

Living with diabetes: Adolescents' perspectives

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Article points

1. Adolescents in this study expressed many concerns, in particular the difficulties they encountered in adhering to their prescribed diet and fears surrounding hypoglycaemia.
2. Concerns were also expressed about undertaking exercise and physical activities and the lack of facilities for undertaking self-care activities in school.
3. Adolescents with diabetes have unique health care needs; it is imperative that healthcare professionals are mindful of these and continue to work closely with young people and their parents or guardians.

Key words

- Adolescence
- Diet management
- Hypoglycaemia
- Support

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As part of efforts to implement measures that could be taken to improve current delivery of care and practice, many have tried to identify reasons for non-concordance and non-adherence to treatment regimens in adolescents with diabetes (Coates and Boore; 1998; Kyngas, 1999; Graue et al, 2005). This study, however, aimed to gain insight into living with diabetes from a phenomenological perspective – that is, describing the ‘phenomenon’ (in this case, diabetes) as it is experienced.

Adolescence is a notoriously difficult time; the transition from childhood to adulthood confronts individuals with an often bewildering set of challenges. It would seem hardly surprising, therefore, that adolescence for those with diabetes should often be characterised by poor glycaemia, sometimes expressing itself as brittle diabetes, leading to acute episodes of ketoacidosis and hypoglycaemia (Rapoff and Barnad, 1991). This presents diabetes care teams managing young people with a particularly difficult challenge regarding when or how to intervene to prevent these potentially life-threatening episodes and how to avert the acute and chronic complications of the condition.

Type 1 diabetes is one of the most common chronic childhood illnesses, affecting 1 in 550 children in the UK (Department for Education and Skills and Department of Health, 2005). Glycaemic control often deteriorates during adolescence and HbA_{1c} levels may be higher than at any other time of life (Mortensen et al, 1998).

Adherence to life-long regimens to achieve good blood glucose control necessitates a substantial change in lifestyle and behaviour (Diabetes Control and Complications Trial [DCCT] Research Group, 1993). However, daily activities

during adolescence are typically less structured than during childhood and adulthood, making adherence to a complex regimen of four blood tests and four injections daily much more difficult. This, coupled with the fact that adolescents are still maturing cognitively and emotionally, results in a justifiable concern that long-term psychological health must not be compromised by treatment (Northam et al, 2004).

Methodology

A descriptive phenomenological approach was adopted to guide this study. The hallmark of the genuinely phenomenological enquiry is the task of describing (Kleiman, 2004). This study therefore describes the ‘essence’ of living with diabetes in adolescence.

Possible ethical issues were anticipated if the first author interviewed people known to her. Therefore, a sample was selected from another hospital in the region that had a well-established adult and paediatric diabetes services and also employed a diabetes nurse specialist.

The inclusion criteria were as follows.

- Aged 13–18 years.
- Diagnosed as having diabetes for >2 years.

Out of a total of 23 identified as suitable for

inclusion in the study six agreed to be interviewed. Later, one participant declined to attend the interview. Three of the participants had been diagnosed with diabetes for more than 10 years, one for approximately 5 years and one had been diagnosed with diabetes for approximately 2 years.

Ethical approval was granted by the hospital's ethics committee, who also requested the consent of a parent or guardian of any participant aged 16 years or less. Each participant or their parent provided written consent. The services of a child psychologist were also engaged before the interviews were scheduled to address any concerns or issues that arose during the interview process.

Data were collected using unstructured, recorded interviews. Each participant was asked to talk about their experiences of living with diabetes.

Colaizzi's (1978) seven procedural steps were utilised for data analysis. Moreover, the credibility of the study was assisted by team analysis. This involved an experienced paediatric nurse, a consultant endocrinologist and a consultant paediatrician comparing and discussing the study findings, following which consensus was reached.

Results

Four main themes emerged following analysis of the data and these are discussed below.

Living in the shadow of hypoglycaemia

Fear of hypoglycaemia was one of the main concerns expressed by all participants. This fear was present on a day-to-day basis and when undertaking daily activities. Adolescents described becoming 'hypo' as being unpleasant with an associated loss of control.

'Hypos are my life and Lucozade is my life. I carry Lucozade everywhere with me in case I have a hypo.' (Participant 1)

'Whenever I am low I can't remember anything, what is going on. I just lose track of everything.' (Participant 3)

Four of the participants spoke at length about their sporting activities. The possibility of becoming hypoglycaemic during sport was a worry and all took steps to avoid hypoglycaemia

by reducing insulin doses or eating extra carbohydrates.

Dietary mismanagement

All adolescents in this study admitted struggling to adhere to a healthy eating plan. A variety of mismanagement behaviours in relation to food were expressed. Two participants admitted to mismanaging their diabetes by eating sweets and chocolate regularly. The other participants admitted to eating sweets and chocolate occasionally, sometimes as a treat or when planning sporting activities.

'...at school and at break-time the lads go to the shop to get sweets, sometimes it bothers me and sometimes it doesn't. Sometimes I have crisps and sometimes I have chocolate. Some weeks I might have one bar of chocolate and sometimes I might have four.' (Participant 1)

Support

The support described by the study participants was primarily from peers and secondly from their family, with support from teachers also reported.

