The experiences and views of children with type 2 diabetes and their families

Victoria SP Lee

An increasing population of children and young people are being diagnosed with type 2 diabetes (T2D). This qualitative pilot study explored the experiences of young people in Bradford living with T2D to inform how to shape services for this patient group. Five young people and their parent/caregiver were interviewed and responses analysed using thematic analysis. Participants discussed factors influencing how they manage their diagnosis and treatment, including experiencing shame, wanting to hide their diagnosis, feeling different from the rest of the family, and cultural influences. They also discussed anxiety about the long-term health consequences of T2D while highlighting the complexities involved with following medical advice. Suggestions are made for how healthcare professionals may begin to address these complexities with families and work towards model of treatment that better meets their needs.

here is growing concern about the increasing prevalence of type 2 diabetes (T2D) in children and adolescents (Kaufman, 2002; Hannon et al, 2005; Dea, 2011; Praveen et al, 2015). It is thought that the rise in childhood obesity is a significant contributing factor (Kaufman, 2002; Hannon et al, 2005; Dea, 2011). Other risk factors include female sex (Pinhas-Hamiel and Zeitler, 2007; Khanolkar et al, 2016), having a first-degree relative with T2D (Dea, 2011) and - in the UK -South Asian ethnicity (Khanolkar et al, 2016). T2D progresses faster in young people (YP) than their adult counterparts (Narasimhan and Weinstock, 2014) and suboptimal management in childhood and adolescence is linked to poorer health outcomes and increased risk of complications, eg cardiovascular problems (Reinehr, 2013; Cahill et al, 2016).

The central aim of T2D interventions in children and young people (CYP) is to maximise time within the target glycaemic range. Interventions include education, medication and lifestyle modification, such as diet and exercise (Pinhas-Hamiel and Zeitler, 2007; Dea, 2011; Ramkumar and Tandon, 2012; Praveen et al, 2015); however, there is limited evidence of the efficacy of these approaches (Copeland et al, 2013; Zeitler et al, 2012).

Despite the importance of managing diabetes well, this very difficult in practice. Living with T2D is challenging emotionally (Huynh et al, 2015) and possible barriers to optimal management in CYP include embarrassment, wanting to be 'normal', balancing competing interests and seeking acceptance (Mulvaney et al, 2008; Protudjer et al, 2014). Adolescence is a barrier to adherence and optimal diabetes control, with parents describing adolescents as lacking concern for the future and not taking the risks and complications of their condition seriously (Mulvaney et al, 2006). Environmental factors have been noted, with issues related to socioeconomic status, school environment, food poverty, a lack of resources to make healthy food choices, and siblings without diabetes having an Citation: VSP Lee (2020) The experiences and views of children with type 2 diabetes and their families. *Diabetes Care for Children & Young People* 10: DCCYP59

Article points

- Type 2 diabetes diagnosis in a young person can be associated with feelings of shame, isolation and stigma for the patient and their family.
- 2. Religious and cultural factors need to be considered when planning successful type 2 diabetes interventions.
- 3. For patients of South Asian ethnicity, extended family members should be engaged in type 2 diabetes education and culturally-sensitive recommendations made by healthcare professionals.

Key words

- Paediatric type 2 diabetes
- Experiences of diabetes
- Barriers to managing diabetes
- Psychological impact of diabetes

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impact on diabetes management (Mulvaney et al, 2006; 2008; Protudjer et al, 2014).

The Children's Diabetes Team (CDT) at Bradford has noticed a steady increase in CYP with T2D over the past 10 years. Patients are referred to the CDT when high blood glucose levels are identified following admission to hospital for an unrelated complaint. There are 18 CYP with a diagnosis of T2D; this number is predicted to rise and is unlikely to reflect the true prevalence within the local community. Currently all CYP with T2D are from a South Asian background. They often have an immediate family member with T2D. Anecdotally, experience to date suggests there may be multiple barriers to engagement for this group. For example, clinicians have reported that patients with T2D struggle to attend clinic appointments regularly, often forgetting their appointment or prioritising other things such as after-school activities. Clinicians have been concerned that families do not always appear to understand the seriousness of the condition in CYP, which may impact on attendance levels. Patients often present with high HbA_{1c} levels, and appear to struggle to control their diabetes well, with low compliance to metformin and insulin injections.

While improving diabetes control in CYP is essential to improving health outcomes, doing so is complex and may require 'multimodal interventions to address individual, family and social processes' (Mulvaney et al, 2008 p675). This pilot study sought to explore how this may be achieved for CYP presenting with T2D in Bradford.

