

A qualitative comparison of needles and insulin pump use in children with type 1 diabetes

Journal of Health Psychology
2018, Vol. 23(10) 1332–1342
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DOI: 10.1177/1359105316653999
journals.sagepub.com/home/hpq



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Abstract

Managing type 1 diabetes mellitus is an ongoing and challenging process; we investigated children's experience of different treatment regimens. Interviews with 17 children (7–15 years) at two time points were analysed using the grounded theory approach. Illness phase and treatment regimen shaped how bodily cues were interpreted. Insulin pump therapy allowed children to listen to and trust their bodily cues rather than override. Shame was a barrier to support engagement. Different internalised and externalised views of type 1 diabetes mellitus emerged. Overall, children were insightful experts of their own experiences. Recommendations for psychological interventions would benefit from empirical testing.

Keywords

children, diabetes, grounded theory, health psychology, treatment

Type 1 diabetes mellitus (T1DM) is a complex metabolic disorder typically diagnosed in childhood and characterised by insufficient insulin production (American Diabetes Association (ADA), 2014). Treatment for T1DM is lifelong and intensive, influencing almost every aspect of daily life for diagnosed children and their families (Moreira et al., 2013). The two primary treatment regimens for insulin adjustment are needles (multiple daily injections (MDI)) or the more recent insulin pump (continuous subcutaneous insulin infusion (CSII)). Appropriate management of T1DM holds important implications for a child's psychological well-being (Kongkaew et al., 2014; Lawrence et al., 2006) and identity formation (Charmaz, 1983, 1995). Understanding the psychological wellbeing of children with chronic illness is important for researchers and clinicians, as mental and physical health are closely intertwined (Yi-Frazier et al., 2015; Soo

and Lam, 2009). Children are a unique group as diabetes management takes place within the context of a child's continuing cognitive, psychosocial and pubertal development (Ahmed et al., 1998). Woodgate (2008) termed this a 'dual crisis', as children not only need to deal with complex normative developmental tasks, but must also manage the treatment of a life-threatening illness.

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†The Editor notes with sadness that Doris McIlwain died on 26 April 2015.

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A body of qualitative research has increasingly shed light on children's experience of managing diabetes (Serlachius et al., 2012; Spencer et al., 2010). Koller et al.'s (2015) qualitative study found Canadian children's experiences of diabetes could be categorised into three key areas: self-care, knowledge and a range of constructive and destructive emotions. The authors concluded that children need to be given an active voice in discussions about their treatment and would benefit from ongoing education and emotional support to manage their illness. Schur et al. (1999) found that adolescents (aged 16–22 years) overcame the shock of diagnosis to develop a relationship with diabetes involving acceptance of the illness, and finding a balance between self-care tasks and daily life. Several studies have found that social relationships with parents, peers and teachers are fundamental to the effective management of diabetes in children (Barrera et al., 2006; Spencer et al., 2010). In contrast, Palladino and Helgeson's (2012) review found peer conflict related to poor diabetes outcomes – confirming peer influences to be important although not necessarily playing a positive role. Thus, the role of peer relationships for children with T1DM remains inconclusive.

Specific to CSII, Berlin et al. (2006) interviewed 20 adolescents, and their parents, who had recently transferred to CSII. The most common difficulties involved self-management tasks such as meal planning, insulin administration and carbohydrate counting. Low et al. (2005) found through open-ended questions that families who anticipated CSII would be a 'cure', or who held other unrealistic expectations, generally had poorer medical outcomes. However, underlying themes of how the child understood diabetes or how it shaped their self-concept were not further explored. Given increasing prevalence rates of CSII use and high financial cost (Australian Institute of Health and Welfare (AIHW), 2012; Colquitt et al., 2004), it is of interest to better understand the comparative psychological impact of such treatments.

Method

Study design

In this study, we sought to better understand the complexities of the lived experience of children and how this may differ across MDI and CSII treatment regimens. Grounded theory was used as a conceptual and methodological framework, which positions children as the experts of their own experiences, rather than a predetermined research hypothesis (Charmaz, 1983, 1999, 2002, 2006; Strauss and Corbin, 1990). To capture changes in children's experiences across time, all participants were interviewed at two time points, once while using MDI and again 4 months later. At the follow-up interview, eight children had transitioned to using CSII for at least 3.5 months, and the remaining nine children were still using MDI.

