

# Perceptions of Adolescent Patients of the “Lived Experience” of Type 1 Diabetes

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## ■ ABSTRACT

The care and management of adolescents with type 1 diabetes presents numerous challenges that are inherent to the fears, attitudes, and perceptions of their illness. This qualitative study aimed to explore the “lived experience” of individuals with type 1 diabetes. In-depth interviews were conducted with 20 patients diagnosed with type 1 diabetes in their adolescent years to elicit their views, perceptions, and concerns regarding living with diabetes. All interviews were conducted and analyzed using the principles of grounded theory. Five categories defining the patients’ lived experience were elicited: Barriers, Develop Skills, Manage Emotion, Social World, and Health Care Professionals.

The problems experienced by adolescents with type 1 diabetes are multifactorial. Existentially, type 1 diabetes affects their daily activities and impinges on their academic achievement and personal aspirations. They have great difficulty coping with their health status and highlight a lack of empathy from health care professionals (HCPs). Their major fear is of hypoglycemia, resulting in their subsequent focus of preventing hypoglycemic episodes. Indeed, regardless of consequence, blood glucose levels are often deliberately kept above recommended levels, which serves to decrease the effectiveness of their health care management. This study shows that the quality of care provided for adolescent patients with type 1 diabetes is failing to meet their expectations and falls short of the essential standards commensurate with current health care policy. Improvements in long-term care management for these patients require changes in both patients’ and professionals’ understanding of the disease and of the ways it is managed.

Type 1 diabetes is an increasing worldwide health problem (1–4). Indeed, of the 35,000 children and young people <19 years of age with diabetes in the United Kingdom, 96% have type 1 diabetes (5). Furthermore, total diabetes care accounts for 10% of the U.K. National Health Service health care expenditure—a figure projected to increase 25% by 2040 (6). Although the cause of the increased incidence of type 1 diabetes in young people is unclear, changes in lifestyle and increased risk of autoimmune disease in children may be contributing factors

(7). In the United Kingdom, the increased incidence of type 1 diabetes is evident (8), with the highest rate being recorded in Northern England (9). Worryingly, the number of children <15 years of age with type 1 diabetes has doubled in the past 20 years, and in the group of children <5 years of age, diabetes is increasing by 2.3% per year (10).

Adolescence is recognized as a challenging time for patients with type 1 diabetes (11–13). Young people with type 1 diabetes endure a lifetime of monotonous and rigorous health care management usually involving

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daily blood glucose monitoring, insulin injections, and constant self-care, often resulting in psychological maladjustment (14). Furthermore, a strong correlation between poor diabetes management and depressive symptoms has been reported (15,16). Indeed, research suggests that individuals with type 1 diabetes are at an increased risk of suicide, and young men with type 1 diabetes were found to have a higher-than-expected risk of suicide (17).

For patients with type 1 diabetes, life-threatening complications develop within 30 years of diagnosis, and these patients are at 3–10 times higher risk of developing cardiovascular problems than the population as a whole (18–20). Anderson et al. (21) found that the incidence of nephropathy increases at a cumulative rate to between 50 and 75% within 10 years of initial diagnosis. Borch-Johnsen et al. (22) reported that 54% of deaths within 35 years of diagnosis were attributed to diabetic nephropathy. An earlier study by Marshall and Flyvbjerg (23) estimated that ~30% of young type 1 diabetes patients will develop nephropathy of sufficient severity to require dialysis or a kidney transplant for end-stage renal failure. An estimated 70–90% of patients will develop some degree of diabetes-related retinopathy irrespective of their A1C level within 20 years of diagnosis of the disease (24,25). Recent guidance from the U.K. National Institute for Health and Care Excellence (26) recommends an A1C target  $\leq 48$  mmol/mol (6.5%) as ideal to minimize the risk of long-term diabetes-related complications.

Rovet and Alvarez (27) found a positive correlation between hypoglycemia and decreased cognitive function, in particular a decrease in the ability to maintain attention, and individuals with a history of hypoglycemia had a significantly lower verbal IQ. The findings from this study mirror those of previous studies, all of which found positive correlations between hypoglycemia and decreased

cognitive ability (28,29). Gaudieri et al. (30) performed a meta-analysis to confirm the effects of hypoglycemia on cognitive function and identified hypoglycemia as the causative factor for subsequent underachievement and underperformance in academia. Similarly, Lawrence et al. (31) highlighted a positive association between hypoglycemia and slower cognitive function on tests, with increased mistakes and slower response rates on basic verbal and mathematical tasks.

Adolescents with type 1 diabetes typically have limited glycemic control, which affects the occurrence of diabetes-related complications (32–35). Adherence to and compliance with treatment regimens are difficult concepts for many adolescents, and because glycemic control is poor, they subsequently run an increased risk of developing serious health problems and a reduced life expectancy (36–43). Moreover, some studies have found that adjustment of metabolic control and attainment of target A1C levels ( $\leq 6.5\%$ ) in adolescents compared to adults is not achievable because of the increased risk of severe hypoglycemia (44,45).

