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Influences on technology use and interpretation among young people living with type 1 diabetes

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Abstract

Aims: To characterise continuous glucose monitor and flash glucose monitor use and related issues (both positive and negative) in the population of children and young people living with type 1 diabetes in the Southern Health and Social Care Trust (SHSCT), Northern Ireland.

Methods: Four focus groups were conducted in the SHSCT with people with type 1 diabetes and their families, to assess opinions of diabetes technology. In addition, questionnaires were distributed to diabetes specialist nurses (DSNs), young people and their families about use and access to diabetes technology.

Results: Questionnaires were completed by 68 children, young people (0–18 years) and their parents/guardians. Nearly all (98.5%) had access to their own diabetes related data, and 70.6% used diabetes data systems, for example, Libreview. Most of those using these systems found them beneficial and easy for daily use and clinical review.

Most DSNs (83.9%) agreed that the systems were easy to use, and 82.3% were confident in interpreting the data accurately. DSNs felt virtual review was beneficial in over half of young people with 62.9% advising changes to diabetes management based on the data.

Focus groups participants deemed diabetes technology a ‘gamechanger’ and ‘lifechanging’. Some drawbacks included ‘disruptive’ alarms, self-confidence issues, visible diabetes technology and problems in school.

Conclusions: Most young people, their families and healthcare professionals reported they were confident in interpreting diabetes data and technology was easy to use. Diabetes technology could improve access to care through virtual clinics, improve clinical outcomes and enhance quality of life.

KEYWORDS
children, diabetes pump, diabetes technology, type 1 diabetes, young people

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© 2022 The Authors. Lifestyle Medicine published by John Wiley & Sons Ltd.
Research shows that the average person with a diagnosis of type 1 diabetes is willing to trade 12% of their remaining life for a life without diabetes, demonstrating the profound impact diabetes has on someone’s life.

The Paediatric Audit on Diabetes in 2017 showed that the prevalence of children and young people with type 1 diabetes had remained stable since 2013/14; however, there was an increase in those aged 5–9 since 2012/13. In England and Wales there were 28,597 children and young people and approximately 2769 newly diagnosed between 2018 and 2019. Our own research shows that there are 2330 young people aged 12–26 are on the Diabetic Eye Screening register in Northern Ireland (NI), but no equivalent information to the Paediatric National Audit is available for NI.

Diabetes technology is continuously advancing with continuous glucose monitors (CGMs), flash glucose monitors (FGMs) and insulin pumps becoming increasingly popular. Studies investigating CGMs/FGMs and insulin pump therapy suggest that benefits include better quality of life, improved clinical outcomes such as lowered Hba1c, increased treatment satisfaction and less familial burden and return to ‘normal life’. This ‘normal life’ means better ability to cope with the fear of living with hypoglycaemia and hyperglycaemic episodes, improved perception of mental health, a chance for flexible eating habits and better sleep patterns.

Clinically, FGM/CGM and pump therapy contribute to increased time in blood glucose target range and shorter duration of hospitalisation, better glucose control and improvement in metabolic parameters with less frequent hypoglycaemic episodes. Parents of children and young people with insulin pumps report experiencing more freedom, flexibility and spontaneity while also providing better glucose control and easier disease management with less painful injections. However, parents often have to rethink their child/adolescent diabetes care as frequent checking and tight control of blood glucose levels can cause further stress. Research shows that fathers felt the pump allowed them to be more actively involved in their child’s diabetes care and improved their confidence in caring for their child alone.

Despite the many advantages associated with insulin pumps, there are challenges. Barnard et al. (2007) outlined that >50% of participants reported downsides to insulin pumps, although only 2%–4% stopped using the pump after a short amount of time. Issues surrounding body image and cosmetic unacceptance are commonly reported as well as problems with infusion site and localised skin reactions. Despite these, most continue to wear their pump as the benefits outweigh the disadvantages.

Diabetes technologies output data that can be downloaded into a diabetes system such as Carelink, Dexcom Clarity, Libreview and Diasend, for remote clinical monitoring. Each of the systems produces their own presentation of diabetes data, which allows the user and their healthcare team to see the results.

The aim of the current study was to investigate diabetes technology use and related issues (both positive and negative) through qualitative assessment, in a population of patients with type 1 diabetes mellitus in the Southern Health and Social Care Trust (SHSCT), NI, UK.

Study design: A prospective qualitative study gathering information through questionnaires and focus groups on the opinions of children, young people and their families on the use of diabetes technology.