Participants and recruitment

Participants ($N=17$) were all patients of the Children's Hospital at Westmead, Sydney. Eligibility criteria included 7–15 years of age and a sufficient level of English. Of the 25 families approached in person, 17 gave their consent to participate in the study. The most commonly cited reason for non-involvement of participants was a lack of time. We stopped recruitment at 17 as the data had reached theoretical saturation.

Ethics approval for this study was gained from the New South Wales (NSW) Health Human Research Ethics Committee and the Macquarie University Human Research Ethics Committee. Participation was entirely voluntary and participants did not receive any form of reimbursement for their involvement. The study was explained to both the parent and child, and both signed a detailed consent form (the child's version used developmentally appropriate language).

Materials

Interviews. All interviews were conducted by one author (M.F.), a provisionally registered psychologist with experience working clinically with children. The interviews used several broad, open-ended prompts such as 'What's the

first thing that you think of, now, when I say the word “Diabetes?”” and ‘How (if at all) has diabetes changed what you are able to do?’ Whenever possible, the interviewer tried to encourage further elaboration on new ideas or themes by asking open-ended questions which used terminology introduced by the children themselves. Interview times ranged from 8 to 45 minutes ($M=25$ minutes).

Demographic and medical information. At the baseline appointment, parents completed a demographic questionnaire to record the child’s ethnicity, family socioeconomic status (SES as measured by ANZSCO; Daniel, 1983), treatment received at the hospital, date of T1DM diagnosis, most recent HbA1c reading and duration of illness.

Qualitative data analysis

Author frameworks. Grounded theory attempts to address the implicit biases of researcher by recommending the framework and approach of the researchers are explicitly stated. M.F. is a penultimate doctorate of clinical psychology student whose training has predominantly been grounded in cognitive-behavioural therapy (CBT), with an emerging interest in psychodynamic psychotherapy. She is sensitive to emerging childhood pathology such as anxiety or mood disorders as a result of her training. D.M. is a psychoanalytically inflected researcher in the experience of emotion and embodiment and a psychodynamic psychotherapist. As a personality researcher, in addition to exploring empathy, morality and charisma, she is sensitive to how individual differences shape forms of coping. D.M. is also interested in how individuals accord meaning to experiences past, present and future.

Transcript preparation. To optimise objectivity, all 34 interviews were transcribed verbatim using an independent transcription service. M.F. checked all transcripts and minimal changes to the original documents were required. These files were uploaded and coded in NVIVO10, qualitative coding software.

Transcript analysis. We simultaneously collected and analysed data until saturation was reached. Saturation is defined as the point at which no new concepts or relationships are identified, indicating a substantial theory has formed (Fassinger, 2005). Transcripts were re-read several times before coding took place to enhance overall understanding. Transcripts were open-coded line by line while concurrently listening to the digital recordings, allowing more subtle verbal cues such as tone, expression and expressed emotion to also be acknowledged and coded. Simultaneous data collection and analysis also allowed the interview and coding process to inform each other. To improve internal reliability and consistency, a second researcher (D.M.) also conducted open coding on all interviews. Areas of difference or dispute between the two researchers were reconciled through discussion.

During open coding, interesting concepts were labelled as nodes as they arose. We clustered similar nodes into themes and subthemes, and memos (the researcher’s interpretive thoughts) were also recorded. Axial coding (Strauss and Corbin, 1990) identified connections between nodes, reconnecting the coded data in new ways. The broader themes, which arose from the open and axial coding, led to the development of explanatory models. During this process, we used constant comparative analysis (Henwood and Pidgeon, 1992) to draw comparisons between provisional hypotheses and different participants. In addition, negative case analysis involves actively seeking cases or examples that may disprove the theory as it is forming. The final models were validated through their application to individual cases, measuring their idiosyncratic applicability (Strauss and Corbin, 1990). When reporting quotes to illustrate themes in this article, each child was given a pseudonym to protect confidentiality.

Results

Participant characteristics

The participants ($N=17$) ranged in age from 7.3 to 15.5 years ($M=11.8$, $SD=2.4$). Ten of the children were female and 7 were male. The average duration of the children’s T1DM

diagnosis was 1.5 years ($SD=1.8$). One child had a comorbid diagnosis of coeliac disease, two were also diagnosed with thyroid disease and two were also diagnosed with asthma. The average HbA1c result at baseline was 8.3 per cent ($SD=1.4$) and 7.9 per cent ($SD=1.0$) at the follow-up time point. The ADA (2014) recommends 6–8 blood glucose readings per day for optimal control, and on average the children in this sample were slightly below this criterion ($M=5.1$ blood glucose checks per day, $SD=1.1$). The average body mass index (BMI) of the current sample was 20.16 at baseline ($SD=3.8$), broadly classified as a healthy weight range (Centers for Disease Control and Prevention (CDC), 2014).

