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

Joanna Brooks, Nicky Kime, Nigel King, Alison Wearden, Warren Gillibrand, Fiona Campbell

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Article points

1. The transition to adulthood is difficult for people with diabetes as they have to take on responsibility for their condition.
2. Adolescents may not want to stand out from their peer group and this could lead to poor management of diabetes.
3. Educating young people about diabetes should be encouraged, as a supportive peer group could help to support good diabetes management.

Key words

- Adolescence
- Education
- Peer group

Authors

For author details, see the end of the article.

Adolescence is a difficult time for people with diabetes and it is often accompanied by a deterioration in blood glucose control. This article looks at the effect the attitudes of peers can have on adolescents with diabetes. Three focus groups of 12–14-year-olds were asked about their knowledge of diabetes and were then presented with realistic vignettes about the condition, which they discussed. They then took part in a myth-busting session to help address misconceptions. The research team identified themes that emerged from the focus groups. Their findings suggest that a supportive peer network may be a valuable resource in good management of diabetes in young people. The research team suggest that more education about the condition is needed in schools and should be designed in collaboration with young people with diabetes.

Type 1 diabetes is one of the most common forms of chronic illness affecting young people in the UK (Murphy et al, 2006). Avoiding adverse outcomes in both the short and long term requires self-management and 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 (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 that also play a role in determining treatment adherence and effective control of type 1 diabetes in adolescence.

Throughout their teenage years, young people with type 1 diabetes 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. Young people with type 1 diabetes do not live with and manage their condition in isolation. Published literature on the potentially important role of wider social influences often focuses on parental and family involvement. However, as young people progress through adolescence, they typically spend increasing amounts of time away from their home. Their social focus tends to 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 (Anderson and Wolpert, 2004). For young people with type 1 diabetes, peer relations may 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 at school. 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 among young people with diabetes (Rausch et al, 2012). As of September 2014, the Children and Families Act has stated that safe and effective care for young people with medical conditions (including type 1 diabetes) must, by law, be embedded within the school system in England (Department for Education, 2014). School leadership teams, teaching staff, healthcare professionals, parents and carers and young people with type 1 diabetes themselves are all recognised as key parties who should be involved in ensuring proper care and support is available in secondary schools (Brooks et al, 2015a). However, while it is recognised that social issues related to diabetes can also be a problem for some young people with type 1 diabetes when they are at school, the role played by their peers has received rather little attention and less still is known about the beliefs and attitudes of adolescent peers towards type 1 diabetes. This knowledge is a crucial first step towards working out ways in which peer beliefs and subsequent behavioural responses may have an impact on adolescents with type 1 diabetes.

It is known that peer influence can have an impact on adolescent behaviours across a range of “risk” behaviours (such as tobacco, alcohol and marijuana use) 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 type 1 diabetes and how best to assist young people with the condition (Greco et al, 2001; Lehmkuhl et al, 2009; Wang et al, 2010). More research is needed in this area, particularly in the UK (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 understanding of and responses to type 1 diabetes among young people, as well as piloting educational materials to increase awareness and understanding of the condition in young people in secondary schools.

Method

Three focus group sessions were held with year 8 and 9 students from two West Yorkshire secondary schools. A letter was sent home with pupils to inform them about the research and to ask for

Table 1. Composition of the focus groups.

Focus group	Participants
1	4 participants: 2 male, 2 female Year 9 class (all aged 14 years)
2	6 participants: 1 male, 5 female Year 9 class (all aged 14 years)
3	5 participants in a mixed group of years 8 and 9 Participant 1: Female, year 8, aged 12 Participant 2: Male, year 8, aged 12 Participant 3: Male, year 8, aged 13 Participant 4: Female, year 9, aged 13 Participant 5: Male, year 9, aged 13

expressions of interest to take part. Written parental permission was also sought at this stage. All participants provided informed written consent and appropriate ethical approvals were also obtained.

Participants in the groups were all aged 12–14 years (*Table 1*). The focus group sessions were designed with the help and feedback of two young people with personal experience of diabetes (one with type 1 diabetes and one with a close friend with type 1 diabetes) and a parent of a young person with diabetes. They provided feedback on the session plans to ensure accessibility and relevance.

