How do children and adolescents understand their diabetes?

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Abstract

While adults have the cognitive skills to understand and process information about a diagnosis of diabetes, children and young people (CYP) can only understand and process medical explanations if they fit with their level of development. The way information is processed throughout development moves from primitive, circular, concrete and egocentric reasoning to more abstract and logical views. The changes in adolescence and move towards independence can pose a challenge as children and families try to find a balance between the appearance of normality and adhering to a condition which can create a significant burden. Young people often wish diabetes away in their desire to be ‘normal’ and as a result sacrifice self-management behaviours to fit in with others. Young people acknowledge that mastery of the skills involved in diabetes self-management is an integral part of accepting the illness and incorporating it into a new identity. Finding ways that enable these self-management skills to ‘fit’ in personal and social settings can enable the young person to become comfortable with their life as a person with diabetes. There is also a dilemma for many as to the extent to which they choose to share this aspect of their lives with others. The goal for all of us is to help CYP realise that there is so much more to them than diabetes. A sound support system, including parents, family members, peers, health care providers, and school nurses can reduce burden, diminish stigma and create a more positive attitude towards diabetes efficacy. Copyright © 2019 John Wiley & Sons.

Practical Diabetes 2019; 36(4): 117–120

Key words

children; adolescents; diabetes burden; social support; identity

Introduction

An adult being given a diagnosis of diabetes after experiencing unexplained symptoms can find the news shocking while at the same time be reassuring. Once the diagnosis is explained adults have the cognitive skills (usually) to understand the complex contribution that genetics and the environment make in relation to the pancreas no longer producing insulin. They can be taught about how to self-manage and prevent low or high blood glucose levels and can review a range of possible treatments alongside the pros and cons of each. The adult brain is presumed to have the capacity to make choices in relation to treatment recommendations and can understand the consequences of different choices they might make both for the short term and longer term. The adult will have established their identity and potentially have some idea of who they are and where they are going.

The developing brain, however, confers a different set of cognitive skills and levels of understanding which means children and young people (CYP) can only understand and process medical explanations if they fit with their level of development. If it is too simple, it is dismissed. If it is too complicated, it is distorted or ignored or forgotten. How CYP understand the information alongside the emotional processing of this information has an impact on how they make sense of what caused them to get sick and ultimately will influence their attitude to how they make subsequent treatment choices and behaviours.

Understanding illness

The way children and adolescents think about the cause of illness follows a progression that matches the changes in cognitive development.1,2 The way information is processed moves from primitive, circular, concrete and egocentric reasoning to more abstract and logical views.

Children aged four or five see the cause of illness as either something magical (i.e. something that they wished to happen), and/or as the consequence of their breaking rules (being punished for doing something wrong). Children of this age can see a diagnosis of diabetes as a punishment...
for them having been naughty or something they did having made the diabetes ‘happen’. Some young children believe that being brought to hospital ‘caused’ them to get diabetes and blame their parents for bringing them to hospital. They may make concrete links between eating sweets and the diagnosis.

By the age of eight or nine, children can begin to understand that illness is caused by germs that make you sick. For children diagnosed at this age, there can be a focus on someone (or something) else being the source of the germs (like a parent or sibling with type 1 diabetes [T1D]). This way of thinking can also impact on the reaction of peers who may see their school friend as now having a condition that they could catch. This can lead to taunting and bullying unless careful developmentally appropriate information is provided to the young person’s peer group.

Around the onset of early adolescence at 11 years old, the capacity to understand the complex and interrelated mechanisms that ultimately cause illness develops. It should be possible for an 11-year-old to understand that their pancreas is not working or making insulin and that the reason to inject insulin is to provide a key that allows the transfer of glucose from the blood stream into cells to convert to energy. However, at this age the young person is still at a level of concrete thinking so will struggle to make sense of delayed effects – for example if insulin doesn’t immediately improve blood glucose levels then the insulin ‘doesn’t work’ so they don’t need to take it.

By secondary school (12 or 13 years of age) young people begin to understand that there can be multiple causes of illness and that the body may respond in different ways to any or a combination of different causes, and that can interact with social and environmental factors to both cause and cure illness.5

However, despite this ability to understand at a rational level what has caused diabetes as well as understand the consequences of poor control, the adjustment to self-care during adolescence is a particular challenge, as young people and their families can struggle with the impact of intensive regimens on daily life.4,5

The 2001 Diabetes National Service Framework states: ‘Diabetes is often more difficult to control during the teenage years and in early adult life due both to the hormonal changes of puberty and to the emotional roller-coaster that often characterises adolescence. Young people have higher rates of diabetic emergencies and death rates are significantly higher than in young people without diabetes. Greater effort is required to ensure effective diabetes control at this time than at any other stage of life both by health professionals and by young people themselves.’

Current theories of adolescent development and emerging neurodevelopmental findings are beginning to make sense of how young people’s thoughts impact on diabetes and self-care behaviour. Experimentation and oscillation in social behaviour also clearly influence patterns of self-care. The journey for young people towards adulthood involves balancing a perception of one’s self as a young vital being against the threatened challenges and consequences of a long-term health condition that is more in keeping with ‘old age’.