All children lived in Sydney and the average ANZSCO rating of SES was 2.7 ($SD=1.1$) for mothers and 2.9 ($SD=1.4$) for fathers out of a total score of 8 (high SES: 1–2.5, medium SES: 2.6–5.4, low SES: 5.5–8). In this study, five of the nine children had been approved for CSII provided by state government health funding.

Key findings

Three central themes arose from the data analysis and coding. These included differences in the interpretation of bodily cues across time and treatment regimen, a variety of supports for the child we termed the ‘distributed system of management’ and cognitive representations of T1DM as an internalised or externalised entity. Each theme is described in detail here.

Interpretation of bodily cues. At different phases of T1DM diagnosis and treatment, children experienced shifts in their awareness, interpretation and response to their own bodily cues. Typically, in the general population, the presence of physiological arousal within one’s body is thought to give rise to ‘evaluative needs’ (Festinger, 1954), triggering a sense-making process of searching for causal explanations which can direct appropriate action. For example, general discomfort in the stomach may be interpreted differently depending on the immediate context including indigestion, hunger or

even anxiety. The process of accurate interpretation is important yet often imperfect and further complicated by the confusing symptoms associated with T1DM. Three stages in the process of interpreting bodily cues emerged from the interview data. First, the child paid attention and attuned to sensations within the body, such as pain or dizziness or a vague feeling of discomfort. Second, the child interpreted the cause of these cues and attributed meaning to their presence, for example, disentangling the cause of dizziness as a sign of low blood glucose levels as opposed to a non-diabetes-related cause such as dehydration or tiredness. Finally, based on the attributed meaning, children and adolescents subsequently experienced and engaged with cognitive, emotional and/or behavioural reactions to the sensation. This process significantly changed for children according to the stage of their illness (i.e. undiagnosed symptoms and diagnosis) and type of treatment regimen (CSII and MDI). An explanation of these changes follows here.

Stage 1 – Undiagnosed: Ignoring vague bodily cues. The symptoms of T1DM largely generalised, not specific to one area of the body, and as a result sometimes contribute to a delayed diagnosis or misdiagnosis. Such symptoms include excessive urination, dehydration and acute vomiting (Anderson and Brackett, 2005). Most children vividly recalled an indefinite period of time of noticing uncomfortable and unexplained sensations, which they needed to ignore in order to continue with daily life. Attempting to cope with these untreated symptoms often prompted a disconnect between the mind and body. Jack (age: 11 years) found it difficult to reflect on his experiences during the early phase of present yet undiagnosed T1DM symptoms. Instead of placing 13th in a running race as he had the week before the interview, he recalled that in the past he had run much more slowly:

I used to come, like 30-something [Interviewer: why is that?] I don’t know. I couldn’t run. I don’t know. I didn’t have enough energy. (Jack, age: 11 years)

Stage 2 – Diagnosed: Applying medical knowledge and overriding bodily cues. Diabetes education provided by health practitioners includes informing children about the link between certain bodily cues and potential fluctuations in blood glucose levels. Following a diagnosis of T1DM, children learnt to interpret their bodily cues differently in light of their medical knowledge about T1DM symptoms. In other words, the child's embodiment of their bodily cues became controlled by 'top down intrusions'. This enables children to cognitively override natural body rhythms and psychological sensations to comply with T1DM treatment demands.

Accurately understanding one's bodily state in the context of T1DM required children to use advanced problem-solving skills and flexibility. To further complicate this process of interpretation, bodily cues were often contradictory. Paradoxically, a feeling of greater energy, described by Cathie as a feeling of being 'brighter', could be a symptom of dangerously high blood glucose levels. Thus, positive bodily sensations needed to be interpreted as dangerous rather than enjoyable or as a sign of energy. The uncertainty and difficulty of accurately interpreting such states is reflected by her pauses and repetition of 'I don't know':

[Interviewer: How do you know when you're feeling unwell? What happens in your body?] I just get a bit of a headache, feel a bit dizzy. That's about it ... but when it's low, you feel it. But when it's high, you feel better than what it was, if it's around seven. So when it's high, you feel a lot better. [Interviewer: Oh, that's tricky. How do you know you're high then?] You can't really tell, but when you know it – when you do it and you know it's high, you just feel better ... I don't know. You just feel – you feel like you have more energy. I just notice I can do a lot more. Play the Wii, play with the dogs. So yeah so – I don't know, you just feel more brighter. (Cathie, age: 11 years)

Stage 3A – MDI and bodily cues. Potentially as a result of the medical focus of interpreting bodily cues, many children who were using MDI explained their bodily states quantitatively through reference to their blood glucose level.