Peer support

All five interviewees spoke about their friends at length; they spoke of the support, encouragement and understanding of their friends that helped them to manage aspects of their self-care.

'Everyone knows I have got diabetes in school and everything, most of my friends know ... if anything happened they would know exactly what to do.' (Participant 4)

'He can give me my injections and he would do my bloods, he does his own blood as well, just so he is not afraid of needles or whatever. I suppose if I was going out at night-time he would always be there or if he was going out I would always be there, and he knows exactly how much I was drinking or if I was drinking too much he would just say 'calm down'...' (Participant 5)

Family support

All five participants spoke of their parents, siblings and extended family as being supportive in helping them to manage ongoing adjustments to their care.

Page points

1. Six participants out of a total of twenty three were identified as suitable for inclusion in the study.
2. Data were collected using unstructured interviews which were recorded. Each participant was asked to talk about their experience of living with diabetes.
3. Four main themes which represent the essence of living with diabetes for this group emerged following analysis of the data.
4. All adolescents in this study expressed their struggle in trying to adhere to a healthy eating plan.

Page points

1. All participants spoke of their parents, siblings and extended family as being supportive.
2. Participants stated that it was difficult at times for them to check their blood glucose levels or inject insulin at school due to lack of facilities for undertaking these activities.
3. The goal for diabetes treatment for young adolescents and adults is now considered to be multiple injection therapy.
4. Excessive fear of hypoglycaemia may have clinical significance as a cause of poor adherence.
5. Meal and snack times should fit in as much as possible with current family practice so young people are not eating alone.

'I have a sister she helps me with it, like she gives me my injection sometimes if my mum and dad are away she will give it to me or if they are away on holidays she will look after me or whatever, it keeps me going.'
(Participant 4)

School support

Three of the adolescents spoke positively about the support they received from their teachers at school and how this helped them cope with managing their diabetes at school. However, there were also three instances where participants stated that it was difficult at times for them to check their blood glucose levels or inject insulin at school due to lack of facilities for undertaking these activities.

'Get used to it'

This theme reflects the adolescent's acceptance of having diabetes. The adolescents who had been diagnosed with diabetes for longer than 5 years spoke of their acceptance in a variety of ways.

'It doesn't bother me that much living with diabetes, I have [had] it a good few years now. It doesn't make any difference really.'
(Participant 5)

However, Participant 2, who had been diagnosed with diabetes for a shorter period of time found the diagnosis more difficult to accept.

Discussion

Fear of hypoglycaemia was highlighted as a major issue that affected the daily lives of adolescents with diabetes. Excessive fear of hypoglycaemia may represent a cause of poor adherence to treatment regimens. Young people with diabetes may avoid hypoglycaemia by maintaining elevated blood glucose levels or they may over-treat early signs of hypoglycaemia. Although excessive fear of hypoglycaemia may interfere with self management, general indifference towards hypoglycaemia may also jeopardise physical well being (Cox et al, 1987).

It is interesting to note that a quantitative study of 61 adolescents with diabetes sampled by Bhatia and Wolfsdorf (1991) suggested that recurrent hypoglycaemia was more frequent in boys than in girls. In contrast, more girls than boys experienced

recurrent diabetic ketoacidosis. However, the higher incidence of hypoglycaemia episodes in boys may also be attributed to the greater involvement of boys in sporting and physical activities than girls (Challener, 1994).

The goal for diabetes treatment for adolescents and adults is now considered to be multiple injection regimen as opposed to conventional treatment (twice-daily insulin) in an effort to prevent the microvascular complications of diabetes. However, it has been reported that a major obstacle in achieving and maintaining strict target levels of glucose control via intensive management is the increase in frequency of severe hypoglycaemia such a regimen can cause (DCCT, 1994). Intensive therapy increased the frequency of severe hypoglycaemia nearly 3-fold compared with conventional therapy. Of adolescents who were intensively treated, 82% had at least one episode of hypoglycaemia that required assistance or resulted in seizures or coma. Results of the DCCT, however, indicate that the reduction in the risk of microvascular complications outweighed the risk of having severe hypoglycaemia (DCCT, 1994).

With regard to the second theme of dietary mismanagement, Weissberg-Benchell et al (1995) report that adolescents engage in a variety of mismanagement behaviours that can focus around food. Nutritional advice should be tailored to the individual's needs, aiming to minimise disruption to day-to-day life. Meal and snack times should fit in as much as possible with current family practice so young people are not eating alone. Maximum adherence therefore requires provision of support that is both practical and emotional, not only to the young person with diabetes but also to their family. It is also interesting to note that reference was made by two of the current study participants to diabetic products. Dietary advice for the past decade has emphasised that these products are no longer recommended due to their high calorie content and laxative effect. However, diabetic products are still available in the UK despite lobbying from national and international diabetes associations for a ban. The European Commission is currently considering how foods intended for people with diabetes should be controlled, as labelling food

Page points

1. Peer support plays a key role in how adolescents with diabetes engage in self-care activities.
2. Where young people have taken responsibility early, their health is generally poor.
3. The main issues for children at school are hypoglycaemia, food and physical activity and advice for teachers tends to concentrate on these issues.
4. The attitudes of family, peers and healthcare professionals all influence the degree to which successful personal management is achieved.

as 'suitable for diabetics' undermines important healthy eating messages (Food Standards Agency and Diabetes UK, 2002).

