

**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 which 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 twenty patients, diagnosed with type 1 diabetes in their adolescent years, to elicit their views, perceptions and concerns of living with diabetes. All interviews were conducted and analysed using the principles of grounded theory. Five categories defining the patients 'lived experience', were elicited: 'Barriers', 'Develop Skills', 'Manage Emotion', 'Social World' and 'Healthcare professionals'.

The problems experienced by adolescent patients with type 1 diabetes are multi-factorial. Existentially, type 1 diabetes impacts on their daily activities and impinges upon academic achievement and personal aspirations. They have great difficulty coping with their health status and highlight a lack of empathy from healthcare professionals. Their major fear is of hypoglycaemia resulting in their subsequent focus of preventing hypoglycaemic episodes. Indeed, regardless of consequence, blood glucose levels were often deliberately kept above recommended levels which serves to decrease the effectiveness of their healthcare management. This study has shown that the quality of long-term provision for adolescent patients with type 1 diabetes is failing to meet their expectations and falls short of the essential standards commensurate with current healthcare policy. Improvements in long-term healthcare management for these patients require changes in both patient and professional understanding of their disease, and of the ways that they are managed.

Background

Type 1 diabetes is an increasing world-wide health problem¹⁻⁴ affecting nearly 25,000 adolescent individuals in the UK⁵. Furthermore, total diabetes care accounts for 10% of NHS healthcare expenditure; a figure projected to rise by 25% by 2040⁶. Whilst the actual cause of the increased incidence of type 1 diabetes in the young is unclear, changes in lifestyle and increased risk of autoimmune disease in children may well be contributing factors⁷. In the UK, the increased incidence of type 1 diabetes is evident⁸ with the highest rate being recorded in Northern England⁹. Worryingly, the number of children under 15 years with type 1 diabetes has doubled in the last 20 years and in the under 5 years age group, diabetes is increasing by 2.3% per year¹⁰.

Adolescence is recognised as being a challenging time for patients with type 1 diabetes^{11,12,13}. Such individuals endure a life-time of monotonous and rigorous healthcare management, involving daily blood glucose monitoring, insulin injections and constant self-care, resulting in psychological maladjustment¹⁴. Furthermore it is suggested that there is a strong correlation between poor diabetes management and depressive symptoms^{15,16}. Indeed research suggests that individuals with type 1 diabetes patients with type 1 diabetes are more at risk of suicide¹⁷ and young men were found to have a higher than expected risk of suicide¹⁷.

For patients with type 1 diabetes life-threatening complications develop within thirty years of diagnosis and are between three and ten times more at risk of developing cardiovascular problems than the population as a whole^{18,19,20}. Anderson et al²¹ found that the incidence of nephropathy increases at a cumulative rate to between 50% and 75% within ten years of diagnosis 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 Flyvbjerg²³ estimated that approximately 30% of young type 1 diabetes patients will develop nephropathy of sufficient severity to require dialysis or kidney transplant for end-stage renal failure. An estimated 70% – 90% of patients will develop some degree of diabetes-related retinopathy, irrespective of their HbA_{1c} level within 20 years of diagnosis of the disease^{24,25}. The Diabetes Control and Complications Trial Research Group²⁶ found that good glycaemic control (HbA_{1c} readings of 53 mmol/mol (7%) or below) reduced the risk of retinopathy.

Rovet and Alvarez²⁷ found a positive correlation between hypoglycaemia and decreased cognitive function, in particular a decrease in the ability to maintain attention and in those individuals with a history of hypoglycaemia there was a significantly lower verbal IQ. The findings from this study mirror those of previous studies, all of which found positive correlations between hypoglycaemia and decreased cognitive ability^{28,29}. Puczynski³⁰ used a case study approach to confirm the effects of hypoglycaemia on cognitive function and identified hypoglycaemia to be the causative factor for subsequent under-achievement and under-performance in academia. Similarly, Yu et al,³¹ found a positive relationship between the incidence

of hypoglycaemic attacks and absences from school, which related to under achievement in patients with type 1 diabetes and a subsequent lower attainment in school grades.

