

Type 1 diabetes in young people: The impact of social environments on self-management issues from young people's and parents' perspectives

Joy Spencer, Helen Cooper and Beth Milton

Citation: Spencer J, Cooper H, Milton B (2013) Type 1 diabetes in young people: The impact of social environments on self-management issues from young people's and parents' perspectives. *Diabetes Care for Children & Young People* 2: 48–57

Article points

1. Young people's abilities to be independent in their diabetes management are embedded within their relationships with significant others in the different environments they inhabit.
2. Interviews were conducted on a small sample of young people with type 1 diabetes and their parents to determine their experiences in the environments of the home, with friends (social), at school and in the diabetes clinic.
3. Findings highlighted that glycaemic control is underpinned by complex self-management processes, dependent on relationships with others in different environments.

Key words

- Parents
- Self-management
- Social environments
- Type 1 diabetes
- Young people

Authors

Authors' details can be found at the end of this article.

In the UK, young people with type 1 diabetes generally have poor glycaemic control. Managing type 1 diabetes in young people is complex, and is underpinned by relationships with significant others in the social environments they inhabit. This qualitative study explores the social environments of young people with type 1 diabetes and their potential influence on glycaemic control. Twenty young people with type 1 diabetes and their parents ($n=27$) were interviewed about their experiences in the environments of the home, with friends (social), at school and in the diabetes clinic. It was found that the diabetes clinic was vital to the medical management of type 1 diabetes, and the family provided stable support for most young people with type 1 diabetes. However, there were barriers to self-management in school and social environments. It was concluded that each family had a unique story about the social factors in the environments they encountered that affected self-management of type 1 diabetes.

In the UK there are about 26 500 young people living with type 1 diabetes (Diabetes UK, 2012). The UK has one of the poorest records of blood glucose control in Europe (Danne et al, 2001), and the recent UK National Paediatric Diabetes Audit reported that only 15% of young people achieved recommended HbA_{1c} levels of <58 mmol/mol (7.5%; Royal College of Paediatrics and Child Health, 2012). This means that over 30% of young people with the condition are at high risk of developing future health complications (NHS Information Centre, 2011).

Blood glucose control in young people is complex. The self-management regimen they are required to follow to maintain healthy blood glucose levels is undoubtedly affected by the psychosocial factors inherent in “growing up” through adolescence

(Cooper and Geyer, 2007; Modi et al, 2012). Qualitative research in the USA, Sweden and Finland has shown that young people face juggling the different demands of their diabetes within the social spheres of family, school, peers and clinic (Spencer et al, 2009). Young people become psychologically and emotionally ready to take responsibility for their diabetes management through learning through their experiences in these environments (Christian and D'Auria, 1999; Karlsson et al, 2008). Peer support is important to enable the integration of diabetes into young people's daily lives, and the pressure of “fitting in” with the peer group may influence self-management decision making for some young people (Williams, 1999; Carroll et al, 2007). In the ideal scenario, parents provide background support for their child while allowing them independence

to develop autonomy for the management of their diabetes (Hanna and Guthrie, 2001; Carroll et al, 2007). However, parental anxiety and the need for control can commonly lead to parent–child conflict (Weinger et al, 2001).

This article reports on one aspect of a larger qualitative study that explored the lived experiences of young people with type 1 diabetes, their parents and the healthcare professionals providing their care (Spencer et al, 2013); the aim of this research was to explore the social environments young people with type 1 diabetes inhabit, and the potential influence of these environments on their glycaemic control. Given the significance of parental involvement in the self-management of type 1 diabetes in young people highlighted in our systematic review (Spencer et al, 2009), and elsewhere in the literature, this included an exploration of parents’ experiences.

Method

An interpretive phenomenological approach was taken to explore the experiences of young people with type 1 diabetes and their parents. This focuses on gathering in-depth descriptions of individual experiences from participants’ own perspectives, enabling exploration of how their cultures, relationships, beliefs, histories and future orientations (their “lifeworlds”) affect their experiences of living with type 1 diabetes (Van Manen, 1997). Van Manen’s (1997) description of Merleau-Ponty’s four existentials of the lifeworld (lived space, lived body, lived time and lived other) influenced the development of the research questions. Exploring these existentials with participants enables the researcher to build a composite picture of a person’s experiences in relation to their lifeworld (van Manen, 1997). *Table 1* outlines the definition of each existential and how they can be applied within the research interview.

This article focuses on the exploration of “lived space”, with the aim of facilitating understanding of the experiences of living with type 1 diabetes in the defined environments of home, school, with friends (social) and the diabetes clinic. Understanding how young people negotiate these different environments can contribute to understanding the fundamental dimensions underpinning their self-management behaviours. The related research questions were “What is it like to live with diabetes – at home, at school, with your friends and at the diabetes clinic?”

