

Adolescents living with diabetes: Self-care and parental relationships

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Article points

1. Adolescents go through a period of adjustment that involves a complex interplay of biologic, cognitive, psychosocial and social change.
2. Adolescents with diabetes are coping with the normal developmental tasks as well as their condition.
3. The focus for adolescents may be their current quality of life; the long-term risks may be less important.
4. There is a trend towards children becoming independent at an earlier age, which means that the transition period starts earlier and lasts longer.

Key words

- Adolescence
- Self-care
- Parents

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For people with type 1 diabetes, the impact of adolescence can have a major effect on their control of the condition. This article explores the transition from childhood to adulthood, with reference to living with diabetes. Among the themes covered are physiological changes, the role of parents and self-care.

There is no exact definition of adolescence, but it is commonly referred to as the transition period between childhood and adulthood (Skinner, 1997). For the purpose of this article, adolescence is taken as referring to people aged 10–20 years. Adolescence is not only a period of change for the young person but also a period of transition for the family – a period of letting go and allowing the child to take control over many aspects of his or her life, including diabetes.

In order to explore adolescence, and the impact this has on diabetes control, a number of core issues will be addressed in this article, including the physiological changes that occur during this time. Additionally, the ways in which the child's and parents' relationship undergoes changes, how parents' reactions to these changes may have a direct effect on the child's behaviour, and how the child chooses to self-manage will be addressed. To facilitate this, some of the psychosocial changes that occur during adolescence will be discussed, and the particular constrictions that diabetes imposes on adolescents will be highlighted.

To illustrate these issues further, and specifically to understand what it is like for

adolescents to live with diabetes during this transition, three core studies will be discussed: Kyngas and Hentinen (1995), Kyngas et al (1998) and Schur et al (1999). These studies have been selected for more focused consideration because they have elicited from adolescents their personal meanings of living with diabetes, whether or not they perceive their parents as being supportive, and the effect that this has on their self-care. The findings from these studies will be discussed, as will emerging themes that have been identified.

Adolescents and diabetes: A UK overview

Adolescence

In the UK, adolescents make up a significant proportion of the population: people between the ages of 10 and 20 years account for 13–15% of the total population (Royal College of Paediatrics and Child Health [RCPCH], 2003). This number is predicted to rise to around 16% by 2011 (RCPCH, 2003). Adolescents' health needs (those relating to sexual health, substance abuse, accident prevention and mental health) have been identified as being greater than those of children or of young adults (RCPCH, 2003).

It has been shown that adolescence is a time when patterns of health behaviour are developed, and these tend to be continued during adult life (RCPCH, 2003). In addition, adolescence is a time when morbidity arises from chronic illness and mental health problems with a likelihood of there being long-term consequences (Kurtz and Thornes, 2000). Indeed, adolescents with diabetes who fail to establish positive health behaviours regarding their diabetes management can have a reduced life expectancy (Diabetes Control and Complications Trial [DCCT] Research Group, 1993).

As far back as 1976, it was recognised that adolescents should be considered as a group having needs distinct from those of either adults or children (RCPCH, 2003). Adolescence is considered to be the most significant period in human life because this is the time when important developmental processes are occurring, such as, developing an adult body image, discovering sexual identity and becoming independent (Newman and Newman, 1984). Whaley and Wong (1995) described the transition period as involving a complex interplay of biologic, cognitive, psychosocial and social change.

The developmental tasks of adolescence highlight the multiple demands placed upon young people (Doherty and Dovey-Pearce, 2005). Havighurst (1953), a professor of education with an interest in human development and education, outlined these developmental tasks and is still cited today. These developmental tasks are:

- accepting one's own body
- adopting appropriate social roles
- developing close relationships
- preparing for occupational roles
- preparing for intimate relationships
- achieving emotional independence from parents
- establishing personal values
- grasping ethics and striving for social responsibility.

Adolescents with diabetes are not only wrestling with their own developmental tasks, but also coping with the demands of their

condition. These require the adolescent to show high levels of motivation and self-control if he or she is to minimise both the short-term and long-term health risks. According to Hentinen and Kyngas (1992), failure to maintain consistent self-care is a major problem among adolescents and is one of the most common reasons for them needing to be hospitalised.