Adolescents with type 1 diabetes typically have limited glycaemic control which impacts the occurrence of diabetes-related complications^{32,33,34,35}. Adherence to and compliance with treatment regimens are difficult concepts for many adolescents and because glycaemic control is poor, they subsequently run an increased risk of developing serious health problems and a reduced life expectancy^{36,37,38,39,40,41,42,43}. Moreover, some studies have identified that adjusting metabolic control and the target levels of HBA_{1c} in adolescents, compared to those of adults (i.e. less than 7.5%) is not achievable due to the increased risk of severe hypoglycaemia^{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 basis⁴⁶. Bateman⁴⁷ suggests that for the adolescent with type 1 diabetes, there is the additional struggle towards the desired independent state of 'normal' development which dictates a dependent state as a consequence to the need for vigilance, daily insulin injections and close glucose monitoring⁴⁸. Adolescence is widely recognised as a rebellious period when rejection and poor adherence to treatment is common^{49,50,51} and is therefore a particularly difficult time for those with type 1 diabetes. Maintaining a strict regime 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 the adolescent's perception of self, their development of assertiveness, self-esteem and positive self-image^{52,53} causing a delay in identity formation⁵⁴ intimate relationships, gaining independence⁵⁵ and developing an established career path^{56,57}.

Studies with families of adolescents with type 1 diabetes clearly highlight the importance of the family context in terms of their general adjustment to the chronic illness^{58,59,60}. Similarly peer-related influences and the role that peers play in terms of treatment management in adolescents with type 1 diabetes and adaptation to chronic illness has also been widely acknowledged with the literature. Timms and Lowes⁶¹ in their study to investigate non-compliance amongst adolescents with type 1 diabetes suggested that peers offer support which may then improve compliance. Similarly, Skinner et al⁶² investigated the role of peers in supporting adolescents' diabetes management. Semi-structured interviews were used to assess the levels of peer support and their impact on metabolic control. Their study positively identified that peers are an important provider of emotional support. Additionally, the results also confirm that peer support is associated with improved metabolic control, suggesting that this group of patients differs, in terms of peer support, from other patient groups⁶³.

Wills et al,⁶⁴ used a retrospective study to review the care and outcomes of young adults with type 1 diabetes. The study participants included individuals diagnosed with type 1 diabetes aged between 16 years and 25 years. Data were collected on glycaemic control, hypertension, clinic attendance and screening for and prevalence of diabetes-related complications. They found that both glycaemic control and attendance at traditional clinic was poor, screening for complications was sub-optimal, resources were limited and that there was inadequate provision with respect to dietetic and psychological services.

The long-term management of type 1 diabetes is predominantly focused in both the primary and secondary care arenas, and goals have been set for healthcare professionals to optimise glycaemic control preventing diabetes-related complications⁶⁵, which is essential to reduce the onset of micro-vascular and macro-vascular complications, and to achieve optimal health⁶⁶. Such measures are essential if early morbidity and mortality amongst diabetes patients is to be avoided, as it is well established that life-expectancy for individuals with type 1 diabetes is reduced on average by 20 years^{67,68}. It is also highlighted that at an individual level, the quality-adjusted life expectancy loss for diabetes individuals is 11.1 years, compared with non-diabetic individuals⁶⁶.

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 mortality⁶⁹, prevalence of the types of diabetes⁷⁰ epidemiological challenges approaches to monitoring⁷¹ and personality and diabetes control⁷². Furthermore, there is little scientific data using a qualitative approach addressing adolescents' perceptions of their type 1 diabetes and the needs of children and young people and calls for a major review in the way in which their care is delivered remains unmet⁷³.

The care based management of type 1 diabetes presents numerous challenges to the attainment of optimal healthcare, many of which are inherent within the fears and perceptions of adolescent patients. Furthermore, the focus of diabetes management lays responsibility on the individual patient to maintain adequate glycaemic control, a difficult concept for any patient, but especially for an adolescent who may

be struggling to cope with other physiological and sociological stresses in their lives. In part, their ability to achieve this goal is governed not only by their attitudes to 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 is important if patients are to achieve good glycaemic control, and so minimise diabetes-related complications and enable implementation of healthcare guidelines.