Adolescents with type 1 diabetes, while undergoing major physical changes in their struggle to establish independence, are forced to consider the limitations of their disease on a daily basis (46). Bateman (47) suggested that adolescents with type 1 diabetes have an additional struggle toward the desired independent state of “normal” development dictated by their dependent state as a consequence of the need for self-care vigilance, daily insulin injections, and close glucose monitoring (48).

Adolescence is widely recognized as a rebellious period when rejection of and poor adherence to treatment are common (49–51) and is therefore a particularly difficult time for those with type 1 diabetes. Maintaining a strict regimen requires considerable self-control; however, various aspects of normal adolescent development may severely compromise

their ability to maintain a prescribed lifestyle. Type 1 diabetes has an impact on adolescents' perception of self and development of assertiveness, self-esteem, and a positive self-image (52,53), causing delays in identity formation (54), intimate relationships, attainment of independence (55), and the development of an established career path (56,57).

Studies involving families of adolescents with type 1 diabetes clearly highlight the importance of the family context in terms of these patients' general adjustment to their chronic illness (58–60). Similarly, peer-related influences and the role peers play in terms of the treatment management of adolescents with type 1 diabetes and their adaptation to chronic illness have also been widely acknowledged in the literature. Timms and Lowes (61), in a study investigating noncompliance among adolescents with type 1 diabetes, suggested that peers offer support, which may then improve compliance. Similarly, Skinner et al. (62) investigated the role of peers in supporting adolescents' diabetes management. Semistructured interviews were used to assess levels of peer support and their impact on metabolic control. This study positively identified that peers are an important source of emotional support. Additionally, its results confirmed that peer support is associated with improved metabolic control, suggesting that this group of patients differs, in terms of peer support, from other patient groups (63).

Wills et al. (64) used a retrospective study to review the care and outcomes of young adults with type 1 diabetes. Participants included individuals 16–25 years of age who were diagnosed with type 1 diabetes. Data were collected on glycemic control, hypertension, clinic attendance, and screening for and prevalence of diabetes-related complications. The investigators found that both glycemic control and attendance at traditional clinic visits were poor, screening for complications was sub-

optimal, resources were limited, and there was inadequate provision of care with respect to dietetic and psychological services.

The long-term management of type 1 diabetes is predominantly focused on both the primary and secondary care arenas, and goals have been set for health care providers (HCPs) to optimize glycemic control to prevent diabetes-related complications (65), which is essential to reducing the onset of micro- and macrovascular complications and to achieving optimal health (37). Such measures are crucial if early morbidity and mortality among diabetes patients is to be avoided. It is well established that life expectancy for individuals with type 1 diabetes is reduced on average by 20 years (66); at an individual level, the quality-adjusted life expectancy loss for individuals with diabetes is 11.1 years compared to individuals without diabetes (67).

Previous research relating to diabetes in the young is extensive. However, it is primarily quantitative and questionnaire-based, with a focus on concerns regarding morbidity and mortality (68), prevalence of the types of diabetes (69), epidemiological challenges and approaches to monitoring (70), and personality and diabetes control (71). Furthermore, there are few scientific data using a qualitative approach to address adolescents' perceptions of their type 1 diabetes and the needs of children and young people, and calls for a major review of the ways in which their care is delivered remain unmet (72).

The management of type 1 diabetes presents numerous challenges to the attainment of optimal health care, many of which are inherent in the fears and perceptions of adolescent patients. Furthermore, the focus of diabetes management lays responsibility for maintaining adequate glycemic control on individual patients—a difficult concept for any patient, but especially for adolescents who may be struggling to cope with

<b>Respondent Number</b>	<b>Sex</b>	<b>Age (years)</b>	<b>Years Since Diagnosis</b>
1	F	16	1.5
2	M	17	5
3	F	18	6
4	M	18	8
5	M	19	6
6	M	18	4
7	F	19	10
8	M	19	9
9	F	21	6
10	M	19	13
11	F	20	14
12	F	16	15
13	M	19	1
14	F	20	12
15	M	18	5
16	F	18	12
17	M	19	2
18	F	16	2.5
19	F	18	2
20	F	18	5

other physiological and sociological stresses in their lives. In part, their ability to achieve this goal is governed by not only their attitudes regarding their initial diagnosis, but also their perceptions of the long-term problems of living with the disease. Current understanding of such attitudes and beliefs is rudimentary, but this issue is important if patients are to achieve good glycemic control and thus minimize diabetes-related complications and enable implementation of health care guidelines.

The aims of this study were to investigate the perceptions of adolescent patients regarding living with type 1 diabetes and to identify areas of focus for improving their glycemic control.

### **Methodology**

A qualitative methodology adopting a grounded theory approach was used to investigate the perceptions of patients diagnosed during their adoles-

cence. In-depth interviews were carried out by a member of the research team, an experienced nurse, and a qualitative researcher, affording the opportunity to ensure theoretical sensitivity (73) (a term related to grounded theory referring to an individual's credibility, understanding, and experience of the research and indicating a degree of sensitivity, heightened insight, and ability to conceptualize and give meaning to the data).

