Suggestions of adolescents with type 1 diabetes mellitus on how they wanted to be supported in school settings.

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Abstract

Objective: To understand the needs and priorities of adolescents with T1DM to enhance self-management in the school settings.

Method: Exploratory, qualitative research using applied thematic analysis.

Results: Adolescents with T1DM wanted their peers and teachers at school to know more about T1DM and its management. Thematic analysis has identified specific knowledge about T1DM that is to be introduced to peers and teachers.

Conclusion: The findings of this study helped to identify precise information about T1DM that, if known by peers and teachers, might reduce some of the physical and psychosocial challenges faced by adolescents while managing their diabetes in their schools. And consequently, improve self-management among adolescents with T1DM in a school setting.

Keywords: Type 1 diabetes mellitus, Adolescents or young people, Stressors, Challenges, School, Educational setting.

Introduction

T1DM is defined as a chronic condition that classically develops in childhood and, as a result of the destruction of B-cells within the pancreas, causes a lack of insulin production [1]. From 1990 to 2008, the global incidence of T1DM among children aged younger than 15 increased by 2.8% to 4.0% per year [2,3]. T1DM represents at least 85–90% of all diabetes cases in adolescents under the age of 20 worldwide [4,5]. An analysis revealed that the UK ranks fifth out of 88 countries for the incidence of T1DM in children [6]. The current estimate of the prevalence of T1DM in children and adolescents in England and Wales is 187.7 per 100,000 [7]. These global and national figures signify an alarming increase in the prevalence of T1DM among adolescents worldwide, which indicates the continual need to focus attention on adolescents with T1DM.

National and professional context

According to the UK Children and Families Act 2014, schools have a legal duty to support pupils with medical conditions such as T1DM. The Department of Health and the Department of Education initiated the National Health Schools Programme (NHSP) in 1999, with the aim of supporting schools in taking a whole-school approach to the promotion of children and adolescents' health and well-being (physical, mental, and social). The school environment influences an adolescent's life and can lead to the enhancement of health and well-being outcomes [8]. T1DM is a life-threatening medical disorder, which can seriously affect the health and well-being of the children and adolescents who have it. Therefore, it is essential that all schools provide a safe environment where adolescents with T1DM can effectively manage their disease. According to a survey by Diabetes UK conducted in 2015 involving 409 parents of children and adolescents with T1DM, one-third of children and adolescents with T1DM were not receiving satisfactory attention in school. These findings highlight how support at school remains a major concern for many children and adolescents with T1DM.

Children's involvement in their health care decisions

The UN Convention on the Rights of the Child states that children and young people have the right to contribute in decisions about their care, including their health care. In this sense, children and young people have the right to voice their views on all matters that affect them [9]. In the UK, the National Health Service (NHS) clearly emphasises that, in order to be completely involved in decision-making about their treatment choices, all patients need information [10]. One review of children and adolescents' NHS services in England [11] explained the importance of integrating children and adolescents' views on aspects related to their health and the delivery of health services. The American Diabetic Association (ADA) has emphasised that diabetic support and education should be patient-centred, respectful, and responsive to individual patient's preferences and needs [12, 13]. Dickinson et al. (2014) and Amiel et al. (2015) highlighted that understanding children's requirements could provide health professionals with the ability to communicate with children and deliver child-centred services more efficiently [14,15]. In addition, Foot et al. (2014) stated that the policy

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had tended to focus mostly on, or express patient involvement in, the form of rights, but that associated responsibilities are inherent in this [16]. Health watch England has emphasised the rights and responsibilities of health and social care in order to ensure that the voice of patients, including children and the public, are heard in the health care system. Reflecting on these recommendations in the school context, there is importance in providing school-based interventions based on the perceptions, needs and priorities of adolescents with T1DM in order to support them in maintaining their health and well-being at school; also, to empower them to take responsibility for their care while they are at school.

Self-management and glycaemic control among adolescents with type 1 diabetes

Self-management is an essential component of diabetes care. However, this can be challenging in adolescence, as this phase includes physical, emotional, and social pressures. Adolescents' self-management of T1DM requires them to check their blood glucose levels on a continual basis, monitor their diet, increase their physical activities, and administer and adjust their insulin dosages. These diabetes-related stressors can cause emotional distress, such as feelings of anxiety and frustration [17-19]. Stress may affect an adolescent's ability to perform self-management tasks, resulting in poor metabolic outcomes [20]. Therefore, self-management has also become a common phrase for health and emotional management and comprises behaviour modifications and learning problem-solving skills as well as how to cope with stressful circumstances [21]. Shrivastava et al. (2013) [22] have identified vital self-management attributes in patients with T1DM that can lead to favourable diabetic outcomes, including a healthy diet, exercise, regular monitoring of blood sugar, adjusting and administering insulin dosage (via injections or an insulin pump), healthy coping skills, problem-solving skills, and risk-reduction behaviours. These attributes are important in achieving health and emotional management.