The aim of this study was to investigate the perceptions of adolescent patients to living with type 1 diabetes, and to identify areas for improving their management of glycaemic control.

Methodology

A qualitative methodology, adopting a grounded theory approach was utilised for investigating the perceptions of patients diagnosed during their adolescence.

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 sensitivity⁷⁴. A term related to grounded theory and refers to an individual's credibility, understanding and experience of the research and also indicates a degree of sensitivity, possessing heightened insight and the ability to conceptualise and give meaning to the data.

Ethical Consideration

Prior to commencement of the study permission was sought from the Sunderland Medical Ethical Committee, City Hospitals Sunderland Ethical Committee and the University of Sunderland Ethical Committee. An outline of the proposed research study was provided to each of the respective committees, together with a copy of supporting documentation; a letter of invitation to the adolescent, a copy of the consent form which also stated that participation was voluntary and that their contribution to the study would be anonymised and that they had the right to withdraw from the study at any time. A letter to be mailed to the general practitioners detailing the study was also submitted.

Sampling and Recruitment

Purposive sampling was employed⁷⁵ to recruit the patients who had a diagnosis of type 1 diabetes were aged between 16 and 21 years of age and who had lived with type 1 diabetes during their adolescence (Table 1) and attended a hospital clinic in the North East of the UK. Patients not within these criteria were excluded from the study. Initially potential participants were contacted via telephone and invited to participate. A letter detailing the study was given and formal written consent was obtained from each participant prior to each interview

Data Collection and Analysis Each patient was 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 healthcare provision (Table 2). In keeping with the principles of grounded theory and as explained by Strauss and Corbin⁷⁶, as each interview took place it was transcribed verbatim. Data analysis commenced following the first interview and the concepts developed were used to inform subsequent interviews. Owing to the complexity of the data and in order to become immersed in its 'richness', each transcript, including field notes taken after each interview was read, re-read and the audio tape was listened to again before the open coding process. The interview data were examined so as to identify those words or phrases which contributed to the overall comprehension of the underlying process. This process, known as 'coding' ultimately led to the conceptualisation of the data, the grouping of concepts and the subsequent emergence of categories. Initially, each sentence and incident was micro analysed using a fluid process known as open coding which involved close examination of the spoken words and of reading the transcript and underlining key words (Table 3) in an attempt to understand the individual patient's experience and conceptualise the data. This intricate process further serves to reduce researcher bias and guard against fictitious interpretations⁷⁷. Key themes were then developed and assimilated into initial categories (Fig. 1). Subsequently this coding process was used to develop conceptualisation of the data, the grouping of concepts and the emergence of categories. Selective coding allowed for the inter-relationships between the categories to be explored. Having open-coded, identified and conceptually labelled events and phenomena and derived categories for these data, the component parts were shaped into a coherent whole that had meaning for both the researchers and all those who contributed to the data⁷⁸. KK and PK reviewed the transcripts and held analysis clinics where codes and categories were negotiated, thus ensuring trustworthiness of the research process^{79,80,81}.

Interviews were audio taped, transcribed verbatim and analysed sequentially by constant comparison. Data were then used to inform subsequent interviews. Data collection was based on the principle of

'theoretical saturation' ⁸² a concept used to confirm that no new information was forthcoming. Data saturation was deemed to have been attained at the sixteenth interview. However, in order to ensure no new material emerged, interviews were continued until the twentieth interview.

Results

The results presented here report the views and experiences of adolescent patients' with type 1 diabetes attending a multidisciplinary healthcare team diabetes clinic. The study population consisted of a heterogeneous group living in an area ranked to be significantly deprived with relative disadvantage remaining widespread across the city exacerbated by the post 2008 recession ⁸³. The results demonstrate initial reactions immediately following their diagnosis, the emotional intensity of shock and confusion, of feeling unwell and of having marked physical symptoms. Their inherent need to conform to regular meal times, the need to avoid certain foods and drinks, daily blood testing and injections of insulin is also highlighted. Additionally, they highlight their perceptions of the constant struggle to prevent both hypoglycaemia and hyperglycaemia, and the fear of developing diabetes-related complications. Moreover, these results illuminate the individual patient's realisation of the truth that type 1 diabetes is a chronic disease, which confines them to a prescribed pathway and dominates their thinking and their lives.