Table 1. Function of the four existentials in the research interview

Existential	Definition	Function in the research interview
Lived space (spatiality)	<ul style="list-style-type: none"> • The felt spaces that surround us • Enquiry into the ways people experience the affairs of their day-to-day existence 	<ul style="list-style-type: none"> • When wanting to understand about people’s experiences, we ask them about their profession, interests, background, childhood, etc. • These things tell the story of a person’s surrounding world and this can help us to uncover the fundamental meaning dimensions of lived life
Lived body (corporeality)	<ul style="list-style-type: none"> • We are all embodied human beings and we experience other human beings through their bodies • Bodies can reveal things about a person, while also concealing the inner-self 	<ul style="list-style-type: none"> • A person’s experience of being in a body will affect the way that he/she interprets the world and the way that others interpret that person • People experience physical symptoms of illness through their bodies. How people cope and deal with symptoms and what happens as a result define their experience of living with an illness
Lived time (temporality)	<ul style="list-style-type: none"> • The temporal way of being in the world and the conceptualisation of the past and the future 	<ul style="list-style-type: none"> • Conceptions of the past involve memories, social practices learned from family and friends, and language and behaviour • The past and the future influence how a person interprets his/herself in the present
Lived other (relationality)	<ul style="list-style-type: none"> • The lived relations maintained with other human beings in the interpersonal spaces shared with them 	<ul style="list-style-type: none"> • A person approaches others with an impression of what that person is like, which influences how he/she acts towards them

From Van Manen’s (1997) description of Merleau-Ponty’s four existentials of the lifeworld

Study sample

A maximum variation sample of 20 young people aged 13–16 years was selected from 117 potential participants attending a paediatric diabetes clinic in North West England; this approach ensured that a range of age, sex, HbA_{1c} (glycaemic control) and duration of diabetes were represented. Forty families were approached in the diabetes clinic

“In-depth interviews were conducted with young people and their parents in their homes by the author; within each environmental sphere (home, school with friends, in the diabetes clinic), young people were asked what it felt like to have diabetes when they were in each particular place, what helped them to manage their diabetes, what did not help them to manage their diabetes, and if anything could be made better for them.”

by the researcher (JS). A verbal explanation of the research was given alongside written information sheets in age-appropriate formats for young people and their parents. Families were given time to read the information sheets and ask questions about the research while in clinic, and could give their informed consent/assent to participate at that point. If families wanted more time to consider their participation, the researcher arranged to contact them in 1 week by telephone.

The final sample comprised 20 White British young people (9 male, 11 female) and 27 parents (7 male, 20 female); the female parent/guardian alone took part in 13 interviews, and both parents took part in seven interviews. Most of the young people lived with both parents; six were from a single-parent family and lived with their mother, and two lived with their mother and stepfather. Two young people had an average HbA_{1c} of the recommended <58 mmol/mol (<7.5%) and two had high levels of >75 mmol/mol (>9%); the rest had levels in between. Four young people had been diagnosed with type 1 diabetes under the age of 5 years, five between the ages of 5 and 10 years, and eleven over the age of 10 years.

Data collection

In-depth interviews were conducted with young people and their parents in their homes by the author, JS, a PhD student with a background in sociology. Within each environmental sphere (home, school with friends, in the diabetes clinic), young people were asked what it felt like to have diabetes when they were in each particular place, what helped them to manage their diabetes, what did not help them to manage their diabetes, and if anything could be made better for them. In families where two parents/guardians participated, the majority ($n=7$) were interviewed together.

A protocol was followed if participants became distressed as a result of the potentially sensitive topic, and a psychologist was available to support families if necessary. The interviews lasted 1–2 hours, were audio-recorded with participants’ consent and transcribed *verbatim*. All data were stored securely, electronically and in locked filing cabinets. Participants’ names were not included in interview transcripts and families were given a numerical code to protect anonymity.

At the point of consent, participants were assured of confidentiality unless the harm of a child was disclosed, and this was prioritised in the presentation of the findings.

Data analysis

Field notes and interview transcripts were read thoroughly, and meaningful themes in each transcript were noted. Thematic data analysis followed a rigorous, eight-step approach (*Box 1*) based on the theoretical assumptions of interpretive phenomenology, the work of van Manen (1997), and literature relating to the exploration of multiple family perspectives (McCarthy et al, 2003). Themes from young people and parents from the same family were then explored to understand the experience from different family members’ perspectives. The data were organised into themes and sub-themes using NVivo software, and relationships were explored between: individuals within families; individuals as a whole; families as a whole; and the researcher and participants. The final stage of the analysis was to explore the sets, themes and sub-themes in relation to the four existentials of the lifeworld. This enabled the emergence of thematic categories; the category relating to negotiating environments is focused on in this article.

Box 1. Data analysis process for each family data set

- Summary of main topics covered
- Thematic analysis of adolescent interview focusing on individual experience
- Thematic analysis of parent interview focusing on individual experience
- Exploration of adolescent interview data in relation to context data (demographics and parent interview data)
- Synthesis of adolescent, parent and context data
- Data organisation (NVivo software)
- Extraction of final sets, themes and sub-themes
- Exploration of the sets, themes and sub-themes in relation to the four existentials of the lifeworld (van Manen, 1997) and the generation of four thematic categories

Two other researchers (PhD supervisors) also studied random samples of the data independently and checked the written interpretations to minimise interpretation bias. Two focus groups were also conducted, with six young people and six parents, to validate the interpretation of the data. All of the interview participants were invited to participate in the focus groups, and all who gave their consent were included. Preliminary qualitative categories were presented to the young people and their parents (using visual flip-charts with quotations for the young people and booklets for the parents), and participants were asked to discuss whether they agreed with the categorisation of the experiences. This promoted further discussion and clarification of the interpretation. All members of the research team were present at the focus groups and involved in the data analysis to further limit interpretation bias.