### **Ethical Considerations**

Before commencement of the study, permission was sought from the Sunderland Medical Ethical Committee, City Hospitals Sunderland Ethical Committee, and University of Sunderland Ethical Committee. An outline of the proposed study was provided to each of the respective committees, together with supporting documentation, including a letter of invitation to adolescents and a copy of the consent form, which stated that

TABLE 2. Illustration of Category Development From Respondent Interviews

Transcript Extracts	Conceptual Labels	Categories
"I'm 19, 20 next month, and I <u>cannot see</u> myself being 30. I can't see myself being 25. The <u>complications that could happen</u> I think stop me thinking about being older".	Altered Imagery; Limitations; Assessing Complications	Barriers
"I <u>had to learn</u> how to inject my insulin, <u>learn how</u> to eat regularly."	Learn; Learn How	Develop Skills
"I had a <u>down day</u> , I just <u>cried</u> all day, didn't want to do anything, didn't want to have my injection. I just didn't want to eat, I <u>couldn't be bothered</u> . . . . Then it was fine, then I'd have <u>another down day</u> again."	Inconsistent Days; Down Days; Negative Attitude	Manage Emotion
"It affected a great deal. I felt <u>left out</u> . We have a crowd, they were all <u>supportive</u> , but I was scared to do things because of my insulin, either having to carry it around or having to go home and get it or think about eating. I couldn't forget it."	Left Out/Supportive	Social World
"I feel that I wish they had a little bit more time to <u>sit and talk</u> about how I'm feeling about things, because there are occasions when I <u>start to worry</u> about things, diabetic things . . . I remember being told <u>when I was diagnosed</u> that diabetic problems can take 15 or 20 years to show up and now I'm <u>not too far away</u> from the 10 years so now I'm thinking <u>anything can happen</u> at any time."	Diagnosis/Movement; Management; Assessing Risk	Health Care Professionals

participation was voluntary, that their contribution to the study would be anonymized, and that they had the right to withdraw from the study at any time. A letter to be mailed to general practitioners detailing the study was also submitted.

### Sampling and Recruitment

Purposive sampling (74) was employed to recruit patients who had a diagnosis of type 1 diabetes, were aged 16–21 years, had lived with type 1 diabetes during their adolescence (Table 1), and had attended a hospital clinic in the North East region of the United Kingdom. Patients who did not meet these criteria were excluded. Initially, potential participants were contacted via telephone and invited to participate. A letter detailing the study was provided, and formal written consent was obtained from participants before each interview.

### Data Collection and Analysis

Patients were visited in their own home and invited to tell their story and describe their reaction to the diagnosis, how they live with their diabetes, their perceptions, and their experiences of their health care provision. In keeping with the principles of grounded theory as explained by

Strauss and Corbin (75), each interview was transcribed verbatim as it took place. Data analysis commenced after the first interview, and the concepts developed were used to inform subsequent interviews. Owing to the complexity of the data and to become immersed in its "richness," each transcript, including field notes taken after each interview, was read and re-read, and the audio tape was reviewed in its entirety before the coding process.

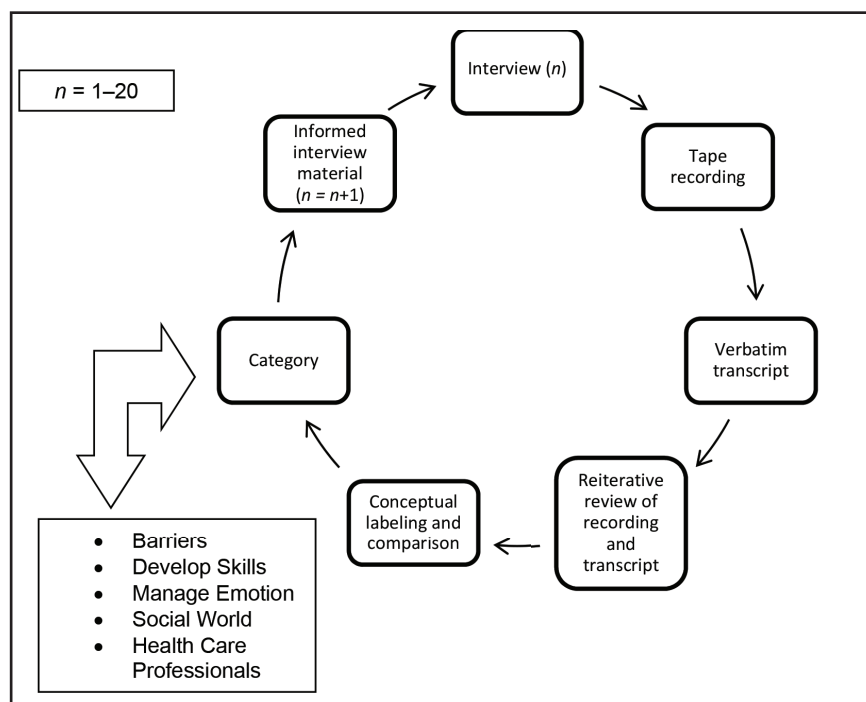
The interview data were examined to identify words or phrases that contributed to the overall comprehension of the underlying process. This process, known as coding, ultimately led to the conceptualization of the data, the grouping of concepts, and the subsequent emergence of categories. Initially, each sentence and incident was micro-analyzed using a fluid process known as open coding, which involved closely examining the spoken words and the transcript and underlining key words (Table 2) in an attempt to understand individual patients' experiences and conceptualize the data. This intricate process further serves to reduce researcher bias and guard against fallacious interpretations (76). Key themes were

then developed and assimilated into initial categories (Figure 1).