A key part of adolescent development is the desire to feel normal – to not be perceived as different from others or set apart from friends or siblings.2 T1D affects how CYP are seen by peers in a social context and therefore is often seen as a social illness by adolescents. As CYP develop increasingly independent behaviours, the need to balance this appearance of normality and adhering to the plan of care poses a challenge for children and families.7

Diabetes has the capacity to make young people feel different from their peers and create the perception of social stigma. These differences are significantly more difficult in social settings particularly when they fear negative reactions from friends.8 Both the treatment and the effects of not treating the diabetes can be very public. Perceived over-involvement of family and teachers, constant questioning, both at home and in public, impacts on the desire to feel and appear normal. Diabetes-related treatments like monitoring or treating blood glucose levels, wearing an alert bracelet, or participation in activities that may require increased monitoring and care can all be public events. Injection sites, finger pricks, and pumps may all be visible to an observer.9 Young people often wish diabetes away in their desire to be ‘normal’. As a consequence, CYP may sacrifice self-management behaviours to fit in with others. Initially not taking care of diabetes may make you believe that you don’t have it as well as superficially appear more like your peers. However, avoiding treatment may result in symptoms of hyper- or hypoglycaemia which create a perception of the adolescent as ‘sick’.

What do children think about diabetes?

The majority of young people and families describe life with diabetes as difficult, complex, and hard. T1D affects daily activities and threatens to impinge on academic achievement and personal aspirations. How an adolescent perceives the impact of this burden can influence their understanding of, attitude toward, and adherence to positive diabetes-related behaviours. Information and education are key elements in dealing with diabetes and various aspects of management. The degree of burden changes over time, increasing and decreasing like a rollercoaster depending on a number of factors. For many the burden can decrease as they gain mastery in dealing with the day-to-day demands. These daily responsibilities are seen as less disruptive to their sense of self when they are part of a routine. However, changing and often unexpected circumstances (like exams or relationship issues) can create a change in the direction and increase in burden.10

Young people can easily describe a significant number of costs of T1D related to thinking about and planning self-management behaviours including the planning of diet and potential dietary restrictions. The checking of blood glucose represents the greatest interruption in their lives for many, as well as administration of insulin. For many CYP, injecting insulin is a major barrier to self-management with estimates that nearly 10% children have needle phobia.11 This is not just when insulin is delivered by injection, as children using an insulin pump also describe the interruptions associated
with the pump as being a burden, albeit easier than injections per se.

However, being driven by the wish to be a ‘normal’ teenager and forgetting about self-management carries its own costs. The physical symptoms associated with high and low blood glucose and worry about health are a major aspect of diabetes-related burden. Hypoglycaemia is a major fear resulting in a focus on preventing hypoglycaemic episodes. Regardless of consequence, blood glucose levels are often deliberately kept above recommended levels, which serves to decrease the effectiveness of health care management. It is also problematic if they are treated differently because of the diagnosis – particularly connected to the potential for exclusion from social events like school trips, team games or sleepovers. Another stress associated with diabetes can be having to carry personal diabetes-related equipment constantly, not being able to eat the same as everyone else at parties, or being watched by peers during blood glucose checks, and being asked personal or ‘stupid’ questions.

Young people see diabetes as a family disease, one that the whole family has to work on. Young people believe that their diabetes often has a negative impact on their family and peers. Young people describe difficulty in controlling blood glucose and subsequent conflict when they need to depend on parents for support while trying to become more independent. There are many costs to family routines: the need for everyone to learn a new schedule, conflicts that can arise for parents between work and hospital appointments, and an increased parental vigilance contrasted with that focused on peers or siblings. There are also conflicts between parents who have different ideas about how to manage the impact of the diabetes where one parent has a more relaxed attitude than the other. There can also be financial costs when parents decide to give up employment to look after their child or young person.

Finding positives
It is possible for young people to be able to identify positive aspects of having T1D. This includes being able to control their lives and take better care of themselves. They identify ‘special things’ – like participating in a day camp expressly for children with diabetes, and extra attention – as something positive. They can also describe missing school sometimes, being allowed to eat in the classroom, skip the lunch queue or leave the playground early as positive.

Young people and parents also describe an improvement in family relations and describe getting closer to their family as a positive outcome. For some the diagnosis is a learning experience with families benefiting from a routine and becoming aware of needing to eat healthily.

Mastery of the skills involved in diabetes self-management was described as an integral part of accepting the illness and incorporating it into a new identity. This may be helped by the use of new technologies to manage the negative aspects associated with treatment, and personalised adaptations to methods for administering insulin and checking blood glucose.

It can take some time before young people start to acknowledge what feels like a paradox where taking care of diabetes has the potential to create less worry in their lives and experience the potential freedom associated with better control. Young people are often surprised to discover that ‘doing more about it means thinking about it less’.

Young people can also develop many constructive ways to deal with the stress that living with diabetes can create. These include playing and listening to music, being mindful, thinking positively and being active.