The categories identified were:

- Barriers
- Develop Skill
- Manage Emotion
- Social World
- Healthcare 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 which they must follow. Concepts developed from the open coding process were: 'altered imagery', 'limitations' and 'assessing complications'. They spoke about their negativity regarding their diabetes and their aspirations for the future. Their overall acceptance that type 1 diabetes is 'forever', for them, and that it is never going to go away. Respondents identified that the diagnosis of diabetes was a difficult concept to understand. Many expressed feelings of confusion and misunderstanding of the complexity of the disease. There were various aspects of the disease with which adolescents had to become familiar, for example, foods that were no longer allowed and the necessity for daily injections.

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

Respondents' not only worried about day to day issues, they also worried about the possible long-term issues and often made reference to how they would cope with long-term management. They were only too well aware that type 1 diabetes can carry a high risk of developing diabetes-related complications. They also spoke freely about their constant worries, about their fear of blindness having problems with their circulation; and how all these worries were always there at the back of their minds and how fearful this was for them.

"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 me self” (R11) “If I ever get problems with me legs, I’d rather be dead than have problems with me legs..... (R15)

Develop Skills

Findings indicate that following the initial impact of diagnosis, there was a period of resignation; of reluctant acceptance and acknowledgement 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 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; of living with type 1 diabetes. Concepts developed from these data were ‘learn’ and ‘learn how’. For the first time in their young lives there was the importance of eating regularly and the need for injections of insulin on a daily basis in order to keep themselves alive, which was going to 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 relates to the emotional turbulence that the respondents’ encountered in their lives. The diagnosis caused emotional difficulties which impacted upon daily living. Concepts developed from these data were ‘inconsistent days’, ‘down days’, and ‘negative attitudes’. The results tell of the intensity that the adolescents faced and their many problems and fears. The interviewees spoke about their ‘nervousness and tension’ associated with their diagnosis of diabetes and of 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 hypoglycaemia. Hypoglycaemia made them feel ill and also frightened them. They particularly feared hypoglycaemia during the night, and many 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 sugars during the night because of their fear of having a hypoglycaemic attack while they were asleep.

““To make sure that I’m ok I set my alarm clock every night to wake up at 1 o’ clock... 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)

The respondents often experienced extreme changes in mood and told of how they often they were depressed about the fact that they had diabetes, was 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 that 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 reminder, 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. It 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 to 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 relate to the sociological issues the adolescents face in their lives and include effects upon peers, parents, work, school life and leisure.

"It affected school. I was in GCSE 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 graded 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 that it was reassuring for them, and gave them peace of mind, to tell others that they had diabetes. Often time was spent sharing information and making sure that, should a hypoglycaemic attack 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 of how they always made sure that they carried glucose tablets, Hypostop™ or Gucagon

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 socialisation 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 how comforting it was for them to know that 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 everyday. They're a good bunch, they take care of me and that's really important to me" (R2)

"They're really good. 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)

Comment [s1]: Repeated quote

The interviewees saw themselves as being different from their peers. Their peers didn't have to watch what they were doing and they didn't 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 regular insulin was a constant reminder for them of their differences. Some told of how they found injecting insulin in public places difficult, others said how they had problems at times having to explain as to 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, which almost everyone did at some stage. Smoking for the interviewees was something that they could do that didn't make them feel different, even though 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 terms of comparison to their peers was very important. Generally they saw themselves as being different, had a feeling that diabetes labelled them and that diabetes often prevented what they wanted to do. The 'ideal' body size was an issue the 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 prior to 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 told that their partner worried about them and how the fear of hypoglycaemic attacks 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 embarrassment when partners had witnessed hypoglycaemic attacks and others 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 a glow and I have to go and have a Mars bar" (R20)