Subsequently, this coding process was used to develop conceptualization of the data, the grouping of concepts, and the emergence of categories. Selective coding allowed for the exploration of interrelationships among the categories. Having open-coded, identified, and conceptually labeled events and phenomena and derived categories for these data, the component parts shaped into a coherent whole that had meaning for both the researchers and all who contributed to the data (77). Authors KMK and PJK reviewed the transcripts and held analysis clinics during which codes and categories were negotiated, thus ensuring the trustworthiness of the research process (78–80).

Interviews were audiotaped, transcribed verbatim, and analyzed sequentially by constant comparison. Data were then used to inform subsequent interviews. Data collection was based on the principle of "theoretical saturation" (81), a concept used to confirm that no new information was forthcoming. Data saturation was deemed to have been attained at interview 16. However, to ensure that





**FIGURE 1.** Illustration of the reiterative process and the development of categories of respondent interviews.

no new material emerged, interviews were continued through interview 20.

## Results

The results presented here report the views and experiences of adolescent patients with type 1 diabetes attending a multidisciplinary health care team diabetes clinic. The study population consisted of a heterogeneous group living in an area ranked to be significantly deprived, with relative disadvantage widespread across the city and exacerbated by the post-2008 recession (82). The results document initial reactions immediately after their diagnosis, including the emotional intensity of shock and confusion, of feeling unwell, and of having marked physical symptoms. Their inherent need to conform to regular mealtimes, avoid certain foods and drinks, test blood daily, and inject insulin is also highlighted. Additionally, the respondents highlight their perceptions of the constant struggle to prevent both hypo- and hyperglycemia and their fear of developing diabetes-related complications. Moreover, these results illuminate in-

dividual patients' realization of the truth that type 1 diabetes is a chronic disease that confines them to a prescribed pathway and dominates their thinking and their lives.

The categories identified included Barriers, Develop Skills, Manage Emotion, Social World, and Health Care Professionals.

### Barriers

This category relates to the manner in which the patients expressed their reactions both to their initial diagnosis and to the difficult path they must follow. Concepts developed from the open coding process were "altered imagery," "limitations," and "assessing complications." Respondents spoke about their negativity regarding their diabetes and their aspirations for the future and their overall acceptance that type 1 diabetes is "forever" for them—that it is never going to go away. Respondents reported that the diagnosis of diabetes was a difficult concept to understand. Many expressed feelings of confusion and misunderstanding about the complexity of the disease. There were various

aspects of the disease with which adolescents had to become familiar (e.g., foods that were no longer allowed and the necessity for daily injections). Representative comments included:

*"I couldn't take it all in. I had people coming and teaching me at different times." (R1)*

*"I didn't understand it really . . . mainly the injections, and all of a sudden I couldn't eat this, and that wasn't nice. I didn't like having to have the injections. I had different people coming and teaching me at different times, and I didn't understand it all." (R11)*

*"I realized quite suddenly that this was how it was going to be for the rest of my life." (R6)*

Respondents' worried not only about day-to-day issues, but also about the possible long-term issues and often made reference to how they would cope with long-term management. They were aware that type 1 diabetes carries a high risk for the development of diabetes-related complications. They spoke freely about their constant worries, about their fear of blindness or having problems with their circulation, and about how all these worries were always at the back of their mind and how fearful this was for them. Representative comments included:

*"I'm 19, 20 next month, and I cannot see myself being 30. I can't see myself being 25. The complications that could happen I think stop me thinking about being older." (R7)*

*"I'm petrified about what might happen to me . . . it's always there at the back of my mind . . . I can't help worrying." (R3)*

*"The possible complications that I'm really scared of is circulation, me eyes, me hearing,*

*hands and feet chopped off, having bad circulation in me feet, bad circulation in me hands, that's really the thing that scares me, getting blind. If I went blind with diabetes, I'll just hang meself."* (R11)

*"If I ever get problems with me legs, I'd rather be dead than have problems with me legs . . ."* (R15)

### Develop Skills

Findings indicated that, after the initial impact of diagnosis, there is a period of resignation, of reluctant acceptance, and of acknowledgment of the need to conform to a new and different way of life. This second category relates to the way the adolescents had to develop a new meaning of keeping healthy and new technical expertise to equip them for the future; in essence, they had to learn a new way of life and of living with type 1 diabetes. Concepts developed from these data were "learn" and "learn how." Respondents reported that, for the first time in their young lives, they faced the importance of eating regularly and the need for daily insulin injections to keep themselves alive, as well as the idea that this would be forever for them, and many admitted it was a struggle.