Petitti et al. (2009) [23] point out that self-management tasks are not easily achieved or maintained by adolescents. For adolescents with T1DM, adolescence is often linked with poorer self-management and worsening metabolic controls [24-27]. At this age, the prefrontal cortex, the area of the brain that controls judgement, reasoning, decision-making, and problem-solving, is still developing, which may explain why many adolescents react inadequately to complex diabetes self-management circumstances [28]. The capacity of adolescents to make sound judgements amid difficult situations will not be at the maturity level of an adult, as the prefrontal cortex that controls many higher-order skills is not yet completely developed until the third decade of life [29]. Moreover, the critical transition to adolescence has the possibility of negatively affecting self-care management because of increasing independence from the family [30]. Another reason for self-management tasks not being easily achieved or maintained by adolescents with T1DM is, according to Borus and Laffel (2010) [31] and Peters et al. (2011) [32], often due to fatigue from taking care of a chronic illness and major psychosocial issues, which generate obstacles to diabetes self-care. Pyatak et al. (2014) [33] found that adolescents with T1DM with a history of major psychosocial life stressors, such as anxiety disorders or unstable interactions with family and peers, may be more likely to experience deterioration in glycaemic control. Adolescents with T1DM encounter the extra challenge of trying to improve glycaemic control while experiencing the physiological and psychological changes of puberty [34]. Many adolescents still do not achieve HbA1c levels low enough to prevent diabetic complications (HbA1c is the amount of blood sugar (glucose) attached to your hemoglobin). Data from the UK National Diabetes Audit indicates that around 17.7% of children and young people with T1DM have an HbA1c below 7.5%, and approximately 30% have an HbA1c >9.5% [35].

Stressors in the school setting

As with other adolescents, those with T1DM spend long hours in school and, therefore, diabetic self-management at school needs to be optimal in order to prevent deterioration in metabolic control. Several studies explored the stressors faced by adolescents with T1DM in schools. The findings identified a need for improvement in the following areas: communication between school staff and parents, after-school support, education of staff, education about managing students with T1DM, school nurse availability, and lunch choices [36]. Other challenges include; a lack of school staff cooperation, a high level of carbohydrates offered in the school cafeteria, hypoglycaemia during physical education classes, and the unfamiliarity of classmates with T1DM [37,38]. Another study, conducted by Schwartz et al. (2010) [39], sought to evaluate the experience of children and adolescents with T1DM and involved the participation of 20 schools in the USA. The study identified several issues, such as a lack of diabetes training in educators, a shortage of trained personnel, a lack of standardisation related to individualised diabetes care plans for each child or adolescent with diabetes in certain school systems, embarrassment and emotional distress due to diabetes-related issues, such as checking blood glucose or taking insulin injections, feelings of disconnectedness, and a lack of nutritional information provided to parents by schools in order to assist parents in planning insulin-dosing requirements. Schwartz et al. (2010) [39] also highlight the need to continue improving the experiences of children and adolescents with T1DM in the school setting and recommend that schools conduct diabetes education programmes for school personnel on an annual basis. They also recommend considering the special physical and psychological needs of children and adolescents with T1DM. Wang et al. (2013) [40] found that adolescents with T1DM can be being confused about their identities and whether they are similar to or different from their peers/classmates (similar yet different) or having doubts about whether or not to tell their peers about their diabetes mellitus, whom to tell, how much to tell, how to tell, and how to answer others' enquiries (covert and overt). Wang et al. (2013) [40] recommended that significant work still needs to be carried out to enhance school management sufficiently in order to support adolescents with T1DM. In this sense, they state that considerable effort remains to be made in order to improve the experience of adolescents with T1DM in school.

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Physical, psychosocial, and emotional challenges play significant roles in adolescents' diabetes outcomes. Diabetes care, in particular, is greatly influenced by these challenges when they affect adolescents' abilities to self-manage the disease and reach metabolic control. Moreover, these challenges can increase the disease load and can cause even more distress, leading to an increased risk of diabetic complications. The school is a critical environment for adolescents with T1DM. Enhancing self-management in school is important in order to empower adolescents with T1DM in managing the day-to-day requirements of their disease. Spencer et al. (2014) [41] highlighted the importance of understanding the environmental facilitators and boundaries to self-management in order to comprehend the difficulties related to adolescents' self-management behaviour and its influence on glycaemic control in schools. Understanding and incorporating adolescents' needs and priorities and involving them in decision-making regarding their health is important for improving the quality of the health care experience among adolescents with T1DM in school settings.

Methods

Exploratory qualitative research using a thematic analysis approach was used to explore the needs, priorities, and ideas of adolescents with T1DM on how they wanted to be supported in their school.

