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Young people with diabetes and their peers

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Background – T1DM and young people

- Amongst the most common forms of chronic illness affecting young people in the UK
- Throughout adolescence, young people need to become increasingly responsible for condition management
- Metabolic control often deteriorates during adolescence
- Due in part to physiological changes - but **other factors** play a role in determining treatment adherence and effective control too...

Peer influences?

- Research on wider social influences tends to focus on parental involvement
- But there is often a marked shift in social focus through adolescence from family to **friends**
- Peer relations become more important
- For young people with T1DM, peer relations may play an influential role in determining both how they think about and how they manage their condition



Our study

- A qualitative study exploring what peers know about T1DM, and their attitudes and responses to the condition
- **Stage 1: Dyadic interviews with adolescent T1DM patients aged 13-15 and a nominated close friend**
- Stage 2: Focus group sessions in secondary schools with participants without any necessary prior knowledge of T1DM
- Template Analysis used to analyse data



Interviews with young people and their friends

- Peers felt to have limited awareness of and various misconceptions about T1DM
- Patients reported they could feel judged and embarrassed (this could impact on management behaviours)
- Considerable variations reported in experiences of support in school



Limited awareness of T1DM amongst peer group

- I don't think they (peer group) know anything (about diabetes) unless, well like unless they know someone who had it.

- They probably wouldn't even know the difference between type one and two and then they wouldn't, they probably wouldn't know that I have to like have injections and stuff

They don't know what a pump is or why you're injecting yourself and what it actually is because I've had, not with close friends, but friends, they're like 'Oh, what's that?' and I'm like 'I have to'. I don't, every time I don't want to explain it all again, it gets quite repetitive.

I've had to tell like various people like what it is and why I'm doing stuff, but they obviously like, like I didn't know what diabetes was when I first got it, so I don't expect them to know.

People don't understand diabetes, not a lot, I've been talking to like a few other people in my class, I don't really talk to them much about it, like not all the time, but they, they literally don't know anything about it, which I don't think is very good because it's like they need to know, they need to be aware of it, I think they need to know about it

Specific misconceptions

It's like well it must be your fault because you ate too much sugar when you were, you know, when you were six or something like that. I feel a bit like sometimes that kind of judgement's there sometimes, and well yeah, I want them to know the difference. Like there's all this stuff around like on telly, eat proper or you'll get diabetes. It's nothing to do with that, not type 1 anyway

People can be like 'Are you allowed to eat that? You're not allowed that', but then it's like well I am allowed it because I go and do my injection. They just go 'Are you allowed that? Are you sure you're allowed it?' It's really annoying.

A lot of people get quite squeamish when he takes the blood things. It's like a drop of blood and they get all 'Urrrgh'.

People are like 'Oh, is that to do with like don't have sweets all the time?' I'm like 'I can have sweets', they don't specifically know that type one's to do with you have no insulin, you have to give it to yourself, but you still can have like sweets and stuff and type two is a bit different ... People don't actually know really, the difference between the different types.

Feeling judged/ embarrassed – impact on management behaviours?

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People do stare and they watch for a while. I'd rather them ask really, just say straight away. I mean I don't mind, but it is a bit awkward just someone like staring at you doing it.

People stare at me and I don't like it, I won't do it. I'll do it later, wait until I can be somewhere private.

If they ask you what you're doing, then that's alright, but if they just look at you, then that's when you feel more like, just go away

A couple of weeks ago at school, this girl were just staring at me when I were doing it and I shouted at her. I told her to stop looking and get out my way. Nosey.

If I'm out with people I don't know as well, I'll just skip it and catch up later, cos like you can't be having everyone waiting for you messing around can you?

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Wide variations in experiences at school

If I feel low and I want to go and the teachers like say you're not allowed to go out and all that, so I just have to walk out. You don't just go sit back down, if you need to go, you need to go. And the more you're standing there arguing with the teacher, the more lower you get, so you get more weak.

She (the school nurse) keeps emailing all the teachers, but none of them really read them. They had a meeting a couple of years ago and like it was alright for like two month and then it just all dropped again.

Teachers at school, they get emails every week from the woman in the medical room to tell them about us diabetic kids, but they just like delete it, they don't read it at all. They don't know nothing about it. Because they probably don't think it's important, they're more bothered about the work.

Diabetic nurses have been to talk to the school loads of times and it just doesn't change nowt.

- In biology classes, when we do something on diabetes, then Miss will usually just ask [patient] about it.

- Yeah, like in biology, it was as [friend] said, kind of asking me about it and I didn't really want the attention of it really.

Greater awareness of T1DM needed

- Participants would welcome increased awareness of diabetes and T1DM specifically to address specific misconceptions amongst their peers and to normalise both the condition and its management (friends found to play an important role in supporting patient and normalising the condition)
- Recommendations included: use of videos and cartoons; targeting the transition from primary to high school; having sessions with older peers with diabetes

Stage 2: Focus group sessions

- Educational materials designed in response to issues raised in the interviews piloted with three focus groups in secondary school settings.
- Sessions were structured as follows: (1) **What do you know already?**; (2) **What would you do?**; (3) **Basic information and myth busting.**
- *We don't need no education? Exploring how young people think about and respond to diabetes in their peers* – Brooks et al, submitted to Diabetes Care for Children and Young People

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