Interestingly, the child's focus on blood glucose levels and specific numbers seemed to dominate other alternatives to understanding one's bodily state. For example, the child learns to reinterpret hunger as a sign of hypoglycaemia instead of a body requirement for nourishment.

After considering a complex algorithm of competing factors, children using MDI more frequently overrode natural body sensations such as hunger and sleepiness to comply with their treatment requirements. This process strongly reinforced the mind–body disconnect:

You have to eat more than what you would without it. So if it goes low, you have to have a Poppa or jellybeans or something like that. You just get sick of it ... it's just the constant taste of jellybeans and Poppas, it just – I don't know. It's just not – you just get sick of it after a certain time. (Jane, age: 14 years)

If you're not that hungry you still have to – you can't – I can't skip a meal. (Sarah, age: 14 years)

During the interviews, using needles for insulin replacement were almost unanimously described as the most painful and disliked component of MDI treatment. The three most common coping strategies that children seemed to utilise to manage their needle injections were gradual habituation, rationalisation and adaptive denial. Overtime children described becoming habituated to using needles, better able to manage their anxiety around needles and even associating MDI with common and widely used needles such as blood tests or immunisations. Using rationalisation, other children vividly described the direct impact and efficacy of an insulin injection, providing the energy required for the morning. This was followed by a subsequent 'drop off' in energy as the injection 'wore off'. Such a notable bodily reaction linked with injections in a time-accurate manner seemed to help children adaptively rationalise their importance. Jack (age: 11 years) demonstrated mild adaptive denial by distancing himself from T1DM risks through a shift in linguistics between first person (when describing his blood

glucose levels) to second or third person (when speaking of negative consequences). This mild denial enables Jack to acknowledge the importance of monitoring and treating his condition while avoiding being consumed by anxiety and fears as to possible highly negative outcomes of which he is nonetheless completely cognizant:

If I'm really high, like, for like two months and I'm high and I stay high for two months, you can lose your eyesight and stuff like that. (Jack, age: 11 years)

Stage 3B – CSII and bodily cues. Children who commenced CSII treatment seemed to re-learn how to listen, attune to and interpret their bodily cues, effectively reconnecting with a bottom-up method of interpreting bodily cues. Children began to attune to their basic bodily sensations with greater trust when using CSII. Sarah (age: 14 years) described the impact of CSII treatment as 'putting her back' before diabetes, this broad statement potentially capturing a return to her usual mind–body connection prior to the onset of diabetes symptoms:

I don't really think it's a big change. I think the change was having to start doing injections. I think this [CSII] just puts me back before I had to think about all this in a way if that makes sense. [Interviewer: When you say back before, before what?] Before being diagnosed. I could just eat when I wanted and not really have to worry about much but now I can eat when I want and just make sure I put it in this pump and that's – yeah. (Sarah, age: 14 years)

Illustratively, the most commonly mentioned impact of transitioning to CSII was increased flexibility in diet and the ability to respond to sensations of hunger. After approximately 3.5 months of treating diabetes with CSII, all children reported a shift in their relationship with food and bodily sensations of hunger or satiation. CSII allowed Sarah to engage in more desire-based eating and allowed children to listen to and satisfy their bodily states. This related to quantity of food, timing of meals and food types. Eating was often forced while on MDI,

and food was treated as 'fuel', necessary to consume for energy, whereas for CSII users food and eating tended to be perceived as pleasurable activity again:

You can be more flexible with it. You don't have to have breakfast at eight o'clock. You can get till 9:00 and it'll be fine. Breakfast – dinner doesn't have to be at 6:00. It could be 8:00. (Jane, age: 15 years)

Now I can eat when I want and just bolus. I like it much better now as I can have the candy cane. I prefer the pump ... there are no injections and I only need to take 1 needle every 3 days instead of like 5 needles a day. (Charlotte, age: 7 years)

The distributed system of management and shame. Children and their families learn a myriad of complex tasks to manage T1DM, including carbohydrate counting, meal planning and a degree of dieting, administration of insulin and checking blood sugar levels (Berlin et al., 2006). Interestingly, when children described these tasks, it was within the context of a network of support and resources. We termed this the 'distributed system of management'. The system included family, school staff (teachers, nurses, principals), diabetes camp personnel (peers, staff, other parents), peers (immediate friends and year group), hospital medical staff (diabetes nurses, endocrinologists, social workers, dieticians), community medical staff (general practitioners (GPs) and pharmacists) and technology (smart phone apps, blood glucose level (BGL) monitor, CSII).