Ethical considerations

The study was submitted for ethical approval through the University's electronic document management system: Ethics and Research Governance Online (ERGO). Following approval from the University's Ethics Committee, the researcher sought permission from the NHS approval system, as the research study involves NHS patients. Health Research Authority (HRA) approval and a research passport were obtained to get access to the NHS. Consent from parents or guardians were taken as the participants were considered minors as they were under the age of 16. However, a written assent form from the participants was obtained to ensure that adolescents can freely participate, at the same time as allowing for the parental obligation to safeguard their children's safety and well-being.

Participants and setting

The purposive sampling method was used to recruit 18 participants from the paediatric diabetic outpatient clinic in one local NHS hospital. The inclusion criteria included:

1. Has been diagnosed with T1DM

2. Is aged between 11–15 years old (as this study focuses on adolescents with T1DM).

3. Speaks and reads English (in order to facilitate comprehension and communication between the researcher and the participant).

4. Is attending school (as the study is focused on adolescents with T1DM in schools).

Data collection

The researcher met with the paediatric diabetic team members at the hospital and discussed the recruitment plan in detail. The researcher was located in the diabetic assessment room, where adolescents with T1DM come and are assessed before seeing the doctor. The diabetic-paediatric nurse identified the eligible participants for this study according to the inclusion criteria and introduced a brief idea of the study to adolescents and their parents/guardians. Interested potential participants and their parents were then approached by the researcher, and the study was further discussed with them. Complete disclosure regarding what would happen during the research and what was expected of the research participants was essential during the recruitment process in order to help alleviate parent and adolescents' uncertainties [42].

Care was taken by the researcher to eliminate or reduce the risk of coercion that might have affected patients' participation in the research. Complete disclosure about the aims and objectives of the research and what is expected from the research participants was presented to the potential participants. Participants were given the opportunity to question and receive accurate information before committing themselves to the study. An information pack was also given out, consisting of an invitation letter, an information sheet for parent/guardian(s) and adolescents, a consent form and a response card. A minimum of 24 hours was given in order to decide whether they wanted to take part in the study. After receiving the response cards by post, the researcher contacted the potential participants by telephone or email (based on the information on the returned response card), and confirmed their agreement to participate, and arranged a date for the interview. On the date of the interview, participants also had the opportunity to ask further questions about the study, and they were reminded that they could withdraw at any point. The researcher is a healthcare worker who has valuable experience working with children and adolescents in hospitals. This experience generated valuable skills in how to communicate with adolescents with medical problems.

Audio-recorded in-depth interviews were conducted using a semi-structured interview guide which was developed based on the literature of adolescents with T1D. The researcher piloted the questions by conducting five 'test' interviews with adolescents who were as close as possible to the target research group (i.e. same age and with or without diabetes). Doing this was very helpful in obtaining a general feel for how the interviews would go. In addition, it provided a better understanding of the clarity, wording, and understanding of the designed questions. The adolescents agreed that the questions were simple, straightforward, and easy to understand. Therefore, no significant changes were made to the interview guide. Face-to-face semi-structured interviews lasted between 30-35 min. The recruitment process was finished when no new themes emerged, indicating data saturation.

Data analysis

Thematic analysis was utilised for the interviews in this study, using computer-assisted qualitative data analysis

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software (NVivo). Data analysis is the most complicated and essential aspect of qualitative research. Qualitative research usually produces large amounts of textual data in the form of transcripts. The systematic and difficult preparation and analysis of qualitative data are usually time-consuming [43]. Therefore, computer-assisted qualitative data analysis software (NVivo) was used to assist in data analysis. One of the main advantages of using computer software is that it can offer greater analytical flexibility and transparency to a research process when compared to manual methods [44]. Software such as NVivo provides transparency mechanisms that can help make the methodological and analytical processes more understandable and easier to trace. However, it is essential to understand that these kinds of software do not analyse data but facilitate data analysis by managing, sorting, and organising large volumes of qualitative data.

The semi-structured individual interviews conducted were based upon open-ended questions and were recorded using compact recording technology. The audio files were professionally transcribed using a professional transcribing service. A confidentiality agreement was obtained before sending the audio files. The researcher checked the transcripts alongside the initial audio recording in order to ensure accuracy. Data analysis was carried out using thematic analysis, which involves six main stages [45]: familiarisation with the data, coding, searching for themes, reviewing themes, naming themes, and writing up. The researcher spent time familiarizing themselves with the data by reading and re-reading the transcribed data. NVivo software was utilised to code each of the participant's transcribed interviews. This phase resulted in a long list of different codes. The researcher read the codes from each participant's interview and then started to search for themes by re-reading and refocusing on the broader level of themes instead of the codes. The codes were then sorted into potential themes. The use of NVivo enabled the researcher to check back and forth between the analysis and the source data in order to read the content line-by-line and code the salient themes. The researcher reviewed the textual data to make sure that the themes were clearly stated by the participants.

