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Exploring how young people think about and respond to diabetes in their peers

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Type 1 diabetes mellitus (T1DM) is one of the most common forms of chronic illness affecting young people in the United Kingdom (Murphy et al, 2006). To avoid adverse outcomes in both the short- and long-term requires self-management involving adherence to complex daily management regimens. Failure to achieve optimum control in adolescence can lead to poor diabetes outcomes in adulthood, but in a 2011 NHS audit, more than 85% of children with the condition in England and Wales did not achieve target levels of blood glucose control (NHS Information Centre, 2011). During adolescence, metabolic control often deteriorates (e.g. Rausch et al, 2012) and this can, at least in part, be attributed to physiological changes associated with puberty. However, it is widely acknowledged that there are a range of other factors which also play a role in determining treatment adherence and effective control of T1DM in adolescence.

Throughout their teenage years, young people with T1DM are required to take on an increasingly independent and autonomous role in the management of their own condition, in addition to facing the usual developmental tasks and social pressures associated with adolescence. Nonetheless, young people with T1DM do not live with and manage their condition in isolation. Published literature on the potentially important role of wider social influences often focuses primarily on parental and family involvement. However, as young people move through adolescence, they typically spend increasing amounts of time away from their home environment. Their social focus tends to progressively shift from family to friends of their own age: peer relations become more important and influential, with increased reference to peers as a source of information, 'normative' behaviours and self-identity (e.g. Anderson & Wolpert, 2004).

For young people with T1DM, peer relations may thus play an influential role in determining both how they think about and how they manage their condition.

Most young people spend a substantial proportion of their time in their school environment. The shift from primary to secondary school is a significant one for young people, and this period of transition is often marked by a deterioration in blood glucose control amongst T1DM patients (Rausch et al, 2012). As of September 2014, the Children and Families Act means that safe and effective care for young people with medical conditions (including T1DM) must, by law, be embedded within the school system in England. School leadership teams, teaching staff, healthcare professionals, parents and carers, and young people with T1DM themselves are all recognised as key parties who should be involved in ensuring proper care and support is available in secondary schools (e.g. Brooks et al, 2015a). However, whilst it is recognised that social issues related to diabetes can also be a problem for some young people with T1DM in the school environment, the role played by classroom peers has received rather little attention, and less still is known about the beliefs and attitudes of adolescent peers towards T1DM. This knowledge is a crucial first step towards elucidating mechanisms by which peer beliefs and subsequent behavioural responses may impact on adolescent T1DM patients. It is known, for example, that peer influence can impact on adolescent behaviours across a range of 'risk' behaviours (tobacco, alcohol and marijuana usage) in both positive and negative ways (Maxwell, 2002). Previous research supports the need for educational interventions aimed at peers to help them better understand both the consequences of T1DM and how best to assist young people with the condition (e.g. Greco et al., 2001;

Lehmkuhl et al, 2009; Wang et al, 2010), and more research is needed in this area, particularly in UK settings (Spencer et al, 2010).

This article reports on a recently completed piece of exploratory research (funded by Diabetes UK) undertaken in West Yorkshire between 2013 and 2014 which explored peer understandings of and responses to T1DM amongst young people, as well as piloting educational materials to increase awareness and understandings of T1DM with young people in secondary school settings.

Method

Three focus group sessions were held with Year 8 and 9 students from West Yorkshire secondary school establishments. A letter was sent home with pupils to inform them about the research and to ask for expressions of interest to take part. Written parental permissions were also sought at this stage. All participants provided informed written consent before participation, and appropriate ethical approvals were also obtained.

Participants in the groups were all aged between 12 and 14 years (see table 1 for participant details). The focus group sessions were designed with the help and feedback of two young people with personal experience of diabetes (one with T1DM, one with a close friend with T1DM) and one parent of a young person with diabetes - they read and provided feedback on the session plans to ensure accessibility and relevance.