Ethical approval was granted by the local NHS Research Ethics Committee.

Findings

A diagnosis of type 1 diabetes led to significant disruptions within the environments of the home, social and school, as well as the introduction of a new environment that families had to negotiate – the diabetes clinic. The interview findings are described as themes within the four environmental categories (home, clinic, school and social). A description of young people's age and sex, and parents' relationship to their son or daughter with type 1 diabetes is given after quotations to protect the anonymity of participants.

Theme 1: Home

The families described how having a young person living with type 1 diabetes disrupted the family environment, mainly by instigating a focus on dietary restrictions and scheduled meal times, blood glucose tests and injections, which all had an impact on family activities. For example, family outings such as day trips and holidays required a great deal of planning. One mother (who had two children with type 1 diabetes) described the preparation involved:

“When you go away it's a mini operation, you've got to do all this and all that...and days out we always have to make sure we've got all the medicine” (mother of 15-year-old female).

Families described various adaptation strategies to support their child, including changing eating habits and integrating routine into family life:

“It used to be no crisps, no biscuits, no junk...I didn't like the idea of eating all that in front of him knowing he can't...now we've adapted to it, you can have biscuits and stuff, just not excessively” (mother of 15-year-old male).

A structured routine gave parents a sense of control over diabetes, as this mother described:

“I'm really looking forward to her going back [to school] tomorrow because I know it's back to a regular thing...once that weekend comes, you know it's going to be stay out until half past ten...they might go shopping to town but then all the Subway meals will start...there's no homemade food getting done for her and things, and that's where she slips...” (mother of 13-year-old girl).

In three families in which the father also had type 1 diabetes, the diabetes routine was already an established part of family life. This appeared to make it easier for the family to adapt to the child's diagnosis, as this quote from a 13-year-old male demonstrates:

“I wasn't that bothered when I was diagnosed because I'd seen my dad doing it loads so I understood basically what they were telling me...I knew quite a lot about it already.”

Mothers described the organisational roles they assumed in their child's self-management, including setting-up injections, recording blood test results, collecting prescriptions and medication, and occasionally administering insulin injections. Some parents mentioned occasionally administering insulin injections to their child if the site was difficult to reach or to relieve the burden of multiple injections:

“He does six injections a day...and the first one every morning we try and relieve the pressure a bit by giving him the injection before he wakes up, so it's one less” (mother of 15-year-old male).

Parents also had a role in reminding their child about self-management and providing adequate meals. Some adolescents described these reminders as annoying, while others described them as instrumental to maintaining a healthy lifestyle:

Page points

1. The families described how young people living with type 1 diabetes disrupted the family environment, mainly by instigating a focus on dietary restrictions and scheduled meal times, blood glucose tests and injections, which had an impact on family activities.
2. A structured routine was beneficial to managing the diabetes regimen; in particular, this gave parents a sense of control over diabetes.
3. Mothers described the organisational roles they assumed in their child's self-management, including setting-up injections, recording blood test results, collecting prescriptions and medication and occasionally administering insulin injections.
4. Parents had a role in reminding their child about self-management and providing adequate meals. Some adolescents described these reminders as annoying; others described them as instrumental to maintaining a healthy lifestyle.

Page points

1. Most of the young people and parents did not describe siblings having a fundamental role in their diabetes management, and many described them as having no role at all.
2. Parents' experiences of the medical environment at diagnosis were determined by their child's presenting symptoms; the majority were referred to the hospital by their GP.
3. Young people and parents from families where the young person did not present in a critical condition generally described a positive experience of care at diagnosis.
4. The young people in the study stayed in hospital following diagnosis for 4–14 days. During this time, they received education to equip them with the skills to manage their diabetes in other environments.

"I think I could cope for a week or 2 weeks [without my mum], but not full time...mainly because your meals are cooked for you so it's easy...when I've had to do my own dinner I've just had soup...but my mum does different meals" (male, aged 13 years).

Most of the young people and parents did not describe siblings having a fundamental role in their diabetes management, and many described them as having no role at all. However, a small number of siblings took a more practical role in helping their siblings to do their injections, particularly if parents were absent:

"Sometimes my sister does [my injection] in the morning, say if my mum and dad aren't here... sometimes my brother reminds me and things like that. So they do help out" (male, aged 14 years).

In this way, siblings provided a "safety net" for parents, who knew they could rely on them for assistance in an emergency:

"She knows when he's going low 'cause she can see it in his eyes or he goes pale and things" (mother of 13-year-old male).