2.1 | Ethical approval: Caldicott guardian approval

Data collection: Qualitative and quantitative data were collected through questionnaires and focus group interviews. Data for questionnaires were collected by a trainee psychologist in the SHSCT between June and August 2019 and focus group interviews were conducted from 12th June 2019 to 24th June 2019. Questionnaires were developed by the SHSCT diabetes team asking questions about diabetes technology and diabetes apps/websites each person or family used to control and keep track of their diabetes. The SHSCT team developed these questionnaires and completed a pilot study of 20 people before it was released to further participants after minor amendments were made changes as suggested in the pilot study. The questionnaires were in paper format and distributed in diabetes clinics in the SHSCT.

All patients attending a paediatric diabetes clinic within the SHSCT were given a questionnaire. Participants then indicated on the questionnaire if they were willing to be a part of a focus group as well. Participants who were willing were then contacted and invited to the focus group closest to them.

In addition, four focus groups led by diabetes specialist nurses (DSNs) and paediatric consultants were conducted. The focus groups followed a semi-structured list of broad themes/questions; however, participants could lead the conversation in the focus group as it naturally flowed. Table S1 shows each theme and relevant quotes.

Four focus group interviews with approximately 10–12 people/families were conducted in two hospital sites (Daisy Hill Hospital and Craigavon Area Hospital) and two community settings (Rannafurly House Dungannon and an Activity Centre, Warrenpoint). The participants included parents/guardians, children and young adults. Focus groups were not recorded; however, two researchers from Queen’s University Belfast, UK took notes during focus groups and compared transcripts to validate discussions. These transcripts were then used to complete thematic analysis using Braun and Clarke’s thematic analysis methods. Each focus group session lasted approximately 1–2 h and was led by members of the inter-professional type 1 diabetes service in the SHSCT. Quotes from each focus group were anonymised in order to keep data confidential and anonymity. Each participant was assigned an anonymised unique code. Codes were assigned with the place and then a number for each participant with diabetes, for example, Daisy Hill Hospital (DH, Newry), Craigavon Area Hospital (CAH, Portadown), Dungannon (DUN) and Warrenpoint (WP) and then a participant number (e.g., CAH1).
Data analysis: The questionnaire responses were entered into an Excel spreadsheet before being converted to SPSS statistical package version 26 for basic analysis of frequencies. Data were not evenly distributed so the median interquartile range (IQR) were used for Likert scale analysis. A thematic analysis of the focus groups was conducted manually using Braun and Clarke’s thematic analysis methods. Thematic analysis was conducted by two independent researchers, one a junior researcher without a medical background and one post-doctorate with a medical background. When both researchers had conducted independent thematic analysis, a meeting to discuss common themes was held and all themes and subthemes were agreed.

3 | DEMOGRAPHICS

Questionnaires were completed by 68 people living with diabetes or by their parent/carer in the SHSCT. Due to the age of participants, parents/carers filled out the majority of questionnaires (47/68, 69.1%) on behalf of their child.

Focus groups included young people and their parents/guardians. Young people were aged 0–18 with a mean age of 11.3. There were varying number of young people with diabetes at each focus groups including 9 (Newry), 9 (Craigavon), 3 (Warrenpoint) and 5 (Dungannon), in addition all children except 1 had at least 1 parent/guardian present.

4 | RESULTS

Respondents were asked about their access and use of diabetes technology. A majority (98.5%, 67/68) had access to at least one device, with 91.2% (62/68) having access via a smartphone. When asked about their use of a diabetes programme such as Libreview or Diasend, 70.6% (48/68) stated they used a diabetes programme with 37.5% (18/48) using Libreview.

Many (64.7% 44/68) stated they checked their blood glucose level using a reader or app at least once per day. There were few respondents (2.9%, 2/68) who checked their blood glucose level a couple of times a week, 11.8% (8/68) checked weekly or fortnightly, 2.9% (2/68) checked monthly and 11.8% (8/68) of respondents stated that they check it ‘sometimes’. Four respondents did not answer the question.

Participants were asked how beneficial (in terms of improving quality of life/ease of diabetes management) using a diabetes programme to interpret diabetes management data was (0 = not at all beneficial, 10 = very beneficial), the median (IQR) was 9 (7 to 10). When asked how easy the systems were to use, median 8, interquartile range 5–8. Many (64.8%) stated that they would attend education about the system but half of those would only attend if they lived nearby.

Many (61.8%) respondents stated they contacted their DSN to review glucose levels outside clinic appointments. In 83.9% (52/62) of virtual reviews, DSNs found that the diabetes technology systems were easy to use for reviewing data and were confident in interpreting the data in 82.3% (51/62). DSNs advised changes to patient’s insulin therapy in 62.9% (39/62). Reviewing virtual data during a virtual diabetes appointment was deemed beneficial in 69.4% of cases (43/62). In eight cases, it was not deemed beneficial due to patient not answering, failure to upload diabetes data or general disengagement.