*"It was a struggle at first, but then you have to get on with it. You've got to; there's no choice. If you didn't, you'd be dead."* (R20)

*"I had to learn how to inject my insulin, learn how to eat regularly."* (R5)

*"All the time you've got to know, and you've got to know the times—the time to eat, the time for your injections. You've got to remember all the time, never let up."* (R10)

### Manage Emotion

This category relates to the emotional turbulence the respondents

encountered in their lives. The diagnosis caused emotional difficulties, which affected daily living. Concepts developed from these data were "inconsistent days," "down days," and "negative attitudes." The results tell of the intensity the adolescents faced and their many problems and fears. The interviewees spoke about their "nervousness and tension" associated with their diagnosis of diabetes and about the need to maintain control of their blood glucose levels because of the associated risk of developing diabetes-related complications, coupled with the fear of hypoglycemia.

Hypoglycemia made them feel ill and frightened them. They particularly feared hypoglycemia during the night, and many reported that they would often lay awake worrying about whether they would die in their sleep. They told about how they would purposely keep their blood glucose levels high to safeguard against such problems, and some admitted to testing their blood glucose during the night because of their fear of having a hypoglycemic episode while they were asleep.

*"To make sure that I'm OK, I set my alarm clock every night to wake up at 1:00 . . . Sometimes I have to go and get something to eat, some toast or whatever, to keep my sugars up."* (R11)

*"It does bother me in case I don't wake up. I'd lay awake at night and think, 'What if I don't wake up?' I need to keep my sugars high; I purposely do 'cos I don't want a hypo. That's scary and what worries me."* (R8)

*"I do keep my blood sugars on the high side. That's so that I don't have a hypo."* (R4)

Respondents reported often experiencing extreme changes in mood and told of how they often were depressed about the fact that they had

diabetes, were different from their peers because of it, and questioned why they should have the disease.

*"It's a pain at times. I can't just do what I want to. When I want, I can't just forget to eat like my friends can. I have to remember all the time. It's like taking a closer look at yourself every single minute of the day or night."* (R2)

*"I had a down day. I just cried all day, didn't want to do anything, didn't want to have my injection. I just didn't want to eat, I couldn't be bothered . . . Then it was fine, then I'd have another down day again."* (R1)

*"I try to brush it off. I always think to myself, I'm on top of it, and I haven't got it. But some days, I wake up and it jumps out and smashes you straight in the face and says, 'I'm in control.'" (R10)*

Some respondents admitted wishing they did not have diabetes. They tried in vain to forget and wanted to be the same as everyone else. They spoke of the regular reminders that they had diabetes and told of the tiring cycle of always having to think about their diabetes and of the need to eat being a daily constant for them, causing low moods and giving them a feeling of "being different."

*"It's annoying because, if I go out for the day, I've got to remember to eat at certain times, and I can't. Before, I used to be able to just do something, so I would just do it. If I was at my friend's house and wanted to sleep over, then we could just do it. But now I can't because I have to have my insulin at tea-time . . . I have to come home."* (R1)

*"All the time I wish I could say I'm alright, but it's always there."*

*I think that's the main thing. That's what gets you tired. It wears you out thinking about it all the time. It's always on your mind. You try to shut it off, but it's always there ticking away like a clock. Every now and then, you come to a bad day, and then it starts over again."* (R17)

*"It's the uncertainty of it all the time, knowing that things can happen. You can never totally guarantee that you won't get anything. You can try, but you never do know. Your blood sugars can go all to pot at any time, so you never can tell."* (R3)

### Social World

Type 1 diabetes also had a major impact socially on the interviewees. The concepts included within this fourth category were "left out/supportive" and "interpreting image of self and others." They related to the sociological issues the adolescents faced in their lives and included effects on peers, parents, work, school life, and leisure.

*"It affected school. I was in GCSE [General Certificate of Secondary Education] year at the time. I was off school for a while getting used to it. I did miss a lot of school. I got OK GCSEs, but I think I would have got better results if I didn't have it."* (R9)

*"I know I got lower grades than I was projected."* (R8)

*"I wanted to be like everyone else, wanted treating the same as others', but I couldn't be though, because I wasn't like the others, was I?"* (R2)

Respondents said it was reassuring for them and gave them peace of mind to tell others they had diabetes. Often, time was spent sharing information and making sure that,

should a hypoglycemic episode occur, then whoever they were with would know what to do and how to cope. Many told that they tended not to go anywhere alone and said they always made sure they carried glucose tablets, Hypostop, or glucagon.

*"Whatever I'm doing, I tell people. Then they know there's something in my bag if I flake out, just to get me 'round. They know where my glucose tablets are. It gives me peace of mind at least, so they all know."* (R6)

Friends made an important contribution to the socialization of the respondents and acted as both companions and guardians. Many told of how they found their friends very supportive, of how useful it was for them to be able to share their feelings, and of how comforting it was for them to know their friends were watching out and caring for them.