Theme 2: Clinic

Parents' experiences of the medical environment at diagnosis were determined by their child's presenting symptoms; the majority were referred to the hospital by their GP. In these cases, mothers had taken their child to their GP with symptoms of concern; the child's blood was tested and they were referred to the hospital. One mother described her daughter's condition at diagnosis as "normal":

"Her blood sugars were 39 and she was just normal. The doctor said...we had a grown man in here the other day with a blood sugar of 38, he was in a coma, she was just sitting there!" (mother of 14-year-old female).

Young people and parents from families where the young person did not present in a critical condition generally described a positive experience of care at diagnosis. However, four adolescents were diagnosed in a critical state, as a result of misdiagnosis by a GP. One mother was turned away from her GP twice before her son was admitted to hospital:

"My doctor didn't take any notice of me...he [my son] was in hospital for a week...we came out...for 48 hours, and he was taken back in again...he was unconscious. Got him back into hospital, he was in for another 3 days, brought him out and the same happened again..." (mother of 13-year-old male).

The experience of having a critically ill child was traumatic for parents. When they arrived at hospital, the environment was perceived as a place of safety for parents, especially when the child's symptoms had been previously misdiagnosed. One mother was turned away from her GP and the hospital before her son, aged 3 years at the time, was admitted to hospital:

"My doctor didn't take any notice of me, I actually went to [hospital] and we had a scan on his head, they told me that was clear and he'd lost so much weight it's untrue. Finally I took him back to the GP, they done his wee and said diabetes and then we got him to hospital and he was very, very poorly, he was in hospital for a week..." (mother of 14-year-old male).

The young people in the study stayed in hospital following diagnosis for 4–14 days. During this time, they received education to equip them with the skills to manage their diabetes in other environments:

"During the time I was staying in hospital, they were giving me lessons on how to manage my diabetes and how to work needles and blood testers and things like that, learning about what foods I'd be able to eat as much as I want of, and what foods contain carbohydrates and things like that..." (male, aged 14 years).

The education delivered related to the age of the child; with younger children, the focus was on educating the parents. Parents were generally satisfied with the education they received at diagnosis, stating that it was delivered at the "right" level — that just enough information was given at diagnosis, which was "topped up" as the family became more used to the diabetes regimen; however, some reported feeling overwhelmed with the amount of information. Ongoing education was important, as young people described feeling motivated following education sessions, but also described losing that motivation soon after.

Young people's and parents' perceptions of the diabetes clinic were mostly positive, and families were satisfied with the care they received. Young people described how the nurses were friendly and interested in their lives aside from their diabetes, which facilitated trustworthy relationships between healthcare professionals and families:

"They...just talk to you, not like a normal person but as if like...they don't just talk to you about your diabetes, like your holidays and things that you've done and stuff so it's not totally based around diabetes so you feel more normal anyway sort of thing" (female, aged 15 years).

Despite the majority of parents appreciating the "one-to-one" level of communication between the young person and nurses, a number of parents described frustrations that the care provided in the clinical setting did not translate into "real life". One mother felt that healthcare professionals sometimes gave advice that was difficult to implement in their daily lives:

"Most of the time I think they're okay, maybe there's the odd time when I think... they don't live with it day to day..." (mother of 14-year-old female).

The prospect of transition to the adult clinic was a daunting prospect for many of the young people, as it meant moving from an environment that they perceived as "safe" to the unknown:

"I've been with them since I was a kid so it will be horrible moving into a new place" (15-year-old female).

Theme 3: School

Most of the young people used an insulin regimen that meant no injections were necessary during the school day. For these young people, self-management involved eating a snack and their lunch at certain times in accordance with the peaks of their insulin, eating additional carbohydrate when participating in physical activity and occasionally treating hypoglycaemia. Most of these adolescents felt that their diabetes was not usually an issue during school:

"It's nothing to worry about 'cause it's something personal to me and it's not something they all [teachers] need to know about" (male, aged 15 years).

Those using basal bolus regimens had to inject insulin at lunchtime, and they were provided with a room to use. Although this support was appreciated, having to leave their friends to inject also made young people feel different to their friends. One male described how he would sometimes miss his injections as they interfered with his lunch activities:

"I used to do it quite a lot, forget about my dinner time injection because I'd want to just go off to the music block for a practice, so I'd forget quite a lot and I'd come back from school in a mood because my blood would be about 20 from my dinner" (male, aged 14 years).

One female overcame the barrier of leaving her friends by injecting in the playground with her friends, as she felt that they accepted her diabetes:

"They did tell me I had to do my injections by the office or where they thought I'd be happy doing it, but there's always teachers and stuff walking around and people just coming up, so I just do it outside because my mates don't care about me doing it...I just get on with it" (female, aged 15 years).

Parents described teachers as supportive of young people's self-management needs. Supportive practices included giving young people a dinner pass to enable them to go to the front of the queue if they needed to eat urgently, and putting a photograph of the young person on the staffroom wall so that teachers were aware of their diabetes. Despite this support, however, many young people described situations where they had been questioned over treating an episode of hypoglycaemia (a "hypo"):

"If I felt low, a few teachers won't let me have... something to get it up, there's always been a few arguments about letting me go out and have something...there was a few teachers that wouldn't let me go, even if I gave them the note" (female, aged 16 years).