The distributed system of management model emphasises that children are constantly coupled to a broader network of support. This ongoing relationship is vital to managing T1DM. The distributed system seemed to provide both emotional and practical assistance, enabling children to navigate the complexities of T1DM treatment. Just as all humans are coupled to a broad social network of co-workers, friends and family, so too do children with T1DM require the support of others. For many children with T1DM, friends adopted a monitoring, checking and assisting role. Chloe

appeared confident allowing her friends to better understand diabetes and welcomed their 'checking in':

I always have a friend who's there to come with me to the office or to wherever I have to go, so it's good ... she comes with me to the office everyday ... she already knows that I have to wash my hands and take it. She writes down the date and the time and the score. She knows what's high and what's low, and what's good and what's bad. Yeah, she's good. (Chloe, age: 13 years)

An important distinction, which often seemed linked to the role accorded to friendships, was the degree of shame or embarrassment the child with T1DM felt towards their condition. For example, Patrick (age: 12 years), who resisted allowing friends to enter the distributed system of management, described embarrassment and an urge to maintain secrecy concerning management tasks for T1DM:

Sometimes when I go out and eat at a restaurant or something I have to do it [a blood glucose check], every time I have to excuse my family, go to the toilet and do it or something ... sometimes we go to a restaurant and order and then sit at a table and the toilet's not near, so I kind of just hide behind the table or something, or my mum tries to cover me or something ... it's just like, kind of embarrassing, having to do the injections with family near ... (Patrick, age: 12 years)

The results of this study suggest a possible explanation for the inconclusive effect of peer relationships found in previous research (Palladino and Helgeson, 2012; Spencer et al., 2010). Overall children viewed their connections within the distributed system of management as an integral part of their diabetes care. However, their willingness to include peripheral relationships such as peers and teachers differed based on their level of shame and embarrassment about T1DM.

Internalising versus externalising view of T1DM. Children seemed to have a relationship with diabetes that characterised the illness as either an externalised object outside of one's self

or a more internalised view of the illness as part of their identity. Axial coding during the data analysis identified a trend for children to fall on a continuum within these two categories.

Some children who viewed T1DM as an externalised object adopted a medicalised description of the illness. This involved repeating knowledge learnt from clinicians explaining the body's functioning, rather than a genuinely understood and personalised understanding of T1DM. Other externalised views of T1DM classified the illness as a 'pest' or something that maintained an annoying presence in their lives:

Externalised Category

Medical: Diabetes is a disease, which comes when you're born or – and in diabetes, your pancreas doesn't work and it doesn't give you any insulin. (Graeme, age: 7 years)

Pest: Like a disease or something that you don't want to have and yeah, you just want it to go away ... Like a sickness or a pest something like that. Like, you don't want it, yeah. (Michael, age: 8 years)

In contrast, an internalised view of T1DM tended to be framed as a form of acceptance and integration of the illness with one's life, acknowledging the presence of T1DM but not feeling overwhelmed or burdened by it. Others adopted T1DM as an internalised illness identity, describing themselves as the 'sick' child who continuously experienced poor health. This study found a distinction in whether children hold an internalised or externalised view of T1DM; it is unknown whether the view relates to medical outcomes or psychological well-being:

Internalised Category

Acceptance: I don't think it's really changed what I'm able to do because I do the same things apart from eat sugar but I

The 'Sick Child':

didn't really do that a lot anyway ... I'm still able to go out so it hasn't changed anything. (Sarah, age: 14 years)

I've been – I'm always sick, even before I got diabetes. I was always sick. I had had about three operations – four operations on my ears, before that. So I was always the problem kid ... Nothing ever happens to my brother. Ever ... It's always me ... Always sick or – but something broken or hurt something. (Cathie, age: 11 years)

Discussion

In this study, we presented an analysis of key themes involving shifts in the interpretation of bodily cues, shame as a barrier to the system of distributed management and differences in how children conceptually understand T1DM. These findings highlight the fundamental role of health psychology research within the field of paediatric T1DM management. Such research contributes to a better understanding of how children with T1DM manage and make sense of their illness and its required treatment. This study also further supports the growing acknowledgement of the value of qualitative research into children's personal experiences of medical care and treatment, and underscores the role for psychologists within health psychology. The children interviewed were articulate and insightful, reflecting their capacity to be experts of their own experiences. Recommendations for potential psychological interventions follow in this discussion.