Methodological rigor

Evaluating the quality of research is critical if findings are to be applied in practice and integrated into care delivery [38]. The criteria used to evaluate the findings of qualitative research are different from those used in quantitative research. In quantitative research, the criteria for evaluating research are reliability, validity, and generalizability. However, in qualitative research, different terms are used to better reflect the different nature of qualitative research. These terms are referred to as trustworthiness criteria, involving credibility, transferability, dependability, and confirmability [46].

To establish credibility, the researcher used analyst triangulation by continually engaging experienced peers in the data analysis process. Peer debriefing was carried out to increase the trustworthiness of the findings. Holloway and Galvin (2016) [47] explain that debriefing is when competent personal in qualitative research reanalyze the raw data, listen to the researcher's concerns and discuss them. This could detect bias or inappropriate subjectivity to ensure the results truly reflected the participants' views. To establish transferability, the researcher provided a clear description of the research process such as settings, context, sample size, sample strategy, inclusion and exclusion criteria. In addition, the exact quotes expressed by the participants were also provided to allow the readers to confirm whether the findings emerged from the data and not from the biases and subjectivity of the researcher. All of this information is needed to allow the readers to evaluate whether the findings of this study can be transferred to their own setting. Dependability and confirmability involve providing a complete set of notes on decisions made during the research process and reflective thoughts [48]. To establish that all the research stages were documented from the start of the research study, and the records of the research path are kept all the way through the study.

Accounting for any personal biases that may influence the findings is one of the most important strategies for ensuring the trustworthiness of qualitative research findings [49]. In this study, it was essential to consider whether the presence of the researcher would affect or constrain the participants from sharing their perceptions. However, as the researcher is not a member of the paediatric diabetic team in the hospital, it would be easier for the participants to freely express their views. Therefore, the researcher's presence could not be construed as a weakness in the research. Burns and Grove studies had to go even further and explain that qualitative researchers have to think about the interaction between the self and the data during analysis [50]. This process of critical examination is called reflexivity. Also, carrying out a literature review before commencing the study was important in understanding the research topic as well as helping to formulate the type of questions that would produce enough information for interpretation. The researcher has maintained reflexivity and engaged in self-reflection by keeping a diary, in which regular entries were made throughout the process of collecting and analysing the data; this enabled the researcher to identify the influence that her beliefs and values may have had on the quality of the data collected.

Results

Eighteen participants were interviewed individually. For reasons of confidentiality, participants are referred to by abbreviation: adolescent (A=Adolescent), number (1–18), and gender (M=male, F=female). The final analysis revealed five themes:

Adolescent's ability to depend on themselves in managing their diabetes in school

All adolescents explained that they depended on themselves for all of their diabetes management tasks, and they understood how to do their daily tasks, such as checking their blood sugar, adjusting insulin doses, administering insulin injections, and counting carbohydrates. The following interview extract demonstrates some of these behaviours.

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"Um, I just do it, like, normally, I do my blood sugar map and checking every two hours, so when I get to school, it'll be around 8 o'clock, so I wait until 9, which is during registration, and I'll check my sugar levels then. Then, I check again at 11, which is break time, and then 1 o'clock, which is the end of lunch, and then at the end of the day, which would be 3 o'clock. That's when I do my final one for school"**.**

Challenges in managing T1DM in the school setting

Although all adolescents demonstrated their ability to take responsibility for their diabetes management in school, when asked about their feelings regarding managing their diabetes in school, the adolescents explained that it could be difficult and challenging. The challenges were categorised into physical challenges, psychological challenges, and social challenges as follow:

Physical challenges

All but one described some physical challenges associated with signs and symptoms of hypoglycaemia, such as general weakness, agitation, thirst, and shakiness.

"Just, if I'm low [low blood sugar], I feel a bit, I feel hungry, sometimes thirsty. I might feel a bit sick and weak" (A8-M-13yrs).

"Normally, like, I can't really move myself very well. I shake a lot" (A17-M14yrs).

Psychological challenges

Another psychological challenge facing adolescents with T1DM as a result of fluctuating blood-sugar levels is mood swings, which can result in a flare-up in temper or other less than-desirable behaviours.

"When my blood sugar is high, sometimes when I am talking to people in school, I can come across quite abrupt with quite a bad attitude, and that has upset some of my friends, but they didn't realise what is going on with me" (A11-M-13 years).

"When I'm high [high blood sugar], my mood just goes off slightly" (A10-M 12 years).

Social challenges

Adolescents expressed some social challenges, such as their uncomfortable feelings and embarrassment due to carrying out diabetic-related tasks in front of their peers, especially if their peers did not know anything about the duties of managing T1DM, such as checking blood sugar or administering insulin injections.

