‘Join us on our journey’: exploring the experiences of children and young people with type 1 diabetes and their parents

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Abstract
This paper focuses on children and young people with type 1 diabetes and on their parents, and their experiences of diabetes care provision.

Nine acute hospitals in the Yorkshire and the Humber region, UK, were recruited to participate in a qualitative research study. Children and young people with type 1 diabetes, aged 6–25, and their parents (approximately 250 participants), took part in talking groups to find out about their experiences of diabetes care provision.

Findings show that there are key areas for improvement in the future diabetes care provision for children and young people, including communication and support, schools, structured education and transition. These have important implications for practice and service redesign.

This study is thought to be the first of its kind to consult with children, young people and parents to find out about their experiences of type 1 diabetes care provision. The research findings add to the current evidence base by highlighting the disparities in care, the urgent need for change in the way services are delivered and the involvement of service users in this process.

Key words
type 1 diabetes; children and young people; service redesign; participation

Introduction
Young people in England have one of the highest incidences of type 1 diabetes mellitus (T1DM) in Europe. At present, over 26 000 young people have the condition,1 which represents the fourth largest population in Europe and the fifth largest population in the world.2,3 More worrying is the fact that young people in England have one of the worst records for glycaemic control in Western Europe. Over 85% of young people with T1DM were recently identified as not achieving NICE recommended HbA1c levels of <58mmol/mol (7.5%) and this figure has remained unchanged for the past seven years.4

Recent evidence has shown that, in addition to poor glycaemic control, there are alarming differences in diabetic ketoacidosis admissions throughout the country and the quality of care and education that children and young people with T1DM receive is hugely variable. Compared with our European and global counterparts this care is below the highest European and global standards.5 Furthermore, inconsistencies in quality of care are highlighted as a possible contributory factor towards poor outcomes. Poor quality diabetes care results in an increased risk of short- and long-term clinical complications, as well as compromised social and psychological wellbeing, leading to increased health care costs.6 Therefore, it makes sense to ascertain current standards of care and identify gaps in service provision, before making recommendations in terms of how diabetes care needs to improve for the benefit of children’s and young people’s health outcomes.

However, in order to gain a clearer and more accurate picture of current care, it is important that service provision is examined from the point of view of all those involved with the service. This includes not only health care professionals but, most importantly, children and young people with T1DM and their parents. Increasingly, greater attention is being directed at gathering information from children, young people and families based on their experiences and
involving them in decision-making, since they are the key stakeholders of the health service.7,8 Indeed, recent policy documents stress the contribution that children, young people and families have to make in shaping the future of health care in the UK.9,10 Therefore, although this study in its entirety explored the views of children and young people with T1DM, their parents and health care professionals, the experiences of children, young people and parents are reported here. The main research aims were:

• To develop a model of care that will deliver the aspirations of the policy document ‘Making every young person with diabetes matter’.11
• To improve the care provision for children and young people with T1DM in England.

Methods
The research, entitled ‘Join us on our journey’, was a three-year, multi-site study. Nine acute trusts across the Yorkshire and the Humber region were involved and overall 300 participants throughout the region took part. Of these, 257 comprised children, young people and parents. The research employed a qualitative approach and process-mapping, using talking groups (a term coined by the children and young people to describe focus groups), was the main methodological component. The rationale behind using a process-mapping approach was to map out the T1DM journey for children and young people who had the condition, which meant establishing what worked well, what worked less well, where the areas of inefficiency were to be found and how a particular area needed to improve. In the case of diabetes care provision for children and young people, this approach enabled the complete journey, from diagnosis through to transition from paediatric to adult services, to be explored.