Strengths, limitations and ethical considerations

This study displays several methodological strengths. Meeting with each child on two separate occasions may contribute to better rapport and allowed children to describe both

immediate and retrospective experiences, particularly pre- and post-treatment regimen changes. Methodological challenges were exemplified by one child in particular, Graeme (age: 7 years), who was less engaged and forthcoming in his responses than other children. His brief answers may have been due to a lack of interest or perhaps a lack of insight into his own experiences. Other qualitative studies involving child interviews have provided drawing or play equipment to allow multiple modes of expression (Darbyshire, 2005; Kortessluoma et al., 2003). While not used in this study, such approaches could be advantageous in future studies. The present sample may also be biased. Demographic information suggests that this sample was in a wealthy SES bracket and generally exhibited satisfactory metabolic control and diabetes management behaviours based on HbA1c and frequency of blood glucose checking. Consequently, these findings may not generalise to other less privileged or engaged populations. Yet, it is still valuable to understand the experiences of children who are able to successfully manage their diabetes. In particular, this study found the mind–body connection and how the children were able to adapt to shifts in this connection across treatment phases may contribute some understanding as to why other children are unsuccessful and could be an area for future research to develop.

Implications for clinical practice

The interpretation of bodily cues. The continual shifts in children's mind–body connections and changes in the interpretation of their bodily cues were important underlying features of this study. This opens a new avenue for research, as very limited research exists on this mind–body connection in children with T1DM. This mind–body connection suggests that at different points in their treatment, involvement in yoga, body scanning, body listening, mindfulness or similar body concentration exercises would be of great benefit for children with T1DM. In particular, after transitioning to CSII children re-learned how to listen to their bodily cues and

were able to respond to them without cognitively overriding sensations such as hunger or sleepiness. Yoga exercises leading up to CSII transition may assist this re-establishment of the child's mind-body connection.

The role of shame in social support. Currently, common psychosocial interventions include attending diabetes camps or providing formal positions for peers to fill within the distributed system of management. At school, this may involve a 'buddy system', nominating a peer to accompany the child when they are feeling unwell. However, the present findings suggest that if the child is not receptive to allowing peers to join their system, shame should be addressed to encourage the child to engage with their distributed system of management and facilitate optimal self-care behaviour.

Specific interventions would ideally target unhelpful cognitive thoughts such as 'they don't think I'm normal', or a felt need to hide self-care behaviours. CBT approaches could encourage children to become 'detectives' of their own thoughts and challenge the unhelpful, inhibiting thoughts (Barlow et al., 1992). In addition, exercises focusing on diffusing from unhelpful thoughts within an acceptance and commitment therapy approach may help reduce the potency of these social concerns (Masuda et al., 2004) and increase the positive effect of psychosocial interventions such as diabetes camps or buddy systems.

Internalised versus externalised view of T1DM. There seemed to be both helpful and maladaptive views of T1DM on the internalised and externalised continuums of child understanding. Learning on narrative therapy traditions, the 'Tree of Life' exercise (Ncube, 2006) may present an opportunity to build a child's self-confidence and self-concept, labelling T1DM as a small component within their overall identity. The 'Tree of Life' exercise encourages children to draw a tree, with the components of a tree metaphorically representing a part of their identity (e.g. roots reflect family of origin). The presence of diabetes could be symbolically presented as different coloured

leaves, acknowledging that T1DM causes parts of the body to work differently, but not reinforcing the idea of being 'damaged' or 'impaired'. This may be important given the high management demands and concerns about peer questions.

Conclusion

This study highlights the idiosyncratic complexities of the lived experience for a child with T1DM. Several constructs have been identified by this study as relevant to children and currently under-researched, such as the role of shame in social support, internalised versus externalised view of T1DM and the interpretation of bodily cues while using MDI and CSII. Although these constructs require further replication in other diverse samples and with other methods, these raise interesting issues for psychological treatment and early intervention. Recommendations for potential psychological interventions have been proposed and would benefit from empirical validation and testing.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship and/or publication of this article.

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