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

- **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 words were then attached to one large flipchart in the middle of the group and discussed among all group members.
- **What would you do?** Participants were given realistic written vignettes of situations involving young people with diabetes. The vignettes were developed from real-life situations described by young people with type 1 diabetes in previous research (Brooks, 2014). The group then discussed the situations described from the viewpoints of the different “actors”. The vignettes were designed to provide sufficient context for

Page points

1. It is part of English law that safe and effective care for young people with diabetes must be embedded within the school system.
2. Peer influence may have an effect on young people’s diabetes management.
3. Adolescents aged 12–14 were asked to consider their attitudes to diabetes during focus group sessions.

“All participants had heard of diabetes, but unless they personally knew someone with the condition, their knowledge of type 1 diabetes was rather limited.”

meaningful reflection while 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 (Barter and Renold, 2000).

- **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 type 1 diabetes [Brooks, 2014]) were printed out in large type and laminated so that the students were able to decide whether they were “true” or “false” before the 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 and the information provided in the final myth-busting section) were designed by the authors, drawing on their own research (Brooks, 2014) and other freely available educational resources (Diabetes UK [www.diabetes.org.uk] and JDRF [jdrf.org]).

A digital audio recording was made of the group sessions (with participants’ consent) and transcribed verbatim. Data was analysed by the research team using the Template Analysis style of thematic analysis (Brooks et al, 2015b).

Results

Preliminary coding of one transcript identified 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. There were initially 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 modifications, and our final template had four top-level themes:

- Knowledge of and beliefs about diabetes.

- Standing out? Diabetes in classroom settings.
- Patient’s perceived emotional responses to diabetes.
- Developing independence with diabetes (Brooks, 2014; 2015b).

All participants had heard of diabetes, but unless they personally knew someone with the condition, their knowledge of type 1 diabetes 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 1 and type 2. 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 1 and type 2.”

“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 type 1 diabetes might feel embarrassed about being different to their peers and participants thought that this could possibly lead to individuals 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 [the person with type 1 diabetes] 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 type 1 diabetes might impact on young people’s normal efforts to establish an autonomous and independent identity through adolescence.

“Oh God, you can just imagine how the parents are always looking over them to make sure they’re okay, 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 type 1 diabetes 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 type 1 diabetes would normalise the condition among 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.”

While some participants felt that it was the responsibility of young people with type 1 diabetes 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 noseey 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, while wanting to understand and help a peer with type 1 diabetes, 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 type 1 diabetes.

“I think that they [the person with type 1 diabetes] 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.”

Page points

1. The participants showed empathy to their peers with diabetes, appreciating that it might have an impact on the development of an autonomous and independent identity.
2. Some participants in the study argued that more knowledge and openness about type 1 diabetes would normalise the condition among their peer group.
3. The young people surveyed said that more information about diabetes would enable them to better support their peers with the condition.

“The findings do suggest that more education about diabetes may be needed in secondary schools, but also – encouragingly – that this would be welcomed by young people themselves.”

Discussion

This exploratory study investigates an area which is currently under-researched – what the peers of young people with type 1 diabetes know about the condition, and how they respond to it. As a small study undertaken in just one geographical area, there are inherent limitations with regard to conclusions that may be drawn from this piece of work. Nonetheless, the findings not only suggest that more education about diabetes may be needed in secondary schools, 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. There are already a number of excellent educational resources available including DVDs, packs and other online resources (e.g. Diabetes UK and JDRF websites). Sensitive and appropriate provision for young people need not be too complicated, onerous or time-consuming and could improve peer awareness of type 1 diabetes enabling peer support. Participants in this study suggested that they would respond well to hearing the experiences of recent school leavers with type 1 diabetes, and there is scope to explore how older peers might be encouraged to contribute in this way. 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). 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 (e.g. from Diabetes UK and JDRF). The authors emphasise the value of drawing on the expertise of young people with type 1 diabetes in designing any future work of this type, especially with regard to their comments on the type of interventions and support they would find acceptable and helpful.

Finally, it is vital that any similar 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 type 1 diabetes in secondary schools, the study team would like to consult teaching staff as well as young people. The literature with regard to teachers’ knowledge of and attitudes towards type 1 diabetes in schools is very sparse, despite acknowledgement of the vital role that they play in this context (Boden et al, 2012).

The importance of developing effective and independent self-management in adolescent type 1 diabetes is rightly emphasised, but the role of social influences in this context also warrants more investigation. The potentially positive role that a supportive peer network can play in this respect should not be overlooked. ■

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