In keeping with the theme, ‘bus stops’ along a ‘diabetes journey’ were used to represent the different stages along the child’s and young person’s diabetes care pathway (see Box 1). The talking groups used the ‘bus stops’ as a basis for generating discussions and all participants the nine acute trusts, via the consultants. A total of 116 children and young people took part, spread across the age range. At the same time, parents were also asked to participate; a total of 141 parents took part. The talking groups involving children and young people were age-band and conducted separately from each other and from those involving parents. Four age bands were identified: 6–11; 12–14; 15–17 and 18–25; talking groups were conducted in each one, varying in size from four to eight participants. Similarly, parents/carers of children and young people from the four age bands were grouped accordingly and separate focus groups conducted.

Appropriate national and local ethical approval was obtained. A written and verbal explanation to the study was given, informed consent obtained and confidentiality assured. The talking groups were conducted by members of the research team and recorded with the participants’ consent. The data from the talking groups were analysed using a thematic approach. This process involved generating categories and coding data so that common themes and links could be identified, while at the same time ensuring the data remained faithful to, and accurately reflected, the participants’ comments.12 At least two researchers were involved in the data analysis process, thereby reducing interpretation bias. In addition, research participants verified the themes as a means of establishing the reliability of the research findings.

Results
The key themes to emerge from the findings were diabetes care, education, communication and support, school, and transition. These are explained below.

Diabetes care
Those participants who accessed the paediatric diabetes clinics were extremely positive about their diabetes care. The few concerns that participants had focused on long waiting times, short consultation times and the rescheduling/cancellation of appointments. In addition,
access to 24-hour diabetes specialist care was reported as not always being available, especially at weekends. In general, participants were satisfied with the care they received from their diabetes team, but less positive regarding the care they received from nursing staff on the wards who seemed to be unsure as to how to treat children and young people with T1DM. In particular, they had little knowledge of treatment around carbohydrate counting and insulin dosages.

Those who accessed the young adult diabetes clinics were not as satisfied with the care they received and made frequent comparisons between the care they had experienced in paediatric services and the current care they received in adult services. Staff attendance in the young adult clinics was a major issue. Many participants felt there was no continuity because they saw a different consultant every time they attended clinic; young people commented on how unhelpful and repetitive it was to have to recite their full medical history afresh to each new consultant they encountered. Participants reported that the adult consultants did not really know them or understand their diabetes.

‘…at the children’s clinic I had thorough appointments and saw doctor, nurse and dietitian. More recently, my appointments are a complete waste of time, seeing a different doctor every time for a maximum of 5 minutes … I can’t remember the last time I saw a nurse or dietitian,’ (Young Person [YP], 22).

Children, young people and parents had little knowledge of a care plan or any idea what was meant by a care plan. Very few participants had been given information following diagnosis about what would happen next, either in the short- or long-term. Few participants had been told about complications, especially long-term complications, nor were they always involved in discussions relating to alternative treatments, e.g. pump therapy.

**Structured education**

Most participants who accessed paediatric diabetes services felt that they had learnt the majority of what they knew about their condition from others with T1DM. They stated that they would welcome the opportunity to attend a structured education workshop similar to the DAFNE course offered as part of adult services. Children and young people who had attended structured education sessions were in the minority, but commented on how helpful they were.

“I was invited to a carb-counting class to help me understand how to read labels and be confident with carb-counting. This class was really helpful,” (YP, 17).

A lack of awareness of T1DM among the public and GPs was highlighted as a major concern among participants. It was noted that most members of the public seemed to be unaware of the difference between T1DM and type 2 diabetes mellitus, and GPs were slow to detect the symptoms of diabetes, which led to a delay in diagnosis.

“I went to the doctor on three occasions and was told each time nothing was wrong. On the third occasion I was told I would be reported to social services for being an over-protective parent!’ (Parent of 16 year old).

In addition, participants thought that ward staff needed more education on T1DM as they were often unaware of how to treat the condition. In general, there was a lack of education provided by diabetes staff in relation to healthy lifestyles, sexual health and pregnancy. Many parents and young adults conducted their own research on the internet, in order to find out what they needed to know.