Table 1: Participant information

Focus group 1	4 participants – 2 male; 2 female Year 9 class (all aged 14 years)
Focus group 2	6 participants – 1 male; 5 female Year 9 class (all aged 14 years)
Focus group 3	5 participants Mixed group of years 8 and 9 Participant 1: Female, year 8, age 12 Participant 2: Male, year 8, age 12 Participant 3: Male, year 8, age 13 Participant 4: Female, year 9, age 13 Participant 5: Male, year 9, age 13

The sessions, which took place either in lesson time (two groups) or after school (one group), incorporated three broad overarching issues:

(1) What do you know already? Participants were asked to write down three words on separate post-it notes that they associated with the term ‘diabetes’ – these were then attached to one large piece of flipchart paper in the middle of the group and discussed amongst all group members;

(2) What would you do? Participants were given realistic vignettes of situations involving young people with diabetes (developed from real-life situations described by young people with T1DM in a previous piece of research – see Brooks, 2014) and, as a group, discussed the situations described from the viewpoint of different actors. The vignettes were designed to provide sufficient context for meaningful reflection whilst

allowing scope for young people to offer and define their own important issues and terms. Vignette research is established in both health and social care research literature as a valuable way of engaging and encouraging young people to reflect on their beliefs, attitudes and responses in the discussion of sensitive topics (e.g. Barter & Renold, 2000);

(3) Basic information and myth busting. For the myth busting section, statements (identified in earlier research by this team as misconceptions encountered by young people with T1DM – see Brooks, 2014) were printed out in large font and laminated so that the students were able to group them into ‘true’ and ‘false’ prior to discussion. The session concluded with some basic information about diabetes. At the end of each group, participants were also asked for their feedback on the session.

Materials used in the sessions (i.e. the vignettes used in the ‘What would you do?’ section and the information provided in the final ‘Basic information and myth busting’ section were designed by the authors, drawing on their own research (see Brooks, 2014) and other readily available educational resources available on the Diabetes UK and JDRF websites (www.diabetes.org.uk; www.jdrf.org).

The group sessions were audio recorded (with participants’ consent) and transcribed verbatim. Data was analysed by the research team using the Template Analysis style of thematic analysis (e.g. Brooks et al, 2015b). Initially, we undertook preliminary coding of one transcript, identifying emerging codes representing themes identified in the data. These codes were then organised into meaningful hierarchical clusters (with broad top level themes encompassing more narrow and specific sub-themes) to create a coding template. We initially had three ‘top level’ themes:

Knowledge about diabetes; Perceived barriers to diabetes management; Peer responses/ experiences. Iterative coding, undertaken by applying our initial template to the full data set, led to a number of template modifications, and our final template had four top level themes: Knowledge of and beliefs about diabetes; Standing out? Diabetes in classroom settings; Perceived patient emotional responses to diabetes; Developing independence with diabetes (see Brooks, 2014 for the full final template and Brooks et al, 2015b for a detailed description of how to undertake Template Analysis).

Results

All participants had heard of diabetes, but unless they personally knew someone with the condition, their knowledge of T1DM was rather limited. For example, although some participants were aware that there were two types of diabetes, they were generally rather uncertain as to how these two types differed.

“- There’s two types, there’s type one and type two, I don’t know which one is which, but there’s like, is there one if you’re like, if you get overweight, you can get diabetes and then there’s another one

- I don’t know what the difference is between type one and type two

- I thought one was like you need sugar and then the other one you need less sugar”

Nonetheless, the groups all engaged well with the focus group discussions. Participants were able to reflect sensitively on the experience of living with diabetes for someone of their own age in discussion based on the vignettes. They reflected on how they thought living with the condition might well be frustrating, and appreciated how being or just feeling conspicuously different to others was unwelcome for people of their age. All groups discussed how adolescents with T1DM might feel embarrassed about being different to their peers – participants thought that this might lead to patients potentially failing to manage their condition properly because they did not want to acknowledge it or talk about it.

“- It’s like you have to behave yourself really, really well all the time and all you get is normal life

- They (person with T1DM) will want to feel independent and if they don’t want to talk to anyone about it, maybe they just want other people to forget, pretend like that she hasn’t got it and make her feel like she hasn’t got it and like she can be as independent as everyone else and stuff

- Yeah, just like skip something you need to do, they’ll think ‘Oh I’ll be alright this time, I’ll just skip and do it next time’”

Participants empathised especially with how managing T1DM might impact on young people’s normal efforts to establish an autonomous and independent identity through adolescence.