Healthcare Professionals

The concepts for this final category were 'diagnosis/movement, 'management' and 'assessing risk'. Interviewees spoke about their hospital experiences, especially in terms of their clinic management. Some continued to attend clinics in the paediatric department while others' had been transferred to the adult department. Generally the adolescents said that they had experienced problems, particularly with some of the healthcare professionals'. Often they felt that they were not treated as individuals when discussions with health care professionals often involved their parents rather than themselves. Others said that 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 patronising, 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)

"I feel that I wish they had a little bit more time to sit and talk about how I'm feeling about things because there are occasions when I start to worry about things, diabetic things... I

remember being told when I was diagnosed that diabetic problems can take 15 or 20 years to show up and now I'm not too far away from the 10 years so now I'm thinking anything can happen at any time" (R14)

The interviewees spoke about their experience of healthcare management, often stating that they met with the consultant and the diabetes nurse and occasionally the dietician. The healthcare professionals 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 as well as inspections of hands and feet.

"They check for glaucoma, they check your HBA_{1c}, 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 dietician 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) Some respondents spoke about how they felt that the healthcare professionals treated everyone the same and had tried to scare them. For example, some told how the consultant had literally banged on the table and told them that they were going to die if they didn't get their blood glucose sugar 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)*

"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 everyone the same. Other people may well have diabetes but it doesn't affect everyone the same way exactly" (R4)

Generally the respondents said that they had had experienced problems particularly with some of the healthcare professionals'. Often they felt that they were patronised and not treated as individuals particularly when discussions with healthcare professionals often only involved their parents rather than themselves. Indeed many said they wished time could be spent discussing their concerns.

"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 my blood sugar and my weight. She wouldn't ask how I was doing" (R8)

"I find them really annoying some doctors. I find them patronising. 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 and he asks my Mum things about me as if I'm not there" (R2)

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, as this would save them from being embarrassed asking questions. In particular they wanted information about sex, smoking and alcohol. Some did say that they had received leaflets about alcohol and diabetes.

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

For the males however, there was more emphasis upon being careful, for example "drudgery of it", "being in control", "watching", "being on guard and never letting go". They spoke about being of control of diabetes rather than it being in control of them. They had resigned themselves to living with diabetes, taking each day at a time. They each spoke about the need to now plan, focus on eating and the need to know when to have insulin. Respondents generally with a diagnosis of approximately five years showed increasing intolerance; however they also spoke of not knowing if they could be bothered by it (diabetes) in the long term. Those with a longer duration of diabetes spoke about their concern of developing diabetes-related complications. All the respondents spoke about their fear of hypoglycaemia and about the worry it caused them (Theme Category – Manage Emotion).

All the respondents spoke about not going anywhere along since their diagnosis and related to friends not only as support but also for keeping them safe (Theme Category – Social World) and their negative experience of healthcare professionals (Theme Category – Healthcare Professionals). Blood monitoring was performed by all the respondents frequently. Some monitored their blood every day, whilst others preferred every other day. However all monitored their blood before going to bed as a form of comfort. All the respondents knew about the need to maintain blood glucose levels to 58 mmol/mol (7.5%) or less (Theme Category – Develop Skills). All the respondents spoke about the uncertainty and fear of hypoglycaemia and they did state that they purposely kept their blood glucose higher than the recommended level in order to reduce the risk of hypoglycaemia. Indeed they said that they felt happier and 'more normal' when their blood glucose was higher than the specified 7.5% (Theme Category – Develop Skills).