Method

Potential participants were approached through attendance at clinic and/or letters sent outlining the study followed by a telephone call. Participants included YP who attended clinic regularly and those the team had struggled to engage with, so it is hoped their views are representative of the larger sample. YP who did not participate either did not respond to recruitment letters or cited reasons such as being too busy with school work or not wishing to talk about diabetes more than they do in clinic. Two further YP agreed to take part but did not attend on the day or respond to further calls from the lead researcher and were withdrawn from the study.

YP with a diagnosis of T2D and their parent/

caregiver were interviewed together using a semi-structured interview. All five YP identified their ethnic group as Asian British, Pakistani background. All were under the care of the CDT in Bradford, were aged between 11 and 16 years and had received their diagnosis over 2 years ago. Four identified as female and one as male.

Participants' responses were transcribed and analysed qualitatively using thematic analysis to identify key themes, ideas and patterns within the data without the limitations of a pre-existing theoretical framework (Braun and Clarke, 2006). The results were discussed with a diabetes nurse from a South Asian background alongside a member of the hospital Muslim chaplaincy; these discussions were used to inform recommendations. Ethical approval was granted by the local research ethics committee and Health Research Authority.

Findings

Four major themes were identified.

Reaction to diagnosis

Experience of being diagnosed

All YP and their caregivers discussed their memories of diagnosis and initial experiences of receiving input from healthcare professionals, see *Table 1*. Some had experienced uncertainty leading up to diagnosis, whereas for others diagnosis was unexpected. Regardless of their experiences, YP and their caregivers described an emotional response to receiving the news.

Ongoing reaction

The majority discussed the gravity of their diagnosis not 'sinking in' for a long time. They described an ongoing emotional reaction with a far-reaching impact on their attitude towards themselves and their treatment, see *Table 1*. Some YP explained that as a result of how their diagnosis makes them feel, they would rather not think about having T2D and 'try to be normal' instead, only acknowledging they have the condition when they are due to attend clinic.

Caregiver guilt

Caregivers expressed some difficult ongoing feelings surrounding the young person's diagnosis in relation to guilt or blame, see *Table 1*.

Table 1. Illustrative quotes relating to participants' reactions to the diagnosis of type 2 diabetes

Experience of being diagnosed

Young person "I was feeling unwell and my mum checked my sugars, it was 30+ so she took me to the doctor's. They did some tests and told me

to go to hospital. I remember hearing them say I had ketones in my wee but I didn't know what that was." "I was really emotional and it felt like a sentence for the rest of my life. I was worried about the future...."

Caregiver

"I remember being a bit emotional about it when he was having the tests for it. He's so young and has his life ahead of him with it." "The most shock was to Mum and Dad. They kept saying she was too young. They never thought she would have it."

Ongoing reaction

Young person "For the first month it was my mum who was the most upset. I said: 'Its OK. Just go with what the doctors have told us. I can handle it and can keep it from getting any worse.' But then after a couple of months I realised it's not as easy, I have to keep on doing it."

> "I was upset about it and I still am. I hate diabetes. I don't want it. I don't feel like myself, it makes me more insecure and I feel down when I compare myself to other people. [...] I've got a 'don't care' attitude about diabetes. I just don't do it."

"Clinics remind me that I've got this illness, and I get really upset about it."

Caregiver guilt

"I feel guilty sometimes when I don't do what he has to. He calls me a hypocrite."

"I blame myself for not watching her weight, but then no one told me to! You can't think like that though, it's happened. I know I have to channel my emotions for her sake but I worry at night time when she's asleep. I worry about her being so young with it, will she have complications? That's the worst fear but I don't talk about it with her because I don't want that to rub off on her."

Understanding of diabetes

Participants discussed their understanding of diabetes, which appears to have developed from a number of sources, see Table 2.

Previous family experiences

All YP and caregivers discussed having other family members with a diagnosis of T2D. This extended family history at times meant that, although still a shock, families felt like a diagnosis was 'inevitable' at some point for the young person.

Understandings (and misunderstandings) about diabetes

Familiarity with the condition meant families had some prior understanding about what having T2D entails, which for some caregivers meant diabetes was seen as "just another thing to get on with". However, some confusion and inconsistencies between different family members' understanding about T2D and the aims of treatment emerged during the interviews, suggesting familial experience of T2D has not necessarily improved understanding, or even been discussed previously at home. Despite prior understanding, participants appeared to be less familiar with T2D presenting in YP, often seeing it

as an 'older person's condition'. They did not discuss any possible differences in how the condition may present, progress or be managed in relation to YP.