Some parents were concerned that teachers were unaware of their child's diabetes. Detentions were a problem if they interfered with the young person's self-management, and one parent had been called into the school to treat his daughter's episode of hypoglycaemia, when he felt the school should have been able to deal with this.

"Parents described teachers as supportive of young people's self-management needs. Supportive practices included giving young people a dinner pass to enable them to go to the front of the queue if they needed to eat urgently, and putting a photograph of the young person on the staffroom wall so that teachers were aware of their diabetes."

Page points

1. School absence as a result of type 1 diabetes was not common. In those that did often miss school, reasons included sickness, stress and hypoglycaemia.
2. Many of the young people described situations in which their diabetes made them feel different from their friends; these were mostly situations in which their self-management behaviour brought them unwanted attention.
3. Many of these situations occurred within the school environment; young people were sometimes asked to talk about their diabetes in class, sent home when experiencing hypoglycaemia, unable to participate in the same activities as their peers and had to eat in class.
4. Knowing that their child did not disclose their diabetes to friends caused anxiety for some parents; some felt a responsibility to disclose their child's diabetes to their friends, or to friends' parents on their behalf, in order to ensure their safety.

School absence as a result of type 1 diabetes was not common. In those that did often miss school, reasons included sickness, stress and hypoglycaemia. Some adolescents described their concentration in school being affected by hypoglycaemia:

"I was in an exam the other day, I couldn't read the questions because I was having a hypo...I just sat through it and I think I've done rubbish in the exam" (female, aged 15 years).

Families also described blood glucose fluctuations affecting the mood and motivation of the adolescents in school. This male described his lack of motivation when his blood glucose was running high:

"When I'm on a high I just can't be bothered doing anything. I've been in lessons on a high and just keep going to sleep in lessons...as long as you keep the blood sugars down it's alright in school" (male, aged 15 years).

Theme 4: Social

Many of the young people described situations in which their diabetes made them feel different from their friends; these were mostly situations in which their self-management behaviour brought them unwanted attention. Parents also recognised this:

"I think it's just made him...feel he's different from the others by getting the biscuits out, and the others go ooh we want to get a biscuit, the fact that he has to makes him different from them, he just wants to be like the rest of them" (mother of 15-year-old male).

Many of these situations occurred within the school environment. Young people were sometimes asked to talk about their diabetes in class, sent home when experiencing hypoglycaemia, unable to participate in the same activities as their peers and had to eat in class:

"Sometimes he doesn't have time for his dinner and he's got to eat so he'd have to miss the basketball or whatever, so that used to upset him" (mother of 14-year-old male).

The unexpected disclosure of having type 1 diabetes to other people through blood glucose fluctuations caused perceived negative reactions from others:

"In assembly when I had a hypo, they used to look at me as if I was the world's worst...people always look at me as if I'm an alien or something different" (male, aged 15 years).

Injecting insulin in public was embedded within perceptions of how others would react to the sight of injections. Some did not wish to inject in public, whereas others, such as this male, demonstrated confidence to do so:

"I do it anywhere really, it doesn't bother me where I do it, it's like whether anyone's like looking or anything like that...sometimes I even just like do it in lesson underneath the table if I can't be bothered going all the way to the office" (male, aged 14 years).

Not disclosing diabetes to friends had the potential of leading to dangerous situations, such as severe hypo- or hyperglycaemia:

"When I was out with my mates one time, I was sitting on the couch and I was having a hypo and she didn't know what was going on because I'd only known her for a day, she said to me are you alright and I was saying yeah because I felt shady saying well no I'm not alright...I ended up going into a diabetic coma" (female, aged 15 years).

Knowing that their child did not disclose their diabetes to friends caused anxiety for some parents; some felt a responsibility to disclose their child's diabetes to their friends, or to friends' parents on their behalf, in order to ensure their safety.

In contrast to these barriers, most of the young people described their friends as supportive:

"... [My friends] understand that I'm not exactly the same as them and they understand that it does prevent me doing the same things as them" (male, aged 15 years).

Supportive peers meant that self-management practices were easier to adhere to, without the obstacle of peer approval to negotiate. Some young people described how their friends were interested in their diabetes, and often asked them questions about it. Although this was interpreted as positive interest, some found it frustrating, as this young female described:

“...Most of the time people like listening, they ask me questions it does my head in, they ask me questions on it like do you inject yourself and all stuff like that, it’s like oh my god yeah I’ve told you about five times!” (female, aged 14 years).

It was, therefore, appreciated when young people were given space and time to deal with their diabetes, as this female explained:

“I feel they’re quite good mates to me because they will like wait for me or something, they will give me the time to do what I need to do” (female, aged 15 years).

Most of the young people stated that they felt safe when they were with their friends. Although they did not have an in-depth knowledge about diabetes, they were confident that they knew what to do in an emergency:

“Nothing’s ever happened but they all know if I ever go into a coma or anything, they’d phone my mum and get me a sugary drink, they know bits about it” (male, aged 16 years).

