managing a diabetic is difficult, managing a sporty one is even harder’ (P03, Father). Two parents with athletic children indicated that sport and exercise was regularly discussed with the hospital team: ‘obviously it comes up every time because it’s a big part of what he does’ (P06, Father). Nevertheless, these parents still wanted further expert advice around competitive sport: ‘people have mentioned specialists but they tend to be more, working on... you know, working with professional athletes at an older age’ (P06, Father). Although most of the parents indicated that discussion about PA was targeted primarily at sporty children, conversely, one parent with a less active child attributed the lack of discussion about PA to the fact that her child was ‘slim and fit looking’ (P05, Mother) and inferred that healthcare professionals would not be likely to raise a need for them to be more active for this reason.

The influence of healthcare professional’s own physical activity interests

It was clearly evident that parents perceived differences between healthcare professional’s engagement in discussion around PA according to their own PA levels, or their personal interest in sport. Parents commented that PA was: ‘not really the focus of conversations in clinic probably because she’s [nurse] not that bothered about sport’ (P02, Father); ‘she’s [nurse] not really said a lot about sport but she’s not the type, I don’t think she’s that way inclined’ (P11, Mother).

Healthcare professionals who promoted PA were commonly seen to be doing so because of their personal interest in exercise, and their health-

promoting activities were often compared with the behaviour of clinic staff perceived to be less interested in PA or less active themselves. Parents believed that: ‘if they do it themselves they’re more likely to try to get you interested in it’ (P09, Mother), and that healthcare professionals who were ‘into running marathons’ (P10, Mother) were more likely to ask children about their physical activities. One mother reported: ‘We have one dietician that talks to us about being active all the time, but she’s super-fit and does a lot of exercise herself so you can see she is really interested in it, in keeping the kids fit and healthy, so it always comes up, the other’s don’t raise it very much’ (P07, Mother). This represented a strong justification for differences that parents observed in health-promoting activities between clinic staff, ‘if they’re not into it themselves they’re not gonna be focusing on getting the kids up and running round are they?’ (P07, Mother).

Theme 4: Challenges of information-seeking

Labour involved in sourcing information

Given the perceived lack of discussion around PA in clinic appointments, parents frequently referred to the significant ‘labour’ (P02, Father; P09, Mother; P11, Mother) involved in searching for information about PA with diabetes: ‘I basically had to find all the information myself – that’s what it felt like at the time’ (P03, Father). Parents highlighted that they needed to be ‘proactive in asking questions’ (P08, Mother) about PA whilst in clinic, or it would not necessarily be raised by staff: ‘they don’t get to it, there’s too much to discuss’ (P08, Mother). However, several parents noted that they would not think to raise questions until the point of decision arrived when the child wanted to engage in an activity such as football or swimming: ‘you don’t think ...and then suddenly she’s talking about swimming and you don’t know what to do’ (P11, Mother). It was generally felt that the families would differ greatly in their willingness to invest time in self-seeking information: ‘I’m sure that some children will just avoid it or not do it because it’s too much hard work...it depends on how motivated they are personally to go and find out about it’ (P03, Father).

The motivation and discipline involved in sourcing health information was described as: ‘hard work, it’s the hardest thing we’ve ever done and I do think

that will put some people off and just not do it’ (P03, Father). Families wanted increased guidance from clinical teams on sourcing quality information about PA with T1D: ‘well they know their stuff and could save us a lot of trawling really’ (P09, Mother). One father used phrases such as ‘unable to find anything’, ‘didn’t know where to start to look’, and ‘cobbling pieces of information from all over the place’ (P03, Father).

Families differ in whether they actively seek health information

Parents described marked differences between families, and children, in whether they actively sought health information. They referred to the challenges of meeting the needs of parents who did not actively seek out information, and those families who were ‘out of reach’ and ‘disengaged’ with the clinical teams: ‘those families whose parents don’t really understand and the kids don’t really understand what’s going on and they’re kind of disengaged from it all’ (P04, Mother). Two parents alluded to health inequalities, and the potential influence of cultural barriers on health-seeking behaviour. They highlighted the risk for lowered engagement with diabetes services in families that were less familiar with the UK National Health Service (NHS) and a need for ‘understanding the needs of the different youth groups’ (P04, Mother).