*"I've got lots of friends. That gives me help and support. I often use them to air how I feel. They're really good around; it means all the world to me, keeps me sane. I see me mates every day. They're a good bunch, they take care of me, and that's really important to me."* (R2)

*"I know they'll see me OK, and that helps me a lot, really. It's reassuring for me to know that my friends know what to do. They asked me what they needed to know, so I told them to give me my sweets if I'm bad, and that helps me."* (R13)

The interviewees saw themselves as being different from their peers. Their peers did not have to watch what they were doing, and they did not have to inject insulin on a daily basis. On the whole, diabetes made them feel left out from many activities. There were times when having to have a meal interfered with what they wanted to do and having to have

insulin was a constant reminder for them of their differences. Some told of how they found injecting insulin in public places difficult, and others said they sometimes had problems having to explain why needles and syringes were in their bags.

*"It affected a great deal. I felt left out. We have a crowd. They were all supportive. They watched out for me. That was good, but I was scared to do things because of my insulin—either having to carry it about with me or having to go home and get it or thinking about eating. I couldn't forget it at all."* (R6)

Most of the respondents saw smoking as normal teenage activity that almost everyone did at some stage. Smoking for the interviewees was something they could do that did not make them feel different, although all considered smoking to be detrimental to their health.

*"I know that I shouldn't, but what am I, 20 years old, and anything can happen even if I don't smoke, so why not smoke and something happen? I know it's stupid, really. When I'm smoking, I'm wondering why am I doing this . . . I didn't want to be different again. I wanted to be normal like them."* (R14)

*"It started when me and me mates started going to the pub. Rather than looking out of place, we all took up smoking—me as well, not wanting to look the odd one out again. I started with all the rest. We were all 16 at the time . . . Peer pressure I think you would call it, so that's why I do it."* (R10)

Self-image relating to how the respondents saw themselves in comparison to their peers was very important. Generally, they saw them-



selves as being different and had a feeling that diabetes labeled them and often prevented what they wanted to do. The “ideal” body size was an issue with which female respondents particularly had problems. Many told how physical exercise had little impact on any attempt to lose weight because of their need to eat substantially before physical activity to maintain blood glucose levels.

*“I mean, if I could be a size 12 or a lovely 10, by exercising, then the thought of it would be good. But I have to eat before I do anything like that and adjust my insulin if I do something, then there's no point. I just have to put up with it. I would love to be smaller. That's what gets to me. But that's diabetes for you.”* (R16)

*“Always trying to watch weight . . . trying to lose weight, but then got to eat something because the sugar's dropping.”* (R3)

The interviewees spoke about their physical relationships and how they relied on their partners to offer support. Many said their partner worried about them and told about how the fear of hypoglycemic episodes caused problems and often made things awkward. Some partners wanted to know more about diabetes, and many had given insulin injections to their partners. Some individuals spoke about feeling embarrassed when partners had witnessed hypoglycemic episodes, and others said their partner at times had given glucagon injections.

*“Me girlfriend, she's fully aware of it, of the implications, what's required. She's actually brought me out of a hypo at night time. Took about 15 minutes, I think. She gave me a glucagon injection, very supportive.”* (R6)

*“I've got a girlfriend. It bothers me that I could have a hypo, and I don't want to be seen having a hypo. I did have a girlfriend before, and I had a hypo in front of her, and it does bother us that it could happen again, and I'd rather not have a hypo in front of someone like that.”* (R15)

*“Sex isn't particularly a problem unless it's particularly energetic and I go hypo. Quite embarrassing really. You're lying there all aglow, and I have to go and have a Mars bar.”* (R20)

### Health Care Professionals

The concepts for this final category were “diagnosis/movement,” “management,” and “assessing risk.” Interviewees spoke about their hospital experiences, and especially their clinical management. Some continued to attend clinics in the pediatric department, whereas others had been transferred to the adult department. Generally, the adolescents said they had experienced problems, particularly with some of the HCPs. Often, they reported feeling that they were not treated as individuals and that discussions with HCPs often involved their parents rather than themselves. Others said they wished they had more time to discuss their concerns.

*“I don't like to go to clinic. They don't treat you as an individual. I mean, I have all the tests and the check-ups, but they just talk to my parents, and I may as well not be there. They seem to think that they can treat everybody the same. Other people may well have diabetes, but it doesn't affect everyone the same way exactly.”* (R4)

*“I find them really annoying, some doctors. I find them really patronizing, like my consultant; he really talks down to me, as if I'm still a kid. He always talks to me as if I'm 6 years old*

*or something, and he asks my mum things about me, as if I'm not there.”* (R2)

The interviewees spoke about their experiences with HCPs, often stating that they met with a consultant and a diabetes nurse and occasionally a dietitian. The HCPs were said to discuss blood glucose levels and insulin dosage. Numerous blood tests were taken at clinic, together with checks for kidney problems; eye sight problems, which included checking for glaucoma; and inspections of hands and feet.