Some young people find it helpful to see diabetes and its associated treatment as an active and necessary part of their daily life. This can involve incorporating the diabetes into their sense of self – of who they see themselves as. For some, coping with the additional demands of diabetes creates improved resilience, problem-solving skills and maturity. All of these thoughts and behaviours have a function in other life areas, but clearly serve a purpose integrating life-long self-management and daily care into a sense of self. This can help them have less concern about what others think and experience a positive change in how they see themselves, being more confident and feeling stronger. There is a shift from describing themselves as ‘diabetic’ to a ‘person with diabetes’. The diabetes is no longer a defining factor in their identity, but an integrated component. This has an impact on motivation to live a healthy life with positive lifestyle changes and behaviours. Normalising diabetes in this way can have an effect on where T1D ‘fits’ in personal and social settings. It enables the young person to become comfortable with their life as a person with diabetes and the extent to which they choose to share this aspect of their lives with others. The goal for all of us is to help CYP realise that there is so much more to them than diabetes.

Social support
The link between social support and health is now well established within the literature, particularly its role as a moderator between stress and health. A sound support system, including parents, family members, peers, health care providers, and school nurses can reduce burden, diminish stigma and create a more positive attitude towards diabetes. How the individual perceives and interprets his or her social network is an important resilience factor in children with chronic physical disorders.

Parents
For younger children, parents tend to be the primary source of social support; however, for older children, siblings and friends are increasingly perceived as providing emotional and informational support.

CYP see parents, particularly mothers, as initially being anxious about diabetes resulting in their behaviour being monitored constantly. There is a perception, however, that mothers and fathers are eventually comfortable with the diabetes – although that may not be how parents actually feel. Fathers can be seen as being uninvolved with their child’s diabetes. CYP see fathers as hiding their feelings, not understanding or being squeamish rather than recognising they may have to become the only bread winner and are therefore out of the house or unable to attend appointments because of work commitments.
Siblings
Siblings can be a positive source of emotional support when the sibling is seen as being comfortable with diabetes and seen as being kinder and more understanding. However, siblings can also be seen in a negative way if they do not get involved in the new routines because they are too young to understand or demonstrate anxiety or annoyance about the diabetes, potentially because they get less attention than their brother/sister.12

Peers
A significant number of young people feel that having diabetes is accepted by their peers and report positive experiences in sharing their diagnosis with friends. They see friends as providing active support systems. Friends are seen as offering emotional support when they are perceived to feel and act no differently (i.e. were unchanged) following a diagnosis of diabetes. Young people can be happy that they have told friends about their diabetes, finding it helpful that they are involved in supporting their treatment. They see questions about the condition or its management as an opportunity to teach their peers about diabetes. Friends may encourage treatment by reminding them to check their blood glucose or take their insulin.12

In contrast, some young people are frustrated by a lack of knowledge when friends ask questions about the insulin pumps they wear or blood glucose tests they need to perform. A number of young people keep their diabetes a secret from their friends due to a belief that there is a lack of understanding, fear of non-acceptance, negative reactions to self-management or simply a desire to blend in with their peers.8,17 Friends are not seen as a support when they feel pity or treat the young person as different because of restrictions on diet or social life. People may have several misconceptions of diabetes (‘caused by eating too much sugar’, ‘it’s catching’) which cause stigma and rejection from peers.

The diabetes clinic
Most young people want clinics that help them keep ‘good control’ of their diabetes and have friendly, approachable and skilled staff who get to know them as people. They appreciate doctors and nurses who remember them from previous visits and who talk to them about their lives and not just their diabetes. They feel more confident if the relationship with staff is more than medical. CYP understand medical staff have to point out their problems but want them to be positive about what can be done to help. For those teenagers who find it harder to live with diabetes as they get older, it becomes more important to have access to a range of health professionals, including dietitians and psychologists.18

The future
As adolescents become future oriented and start to think about whom they want to be and what they want to be, this can be impacted upon by perceived limitations of living with diabetes. As they transition into ‘emerging adulthood’ abstract goals, such as responsibility and independence, can be hijacked by feelings of ambiguity and experimentation and may affect how they see themselves in the future. They can experience diabetes as potentially limiting their job choices; they can worry about how diabetes will affect them being in relationships and struggle with the potential long-term impact on fertility, pregnancy and children. Adolescence through into young adulthood is, therefore, “a unique and critical period of development when specific prevention and intervention strategies may still alter trajectories and decrease threats to health along the adult life course”.19,20

Conclusion
It is essential that health care professionals understand the developmental level of young people at the point at which diabetes enters their lives. This understanding is a prerequisite for developmentally appropriate health care and education. This allows us to enter into the young person’s experience in an empathic way, reassuring parents that behaviours are within normal limits and, where they are not, seeking appropriate support from other professionals such as psychologists. Understanding diabetes is never static – how it is understood and its meaning for the young person is never static – how it is understood and its meaning for the individual and their family and friends change over time. As George Bernard Shaw said: “The single biggest problem in communication is the illusion that it has taken place.”

Declaration of interests
There are no conflicts of interest declared.

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