This reassured parents, who could be confident that their child’s friends were capable of assisting their child in such situations.

Discussion

The strength of this study lies in its rigorous qualitative methodology to explore an area of limited research in the UK. Applying an interpretive phenomenological approach to the collection and analysis of rich qualitative data enabled the in-depth exploration of participants’ lifeworlds. Employing Merleau-Ponty’s existential of lived space (as described by Van Manen, 1997) to explore the management of type 1 diabetes within the home, medical, school and social environments has led to an understanding of the barriers and facilitators to the self-management of diabetes in daily life, which ultimately impacts on blood glucose control. The limitation of interpretive enquiry is that the findings are the interpretation of one researcher, and give a snapshot of the lived experiences of one particular group of young people and their parents at a moment in time. Credibility was enhanced, however, through investigator triangulation and the use of focus groups for data validation to minimise bias.

Adaptation to the diagnosis of type 1 diabetes and the implementation of routine was necessary within the family to maintain a balance between diabetes management and family life. Being “in control” of diabetes through organisation and routine enabled diabetes to exist in the background of family life. Elsewhere, routine has been shown to contribute towards the normalisation of type 1 diabetes within the family (Clawson, 1996), through decreasing parental anxiety (Wennick and Hallstrom, 2006) and minimising impact on life outside the family. The adaptation processes illustrated by families in this study support Knafl and Deatricks’ (1986) definition of normalising behaviour within families following the diagnosis of chronic illness in childhood. It has also been argued that family adoption of a normalised view of chronic illness may lead to the young person feeling more confident in situations outside the family home (Amer, 1999).

The medical environment provided families with safety and information about how to manage the illness from a clinical perspective. Families needed this support to be able to negotiate environments outside of the clinic. It is possible that the traumatic experiences described by some families influenced parents’ perceptions of the hospital environment as “safe” and “protective”. It has been recognised elsewhere that events leading up to a diabetes diagnosis are often tainted with a slight suspicion of diabetes, culminating in a climax of urgency and panic once the diagnosis is made (Lowe and Gregory, 2004).

The tailoring of education to meet the needs of the family at diagnosis and ongoing care supports findings that there is a “right” time to learn for every individual, and diagnosis may not be an appropriate time for everyone (Cooper et al, 2004). Spending time in hospital highlighted the medical side of diabetes. This supports the personal models theory, which suggests that personal models of diabetes are developed through emotional responses to the illness experience (Hampson et al, 1990). In contrast to other research that found a lack of trust in young people in the care plans issued to them by healthcare professionals (Karlsson et al, 2008), this study found that young people had open and trustworthy relationships with their healthcare team. Families’ concerns about transition to adult services highlighted in this study support other

“Adaptation to the diagnosis of type 1 diabetes and the implementation of routine was necessary within the family to maintain a balance between diabetes management and family life. Being ‘in control’ of diabetes through organisation and routine enabled diabetes to exist in the background of family life.”

Page points

1. Overall, young people and their parents felt that more awareness from teachers about type 1 diabetes was needed in order to make self-management easier for the young person and to enable parents to feel confident that their child is in a safe and supportive environment when at school.
2. Despite the social advantages of not disclosing diabetes for some young people in this study, other qualitative studies support the finding that disclosure of diabetes to friends is important, to advocate a feeling of safety.
3. The findings suggest that peer support is instrumental to the management of type 1 diabetes outside the home environment. Lack of peer support or young people's perceptions of negative peer reactions may partly explain reports of reduced adherence to the diabetes regimen during adolescence.
4. An appreciation of the environmental facilitators and constraints to self-management behaviour is needed in order to understand the complexity underpinning young people's self-management behaviour and the impact of this on their blood glucose control.

findings that the process of transition to adult services is underpinned with psychosocial barriers, including parents being suspicious of adult healthcare professionals and anxious about the quality of care their child will receive (Fleming et al, 2002).

Within the school and social environments, there were a number of barriers restricting young people's self-management. The lack of diabetes knowledge in schools described by the participants in this study is supported by the findings of a number of other studies conducted in the UK (Waller et al, 2005; Newbould et al, 2007). Evidence suggests that increased school absence may be present in young people with type 1 diabetes (Aspey, 2001), but a systematic review also found that young people with type 1 diabetes perform equally well at school as their peers, despite increased rates of absence (Milton and Whitehead, 2006). Overall, young people and their parents felt that more awareness from teachers about type 1 diabetes was needed in order to make self-management easier for the young person and to enable parents to feel confident that their child is in a safe and supportive environment when at school.

Despite the social advantages of not disclosing diabetes for some young people in this study, other qualitative studies support the finding that disclosure of diabetes to friends is important, to advocate a feeling of safety (Carroll and Marrero, 2006). La Greca (1992) and Lightfoot and colleagues (1999) also found that peers were generally supportive of young people's diabetes. Young people can "forget" about their diabetes when with their peers (Karlsson et al, 2008), thus facilitating normalisation of type 1 diabetes in the social environment. Negative reactions to injecting themselves influenced some young people not to inject in public, and not disclosing diabetes to friends led to potentially serious situations if hypo/hyperglycaemia occurred. This is supported by evidence that poor psychosocial support impacts on adherence to the diabetes regimen (Kyngas, 2000).