Fear of consequences

All participants discussed worries about the consequences of T2D, referring to short- and longterm concerns and fear of complications. While YP discussed ongoing worries about their health, this did not necessarily equate to a change in behaviour; at times it led to inaction, minimising the effect of treatment, or ignoring the diagnosis all together.

Adjustment to living with T2D

What does it mean about me?

YP appeared to be trying to make sense of their identity in relation to their diagnosis. They discussed feeling 'different' and were concerned about being treated differently because of their T2D. Some discussed wanting to hide the fact they had T2D and appeared to feel some shame in relation to their diagnosis, see Table 3.

One caregiver discussed feeling upset and judged or stigmatised when offered extra support around their child's diet: "The family did lots to help her [...] lose weight but [the CDT] involved [an external

Table 2. Illustrative quotes relating to understanding of diabetes

Previous family experience

Young person "Mum takes metformin too. Granddad has it and said: 'It's in your hands how you look after yourself.' He's a good role model."

"I was told I was bound to get it coz of my diet. Dad was saying Pakistani Muslims eat a lot of carbs and that can give you diabetes."

Caregiver "There is a big family history: his mum has it, both grandmothers, aunties..."

"I thought the older you get, it's just part of life to get diabetes, but he is so young to have it now."

Understandings (and misunderstandings) about diabetes

Young person "[Diabetes] is about too much sugar in your blood and you have to have treatment to make it go lower. But if it's too low you can faint. And it can go away if you do the treatment." (Caregiver interrupts: "No, no it can't! No one else I know has ever got rid of it.")

"Everyone was surprised I got it at a young age. No one expected it."

Caregiver "I worked very hard to stick to a diet and exercise and I've brought my [blood glucose] levels down from 13 to a 6–8. Now I only need to take one tablet in the morning, it used to be two a day." (Young person interrupts: "I didn't know that! I thought Mum had

"I had heard of it in children before but she didn't have a bad diet, she didn't have a huge amount to eat."

it passed on from her Dad and that's why she had it. I didn't know she had done a diet and exercise to bring it down!")

Fear of consequences

Young person "If I don't look after myself I would have to do injections."

"It's really important to follow medical advice to reduce blood sugars and not have medical problems like with my kidneys."

"I've been ill, and I think it's coz of diabetes. I do get scared. I get scared that people with diabetes get their legs chopped off."

service] about food. No one else I know has had that, it's upsetting. It's not like we're forcing her to eat bad stuff."

YP discussed how the diagnosis has affected interactions with their family. Lots of people were giving them advice, whether they asked for it or not. This resulted in them feeling 'nagged', which at times affected their behaviour.

Going to clinic

YP and caregivers discussed positive aspects of clinic attendance, such as having the opportunity to gain medical advice, getting ideas for how the family can make changes, and a temporary boost in motivation. However, YP discussed hospital appointments as provoking anxiety at times and being an unwelcome reminder of their condition, see *Table 3*.

Looking after myself

Following advice

YP tended to discuss what was going well for them in relation to elements of the treatment regimen they were adhering to, see *Table 4*. However, most spent time discussing aspects of their treatment regimen they were finding difficult to 'stick' to and frequently referred to "what I should be doing but

don't". These discussions enabled participants to explore potential barriers to making changes in line with advice, including their own motivation, the family approach and their immediate environment.

What gets in the way?

YP discussed their motivation to follow advice from healthcare professionals as being 'short lived' and referred to struggling to maintain the daily effort required to stick to diets and regular medication. They often referred to this as being a personal fault or flaw, which in turn led them to feel helpless in terms of whether they could make lasting changes. They talked about how food preferences, the environment around them and cultural factors can impact how able they feel to make dietary changes, eg discussing the proximity of fast food outlets to their home and having siblings who freely consume those foods. Families with experience of visiting or living in Pakistan noticed the impact this change in environment can have on health. They attributed changes to the availability of fresh food, the opportunity for exercise and the scarcity of fast food outlets in rural areas, eg: "I went to Pakistan [...] for a month and lost loads of weight. People were saying I looked skinny when I got back."

Table 3. Illustrative quotes from young people relating to adjustment to living with type 2 diabetes

What does it mean about me?