**Communication and support**

Those participants who accessed paediatric diabetes services reported having a good relationship with their diabetes team. In general, parents felt that communication was not a problem, since they were able to contact their diabetes specialist nurse at any time about their child. However, those children and young people who had a greater understanding of their diabetes wanted to have more input into their care, be involved in decision-making and be given more responsibility. They felt their diabetes was controlled by their doctor and their parents rather than by them. Many children and young people, even those of a younger age, stated that they often felt ignored in consultations and the adults tended to talk to one another as if they were not in the room.

“I don’t like it when they all talk about me at the same time … they talk about me as if I’m not there,’ (YP, 8).

A lack of psychological support was reported by most participants. Children and young people felt isolated among their peers and thought they would benefit from the opportunity to talk to others of the same age who also had T1DM. Those who had attended a diabetes camp or a programme such as ‘Getting Sorted’ commented on how helpful they had found it, because everyone had the same condition and, therefore, having diabetes was perceived as ‘normal’. While some parents had access to a parents’ support group, many parents had no support. Young people spoke about how psychological support would help them cope better with their diabetes, especially as they did not feel able to talk to their consultant. Likewise, parents commented on how the support from a psychologist or counsellor would help them to deal with the shock of diagnosis and assist them in the on-going management of the condition. Participants stated that they would benefit from a psychologist in attendance at clinic as there was often no one to talk to at this time.

‘I find it hard to cope sometimes and get extremely stressed, down about things, where counselling would help,’ (YP, 23).

**School**

Diabetes management in schools and the quality of care varied enormously, particularly between primary and secondary schools. In general, children in primary schools had a more positive experience than young people in secondary schools. The young people attending secondary school stated most of the school staff did not know how to deal with them because they had
T1DM and, therefore, they had more negative experiences than positive ones.

‘Teachers complain about me having to have snacks and have drinks and go to the toilet,’ (YP, 15).

The majority of school staff were unfamiliar with T1DM and, therefore, had little knowledge of what a child or young person needed. Diabetes specialist nurses did attend school when a child was newly diagnosed to agree a care plan, but parents felt the majority of the ongoing education and care was left to them. Many parents and young children in particular relied heavily on the goodwill of a school volunteer to help them, usually the receptionist, rather than the enforcement of school policies, which were often not in place. Participants emphasised the need for consistency in terms of policies and practices within schools and colleges, for example, policies relating to classroom management, the storage of insulin/medical kits and the provision of a safe place for children and young people to take their insulin.

**Transition**

Young people and parents commented on how the period of transition from paediatric to adult diabetes services was a vital time in a young person’s diabetes journey and this had important implications for the ways in which young people continued to manage their diabetes. The general feeling was that young people and parents needed to be better informed of the process. Participants did not necessarily know what the transition process meant and when they were in transition they were often unaware of what was happening and why.

‘I was originally told that because I was 13 I would be slowly put into the adult clinic, but I’d spend half of my time in paediatrics and half of my time in adults to get me used to swapping over, but that never happened. I didn’t know I was in a transition clinic,’ (YP, 22).

Participants felt that more communication was needed between paediatric and adult diabetes services regarding young people’s individual needs, rather than assuming that all young people moving into adult services were a homogeneous group. Those young people who had been through transition thought a year or more was appropriate for the transition process, since this enabled the young person to spend time with the paediatric and adult diabetes teams and, therefore, build up a comfortable rapport.

**Discussion**

The focus of this research was on the delivery of diabetes care and in particular the experiences of children and young people with T1DM and their parents. It is the first study of its kind to consult with over 250 children and young people with T1DM and their parents about diabetes service provision across Yorkshire and the Humber, one of the largest regions for diabetes care in the UK. The findings provide a valuable insight into the key issues confronting families, while reinforcing, yet again, the disparities in care that exist for children and young people throughout the region.\(^5\) These disparities in care indicate that there is an urgent need for change, both in the way that diabetes services are delivered and the care that children and young people receive.