Diabetes

Type 1 diabetes is a chronic illness, with the most common age of onset being late childhood or early adolescence (RCPCH, 2003). In the UK, the rate of diagnosis of the condition in those aged under 15 is around 16 per 100 000 per year (EURODIAB ACE Study Group, 2000). This figure, according to the EURODIAB ACE Study Group (2000), increased by a yearly average of 2.4% between 1989 and 1994.

Diabetes in adolescence was described by Bateman (1990) as being traumatic. This is mainly because it is during this time that the management of diabetes is more problematic (Tattersall and Lowe, 1981). Metabolic control is confounded by the physiological and psychosocial changes of puberty, and there is also a high level of self-care that is required to manage the condition.

The function of diabetes treatment is to maintain blood glucose levels, ideally within normal limits (Schur et al, 1999). There is the constant risk of short-term complications such as hypoglycaemia, hyperglycaemia and ketoacidosis. In addition, the findings from the DCCT (DCCT Research Group, 1993) highlighted the importance of 'tight' blood glucose control ($HbA_{1c} < 6.05\%$) in order to reduce the onset of long-term complications. These complications can induce a sense of fear in adolescents if diabetes self-care is neglected (Kyngas and Barlow, 1995; Doherty and Dovey-Pearce, 2005).

It is debatable, however, whether such a goal of 'tight' control is achievable or appropriate (Anderson, 1995). The focus for adolescents may well be their current quality of life, and they may, therefore, consider the long-

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1. It has been shown that adolescence is a time when patterns of health behaviour are developed, and these tend to be continued during adult life.
2. Adolescents with diabetes who fail to establish positive health behaviours regarding their diabetes management can have a reduced life expectancy.
3. Adolescents should be considered as a group having needs distinct from those of either adults or children.
4. Adolescents with diabetes are not only wrestling with their own developmental tasks, but also coping with the demands of their condition.

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1. Parents may experience difficulties during the adolescent's transition to adulthood in striking the right balance between showing general interest and attempting to control self-care activities.
2. Parents may be concerned that their child regards other things as being more meaningful in his or her life than taking care of diabetes.
3. Parents who understand what diabetes means to their child are in a better position to provide him or her with the necessary support.

term risks as being less important than the intrusiveness of caring for their diabetes in the present (Kovacs et al, 1992).

The reduction of both short-term and long-term risks is achieved through a balance of healthy diet, exercise, monitoring of blood glucose levels and insulin injections (Schur et al, 1999). In order to achieve this, it is necessary to be very self-disciplined, as self-care is central to diabetes control. The demands of diabetes self-care may challenge the adolescent's ability to become autonomous. It is not unusual for some adolescents to need ongoing adult guidance. If, as Havighurst (1953) suggests, one of the developmental tasks of adolescence is the need to achieve emotional independence from parents, though, conflicting feelings in adolescents could result (Lustman et al, 1991). On the one hand, they want to distance themselves, while on the other hand they still require parental support. Consequently, for adolescents who still require parental guidance, it could result in their independence being somewhat limited. Should adolescents view this as an obstacle to becoming independent, it could be argued that it makes adolescence more difficult. This can result in adolescents sacrificing their diabetes control for their independence.

Parental perspective

Parents may also experience difficulties during the adolescent's transition to adulthood in striking the right balance between showing general interest and attempting to control self-care activities, which may prevent the adolescent from developing into an independent adult (Satin et al, 1989). According to Kyngas and Barlow (1995), parents can have problems supporting their adolescents with diabetes because they do not understand the type of support they require or how to behave in a supportive way.

This can be made more difficult because it is during this time that adolescents start to spend increasing amounts of time away from home, further raising parental anxiety. Parents may be concerned that their child regards other things as being more meaningful in his

or her life than taking care of diabetes. These differing perspectives can result in a changing relationship between the adolescent and his or her parent because the priorities of the parents and those of the adolescent may be different (Kyngas and Barlow, 1995).