The third theme presented suggests that peer support plays a key role in how adolescents with diabetes engage in self-care activities. Kyngas and Rissanen (2001) report that support from friends was typically expressed as friends reminding the adolescents about their self-care and trying to change their own lifestyle and behaviour to fit in with the young person with diabetes' lifestyle. However, when friends dominated their lives, young people with diabetes adopted their friends' lifestyles and if the demands of diabetes self-care did not fit in with this lifestyle the individual was tempted to depart from their required health regimen. Other studies also report that the support of friends is considered to be crucial to the management and treatment adherence of young people with diabetes (Kyngas and Rissanen, 2001; Cheung et al, 2006).

Adolescents in this study spoke of the support they received from parents. Study findings from La Greca (1990) and Kyngas and Rissanen (2001) also highlight the importance of parental involvement in diabetes care. Where young people have taken responsibility early, their health is generally poor. Parents and guardians who negotiate a gradual hand over of responsibility tend to be raising young people with higher levels of self care (La Greca, 1990).

Kyngas et al (1998) report that young people with diabetes who perceive parental actions as motivating or accepting tend to report good adherence. Yet many parents and guardians report being unsure about how they could best support their child with diabetes in their self-care (Satin et al, 1989). Parents and guardians may therefore need education in how to facilitate independence of actions by adolescents. In the authors' health service area, this involves an individual consultation with the adolescent, following which a joint consultation with a parent or guardian is held. Furthermore, education support programmes for parents and guardians are available and a support network for them is in place via the Diabetes Federation of Ireland.

Three study participants spoke of positive support from teachers; however, the other two

received little or no support. Moreover, the lack of facilities that three study participants had at school for performing their self care activities was highlighted. The general guidance for diabetes in the school setting recommends that each school provide a private and safe area where insulin injections and blood tests can be performed (Diabetes UK, 2003). However, the main issues for children at school are hypoglycaemia, food and physical activity and advice for teachers tends to concentrate on these issues. In the US legislation is in place requiring every school to provide for the educational and health care needs of children with diabetes (ADA, 2006). In the UK, young people with diabetes in education are covered by the Disability Discrimination Act and, furthermore, there are recommendations from the Department for Education and Skills and the Department of Health (2005) that form part of a good practice guide for supporting young people with medical needs.

A novel approach to addressing the needs of adolescents with diabetes in the school setting was developed in Rochdale, UK (Dalton, 2001): the idea of a diabetes clinic in schools was developed and the initiative piloted in two schools. These clinics were held during school time with the support of the diabetes care team and school staff. The clinics facilitated adolescents' attendance at clinics and also increased knowledge about diabetes as teachers and peers were also invited to attend. Notable also is Dalton's finding that participants at the school clinic had a decrease in HbA_{1c} levels over a 9-month period.

The theme 'get on with it' reflects an acceptance of living with a diagnosis of diabetes. Gardiner (1997) studied the social and psychological implications of living with diabetes in a group of adolescents and found some evidence to suggest a correlation.

Conclusion

In conclusion, the attitudes of family, peers and healthcare professionals all influence the degree to which successful personal management is achieved. Therefore, a high degree of positive support is required from all of these people to allow adolescents with diabetes to maintain the best control achievable for themselves, thus

Page points

1. Carers of those young people need to be mindful of the various stages young people with diabetes progress through from diagnosis to denial and finally to acceptance.
2. As a result of the findings of this study, adolescents with diabetes may soon be included in the DAFNE programme on a trial basis.

minimising the risk of complications in later life.

The study presented here also highlights acceptance of diabetes, expressed by many as 'getting used to it.' Carers of young people with diabetes need to be mindful of the various stages that their charges progress through from diagnosis to denial and finally to acceptance and understand the manner in which people with diabetes express themselves during each stage (Zangerle and Rathner, 1997).

A limitation of this study is the small sample of participants which means the findings cannot be generalised to the whole population of adolescents with diabetes. Moreover, only one participant was female and thus the results may be biased towards a male view. However, the outcomes of this study mirror those of international studies on this subject (Kyngas and Rissanen, 2001; Lorensten and Bergstad, 2005) and also contribute to the provision of a richer understanding of adolescents' unique health care needs.

Looking to the future, for over 20 years a team from Düsseldorf, Germany, has used a 5-day structured inpatient training programme on intensive insulin treatment where inpatients are taught to dose-adjust for normal eating. The UK initiative based on this model, Dose Adjustment for Normal Eating (DAFNE), has shown sustained improvement in glycaemic control, achieving a 1% reduction in HbA_{1c} values without increasing the frequency of severe hypoglycaemia (DAFNE Study Group, 2002). The DAFNE programme is now being provided in many centres in the UK and commenced in 2006 in the authors' health region. As a result of the findings of this study, adolescents with diabetes may soon be included in this programme on a trial basis. ■

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