There were marked differences in the way that parents described their children with regards their health information seeking behaviour. Some parents had children who self-sourced information: ‘she quite frequently comes up with random bits she’s found’ (P05, Mother), although they noted that this required parental monitoring as the information may be irrelevant, inaccurate or of undetermined quality. Many of the parents felt that their child did not actively seek information either about their diabetes or about PA, and although this was certainly the case for parents of all of the youngest children (who may be less likely to be accessing the internet independently), it also applied to parents of older children and so differences in information-seeking are perhaps attributed to individual differences rather than age. Some parents conveyed that personality traits may prevent their child from asking questions about PA in clinic appointments: He was extremely shy anyway and he was before and he still is now really so he would probably

never go and say “I’ve had this issue with my exercise what do I do?”...’ (P03, Father). The concept of ‘diabetes ownership’ (or lack of) was alluded to by four of the parents, who described the challenges involved in getting their child to take on board even the most basic and critical information about their diabetes. These parents attested that their child would not actively seek information (either verbally or online) that was not directly provided to them by the clinical team: ‘I think the problem at this age is, as much as you’d love them to be taking control as in taking interest and ... taking that on board and then working with the hospital, its much more, it feels as though it’s a nag from the hospital as well as the parents so it’s kind of listening to what’s essential more than taking it on board, taking ownership’ (P06, Father).

Theme 5: Importance of message pitching, framing and timing

Talking about sport is not motivating for many families

Parents frequently alluded to the physical activities of daily life and only two parents explicitly talked about their child being engaged in ‘sports’ (P06, Father; P11, Mother). It was highlighted by many of the parents that the use of the terms ‘sport’ and ‘exercise’ might be off-putting for those children (and families) who do not consider themselves to be sporty, even if they are regularly physically active, and they recognised that this may prevent them from seeking out information about PA and T1D, or paying due attention to information about T1D and sport if this was raised by a member of the clinical team. They proposed that some parents of children with T1D: ‘just don’t realise that any type of walking or exercise can bring on hypo’s pretty quickly, unless you have pre-empted that and given something or reduced something to kind of catch it before it happens’ (P03, Father), and this lack of knowledge was seen to put children’s health at risk. Parents used phrases such as ‘sport isn’t her thing’ (P05, Mother) and ‘exercise isn’t really a huge motivator’ (P05, Mother).

Parents felt that some children were active but did not consider themselves to be as they didn’t engage in sports: ‘Despite the fact that she doesn’t think she does exercise, that’s what she’s doing last week, this week and next week...’ (P05, Mother). It was noted that healthcare professionals needed to discuss PA in the context of lifestyle behaviour (e.g.

running around the garden, walking to school) and that some families may need support with these activities: ‘Lots of children are probably not footballers or swimmers for example, but they might do something else that still uses up quite a bit of energy, and need help, and might be managed in the same sort of way...because if it [health advice] seems to be just focused on your traditional sport you lose a lot of children’ (P05, Mother).

Parents want information about physical activity and exercise earlier

Information about PA (or sports and exercise) with T1D was generally seen to be offered too late: ‘probably a year after she was diagnosed’ (P08, Mother). The lack of knowledge at the outset contributed to the burden of information-seeking and self-education for some families: ‘by the time I’d accessed the professional information from [consultant] and understood what the dieticians were talking about we probably learnt it along the way’ (P03, Father). This seemed to be the case for the majority of the parents irrespective of the prior activity level of their child. Unavailability of information at the time it was needed seemed to create unnecessary emotional stress: ‘You panic at the start, you’re going to the other families and asking them what they do and how they cope, and whether it’s ok’ (P02, Father); ‘kids are just going to start running round without thinking about it, aren’t they, and if you don’t know what it all means it’s worrying’ (P09, Mother). Some parents indicated that receiving more information at the outset may have alleviated their stress, provided reassurance, or reduced the burden associated with accessing information: ‘it’s months and years of findings scraps of information, not sure whether it’s right or not. Do this, don’t do that. Why don’t they give you this at the beginning so I didn’t have to spend all that time searching and asking questions?’ (P11, Mother).