Research with the general population of young people has found that behaviours that receive approval from their peer group are likely to be repeated (Allen et al, 2005), and qualitative evidence suggests that young people with type 1 diabetes are concerned with fitting in with the general culture (Dickinson and O'Reilly, 2004). This explains why some young people prioritise social behaviours

over diabetes self-management in order to integrate within their peer group. As in this study, non-adherence has been found to have the perceived benefit of enabling some young people to fit in with their peers more adequately (Herrman, 2006). "Preventive disclosing" (Joachim and Acorn, 2000) of type 1 diabetes to young people's peers had the positive effect of enabling the peers to assist with self-management and gave parents peace of mind for their child's safety. Peer acceptance facilitated positive self-management behaviour, as practices were easier to adhere to without the obstacle of peer approval to negotiate.

These findings are supported by other reports of young people receiving unwanted attention when testing or injecting in public (Herrman, 2006), jeopardising their ability to fulfil their self-management regimens as a consequence (Carroll et al, 2007). Shiu and colleagues (2003) suggest that when those with diabetes perceive the external environment as non-supportive, they have difficulty transferring what they have learnt about diabetes management into practice. The findings suggest that peer support is instrumental to the management of type 1 diabetes outside the home environment. Lack of peer support or young people's perceptions of negative peer reactions may partly explain reports of reduced adherence to the diabetes regimen during adolescence (Timms and Lowes, 1999).

Conclusions

Each family in this study had a unique story to tell about their diabetes journey and the social factors in the environments they encountered that hindered and helped them to manage type 1 diabetes. Although the population was small and context-specific, this study has highlighted that glycaemic control is underpinned by complex self-management processes for each individual, dependent on the relationships they have with others, and their and others' perceptions of their self-management behaviours. An appreciation of the environmental facilitators and constraints to self-management behaviour is needed in order to understand the complexity underpinning young people's self-management behaviour and the impact of this on their blood glucose control.

Data from this study have been used to inform the production of an on-line interactive "Adolescent Diabetes Needs Assessment Tool" (ADNAT) for

young people with type 1 diabetes (Cooper et al, 2010). The tool assesses individual learning and support needs, including psychosocial support in the environments highlighted in this study. For example, environmental scenarios highlighted in this research, such as going to parties and on outings with families, are incorporated within the tool to give an indication of young peoples' self-management decision-making processes. The tool enables an important insight into these underpinning influences on glycaemic control for healthcare professionals and communicates learning needs electronically to young people and healthcare professionals to aid feedback and discussion. ADNAT is currently being tested with a clinic population in North West England, and has the potential to improve blood glucose outcomes for young people through the delivery of education tailored to their needs, through an understanding of their social contexts and beliefs, and improved communication with their healthcare professionals. ■