"I think the fact that you have to inject yourself in public, and things like that, is just a bit, like, you don't want to do. It's almost a bit embarrassing, you know? Like, not the fact you have to inject yourself. It's the fact that there are other people" (A9-F-15yrs).

Peers at school and teachers to improve knowledge and understanding about T1DM.

When asked about how adolescents with T1DM wanted to be supported to make their self-management better in school, sixteen of the adolescents would want all of their peers and teachers to know more about T1DM.

"Diabetes and things to do with diabetes so all teachers and all students at school should know, you know? Everyone at school to know about it [diabetes]" (A18-M-13 years)

Suggestions in which knowledge and understanding of T1DM can be enhanced

All of the adolescents suggested that their peers and teachers become more familiar with diabetes as well as signs and symptoms of hypoglycaemia and its management so they will be able to manage in emergencies.

"Umm, know the symptoms of feeling low [low blood sugar] and feeling high [high blood sugar], and know how to act in case of emergencies" (A2-F-11yrs).

Seven of the adolescents reflected that if their peers and teachers knew about diabetes, they would understand the effect of hypoglycaemia on their mood and changes in their behaviours, so they would not get angry.

"Understand how it affects my temper and not getting angry with me. Just to genuinely, like, understand what people with diabetes go through, like my attitude changes quite drastically, and just don't get angry at me, in a way, and wait till I'm alright again" (A17-M-14yrs)

Half of the adolescents also specified that teachers and peers to know about the effect of blood fluctuation on behaviour; therefore, they would be able to remind them to test their blood sugar.

"If I start acting weird in a class before lunch and no one encourages me to do a blood test, then I come after lunch, my sugar could be all over the place, and it could escalate into something a lot more that could have been prevented, really" (A15-M-15yrs)

Six of the adolescents would like peers to know about their diabetes because their understanding of the disease could allow adolescents with T1DM to manage their tasks without having to answer many questions, and it would give them space to do their tasks.

"To understand that I need some space to do my diabetes tasks" (A10-M-12yrs).

Because then people actually understand it [diabetic management]. They don't ask a load of questions" (A13-M-11 yrs).

Two of the adolescents explained that because peers do not know about insulin injection, they had to inject themselves under the table because they thought that some of their peers would become scared or misunderstand the purpose of injections.

"Kind of, do it [injecting insulin] under the table where no one can see it, or something, because I think some, you know, like, some people can be a bit funny about, like, needles and stuff like that, and blood. Because I am, which is quite ironic, being diabetic, but, like, if I mean, I know if I saw someone injecting, I'd be like, 'Oh my God." (A9-F-15yrs)

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Three of the adolescents also explained that their peers and teachers do not understand why they need to eat during the lesson to treat their hypoglycaemia.

"Because I went in the lesson one time, and I was eating my dextrose, and she [teacher] told me, 'Spit your chewing gum out" (A7-M-12yrs)

"It's just a bit annoying that people [teachers and peers], it's like, stereotypes of why diabetic people, eat in the class" (A8-M-13yrs)

One adolescent explained that he had to wait for 15 minutes to be allowed to go to the medical room to treat his hypoglycaemia.

"I went up to the reception desk to say I felt low, and she [receptionist] made me wait for about 15 minutes or something before she'd let me go and get my medication"(A6-M- 13yrs).

Two of the adolescents stated that some peers do not know the actual cause of T1DM, and they think it happens because of eating so much sugar or because of being overweight or drinking alcohol. The misconception about the causes of T1DM can be frustrating.

"Make them [peers] aware, maybe explain what it is. Like they said, 'How did you get it? Eating too much sugar? Are you eating too much? Are you fat?' It is frustrating and annoying, and I went, 'Um, oh, yeah, my pancreas stopped working'. They [peers] were searching up something about alcohol, and he went, 'Oh look, it could give you diabetes'. I went, 'Yeah, it's not how I got it'. And then I said, 'It's where I got a cold, and it stopped my pancreas" (A18-M-13yrs)

Eight of the adolescents expressed that there was a lack of awareness regarding what T1DM is and how it differs from T2DM. They expressed that more knowledge can lead to a better understanding of the tasks of T1DM.

"So, I think the biggest problem is the awareness in the school. Teachers and students are, actually, should be made much more aware of what is type 1 diabetes. It is not like type 2 diabetes. It [type1] needs much more care" (A4-F-15yrs).

One of the adolescents stated that some of their peers need to know the importance of carrying their diabetes bag (a bag containing an insulin pen and a blood glucose meter) at all times.