It may, therefore, be necessary for parents – in order to gain insight and meaning into their child's diabetes self-care – to appreciate their child's personal understanding of what diabetes means to them. Anderson et al (1988) suggested that the personal meaning of having diabetes is strongly related to the individual's self-care and Schur et al (1999) proposed that individuals then act on the basis of this meaning. Parents who understand what diabetes means to their child are in a better position to provide them with the necessary support.

Personal meaning attached to diabetes:

Three studies

Kyngas and Hentinen (1995)

The personal meaning adolescents attach to their diabetes self-care, and the perceived impact this condition has on their lives, were identified in a study undertaken in Finland (Kyngas and Hentinen, 1995). A sample of 51 adolescents aged 13–17 years with type 1 diabetes was interviewed. The data were analysed by continuous comparative analysis.

Four categories of behavioural patterns were identified which related to diabetes self-care. Each category offered meaning about how the adolescents viewed their diabetes self-care. The study also identified parental actions, as described by the adolescents, within four categories and also how supportive, motivating or not their parents' actions were perceived as being. The four categories were as follows.

1 The first category comprised adolescents who took care of themselves and followed health regimens regularly; these adolescents undertook their self-care voluntarily and were proactive in it and took responsibility for it. Self-care was perceived as a natural part of their lives. When discussing their parents, this group of adolescents described the actions of their parents as being a

significant source of motivation. Their parents accepted them as they were and showed interest in their self-care without being over-worried about them. Parents of the adolescents in this category planned self-care together with their child and gave positive feedback or other forms of reward.

- 2 The second category consisted of adolescents who deviated slightly from health regimens. This was because they felt that self-care was an obligation forced on them. Self-care for these adolescents had no positive meaning; instead, it had several negative meanings, including making them feel different, guilty and dependent, tired, fearful, restricted, and thus stressed. The parents of adolescents in this category were perceived as exerting strict discipline. In turn, the adolescents in this group associated this with negative feedback and their parents wanting continuous control of their behaviour. This kind of behaviour resulted in the adolescents feeling that their parents did not trust them.
- 3 The third category was made up of adolescents who described their self-care as constantly deviating from their health regimens. They were characterised by a lack of well-being – perceived as a state of low physical, mental and emotional activity – which was reflected by apathetic and depressed behaviour. Parents in this category were perceived as always nagging and trying to force them to comply with health regimens. For this group of adolescents, lying was often a feature of these conflicts because it was the easiest way to avoid arguments. These adolescents feared the development of long-term complications but were unable to change their behaviour to conform to their health regimens.
- 4 The fourth category comprised adolescents who did not take care of themselves at all according to health regimens. This group of adolescents described their self-care by saying either that they did not care for themselves, or that they cared for themselves as they wished. The adolescents valued freedom and did not want to sacrifice it for a self-care routine. They felt self-care was a

waste of time and insignificant in their lives. This was despite them getting headaches and feeling tired and run-down. Adolescents in this category felt that their parents did not encourage them.

Although this study cannot necessarily be applied to the UK, and it did not state exactly how many adolescents were in each of the four groups or define the disease duration of each group, it did offer perspectives from a group of adolescents living with diabetes and the personal meaning they attached to their self-care. For those adolescents who were proactive in their diabetes self-care and took responsibility for it, their parents were a main source of support for them – they accepted them as they were and offered positive feedback. It could be that, for these parents, observing their child taking the responsibility of self-caring for his or her diabetes enabled them to adopt a more relaxed approach and, hence, to ‘nag’ less.

In the categories where the adolescents’ health regimens were described as deviating slightly, deviating constantly or being non-existent, parents were perceived as not encouraging their child and being controlling, non-trusting and ‘nagging’. This perceived lack of parental support described by the adolescents may have resulted from the fear and anxiety that their parents were experiencing. These parents may have been aware of the increased short-term and long-term risks that their child’s health behaviour was predisposing them to.

A situation such as this could place further stress on the parent–child relationship and also have a direct physiological effect on the adolescent’s diabetes control. This is because experiencing stress increases the stress hormone levels in the body and this produces a rise in blood glucose levels (Halford et al, 1990), resulting in a worsening of glycaemic control. It may also be that parental actions that are described by adolescents as being controlling, non-trusting and ‘nagging’ could be interpreted as parents being more interested in their illness and less in recognising them as

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2. It is possible that parental actions that are described by adolescents as being controlling, non-trusting and ‘nagging’ could be interpreted as parents being more interested in their illness and less in recognising them as people in their own right.