*“They check for glaucoma. They check your HbA<sub>1c</sub>. They check for everything that diabetes affects: your kidneys, they check your feet, they talk about your blood sugar levels, they check your hands.”* (R16)

*“I don't really see the dietitian anymore. I don't know if she could tell us, help us. I don't think so. I see the consultant and the diabetes nurse, and they just talk about blood sugars and ask if I've done anything to bring them down and if I've done anything differently, with them being higher, and then just talk about insulin dosage. I don't know what to do with it, and I don't think they do.”* (R4)

*“The nurse looked at us. Most of the time, she used to ignore me and speak to my mum. That really annoyed me. She wasn't interested in me, just her figures.”* (R7)

*“I don't know why I need to go and see the nurse anyway. She would give us this lecture about how I was taking me blood sugar and me weight. She wouldn't ask how I was doing.”* (R8)

The respondents spoke about how they felt that their HCPs tried to



scare them. For example, some told how their consultant had literally banged on the table and told them that they were going to die if they did not get their blood glucose level down.

*"They try to scare us." (R17)*

*"There was one consultant, he just banged his hand on the table and told me, 'You're going to die.'" (R7)*

On the whole, the respondents' experienced difficulty asking about issues other than their diabetes. Many felt stupid asking questions, and many expressed the need for more information in the form of leaflets, which would save them from being embarrassed while asking questions. In particular, they wanted information about sex, smoking, and alcohol. Some did say that they had received leaflets about alcohol and diabetes. HCPs had encouraged questions; however, this was said to be difficult in the presence of a parent.

*"I wish I could have more information on sex and things like that 'cos you never get told things like that at hospital. You feel stupid asking. I think they should just do a leaflet about it, like smoking and sex and alcohol. A leaflet about all three things, and that'd be just class because you'd save yourself the embarrassment of asking." (R12)*

*"One thing I don't like is some doctors say, 'We want you to be grown up and come and tell us if you have any problems or anything' and then say, 'Oh, we won't see you unless you're with your mum or dad.' If you wanted to ask about personal things like contraception, you don't want your mum or dad there . . . I was told that alcohol can alter your blood sugar, and they*

*said, 'Oh, but you don't need to know that yet.'" (R1)*

*"I feel that, if they had a little more time to sit and talk about how I'm feeling about things, because there are occasions when I start to worry about things, diabetes things . . . I remember being told when I was diagnosed that diabetes problems can take 15–20 years to show up, and now I'm not that far away from the 15 years, so now I'm thinking anything can happen at any time." (R14)*

### **Interpretation of Patient Interviews**

To address possible sex-related differences in respondents' attitudes about their diabetes, detailed analysis of individual interviews separated those of male respondents from those of female respondents. One of the major findings of the female patients was that the diagnosis of diabetes made them angry. They said it was annoying; it was intrusive, interfered with their life, and imposed restrictions on them (Barriers category). Diabetes made them feel different from their friends and got them down. They spoke of down days and how they cried and became upset (Manage Emotion category).

For the males, however, there was more emphasis on being careful (e.g., the "drudgery of it," "being in control," "watching," and "being on guard and never letting go"). They spoke about being in control of diabetes rather than it being in control of them. They had resigned themselves to living with diabetes and to taking it one day at a time. They spoke about the need to plan, to focus on eating, and to know when to have insulin.

In general, respondents who had had their diagnosis for ~5 years showed increasing intolerance; however, they also spoke of not knowing if they could be bothered by diabetes in the long term. Those with a longer duration of diabetes expressed

their concerns about developing diabetes-related complications. All the respondents spoke about their fear of hypoglycemia and the worry that it caused them (Manage Emotion category).

All of the respondents also spoke about not going anywhere alone since their diagnosis and related to friends not only for support but also for keeping them safe (Social World category). They also related their negative experiences with HCPs (Health Care Professionals category).

All of the respondents reported performing blood glucose monitoring frequently. Some monitored their blood glucose every day, whereas others preferred every other day. However, all monitored their blood before going to bed as a form of comfort.

All of the respondents knew about the need to maintain blood glucose levels (Develop Skills category). All spoke about the uncertainty and fear of hypoglycemia and stated that they purposely kept their blood glucose levels higher than recommended to reduce the risk of hypoglycemia. Indeed, they said they felt happier and "more normal" when their blood glucose was higher than the specified A1C target of 48 mmol/mol (6.5%) (Develop Skills category).

### **Discussion**

The data reported here show that adolescents in this group experienced considerable difficulties regarding their daily blood glucose control and the risk of hypoglycemic episodes, and as a consequence, their main focus was on avoiding of hypoglycemia. This intense attention to detail had a powerful emotional effect on the adolescents, as well as on their social interactions with family members and peers. Analysis of the transcripts identified five categories: Barriers, Develop Skills, Manage Emotion, Social World, and Health Care Professionals.

The adolescents experienced a constant daily struggle of having to

conform to a prescriptive way of life relating to the disease process, emotions, their social world, the practical aspects of having diabetes, and health care maintenance. They lacked the luxury of expressing the spontaneity that is an acknowledged trait of others in this age-group and were forced into the realization that they have an additional level of responsibility to themselves.