"Yeah, I've had issues with boys, like, taking my diabetes bag. Just boys are messing about it in the classroom, throwing the diabetic bag around. So, I had to tell the teachers because I need that kit on a daily basis. They're not, very, um, good at dealing with it. I guess they need to know how the kit is important to me" (A8-M-13yrs).

Six of the adolescents expressed that, some peers and teachers had no idea what the insulin pump is. They thought it was an MP3 player or a mobile and tried to pull it off.

"One teacher tried to pull it off of me. Well, in a sort of way, they won't help me because they don't know how much it means to you to have an insulin pump" (A15-M-15yrs).

One adolescent stated that the teachers could provide more support.

"Well, maybe for the teachers just to give a little bit of like, support, like it's okay and stuff, so we feel good" (A1-M-11yrs).

Five of the adolescents stated that some teachers do not know that they have students with diabetes in their class. The participants expressed frustration of having to repeat telling the teachers that they have diabetes.

"Teachers, they can make them more aware, maybe, because some teachers just don't know. Like, my English teacher, she'd asked me to take this band off before that says 'diabetic', and I've explained to her, I think two weeks ago. It was the third time she asked. It is annoying, repeating the same thing over and over, so, she wasn't aware that I actually had diabetes" (A8-M- 13yrs).

Three of the adolescents suggested some ideas for how their teachers could know that they have students with medical problems, such as names on the staffroom board or documentation on each child for the teachers.

"To have, like, a sheet of paper with a photo of us and then, like, the medical condition we have, and this will be better, so they [teachers] know about us and support us" (A14-F-13yrs).

Also, the lack of knowledge about how to support adolescents with diabetes during specific activities can cause adolescents to drop important activities, such as PE, specifically for those who need more support to do their tasks. Three out of 18 adolescents expressed this sentiment.

"I do not do PE; they [PE teachers] have allowed me to drop PE instead of putting someone to support me, to actually check my sugars, through the PE, half-way through it, to check it again" (A5-F-13yrs)

Four of the adolescents suggested that the canteen should provide more information about carbohydrates, so they can adjust their insulin dosage.

"The canteen at school doesn't have anything on show about how many carbs and stuff. I think that would be helpful, though, if they did" (A16-F- 15yrs).

"If the school could label food, they sell at break/lunch time with how many carbs that will be helpful to adjust our insulin dosage" (A6-M-13yrs).

The suggested information about T1DM (as obtained from data) for peers and teachers to be included in the intended intervention is summarised as follows:

1. Information about diabetes mellitus and its causes.
2. Information about the differences between T1DM and T2DM
3. Information about signs and symptoms of hypoglycaemia to act on in an emergency.
4. Knowing that fluctuation of blood sugar can cause mood swings.

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5. Knowing to remind someone with diabetes to check their blood sugar if their behaviour has changed.
6. Information about insulin pens.
7. Information about insulin pumps.
8. Information about the need to eat in class.
9. Information about the importance of carrying the diabetes bag.
10. Knowing that teachers can give emotional support.
11. Knowing about a student with diabetes in the class will help a student with T1DM not to repeat information about themselves over and over.
12. Information about teachers to keep a register for students with diabetes
13. Information about how hypoglycaemia should be treated immediately.
14. Information about how PE teachers can support a student with T1DM during a PE lesson
15. Information about the importance of providing nutritional information.

Approaches to educate peers and teachers about T1DM

Adolescents suggested different ways to educate peers and staff about diabetes, such as during enrichment days at school.

"At my school, we have enrichment days, where we have a day full of activities to do with our learning. I think, maybe, on one of those days, or maybe on a Friday afternoon, we could do, like, and activity where people [teachers and peers], like, become familiar with diabetes" (A4-F-15yrs).

Few participants suggested PowerPoint or short video presentations to be watched during a tutor session.

"Maybe they could have someone make a PowerPoint or short video, which they [teachers] then can show to the whole school during tutor session. Well, our years are split into French and Spanish, and all me, x, and y are all diabetic; we're all on the Spanish side so that the French side wouldn't know anything about it" (A8-M-13yrs)

Discussion

The findings of this study suggested that adolescents with T1DM are still confronting physical and psychosocial challenges in managing their diabetes in school. The findings also identified the priorities of how adolescents with T1DM wanted to be supported in school. It indicated that adolescents with T1DM wanted their teachers as well as their peers to improve their knowledge about T1DM as this can lead to reduced psychosocial challenges and consequently improved their self-management in their schools. The thematic analysis of the data has also enabled a greater understanding of what intervention content that has been pointed out by the participants is required to enhance the knowledge and understanding of T1DM among peers and teachers.

Cognitive changes during adolescence improve complex thinking, and previous life experiences help adolescents develop new knowledge [51]. Therefore, they are usually able to understand the complexities of their disease and can assert their independence by recognising the changes in their physical and mental health that constitute a threat [52]. As children enter adolescence, they become less dependent on others and more competent in making their own decisions [53]. Consequently, they become more able to solve their diabetes problems with self-care management tasks [54].