4.1 | Focus groups

Five main themes were found: benefits and drawbacks of diabetes technology diabetes technology, the impact on familial and social relationships, school issues and the use and understanding of diabetes device output data. See Table S1 for main themes and sub-themes and Figure 1 for most prominent issues.

Overall, participants focused more on positive aspects of the technology. Some of the most common subthemes were that it was a ‘gamechanger’ (DHH2, CAH3) and improved quality of life in young people with diabetes. Participants used phrases such as ‘my life has changed,’ ‘gamechanger’ and ‘transformational’ (CAH4). A lot of parents and young people said that their lives had changed and they ‘couldn’t go back’ (DHH7) to injections.

Many participants shared anecdotes of having to get up during the night and set alarms to check their child’s blood glucose level. However, with the diabetes technology in place parents stated, ‘we can sleep through the night as we trust the alarms’ (CAH6, CAH4). In addition, prior to diabetes technology advances, parents were often anxious about their child not eating enough for the dose of insulin administered before the meal. One parent stated that ‘mealtimes are easier because we don’t have to inject before eating and then make them eat enough for the amount of insulin we gave’ (WP2, DUN4). Participants also stated that diabetes technology allows much better ‘flexibility and convenience’ (WP1, DHH1, DHH3). One parent acknowledged that the technology allowed her child to ‘manage [diabetes] himself’ (DHH8).

Many described no real drawbacks as the technology changed the lives of the person with diabetes’ and their immediate family for the better. Some parents found the initial adaptation period challenging.
you really have to learn diabetes again’ (DHH2, DHH3, WP2). Some parents described alarms as ‘disruptive’ (DHH1, DHH8, DHH6, CAH3) and ‘driving [them] crazy’ (DHH2). Parents also admitted to a tendency to fixate on their child’s glucose levels as easy access to the high volume of diabetes data fuels their compulsive need to ‘constantly check their phone’ (DHH1) and ‘overanalyse’ (DHH9). They felt that often ‘ignorance was bliss’ (DHH1).

Many parents and young people with diabetes had anecdotes about being ‘self-conscious’ (DHH4, DUN4) and having ‘confidence problems’ (DHH4, DUN2). Many were aware of the marks left by diabetes technology on their skin with people describing ‘inflamed skin’ (DHH2) and that their ‘skin is destroyed’ (DHH8). One parent even reported that their teenage daughter would not wear a bikini due to the marks left by the device. Young people were worried about what they could wear in school as they did not want their diabetes devices to be visible especially through their standard white uniforms. Name calling in school was reported, leading to diabetes management and confidence issues.

Many young people described teachers shouting at them due to using their phone in class, despite the necessity of use for diabetes management. In addition, many pupils describe not being allowed to leave class if a diabetes management emergency arose such as the need to check their blood glucose levels, change a site or treat a hypoglycaemic episode. Many parents described schools as ‘rude’ about their child having type 1 diabetes with teachers describing it as only ‘another thing to deal with’. In general, parents and young people were happy with their primary school experience however often feared going to secondary school with multiple teachers and substitute teachers who may not understand needs related to the continuous management of chronic conditions such as diabetes.

The stress of school on both parents and young people is just one of the impacts on family dynamics. Many parents describe the ‘whole house [being] affected by it’ (DHH8), with conversations often centring solely around diabetes. This in turn causes sibling animosity with parents stating siblings ‘jealous of the attention’ (CAH5, CAH6, DUN3). Often siblings found it unfair commenting ‘he/she’s type 1, or he/she doesn’t have to do anything like chores’ (CAH4).

Diabetes also affects the young person’s social and personal life, parents described ‘no parties, no invitations’ (DHH5, DHH7, CAH 4, CAH5) because other parents’ feared diabetes. Parents of children with diabetes often act as a ‘spare wheel at parties’ (DHH5). Parents describe a general lack of understanding from other parents constantly asking, ‘can he/she eat this?’ (DHH5, DHH6).

Parents explained during group-session that the ‘new generation embraces technology, (while) older people are intimidated by technology’ (DHH3). Some parents identified that their own ‘fear of technology’ (CAH7, CAH8) limited their children opportunities. Nonetheless, most parents said that they ‘loved seeing the (results) graphs’ (DHH3) and deemed the percentage time in target most helpful for ‘peace of mind’. The rest of the data displayed was described as ‘complicated’ and ‘difficult’. Despite the helpful nature of some graphs, parents often described being ‘fed-up’ of diabetes management and wanting to have ‘ME time, I’ve had enough of diabetes by the end of the day’ (DHH3).