One parent whose child engaged in competitive sport raised the need for an early, personalised approach depending on the activity level of the child, and indicated that following the T1D diagnosis: ‘not a lot of emphasis to us was put on managing sports and perhaps we were managing a lot more sport than other people’ (P03, Father). Some patients felt either lost or frustrated by the ‘trial and error approach’ (P10, Mother) advocated by their clinical team. One father stated: ‘our

particular nurse at the time had a very laid back attitude and it was kind of ‘let’s just see what happens’ and I was thinking in my head ‘well where do I start with this? What do you mean let’s see what happens?’ (P03, Father). Whilst recognising that children vary in their responsiveness to particular strategies, parents alluded to a preference for more prescriptive information being given in the early stages following diagnosis: ‘it is very important for the doctors and for the nurses to be very specific and at least to give you tips to try out...it doesn’t mean that there is one answer for everything’ (P08, Mother). Parents proposed it would have: ‘been less work in searching around’ (P08, Mother), ‘taken that uncertainty away’ (P07, Mother) and ‘would have been ‘invaluable’ (P10, Mother).

Theme 6: Scarcity of resources for children with T1D

Lack of suitable digital resources about physical activity with T1D

It was evident that there was a lack of resources about PA targeted towards children with T1D and their families. The vast majority of the parents indicated that they had not been provided with any resources relating to PA or sport by the hospital clinic, at any point since their child was diagnosed, with just one parent speaking of accessing an ‘online Powerpoint presentation’ about paediatric T1D by a paediatric dietician (P08, Mother). They all reported that they were not aware of any age-appropriate digital resources that were focused on PA. Those who had actively searched for online information about PA and T1D had been unable to locate any appropriate materials: ‘I’ve not really come across anything to be honest, we’ve searched around ourselves but we didn’t get anything that was all about physical activity and the clinic never gave us anything’ (P07, Mother). A father of a child who engaged in competitive sport had emailed the junior team GB doctor ‘in desperation’ and ‘he just pointed me to a site called runsweet.com’ (P03, Father). Three parents remarked on this particular website, although both testified to the complexity of the materials it contained and inferred that their child would not independently use the site: ‘he wouldn’t necessarily read it but he’d understand it if I explained it to him’ (P03, Father); that it was not age-appropriate for their child: ‘aimed at older athletes really and it seemed a lot, too much’ (P03,

Father); or that it was ill-suited to less sporty children: ‘she doesn’t do any proper sport if that makes sense... I’ve not felt it necessary to look into that at the moment because she doesn’t do that intense of an exercise’ (P05, Mother). Overly complex materials were daunting for some parents and created barriers to exercise for the child: ‘it put him off because it was all really complex, aimed at kids who are proper athletes and no doubt sporty parents, but we’re not like that, what about your average kid that just wants to know what to do at swimming lessons or running round’ (P10, Mother). The lack of availability of suitable materials was clearly evident, and parents proposed the development of online resources for both children and parents, although it was highlighted that resources should not be at financial cost to families: ‘If it going to cost something we would perhaps be put off straight away’ (P01, Mother).

Theme 7: Digital resources as facilitators of physical activity

Role of digital resources in facilitating health education and diabetes ownership

All parents attached value to potential provision of digital resources for promotion of PA: ‘something simple and aimed at children at different stages would be really, really useful’ (P03, Father). Parents spoke of ‘education’ (P05, Mother), ‘learning’ (P07, Mother), ‘self-improvement’ (P09, Mother), ‘control over health’ (P10, Mother) and ‘ownership’ (P02, Father; P11, Mother). Many of the parents referred to the benefits of having information readily at hand, and accessible away from the clinic setting, ‘it would be invaluable for them to have something available’ (P03, Father). The notion of concurrent and shared learning between parent and child was alluded to: ‘she’ll learn things that she wouldn’t learn otherwise and I might learn things as well. We like to learn things together anything that makes coping with diabetes easier is good’ (P05, Mother). One parent referred to the ‘great satisfaction’ (P05, Mother) her child would likely feel through engagement with, or completion of digital materials. Six parents proposed that digital resources may encourage the child to take ownership of the T1D: ‘take ownership and understand it’ (P08, Mother), particularly if the resources were child-centred: ‘if there was something that he could think ‘oh that’s

just for me and not for my mum... just for me' (P03, Father).

Parents highlighted that digital materials should be engaging and not simply instructional, without reprimanding the child for being sedentary or failing to manage their T1D, and aimed at stimulating goal attainment without criticism or judgement: 'It's not about being told off or told the right thing to do somehow. It seen as something fun to do, perhaps challenging yourself rather than being marked on what you've done, it's improving yourself...' (P05, Mother). For the child to take ownership, parents proposed that the digital resources should not be sourced by the parent: 'if it was someone else saying, it would probably have a more positive effect' (P05, Mother); whilst raising the challenge of 'how to get it to them without thinking mum has pointed them in that direction' (P05, Mother), and providing a solution of materials 'coming from a clinic, or if Diabetes UK were publicising it that would help'. (P05, Mother). One father suggested that sports role models may be important for children to engage with online resources, and proposed that materials should be 'spearheaded by those people' and that 'they'd listen to a role model rather than parents or the hospital' (P06, Father).