- Allen JP, McFarland FC, Porter MR, Marsh P (2005) The two faces of adolescents' success with peers: Adolescent popularity, social adaptation and deviant behavior. *Child Devel* **76**: 747–60
- Amer KS (1999) Children's adaptation to insulin-dependent diabetes mellitus: A critical review of the literature. *Pediatr Nurs* **25**: 627–41
- Aspey C (2001) *The Educational Disadvantages of Students with Insulin-Dependent Diabetes: A Problem-Based Enquiry*. South Downs College, Portsmouth
- Carroll AE, Marrero DG (2006) The role of significant others in adolescent diabetes management: A qualitative study. *Diabetes Educ* **32**: 243–52
- Carroll AE, Downs S, Marrero DG (2007) What adolescents with type 1 diabetes and their parents want from testing technology. *Comput Inform Nurs* **25**: 23–9
- Christian BJ, D'Auria JP (1999) Gaining freedom: Self-responsibility in adolescents with diabetes. *Pediatr Nurs* **25**: 255–66
- Clawson JA (1996) A child with chronic illness and the process of family adaptation. *J Pediatr Nurs* **11**: 52–60
- Cooper H, Braye S, Geyer R (2004) Complexity and interprofessional education. *Learning Health Social Care* **3**: 179–89
- Cooper H, Geyer R (2007) *Riding the Diabetes Rollercoaster: A New Approach for Health Professionals, Patients and Carers*. Radcliffe, Oxon
- Cooper H, Spencer J, Wheeler S et al (2010) Development of an Adolescent Diabetes Needs Assessment Tool (ADNAT study). *Diabet Med* **7**: 118
- Danne T, Mortensen HB, Hougaard P et al (2001) Persistent differences among centres over 3 years in glycaemic control and hypoglycaemia in a study of 3805 children and adolescents with type 1 diabetes from the Hvidovre Study Group. *Diabetes Care* **24**: 1342–7
- Diabetes UK (2012) *Diabetes in the UK 2012: Key Statistics on Diabetes*. Available at: <http://bit.ly/14Q0pd3> (accessed 21.10.13)
- Dickinson JK, O'Reilly MM (2004) The lived experience of adolescent females with type 1 diabetes. *Diabetes Educ* **30**: 99–107
- Fleming E, Carter B, Gillibrand W (2002) The transition of adolescents with diabetes from the children's healthcare service into the adult healthcare service: a review of the literature. *J Clin Nurs* **11**: 560–7
- Hampson SE, Glasgow RE, Toobert DJ (1990) Personal models of diabetes and their relations to self-care activities. *Health Psychol* **9**: 632–46
- Hanna KM, Guthrie D (2001) Parents' and adolescents' perceptions of helpful and non-helpful support for adolescents' assumption of diabetes management responsibility. *Issues Compr Pediatr Nurs* **24**: 209–23
- Herman JW (2006) Children's and young adolescents' voices: Perceptions of the costs and rewards of diabetes and its treatment. *J Pediatr Nurs* **21**: 211–21
- Joachim G, Acorn S (2000) Stigma of visible and invisible chronic conditions. *J Adv Nurs* **32**: 243–8
- Karlsson A, Arman M, Wikblad K (2008) Teenagers with type 1 diabetes – a phenomenological study of the transition towards autonomy in self-management. *Int J Nurs Stud* **45**: 562–70
- Knaff K, Deatrick J (1986) How families manage chronic conditions: An analysis of the concept of normalisation. *Res Nurs Health* **9**: 215–22
- Kyngas H (2000) Compliance of adolescents with chronic disease. *J Clin Nurs* **9**: 549–56
- La Greca AM (1992) Peer influences in pediatric chronic illness: An update. *J Pediatr Psychol* **17**: 775–84
- Lightfoot J, Wright S, Sloper P (1999) Supporting pupils in mainstream school with an illness or disability: young people's views. *Child Care Health Dev* **25**: 267–83
- Lowes L, Gregory JW (2004) Management of newly diagnosed diabetes: Home or hospital? *Arch Dis Child* **89**: 934–7
- McCarthy JR, Holland J, Gillie V (2003) Multiple perspectives on the "family" lives of young people: methodological and theoretical issues in case study research. *Int J Soc Res Methodol* **6**: 1–23
- Milton B, Whitehead M (2006) The social and economic consequences of childhood-onset type 1 diabetes mellitus across the lifecourse: A systematic review. *Diabet Med* **23**: 821–9
- Modi AC, Pai AL, Hommel KA, Hood KK et al (2012) Paediatric self-management: A framework for research, practice and policy. *Pediatrics* **129**: e473–85
- Newbould J, Francis S-A, Smith F (2007) Young people's experiences of managing asthma and diabetes at school. *Arch Dis Child* **92**: 1077–81
- NHS Information Centre (2011) National Diabetes Paediatric Audit Report 2009–2010. Available at: <http://bit.ly/13uxsPL> (accessed 26.06.2013)
- Royal College of Paediatrics and Child Health (2012) National paediatric diabetes audit report 2010–11. Available at: <http://tiny.cc/z399yw> (accessed 26.06.2013)
- Shiu ATY, Kwan JJYM, Wong RY (2003) Social stigma as a barrier to diabetes self-management: Implications for multi-level interventions. *J Clin Nurs* **12**: 149–50
- Spencer J, Cooper H, Milton B (2009) Qualitative studies of type 1 diabetes in adolescence: A systematic literature review. *Pediatr Diabetes* **11**: 364–75
- Spencer J, Cooper H, Milton B (2013) The lived experiences of young people (13–16 years) with type 1 diabetes mellitus and their parents – a qualitative phenomenological study. *Diabet Med* **30**: e17–24
- Timms N, Lowes L (1999) Autonomy or non-compliance in adolescent diabetes? *Br J Nurs* **8**: 794–7
- Van Manen M (1997) *Researching Lived Experience: Human Science for an Action-Sensitive Pedagogy*. Althouse Press, London, Ontario
- Waller H, Eiser C, Heller S, Knowles J, Price K (2005) Adolescents' and their parents' views on the acceptability and design of a new diabetes education programme: A focus group analysis. *Child Health Care Dev* **31**: 283–9
- Weinger K, O'Donnell KA, Ritholz MD (2001) Adolescent views of diabetes-related parent conflict and support: a focus group analysis. *J Adolesc Health* **29**: 330–6
- Wennick A, Hallstrom I (2006) Swedish families' lived experience when a child is first diagnosed as having insulin-dependent diabetes mellitus. *J Family Nurs* **12**: 368–89
- Williams C (1999) Gender, adolescence and the management of diabetes. *J Adv Nurs* **30**: 1160–6

Authors

Joy Spencer, Research Associate, Institute of Translational Medicine, University of Liverpool; Helen Cooper, Professor of Community and Child Health, Faculty of Health and Social Care, University of Chester and Research and Development Department, Alder Hey Children's NHS Foundation Trust; Beth Milton, Honorary Fellow, Department of Public Health and Policy, University of Liverpool.