The major fear for these patients was hypoglycemia, and their main focus was on preventing hypoglycemic episodes. Regardless of consequence, they often deliberately kept their blood glucose above recommended levels in an attempt to decrease the likelihood of a “hypo” occurring. Such actions demonstrate some adolescents' attempts to take some degree of control over their lives and their fight for independence.

The subjective nature of the lived experience identified by these patients correlates closely with similar observations by Karlsson et al. (83) and previous studies (84–86). These authors reported that patients often depended on social networks and concentrated on avoiding hypoglycemia, findings also identified in our study.

Our findings suggest that adolescent patients and their HCPs rely on different strategies for addressing and coping with chronic disease. Although the HCPs appear to adopt a prescriptive medical model approach to chronic disease management, the adolescent patients in this study adopted a more complex series of coping strategies based on their personal attitudes and fears regarding their diabetes.

The results of this study suggest that poor communication is a common underlying problem for adolescent patients, supporting earlier reported evidence (87–90). Communication problems are based on a multifactorial paradigm between patients and HCPs stemming from differing levels of knowledge, understanding, vocabulary, and measures

of success. There were many problems for this group of patients based on attitudes about HCPs, often related to communication problems between adolescents and adults.

In comparison to other studies involving adolescent patients, it was found that symptoms of depression were related to poor medication adherence (91). Casier et al. (92) found that accepting limitations imposed on adolescents with cystic fibrosis has a positive impact on readjustment of life goals and on psychological functioning. Oruche et al. (93) in their study investigating barriers to and facilitators of treatment participation by adolescents in a community mental health clinic found that clinic staff who were respectful, involved teenagers and their parents, and had good communication positively influenced clinic attendance. Another study involving adolescents with asthma and their parents found that developing a partnership approach between patients and HCPs could successfully improve the care of asthma patients (94).

In part, the data reported in our study confirm observations by other researchers (95–99). However, we also identified a number of factors that further contribute to existing knowledge of how adolescent patients cope with chronic illness (99). Namely, adolescents with type 1 diabetes are forced into a lifestyle of closely monitored self-surveillance. Indeed, La Greca et al. (100) reported compliance problems with this age-group. However, often not recognized and not previously reported is the lengths to which these individuals are prepared to go to deliberately keep their blood glucose levels high to avoid hypoglycemia. Although HCPs are crucial for offering support, many may neglect to discuss preferences and values with their adolescent patients (101,102). This study highlights gaps in and barriers to care and importantly identifies that the adolescents may purposefully maintain hyperglycemia to reduce their

risk of hypoglycemia. Not only does this activity have potentially harmful consequences for patients, but it also poses a major problem for their HCPs.

### **Study Limitations**

This study was based on in-depth interviews with adolescents and sought to explore individuals' perceptions of living with type 1 diabetes. However, the data collection process (known as theoretically sampling) represented broad variation in terms of respondents' demographic characteristics, which was necessary to realize the aims of the study. The reiterative process, coupled with the trustworthiness of the findings, serves to substantiate confidence in the findings. The interview process continued until no new material emerged and saturation was deemed to have been achieved. It could be argued that the adolescent sample does not contain sufficient variation. However, the findings from the study may well be transferable to similar heterogeneous groups and used to inform and enhance health care practice for adolescent patients with type 1 diabetes.

### **Implications for Practice**

This study provides a deeper understanding of adolescents' experience of living with type 1 diabetes. Significant gaps have been identified that present an opportunity to improve the provision of health care services for adolescents with type 1 diabetes.

This study centered on the ways in which adolescent patients describe their diabetes and lifestyle. In this group of patients, communication played an important role in their interactions with their peers, and, typical of adolescents, the style of communication used did not allow for effective communication with HCPs.

The problems experienced by these adolescent patients are multifactorial; they experienced a constant daily struggle of conforming to a prescriptive way of life. The constant fear of hypoglycemia was so great that many admitted to purposely keeping their

blood glucose levels high. Making improvements in long-term health care management for these patients, and specifically developing interventions to address their avoidance of hypoglycemia and facilitate the effective transfer of knowledge, will require improvement in our understanding of their perceptions of their disease and of their interactions with HCPs.

## Conclusion

Currently practiced health care provision based on a traditional medical model was not perceived by these patients as a high-quality and effective means of reducing their perceptions and fears regarding morbidity and mortality. The authoritarian nature of their interactions with their HCPs served to reduce the effectiveness of message transfer such that the adolescent patients did not understand or appreciate the significance of their strict adherence to the physiological parameters that determine their outcomes. Conversely, total dependence on an informal, unstructured, laissez-faire approach to care likely would be equally unsuccessful in providing the required quality of care. Effective care for adolescents with type 1 diabetes lies somewhere between these two extremes; a clear, well-structured approach to message transfer, tailored to meet the individual needs of these patients and delivered in a manner that neither alienates nor intimidates them, may well contribute to an enhanced level of care provision.

## Duality of Interest

No potential conflicts of interest relevant to this article were reported.

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