Digital resources as a platform for engaging the child in self-care

Parents wanted their child to engage in self-care and take responsibility: 'you can put all the options in front of them and hope' (P03, Father). They generally believed that involvement in diabetes self-care would increase with greater availability of options, including digital resources, and this would be a 'powerful way to connect with them' (P04, Mother). Children were described as being naturally 'inquisitive' (P04, Mother), and so parents believed that digital resources aimed at children would be most useful if they contained interactive elements: 'like...we've added this bit here, have a look at this' (P05, Mother). Parents believed children and young people preferred digital information: '[son] would prefer something that he accessed online because that's pretty much ...how they work' (P01, Mother). Digital resources were perceived to be a conceivable mechanism for engaging children's curiosity: 'makes them want to log in again and have a look and see what's happening' (P05, Mother). Six of the parents

referred to the possible opportunities afforded by digital tools for social contact and support. They proposed that children could 'swap ideas' (P03, Father) and 'connect with other kids who are in similar situations to them' (P04, Mother). Parents highlighted the value of embedding information within online resources relating to local or regional events and activities.

Several parents alluded to the fact that continual parent-child discussion about T1D could be burdensome and generate emotional labour, and that digital tools might provide an opportunity for independent learning whilst allowing the child to be 'ordinary': 'particularly in the teen years you [parent] become white water noise, you're asking them to do this, read that... but sometimes, particularly for this age group they just want to go out and be normal teens and it just another burden and we've talked about it enough all day' (P03, Father); 'there's a point where she wants everybody to stop talking about diabetes' (P08, Mother).

Four of the parents highlighted that a child engaging with digital resource about PA may be more inclined to independently initiate discussion about PA in clinic appointments, for example, to 'discuss their learning and how it relates to their activities and sugar levels' (P09, Mother), and to 'share their activity goals and achievements with the nurse or dietician' (P10, Mother). Similarly, they noted that it may serve as a discussion point about PA for healthcare professionals: 'we can talk about it next time you come' that might be a nice prompt' (P05, Mother). Parents alluded to the self-care goals that children might attain, for example, if they had completed some online learning, or undertaken a programme of PA tracking and reached their target. One mother indicated that, at the child's annual review, 'to be able to say that she's done that would be quite something...And I think the clinic would, they'd like it as well because they'd think 'well done you, what have you learnt?' and engage them that way' (P05, Mother). Most of the parents commented on the potential for digital resources to support the child in learning to manage their condition and one alluded to the emotional support this would provide to the parent: 'My biggest worry is that he doesn't think and that he launches straight into something and hasn't properly prepared and any extra help with that is going to give me more piece of mind' (P01, Mother).

Theme 8: Challenges for access to, and engagement with digital resources

Importance of trust in the information source

Parents referred to the high volume of health information online, and their concerns over the quality of materials. They referred to ‘much conflicting information’ (P02, Father; P07, Mother) and being ‘wary about any information out there that could send them off on the wrong track’ (P03, Father). Information signposted by, or coming from the clinical team was seen to be more credible: ‘if you get it from the hospital you know that all the checks as far as possible have been done to make sure the information is as good as it can be’ (P03, Father) and ‘for it to have some kind of accreditation or some acknowledgement that it’s approved by ‘whoever’ it kind of adds a bit more substance to it really’ (P03, Father). Most of the parents alluded to the importance of ‘trust’ in the information source; they referred to the value of PA ‘messages being put out by the clinic’ (P04, Mother) through nutritionists or clinicians, and several parents used the phrase ‘endorsed by the hospital’ (P02, Father, P07; P09; P10, Mother). One parent suggested the use of individual passwords from the clinic to increase trustworthiness in accessing digital resources: ‘so that you couldn’t get people joining in who perhaps shouldn’t be there’ (P05, Mother). One Mother referred to a need ‘to see what security is set up’ (P08, Mother). Although all of the parents indicated they would have no concerns about information that was provided by the hospital team.