Page points

1. Diabetes is a demanding chronic illness, which requires that the adolescent accepts increasing and extensive responsibility for carrying out treatment.
2. Parents are in a position where they can support their child with these responsibilities as long as they do not see just the diabetes, but also recognise the adolescent's personal understanding of living with diabetes and the personal meaning he or she attaches to self-care.
3. A supportive parent-child relationship built on mutual trust can promote self-care which will lead to better control of diabetes and fewer long-term complications.

people in their own right.

Kyngas et al (1998)

Kyngas et al (1998) interviewed 51 adolescents aged between 13 and 17 years and explored how adolescents perceived the actions of parents and others in relation to compliance with diabetes self-care. This study supported the findings of Kyngas and Hentinen (1995) and suggested that adolescents who viewed parental behaviour as being disciplined and controlling were more likely to demonstrate poor compliance and poor self-care. Parents who helped to solve problems associated with self-care and who provided positive feedback and did not try to take too much control of the adolescents' lives were described as being motivating and supportive by the adolescent. This level of support appeared to result in good compliance and better diabetes self-care.

Schur et al (1999)

Schur et al (1999) interviewed eight adolescents aged between 16 and 22 years, as part of a UK phenomenological study. The aim of the study was to explore adolescents' experiences of living with and coping with diabetes. Some adolescents expressed fear of diabetes controlling their lives and reducing the level of control and success they would experience. For others who were beginning to learn to live with diabetes, parental involvement that provided support and guidance helped to normalise and depersonalise diabetes and these parents were described by the adolescent as being supportive. Some adolescents felt their parents' response to diabetes was an important influence on how they learnt to live with it.

Concluding remarks

Although there is no definitive definition of adolescence, the transition from childhood to adulthood can be seen to be a time of great change. Children are becoming increasingly independent at a younger age and the transition period to adulthood is thus starting earlier and becoming more extended.

This period of change involves a complex interplay of biologic, cognitive, psychosocial

and social change, and it is during this time that adolescent patterns of health behaviour are developing which continue throughout adult life. For the adolescent with diabetes who is dealing with these changes and also working towards an independent state of self-care, life is made more difficult because metabolic control of diabetes is confounded by the physiological and psychosocial changes of puberty.

In order to support adolescents to adopt positive health behaviours, parents need to have an understanding of the personal meaning their child attaches to living with and caring for his or her diabetes. The manner in which this 'support' is delivered by parents is likely to be both remembered and valued (either positively or negatively) by the adolescent (Kyngas and Hentinen, 1995; Kyngas et al, 1998). Far from wanting their parents to 'stand back' and let them just get on with it, some adolescents appeared to actually value parental support, provided that parents did not try to take too much control of their lives. To do this, parents may need assistance in learning how to let go and facilitate independence of actions for the adolescent.

Diabetes is a demanding chronic illness, which requires that the adolescent accepts increasing and extensive responsibility for carrying out treatment. Parents are in a position where they can support their child with these responsibilities as long as they do not see just the diabetes, but also recognise the adolescent's personal understanding of living with diabetes and the personal meaning he or she attaches to self-care. It is hoped in doing so that both the parents and the child see their relationship during the child's transition from childhood to adulthood as being a supportive one built on mutual trust.

Indeed, this type of relationship can promote self-care which will lead to better control of diabetes and fewer long-term complications. On the other hand, a relationship that is not built on support and mutual trust can have grave implications for the adolescent and parents, in both the short term and the long term. ■

Authors' recommendations for practice.

- Diabetes management must be tailored to an individual's developmental stage.
- Parents may need assistance in recognising the 'normal' developmental tasks of adolescence.
- Parents may need help in enabling their child to become independent.
- Parents need support in recognising the personal meaning their child has about diabetes.

'A relationship that is not built on support and mutual trust can have grave implications for the adolescent and parents, in both the short term and the long term.'

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