- "I don't like to share things; I don't even want my family to know. My grandma told everyone; I hated that people knew."
- "I even lost contact with my friends for a bit [after diagnosis]. I just didn't want to be with them. I was feeling like I didn't fit in."
- "I get lots of advice from family [...]. Sometimes I listen but most of the time I think 'Here we go again'. It's easy to lose motivation and get side-tracked as soon as something puts me off."

Going to clinic

- "After clinic it motivates me, and I do [what is advised] for a couple of weeks or so then stop again."
- "I always feel welcome, everyone is sweet and nice, but I don't like hospitals. It puts me off. I think about death, disease and people in pain..."
- "I can be quite anxious when lots of doctors are in the room. I get anxious before appointments too, thinking about whether I might have done something wrong to affect my blood sugars even though I know I haven't."

Further barriers to 'looking after' T2D included other aspects of life, such as school ("work takes priority over diabetes") and where the family locate responsibility for change. When families placed responsibility with the individual with T2D, the young person often felt singled out and blamed for the condition. They discussed finding it difficult to make changes that were not being upheld by other family members.

What helps?

In contrast, when a family-wide approach was used to manage diabetes, YP and caregivers discussed seeing positive results for the whole family, see *Table 4*. Other factors that appeared to have a positive impact on YP's ability and confidence to make changes included increasing their understanding of the condition by researching and asking questions themselves, and having goals to focus on in order to have a positive reason for maintaining their health.

Ideas for future care

Participants were asked for ideas about how they might like to receive support from the CDT. Suggestions tended to focus on healthy eating and cooking, and were more practical-based than traditional multidisciplinary team appointments. Although the majority discussed the potential benefits of a group setting, one participant indicated that they would not attend as they would find this too embarrassing.

It appears that, while most participants wished to appear grateful for the service they had received, the benefits of clinic appointments were often seen as short-term and appeared to be short-lived. Findings suggest the focus on patient-only diabetes clinics may need to shift to better suit this group's needs.

Discussion

This small study has provided further insight into the experience of T2D for YP and their caregivers from a Pakistani background. Findings highlight possible barriers to accessing current healthcare services. Previous research has emphasised the need for parental involvement in improving YP's ability to manage a long-term health condition (Cahill et al, 2016), however it seems a wider family approach is important for this group. Participants often lived with or had daily contact with extended family. When considering a 'family approach' to T2D, it is important to consider who is in the family and people's expectations and beliefs in the context of their religious and cultural background. Pallan et al (2012) found that within South Asian households where extended family members are present, the grandmother often influences younger family members' diets and may have different views around food, including seeing overweight children as healthy. Barriers to engaging with advice about weight management may include parental concern that doing so could undermine YP's emotional wellbeing and lead them to develop eating disorders in later life (British Psychological Society, 2019). Lawton et al (2008) highlighted the importance of consuming certain foods to maintain cultural identity; not eating together or accepting food offered by family or community members can cause offence or alienation in South Asian culture. Many South Asian families require quick energy-rich foods to be consumed once YP have finished school

Table 4. Illustrative quotes from participants relating to looking after themselves

Following advice

Young person

"It's going OK at the minute. My parents do most of it for me but I know I have to be more active and take tablets."

"It's easy to take the medicine. I'm in a routine so it's automatic and I even give it to Mum, so we take it at the same time."

"The medical advice is three things: diet, exercise and medication. It's very hard to do all three."

"I don't test my sugars, I don't remember to do it. The hardest thing is not eating cake or nice things like that. And sometimes I skip meals, which I'm not supposed to do."

What gets in the way?

Young person

"I'm a 4/10 motivation to change. Four because I do want to help myself and don't want no legs or to die young [but] I give up really easily." "My motivation tends to be highest after clinic and it is an 8/10 [...] then the day after it will be a 7, then a 6.5, then a 6 and then it's a –1!" "I'd swap the grilled chicken for fried because it tastes nicer."

"When we go visiting they always put chocolate and fruit out. I was talking to my sister about it: "Why do they put chocolate AND fruit?" It's hard to resist the chocolate, and we have things for if guests come round too. (Caregiver answers: "It's about being a good host. In our culture we put things out for people.")

What helps?

Young person

"Learning about food and diet plans help me change the way I eat. [...] I like to know about what is going on and it means I stop snacks and have less sugar because I know it can increase my sugar levels and that's not good."

"Having goals helps – I want to be a [healthcare professional] but to do that I need to be well, so I need to look after my diabetes."