Challenges in pitching digital materials

The challenges of pitching materials were alluded to, since PA was seen to be a ‘very individual thing’ (P03, Father) depending on the PA level of the child and the family, and was recognised to be complex: ‘it’s a bit of a minefield’ (P06, Father). Parents communicated that with regards health information, ‘one size does not fit all’ (P11, Mother) and that the level of interest would ‘very much depend on the age of the child’ (P03, Father) as well as individual interests, personality traits, prior exposure to technology, the gender of the child, developmental capabilities and the child’s readiness for self-care. Two mothers suggested that the optimal age for digital intervention would be around 10-12 years. One reported that that children most likely to be

engaged would be ‘just starting secondary school’ (P04, Mother); another recounted that her daughter was ‘eleven and fairly malleable...I think now she’d probably be quite keen’ (P05, Mother). Several parents highlighted the challenges of creating materials for adolescents: ‘13 year olds may not be quite as enthralled’ (P05, Mother); ‘teenagers are really difficult because it’s got to be something cool’ (P06, Father). The nature of the digital resource and the way in which information was presented was viewed as important in ensuring materials were age-suitable: ‘the way the information is pushed out...if it’s a huge essay they’re not going to read it but if it’s a small tid-bit of information...’ (P04, Mother). They reflected on the importance of simplified materials: ‘nice and simple basic facts ...maybe with colours or pictures or reminders and characters, that seems to speak better than giving them lots of things to read’ (P03, Father).

The nature of the presentation of materials was seen to be important. It was felt that many children would not respond well to an instructive approach: ‘it musn’t come from a preachy ‘you must do more exercise’ angle’ (P05, Mother), but would respond more positively to suggestions about how PA might help them to better manage their diabetes, perhaps including: ‘nudges and notifications’, ‘inspiring stories for kids and young adults’ (P04, Mother), ‘role models’ (P02, Father), ‘an online community’, ‘online games’ or ‘online reward systems’ (P08, Mother). Although parents universally referred to the importance of information being delivered or endorsed via healthcare systems, there was a concern that: ‘NHS information may be viewed as boring by children’ (P04, Mother) and would result in: ‘an uphill battle to get people engaged’ (P04, Mother). One mother proposed that healthcare organisations would benefit from ‘partnership with an organisation that knows how to push out and connect with kids’ (P04, Mother). Two of the parents referred to the emotional impact on the child of diabetes, and the need for digital tools to focus on the positive aspect of exercise and T1D rather than generating fear: ‘I would portray the information as tools for them to feel better as opposed to preventing complications’ (P08, Mother).

Balancing engagement with labour

Parents were cognisant of the labour involved in managing T1D and the potential for digital resources around PA to become an additional arduous activity that would add to the heavy burden of condition management. One proposed option to reduce labour and increase the likelihood of engagement was: ‘to link in with what they already do, rather than it being parents and hospitals saying: “Look, come and look at this thing...”’ (P06, Father). Parents referred to digital resources that contained information alone; some parents felt their child would enjoy the reading and ‘dipping in and out’ (P07, Mother), although this was more likely to be acceptable to older children whereas parents of younger children felt that they may not read through web-based materials independently. Given the labour involved in the child in utilising digital resources and difference in individual learning styles, parents perceived likely variation in the level of engagement between children, with some children requiring face-to-face discussion for learning; as such a combination of digital resources and face-to-face discussion would be important. One mother stated: ‘the kind of engagement you get from a digital product is different than the sort you get say from a health educator that’s going to say ‘right we need to teach kids that physical activity is important’ (P04, Mother). One parent referred to the potential benefit of ‘little pushes of information’ for younger children (P04, Mother). Other parents felt that their child would become bored without a greater level of interactivity. Digital resources that include interactive elements, such as PA tracking, generated both positive and negative feelings related to the perceived amount of effort involved. Six parents felt that tracking would be motivating for the child and empower them to think about their own health: ‘if they could see how much they were doing and make a little plan to stick to, it would spur them on’ (P11, Mother). Two parents mentioned that adding PA tracking to digital resources (where children were required to enter information themselves) would prevent children’s engagement with the resources. One reported that ‘the added thing of tracking your physical activity I think that’s going to be a barrier’ and referred to health resources they had seen where ‘people don’t keep using it because it’s just too much’ (P04, Mother). This mother likened the concept to digital weight management tools for adults, where ‘they

get fully stuck in for two weeks and then it becomes oppressive and they can’t do it anymore’ (P04, Mother). Several parents referred to the potential benefits of using automated methods of activity tracking, such as wrist-worn activity monitors: ‘a lot of kids engage with the statistics side of it don’t they, so it might be quite good’ (P06, Father).