Discussion

The data reported here show that adolescents experience considerable difficulties regarding their daily blood glucose control, the subsequent risk of hypoglycaemic episodes and as a consequence, their main focus was the avoidance of hypoglycaemia. This intense attention to detail had a powerful emotional effect upon the adolescents, as well as an effect upon social interactions with both family and peers. Analysis of the transcripts gave rise to the identification of five categories namely; Barriers, Manage Emotion, Social World, dDevelop Skills and Healthcare Professionals. The adolescents experienced a

constant daily struggle of having to conform to a prescriptive way of life relating to the disease process, emotion, social world, practical aspects and healthcare maintenance. They lacked the luxury of expressing the spontaneity that is an acknowledged trait for all others of this age and forced into the realisation that they have an additional level of responsibility to themselves. The major fear for these patients was hypoglycaemia, and their main focus was the prevention of hypoglycaemic episodes. Regardless of consequence, blood glucose levels were often deliberately kept above recommended levels in an attempt to decrease the likelihood of a 'hypo' occurring. Such action demonstrates some adolescents' attempts to take some degree of control over their lives and their fight for independence.

In part, the data reported in our study confirms observations by other researchers. However a number of additional indicators have been identified that may serve to further contribute to our knowledge of how adolescent patients with type 1 diabetes cope with their chronic illness. The subjective nature of the 'lived experience' identified in these patients correlates closely with similar observations by Karlsson et al.,⁸⁴ and previous studies^{85,86,87}. These authors reported that patients often depended on social networks and concentrated on avoiding hypoglycaemia; an aspect identified in our study. Not only does this activity have potentially harmful consequences for the patient, but it also becomes a major problem for their healthcare practitioners. These observations suggest that patients and healthcare professionals adopt different strategies with which to cope with chronic disease. Whilst the professionals appear to adopt a prescriptive medical module attitude to chronic disease management, the adolescent patients in this study adopted a more complex series of coping strategies based upon their personal attitudes and fears of their diabetes.

The study reported here suggests poor communication as the common underlying problem for these patients supporting earlier reported evidence^{88,89,90,91}. These communication problems are based on a multifactorial paradigm between patients and healthcare professionals based on different levels of knowledge, understanding, vocabulary and measures of success. There were many problems for this group of patients based on attitudes to healthcare professionals often perceived to be at the base of communication problems between adolescents and adults.

However a number of additional indicators have been identified that further contribute to our knowledge of how adolescent patients cope with chronic illness. In parallel studies it was found that symptoms of depression related to poor medication adherence⁹². Casier et al,⁹³ found that accepting limitations imposed on adolescents with cystic fibrosis has a positive impact on re-adjustment of lives goals and upon psychological functioning. Ormiche et al.⁹⁴ in their study to investigate barriers and facilitators to treatment participation by adolescents in a community mental health clinic found staff who were respectful, involved teenagers and their parents and had good communication positively influenced clinic attendance. A further study involving adolescents with asthma and their parents found that developing a partnership approach between patients and healthcare professionals could successfully improve the healthcare of asthma patients⁹⁵.

In part, the data confirm observations made by earlier workers. However, a number of additional indicators have been identified that further contribute to knowledge of how adolescent patients cope with chronic illness. The subjective nature of the 'lived experience' identified in these patients correlates closely with similar earlier observations^{96,97,98,99,100}. Namely, type 1 diabetes individuals are forced into a lifestyle of closely monitored self-surveillance. Indeed La Greca et al,¹⁰¹ reported compliance problems with this age group. However often not recognised and not previously reported is the extent to which individuals are prepared to go to deliberately keep their blood glucose levels high to avoid hypoglycaemia. Healthcare practitioners are crucial for offering support however many may omit to examine preferences and values with their patients¹⁰². This study highlights gaps and barriers in care and importantly identified that individuals under study purposefully maintain hyperglycaemia in order to reduce their risk of hypoglycaemia. Not only does this activity have potentially harmful consequences for the patient, but it also poses a major problem for their healthcare practitioners.

Conclusion

Current healthcare provision, based upon a medical model, is not perceived by the patients as providing a quality provision, which successfully serves to reduce their perceptions of morbidity and mortality. The

authoritarian nature of their interactions with their healthcare professionals serves to reduce the effectiveness of message transfer such that the adolescent patients do not understand, or appreciate, the significance of their strict adherence to the physiological parameters that determine their outcomes. Conversely, total dependence upon an informal, unstructured, 'laissez faire' approach to care would be equally unsuccessful in providing the required quality of healthcare provision. Reality lies somewhere in between these two extremes; a clear, well-structured approach to 'message transfer' tailored to meet the individual needs of the patient, and delivered in a manner that neither alienates nor intimidates the patient, may well contribute to an enhanced healthcare provision.