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“-Oh god, you can just imagine how the parents are always looking over them to make sure they’re ok, but they want to be like their own person and have fun and they can’t if their parents are watching their every move

- Or like teachers. You’d be so put off, I wouldn’t even want to go to school”

Some participants felt that people with T1DM should conceal both their condition and management tasks:

“She could like take her test separately, so like they’re not all staring at her in class. Like just don’t do that in front of everybody in public. It is a bit like gross. Go to the toilets. We don’t need to know.”

Others argued that more knowledge and openness regarding T1DM would normalise the condition amongst their peer group.

“- Because like people know about asthma and everything don’t they, they just kind of accept it and it’s just not a big deal, so I think that people just need to learn more about it to accept diabetes

- Yeah, like I think if people learnt more about it, they’d just act as if it was like asthma, you know, just like a normal everyday thing”

Whilst some participants felt that it was the responsibility of young people with T1DM themselves to disclose information about their condition, others felt that this information should be provided in school lessons.

“- It's like her choice if she wants to tell people she has it

- Yeah, but she could just tell them about it, like let them know what she's doing and stuff so they're used to it

- I'd feel like people were being nosey if they kept asking me about it.

- I think it should just be part of what we learn about like in school, don't like single someone out, that's well unfair”

However, participants suggested that teachers were not necessarily the preferred source of information.

“- They could do something like this, like have a lesson about diabetes and stuff

- Someone who has diabetes could like come and tell us about it

- Because it gives it a change of like just the teacher talking and then it just sort of shows what their point of view is as well

- Yeah, because maybe it would be good to like hear about what it's actually like rather than a teacher just telling us about what it is”

A number of participants also expressed a worry that, whilst wanting to understand and help a peer with T1DM, they felt that they did not currently know enough about the condition and would be fearful of doing or saying

the 'wrong' thing. They felt that more information about the condition would enable them to better support peers with T1DM.

"- I think that they (person with T1DM) probably need to talk about it, I don't know how you'd make them talk about it though

- Because you might have tried to make the person feel better, but actually made them feel worse. Like if someone's trying to think they know what's best for them and help them. They might get proper angry

- I can understand where that were coming from though, if they respond like that. I suppose if everyone were looking and pestering, I'd probably do the same after a while.

- I'd probably feel a bit disappointed in myself then, I'd feel a bit guilty that I asked, as if like it offended her or something"

Discussion

This exploratory study investigates an area which is currently under-researched - namely what the peers of young people with T1DM know about the condition, and how they respond to it. As a small study undertaken in just one geographical area, we acknowledge the inherent limitations with regards to conclusions that may be drawn from this piece of work. Nonetheless, our findings do suggest that more education about diabetes may be needed in secondary school settings, but also - encouragingly - that this would be welcomed by young people themselves.

The simple and easy to run educational sessions undertaken as part of this study were well-received by participants and there also exist a number of excellent educational resources readily available including DVDs, packs and other online resources (see the Diabetes UK and JDRF websites). Providing provision for sensitively and appropriately increasing peer awareness of T1DM and facilitating peer support need not necessarily then be too complicated, onerous or time-consuming. Participants in this study suggested that they would respond well to hearing the experiences of recent school leavers with T1DM, and there is scope to explore how older peers might be encouraged to contribute in this way (and their contributions adequately recognised). Healthcare professionals (specifically, Children's Diabetes Specialist Nurses) are also often very keen to assist schools and can provide appropriate information and toolkits, as well as a wealth of knowledge and advice (Brooks et al, 2015a). Whilst the participants in this study were young people in school settings without any necessary prior knowledge of diabetes, the materials used in our focus group sessions were designed based on earlier research with young people with diabetes and their close friends (see Brooks, 2014). We would emphasise the value of similarly drawing on the expertise of young people with T1DM in designing any future work of this type, especially with regards to their comments on the type of interventions and support they would find acceptable and helpful.

Finally, it is vital that any such interventions are designed with the input and support of both teaching staff and school management teams. In future research looking at how best to appropriately raise awareness of T1DM in secondary school settings, we would also like to include consultation with teaching staff themselves as well as young people. The literature with

regards to staff knowledge of and attitudes towards T1DM in school settings is very sparse indeed, despite acknowledgement of the vital role of teachers play in this context (e.g. Boden et al, 2012). The importance of developing effective and independent self-management in adolescent T1DM is often (rightly) emphasised, but the role of social influences in this context also warrants more investigation and the potentially positive role that a supportive peer network can play in this respect should not be overlooked.

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