Caregiver

"You have to do it as a family. We all have the same diet and all eat healthily because it helps everyone, not just the person with diabetes. And the person doesn't feel left out then and we do things together like walks. And cooking at home instead of takeaways." "I've been researching sugar in food and realised there is lots of sugar in things like fruit juices."

Ideas for future care

Young

"I've done a [...] group about food labels and Change4Life. It was useful and I feel I learnt more than in clinic."

person

"I would go to a cooking group; I had one in primary school. [...] I would like a group where you meet up with other people with diabetes and do things together like trips or visits to nature places. I would feel better and could relate to people."

Caregiver

"You could give more activity-based classes like cooking classes."

and before attending mosque (Pallan et al, 2012), something commented on in the current study. YP appeared to be aware of some of the complexities surrounding food and eating, recognising there are psychological reasons for eating, eg for comfort when angry or upset, as well as cultural and religious aspects, eg providing sweet food for guests.

YP and caregivers discussed difficult feelings regarding the diagnosis of T2D. The psychological impact appeared to be far-reaching, with YP feeling shame, low mood and different/isolated from friends and at times family. YP discussed their motivation or will power as being a main barrier to following advice, viewing this as a personal fault and another source of shame or stigma. The presence of negative feelings around diagnosis is likely to impact on whether YP engage with advice; shame and stigma have been cited by newly-diagnosed adults

as reasons for not attending T2D education groups (Winkley et al, 2015). Caregivers also discussed difficult feelings around diagnosis, including guilt, sadness and feeling blamed or judged for their child developing a health condition, which may impact their likelihood of engaging with medical guidance. Similarly, feeling blamed for a child being overweight or obese may prevent parents from accessing lifestyle modification programmes for their children (Kelleher et al 2017).

YP reported an ongoing adjustment process, in contrast with other research suggesting adjustment to T2D diagnosis gets easier over time (Protudjer et al, 2014). Participants remained aware of their condition and discussed concerns about the long-term health consequences, and feeling anxious, depressed or helpless about their diagnosis. Increased awareness and fear of negative

consequences does not necessarily lead to behaviour change (Hood et al, 2015; Kelly and Barker, 2016); participants discussed how fear and anxiety led to them ignoring the consequences of T2D or at times acting against medical advice.

Recommendations

Common recommendations based on the limited research investigating the efficacy of approaches to T2D management in CYP include a combination of medication and lifestyle changes, such as weight management and taking into account psychosocial aspects of living with the condition. Based on the findings of the current study, a number of recommendations can be made for working more effectively with YP with T2D, see *Box 1*.

Conclusion

This study provides further information about the impact of T2D diagnosis on YP and their families as well as possible barriers to successful management. Continuing to apply a traditional type-1 model of treatment is unlikely to be successful. The recommendations are a useful starting point when considering how to develop services to engage with and meet the needs of this patient group. Additional research with a larger, more heterogeneous population of YP with T2D would contribute further ideas. It is imperative to work in creative and innovative ways to achieve the best possible outcomes.

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Box 1. Recommendations for working with young people with type 2 diabetes

- A wider family approach to managing diabetes including education about healthy eating and medication that includes important family members who may influence the young person's diet. Clinicians should use culturally-sensitive teaching and recommendations that fit the lifestyle and preferences of the young person and their family.
- Holistic assessment prior to beginning an intervention that considers factors influencing a family's ability to work on and change the areas needed to maximise engagement. The COM-B model of behaviour change (Michie et al, 2014) is recommended: the individual needs the Capability (skills, knowledge and abilities) for a behaviour; the Opportunity to enable the behaviour; and the Motivation to do what has been suggested. Interventions need to take these issues into account and individual work may be required prior to accessing any group work.
- A group intervention approach may help counteract stigma and shame surrounding
 the diagnosis. A focus on practical skills (eg cooking demonstrations and portion size)
 can help to improve the patient's and family's understanding and self-management.
 This could include explorations of families' religious perspectives and work with faith
 leaders to tailor information to suit the group's needs.
- Psychological intervention to help young people adjust to having the condition. This
 could include exploration of how the condition fits in with their identity and any
 psychological factors relating to food.
- Including outcome measures other than glucose monitoring, eg quality of life and psychological wellbeing, to gauge the impact of interventions.
- Engage with local communities to provide opportunities in schools and public places
 to allow for increased physical activity and decrease the availability of unhealthy food
 (Department of Health and Social Care, 2018). It is important for healthcare services
 to make links wherever possible to existing local initiatives.

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