Study Limitations

The study was based on in-depth interviews with adolescents and sought to establish individual perception of living with type 1 diabetes. However the theoretical sampling process represents broad variation in terms of the specific demographic characteristics necessary to realise the aims of the study and the constant re-iterative process coupled with the trustworthiness of the findings serve to substantiate confidence in the study's 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 utilised to inform and enhance healthcare practice for adolescents 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 which gives the opportunity to improve adolescent type 1 diabetes healthcare provision and management. This study centred upon the communication used by patients to describe their diabetes and life-style. 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 healthcare professionals. The problems experienced by the adolescent patients are multi-factorial; they experience a constant daily struggle of conforming to a prescriptive way of life. The constant fear of hypoglycaemia was so great that many admitted to purposely keeping their blood glucose levels high. Improvement in long-term healthcare management for these patients specifically focussing on interventions based upon avoidance of hypoglycaemia and effective knowledge transfer for this group requires changes in our understanding of their disease and of the ways that they are managed by their healthcare professionals.

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Comment [s2]: Might it be worth stating that interventions focussing upon 2 issues will enhance the outlook for this group i.e. measuring the avoidance of hypoglycaemia and effective knowledge transfer to this patient group.

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Table 1. Demographic Characteristics of the Respondents

Respondent No.	Sex	Age	Years since Diagnosis
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

Table 2 Interview Topic Guide

During the Interview process the adolescents were asked to share their experience of:
<ul style="list-style-type: none"> • Their reaction to their diagnosis • Living with type 1 diabetes • Their healthcare management

Figure 1. Illustration of the Reiterative Process and the Development of Categories of the Patient Interviews

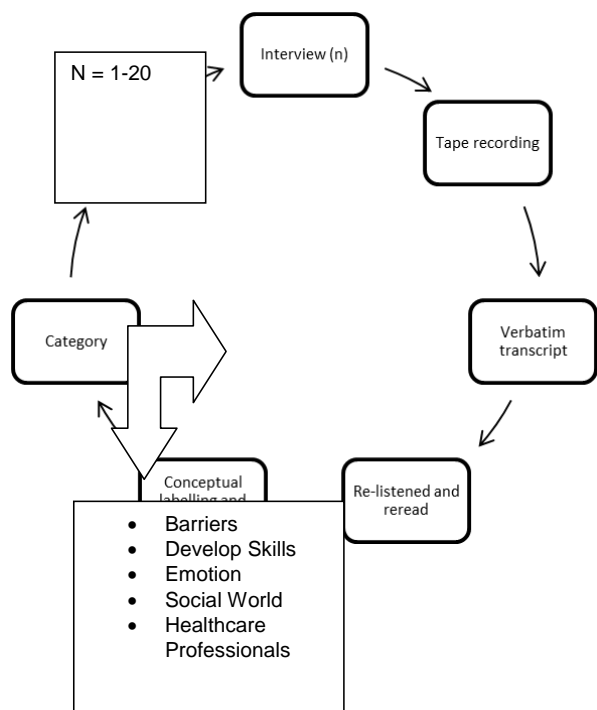


Table 3. Illustration of the Category Development from the Respondent Interviews

Extracts from transcripts	Conceptual labels	Categories
"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"	Altered imagery / Limitations Assessing Complications	Barriers
"I had to learn how to inject my insulin, learn how to eat regularly"	Learn / Learn How	Develop Skills
"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"	Inconsistent days Down Days Negative attitude	Manage Emotion

<p>"It affected a great deal. <u>I felt left out</u>. We as 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".</p>	<p>Left out / Supportive</p>	<p>Social World</p>
<p>"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 <u>I 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 <u>I'm not too far away</u> from the 10 years so now I'm thinking <u>anything can happen</u> at any time".</p>	<p>Diagnosis / Movement Management Assessing Risk</p>	<p>Healthcare Professionals</p>

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