5 | DISCUSSION

Most notably, focus groups showed that diabetes technology improved quality of life and daily living tasks often being described as ‘transformational’ and a ‘gamechanger’. Diabetes technology allowed for more flexibility with frequency of eating, amount of food eaten and reduced carb counting stress. Our results are consistent with other studies highlighting a reduction in stress when diabetes technology is used. As outlined in previous literature, FGM/CGM gave parents and children a more restful sleep with parents no longer having to check their child’s blood glucose several times per night.

The results of our study show that young people and their families do find the devices and data useful, and almost all (98.5%) have access to a device, which they can view the data on. Parents also suggested that the access to everyday/weekly data is helpful, and it is easy to identify patterns. Information regarding glucose fluctuations was also useful, making it easier to manage insulin doses and meal plans.

The devices also allow independence and freedom for young people with diabetes with many recognising that children and young people can often manage their diabetes independently. It was also clear that parents were more comfortable with independent management as they could monitor any issues on their own devices. It should be noted that children and young people must allow parental access for this. One child in the focus group commented that they felt ‘normal’ now with the use of diabetes devices, which corresponds with previous literature. Despite this, parents reported that they could be obsessive about checking levels on their phone, especially when their child was in school which can lead to parental stress such as in previous studies.

Parents reported a transition period when moving from injections to pumps, which can last several months but is worth it. A study undertaken by Bolyai et al. (2004) showed that it took parents between 10 days to 2–3 months to become comfortable with pump management.

Along with infusion site problems and local pain, the biggest issue raised was around body image. Focus group discussions stated that infusion site marks, bruises and visible technology prevented young people wearing certain clothes. Pettus et al. (2017) describes people being psychically and emotionally uncomfortable with wearing diabetes technology. Devices were also clearly visible under standard white shirt school uniforms shirts and this often led to bullying and name calling such as ‘robot-man’. Many parents and children were concerned that the move from primary to secondary school would be difficult because of multiple teachers, substitute teachers and differing classrooms. Many young people have been shouted at by teachers while using their diabetes technology and were often denied time to deal with any diabetes related issues during class. This is in line with the findings of Rankin et al. (2016), that different schools offered different levels of support.

This study was conducted prior to the outbreak of COVID-19. Lockdowns led to young people spending more time at home, having school lessons at home and seeing their diabetes clinical team virtually. Virtual clinics have been adopted and are likely to change how medicine is practiced in the future. Further research to demonstrate the safety, effectiveness and cost of these virtual clinics is required for the future.
Questionnaire responses showed that 80% of participants felt that upload to a diabetes system was easy and that they were confident in doing so. DSNs felt that virtual clinics were useful in approximately 75% of patients; however, if the patient was disengaged (not answering their phone/uploading) then the virtual review is not adequate for them. These may be the same patients who regularly do not attend clinic appointment and despite intensive input display suboptimal type 1 diabetes management. Interestingly, just over half of patients were happy to be reviewed virtually.

This study informs diabetes professionals on how young people and their families feel about its use. While this study agrees with many aspects of other studies, it offers further information into what diabetes data are most useful to people who live with the disease. In addition, this study provides a novel geographical context in diabetes technology.

The strengths of the study are the number of young people and their families who answered questionnaires and attended focus groups. The data we collected was rich and offered an insight into the use of diabetes technology in a local context, which is likely to resonate in other parts of the world.

Some limitations included that while the study was conducted with a wide variety of people, many respondents were parents rather than the young people themselves, therefore, we only capture a small amount of young people’s opinions on the topic. In addition, this study focuses a lot on diabetes technology; further discussions are needed into the true impact of this technology on families, social lives and schools.

In addition, demographic data including age data of respondents, diabetes duration and HbA1c were not collected in the questionnaire. Data on FGM/CGM and pump usage/duration of usage were also not available. Despite this information being missing, we know everyone with type 1 diabetes in NI is entitled to a libre sensor.

Further research should focus specifically on young people’s opinion on data and data management and should collect more in depth medical and diabetes technology data.

While many parents and young people are comfortable with diabetes technology and benefits linked to its use significantly outweigh any potential drawbacks, there is a need for a transition period to adapt to using it. We would recommend further education into interpretation of the diabetes data and use of available systems should be offered to improve diabetes care and management. In addition, further education for teachers, teaching assistants and other school workers could be provided in order to raise awareness of diabetes and diabetes devices. By increasing general awareness and knowledge amongst the general public, peers and teachers, diabetes symptom recognition and diabetes management could be improved.

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CONFLICT OF INTEREST

The authors declare that there is no conflict of interest that could be perceived as prejudicing the impartiality of the research reported.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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REFERENCES


**SUPPORTING INFORMATION**

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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