Challenges of technological advancement

Many of the parents referred to the changing nature of technology and the need for digital intervention to address the needs of today’s children and young people. Providing digital materials was seen to be the most preferable method of delivering information to children and young people: ‘this generation responds to that more than anything’ (P08, Mother). However, they spoke of technology ‘changing radically over the next few years’ (P02, Father) and the need to ensure that digital materials were accessible on mobile devices, due to the ubiquitous nature of mobile phones meaning information would be highly accessible (‘seeing as they’ve got it with them’ P07, Mother), and also because advances in technology will change the preferred medium: ‘internet connectivity on mobile phones has surpassed desktop access’ (P04, Mother). However, one parent warned of the challenges for some families if some aspects of clinic-delivered information were to be fully replaced by digital materials and spoke of concerns relating to ‘the assumption that everybody’s got access to internet’ (P05, Mother).

Discussion

This study highlights a need for more information and support around PA in parents of children with T1D, and demonstrates parent’s positive attitude towards the use of digital resources for this purpose.

This study supports prior work showing that parents feel positively towards PA and feel that efforts should be made to normalise PA for children with T1D [3]. Parents experience significant challenges when their child engages in PA, sport and exercise as identified previously [3]. Parental fear of hypoglycaemia has previously been identified as a barrier to PA [17] and our discussions with parents suggested that a lack of knowledge or confidence about PA may reduce PA engagement of children with T1D.

It has been shown that parents value the support they receive from diabetes clinics [3], and believe that their experiences should be a focus for diabetes teams [18]. While the internet could be used to satisfy parental need for information and support [18,19], in the current study, parents feel that more information about PA with T1D should be provided to them by clinics at an earlier stage to reduce the ongoing family burden of information-seeking from potentially unvalidated sources. Indeed, recent research has warned of the risks of online information with regards whether it is accurate, understandable or provided by health professionals or advocacy groups [20,21]. We found that health information about PA is more likely to be trusted when it comes from, or is endorsed by the clinical team, although parents highlight that PA is not commonly discussed in routine clinic appointments and resources are not routinely provided to CYP and their families relating to lifestyle PA.

Interviews with parents suggested that information coming from clinics should include the relationship between lifestyle PA and T1D rather than focusing only on 'sport and exercise', and use of the term 'sport' may be off-putting and deter some families from engaging. Parents in this study reported that clinic discussion around PA is seen to be reserved for children who were particularly sporty prior to diagnosis and this is concerning since those who are least active may be at increased risk for diabetes complications and chronic disease [22]. Further, PA was seen to be raised only by physically active healthcare professionals showing personal engagement in healthy lifestyles. This parental perception concurs with prior research indicating that the lifestyle behaviours of healthcare professionals may influence their health promotion practices [23,24].

Parents highlight a lack of age-appropriate information and resources around PA in children with T1D. They view digital resources as a potentially useful way of reaching and educating families about PA and supporting the child's ownership of diabetes, so long as the resource is engaging, low-burden for the child and keeps up with rapid advances in technology.

These findings are based on a small sample of parents of children with T1D. Participants were self-selected and as with all qualitative studies, findings cannot be generalised to all parents of

children with T1D. No attempt was made to achieve a representative sample, so the potential influence of demographic factors (such as age, educational level and ethnicity) on participant's views cannot be determined.

The interviews were conducted with English-speaking participants recruited from support groups and a web-based social media site. The findings may therefore not reflect the views of parents of ethnic minority origin, or those who are less actively involved in seeking support for their role in caring for a child with T1D. However, the findings enhance our understanding of parent perceptions of the way in which PA is communicated in clinic settings, and highlight the lack of availability of evidence-based resources for families relating to PA, and parents' positive views towards the use of digital resources for PA promotion.

Conclusion

Diabetes healthcare professionals should consider providing families with age-appropriate digital resources to promote PA in children with T1D, early after diagnosis. This may help to promote PA in children with T1D and support clinical teams by serving as an adjunct to routine clinic discussions to facilitate communication about healthy, active lifestyles.

Declaration

Ethical approval and consent to participate:

Written informed consent was obtained from all the parents including publication of anonymised quotes. Ethical approval was obtained from the University of Nottingham Faculty of Medicine and Health Sciences Research Ethics Committee (REC reference: G18062015 SoHS).

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