T1DM is a very demanding and challenging condition. Some challenges explained in this study were associated with the nature of T1DM and its management but also arose as a result of the social difficulties that restricted them from managing their diabetes within the school environment. This study's findings explained some physical challenges that can be caused due to fluctuations in blood sugar levels, such as weakness and shakiness. However, these physical challenges can lead to social challenges such as embarrassment. The findings of this study reinforce the findings reported by Schwartz et al. (2010) [39], who evaluated the experience of children and adolescents with T1DM in school by surveying them. They found that 23% of the surveyed children felt embarrassed at school after experiencing a hypoglycaemia episode. A feeling of the embarrassment of managing diabetes in school was indicated in this study. The result of this study concurs with Ye et al. (2017) study, which aimed to understand issues that concern teens to develop more successful interventions to improve diabetes self-management [55]. Teens reported being embarrassed about blood glucose monitoring and insulin injections in public. Comparable findings were also reported by Lu et al. (2015), who asked teens about barriers to self-care. They found that adolescents were embarrassed managing their diabetes in front of their peers [56].

Adolescents in this study reported that diabetes makes them feel different from their peers. The findings of this study are similar to Wang et al. (2013) study, which investigated the school experience of adolescents with T1DM. They found that adolescents were often confused about their identity and hesitant of whether and how much they were similar or different from their classmates [40]. None of the participants in Wang et al. (2013) study was happy to perform their diabetes task in front of others because of associated unwanted attention, which emphasises the sense of being different [40]. Charmaz (1995) discussed that identity is made up of various factors, including self-concept, personal values, self-efficacy, relationship roles, and opportunities for the future [57]. These factors are affected by a chronic condition such as T1DM, as the illness will affect how adolescents with T1DM view themselves, and how they want others to view them or the priorities they assign to managing their illness.

Rapid physical development, hormones and taking responsibility for managing their diabetes may cause psychological and emotional problems in adolescents with T1DM [58]. These findings are also supported by other studies, which found that blood glucose fluctuation, particularly hyperglycaemia, has affected the mood and motivation towards different activities of the adolescents in school [41].

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Storch et al. (2006) indicated that there is an association between diabetes-related bullying and diabetes self-management. They found that children with T1DM who are bullied about their medical condition may avoid engaging in self-management behaviours that are easily observable by peers and, by virtue, have a higher likelihood of being targeted [59]. Similarly, Greening et al. (2006) and Horton et al. (2009) stated that diabetes and negative life events (bullying) are chronic stressors that harm children's behavioural adjustment [60, 61]. Understanding the physical and psychological challenges that might face adolescents with T1DM might provide better ways to support adolescents with diabetes in school. Also, it might help adolescents with T1DM to respond to these challenging situations properly without compromising their diabetes self-management in school. In this current study, bullying was specified (messing with the diabetes bag); knowing what type of bullying adolescents with T1DM are facing in school could help in finding some strategies that might tackle this problem, such as increasing the awareness of the importance of diabetic bag.

Similar to the findings of other research [40, 62, 63], this study demonstrated the reluctance of some adolescents with T1DM to reveal their condition to their peer group because they fear that their diabetes identifies them as different. Similarly, Balfe et al. (2013) found that adolescents with T1DM, confronting the challenge of feeling self-conscious about their diabetes and its management, were concerned about how other people viewed them [64]. They found that adolescents with T1DM have strong stigma-related perceptions of other people and tended to sidestep activities that they felt would highlight or disclose their diabetes to others. Many adolescents with T1DM fight with body image, self-esteem, and peer-related issues. During adolescence, peer relations and acceptance by friends are vital. Therefore, adolescents with T1DM may engage in inactive coping approaches, for example, avoiding diabetic-related activities such as testing blood sugar or even injecting insulin to avoid being different to others [65].

Despite that, the data reported by most of the participants in this study recommended that peers and teachers know more about T1DM and its management. These findings are supported by Brooks et al. (2015), who concluded that a supportive peer system could be a valuable source in good management of T1DM in adolescents [66]. Also, Lu et al. (2015) suggest that sharing knowledge about diabetes with friends allowed them to overcome the social embarrassment related to diabetes-related tasks [56]. Irani et al. (2014) also emphasised that to overcome T1DM-related social stigma, community-based strategies including education, advocacy, and interaction should be introduced [67]. However, the above studies focused on other contexts and not in school. The uniqueness of this current study is that the participants wanted that all school peers as well as teachers, in school particularly, to know about their diabetes.