The research findings presented here substantiate what has been stated in the diabetes literature over the course of the previous decade, namely that there is a need for a redesign of diabetes services, in order to improve the variations in care and diabetes outcomes throughout the whole of the UK. Even though there have been numerous publications and reports highlighting this issue,\(^13–17\) it is still the case that shortfalls in care exist. While a significant number of children and young people receive a high standard of care from highly skilled and trained health care professionals, there are others who, because of inadequate service provision, are failing to receive the highest levels of diabetes care available.

However, the situation may be about to change with the introduction of the Best Practice Tariff (BPT), which outlines minimum standards of care for paediatric diabetes services.\(^18\) The BPT standards have been in place since April 2012 and they clearly define the criteria that diabetes centres have to achieve if they are to receive the enhanced tariff of £3189 per individual per year, as opposed to the standard ‘payment by results’ tariff of £119, a fixed payment from the Department of Health for outpatient activity. The BPT addresses many of the issues highlighted in the findings of this study and, therefore, it is hoped that it will provide a mechanism for raising standards and, in so doing, ensure high-quality care for all children and young people with T1DM, no matter where in the country they live.

It is acknowledged that it will take time for standards to improve and for the BPT to have any long-term impact on outcomes, but nevertheless the BPT is the first new initiative in paediatric diabetes for some time and there are high expectations. However, it is important not to make
the mistake of focusing exclusively on the BPT as the panacea for diabetes care. We need to consider what other changes can be made to improve services and, ultimately, paediatric diabetes outcomes. A crucial factor in future planning and decision-making, especially where service improvement is concerned, is the participation of children and young people with T1DM and their parents. If the needs of this population are to be met, it is vital that we listen to them and involve them in any decision-making processes centred on service redesign. Furthermore, it is imperative that we continue to gather information on their experiences, in particular those of children and young people, as part of a wider philosophy of service user involvement. Only by doing this will we achieve the best outcomes for children and young people with T1DM and their families.

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Declaration of interests

There are no conflicts of interest declared.

References


News

Magnesium level correlates with metabolic control in T1DM

A recent study has demonstrated that low serum magnesium levels are associated with increased risk for poor glycaemic control (0.79±0.09 versus 0.82±0.09 mmol/L, p=0.002), potentially contributing to the early development of cardiovascular complications.

The study, reported in the Journal of Diabetes by Dr Galli-Tsionsopoulou et al., took a sample of 138 young people with T1DM. The data indicate that intervention studies are still needed to further elucidate whether restoration of magnesium balance could improve disease control and prevent potential future complications.

New genetic causes of neonatal diabetes found

New research by the University of Exeter Medical School and published in Cell Metabolism has revealed mutations in two specific genes (NKX2-2 and MNX1). The genes, which cause neonatal diabetes, are important for the development of the pancreas. These findings increase the number of known genetic causes of neonatal diabetes to 20. Knowing the cause of the diabetes will result in improved treatment; it will also provide important information on the risk of neonatal diabetes in future pregnancies.

Development of Takeda’s fasiglifam terminated

Takeda has announced that it has decided voluntarily to terminate development activities for fasiglifam (TAK-875), an investigational treatment for type 2 diabetes, due to concerns about liver safety.

The drug was in a phase 3 development programme.

Diabetes plan released

NHS England has set out a vision for how it wants diabetes care to be tackled in 2014 in a new document entitled Action for Diabetes. The vision pledges that NHS England will continue to roll out the NHS Health Checks; it also details how GPs will be helped to provide good care and outlines resources available to commissioners of hospital-based care. Key points include:

• Improvement in diabetes care will be based upon integrated services around the needs of the individual.
• Tasking NHS Improving Quality to work with primary care services to try out new tools to help earlier diagnosis of type 2 diabetes, and to work on reducing death rates associated with diabetic foot disease and on transition of young people to adult services.
• NHS England has published an additional 40 general practice level indicators on the NHS Choices website, eight of which are related to diabetes care.

Original article

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