More knowledge about diabetes and its management could prevent adolescents with T1DM from receiving unwanted attention when testing or injecting in public or carrying an insulin pump treating their hypoglycaemia. Unwanted attention can hinder their ability to fulfil their self-management routines as a result [41]. It was important for the participants in this study to know that they will be properly supported. Many studies had suggested teachers improve their knowledge or receive a basic knowledge of diabetes [68-70] so they can act in case of emergencies such as hypoglycaemia. Having reliable, knowledgeable support within school is helpful to give adolescents with T1DM a sense of security in managing diabetes [71]. In this study, participants with T1DM had recognised the importance and the need to have peers in school around them who knew about their diabetes, to feel more secure, even if they felt confident about their own ability, meaning that they are less alone with this condition.

Knowledgeable peers and teachers in school will be helpful to reduce some of the psychosocial challenges as indicated in this study. Malik and Koot (2009) found that protective factors such as self-worth and social support may mediate the effects of psychosocial stressors with adolescents with T1DM and thus should be encouraged [72].

It was also found that good knowledge about diabetes will allow PE teachers to adequately support and remind adolescents with T1DM to do the necessary task before engaging in any physical education classes. These findings are comparable to MacMillan et al. (2015) study, where adolescents with T1DM were excused from participating in PE sessions due to a lack of diabetes knowledge among PE teachers [73]. MacMillan et al. (2015) highlighted the necessity to improve support for adolescents with T1DM in schools in general and specifically in PE lessons [73].

Strengths and Limitations

One of the strengths is what has been learned about particular support needed in school from the adolescents with T1DM themselves. The suggestions of the specific information needed to be learned by the school peers and teachers that emerged from this study will be used to develop a school-based intervention that could enhance self-management among adolescents with T1DM in the school setting.

The limitations of this study involved using a sample of mainly white British adolescents. Also, the findings are based on the experiences and perceptions of the adolescents involved and might therefore not be a reflective of the view of other people within the school environment. Therefore, further research involving a larger and more diverse sample (diverse ethnicity) would be justified, and perhaps including staff, peers and other school personnel experiences will provide a balance to the overall picture.

Implications for future research and clinical practice

This study points to some possibilities for further research. First, the findings from this study helped in building an in-depth understanding of the viewpoints of the adolescents with T1DM in how they wanted to be supported in schools, which will be used to guide and shape a school-based intervention to enhance self-management among adolescents with T1DM. The intervention development details is discussed elsewhere [74]. Second, an essential source of support that emerged from

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the result was that of peers' support along with the teachers' support; however, there is no information on the views of peers themselves about their own roles and associated support needs to support someone with T1DM in school. Research in exploring the views of the school peers in this regard is needed.

Implications for clinical practice

The findings of this study identified several implications for professional practice that are pivotal to meet the enhanced management of adolescents with T1DM in school. Adolescents with a chronic disease such as T1DM should always be encouraged to participate in their health choices. Their participation is likely to yield essential information for effective and important insights into how they want to be supported in their school. Health care professionals must provide continuous and accessible support to assist with the needs and priorities of adolescents with T1DM. The assessment should investigate the perception of school support. It should involve asking adolescents with T1DM if the given support is enough and what could be done to improve or enhance it.

Interventions should be designed to enable others (peers in school and teachers) to successfully fill their roles in supporting adolescents with T1DM in a school setting. The diabetic team needs to ensure that schools are aware of the existing guidance in supporting students with T1DM. They should ensure that schools understand its implications and are implementing the guidance.

Teachers and peers in school need adequate knowledge and appropriate attitudes to become more competent in supporting adolescents with T1DM in school. Therefore, effective policies should be available to improve school awareness about different chronic diseases. All schools' policies need to ensure that teachers know about their students with chronic illness and their particular needs.

Conclusion

School is a critical environment in influencing the health and safety of adolescents with T1DM. Adolescents with T1DM need to manage daily tasks of medication, with regular monitoring of blood sugar, balancing food intake and physical activity. Given the importance of school-based diabetes self-management, this study sets out to gain more understanding about the needs and priorities of adolescents with T1DM, to understand how they wanted to be supported in the school setting. It was also to gain more understanding about what intervention features and components, considered as a priority in enhancing their self-care in the school.

The findings of the study supported earlier work in identifying the challenges of self-management among adolescents with T1DM in school and added to the literature by also identifying key points related, including the adolescents expressing how they wanted to be supported in school. A precise need emerged from the findings of this study, which is improving knowledge and understanding of T1DM and its management among teachers and also peers. This study highlighted the importance for peers in conjunction with teachers to understand about the disease. It also identified a key point regarding specific information about T1DM, which was suggested by the participants, to be known by peers and teachers and assumed by the participants to be helpful to reduce some physical and psychosocial challenges and thus enhance self-management at school.

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Conflict of Interest

No conflict of interest has been declared by the author.

Consent for Publication

Consent to publish data from those participating in the in depth-interviews was obtained.

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