Young people’s experiences of living with type 1 diabetes

Authors
Cheryl Scholes is a family nurse practitioner; Barbara Mandeleo is professor emerita; Susanne Roper is associate professor and associate dean; Karen Dearing is associate professor and graduate coordinator; and Donna Freeborn is assistant professor; all at Brigham Young University, Provo, Utah, United States.

Abstract

Young people with type 1 diabetes mellitus face a unique set of challenges: their own and their family’s perspectives of the disease and treatment impact on how well they manage metabolic control. Hormonal changes, desire for autonomy and emotional distress can influence self-management. Parental support and involvement is related to how well young people are able to manage metabolic control during adolescence. Positive parental involvement, open communication and encouraging independence are known to enhance adherence (Palmer et al, 2011). However, poorer metabolic control can occur if there are higher levels of diabetes-specific family conflict (Sander et al, 2010) or if mothers demonstrate higher levels of monitoring (Ingerski et al, 2010).

A young person’s attitude towards their condition can also affect glycaemic control in young people with type 1 diabetes (Karlsson et al, 2008). Those who accept it are more likely to have better glycaemic control than those who do not or who have a low self-concept or self-efficacy (Luyckx and Seiffge-Krenke, 2009). To help young adults who have the condition to confront the challenges they face, we need to understand their perspectives. This study explored the perceptions of young people with type 1 diabetes about their condition and determined whether these varied according to metabolic control levels.

Method
After receiving appropriate institutional review board approvals, we used purposive sampling to recruit 14 young people between the ages of 11 and 22 years who had been diagnosed with type 1 diabetes for at least two years. After obtaining consent from participants and their parents [where necessary], participants discussed their experiences of living with diabetes during an open-ended 60-90-minute audio-recorded interview. The interviews were

In this article...

- Why young people may often struggle to self-manage diabetes
- Differences in attitudes according to HbA1c levels
- Guidance for nurses working with this patient group

Type 1 diabetes can be difficult to control during adolescence, so health professionals should take into account individuals’ needs and involve their family when planning care.

5 key points

1. Young people can find diabetes management is affected by hormonal changes, desire for autonomy and emotional distress
2. Those who believe diabetes will be cured are less likely to effectively self-manage their condition
3. Assessing perceptions in relation to a cure can help to determine how well young people are likely to self-care
4. Interactions with others who are successfully managing their diabetes may help young people handle their self-care activities and metabolic control levels
5. Parental involvement increases the likelihood of a young person adhering to treatment and taking responsibility for their health
Adolescents may need help and support to self-manage their diabetes successfully transcribed verbatim and themes were identified. Full details of the method can be found in Scholes et al (2013).

Participants were split into two groups. An average of four consecutive HbA1c values was calculated for each participant; these were obtained during a chart review to ensure illness, holidays or growth spurts did not affect the results. If four HbA1c values were unavailable, two or three available values were averaged. Those participants with HbA1c values of >7.5 were placed in the low group and those with HbA1c values of <7.5 were placed in the high group.

**Results**

**Similarities**

Themes common to low and high HbA1c-level participants included their perceptions of family members, people outside the family, health professionals and their knowledge about diabetes.

**Family.** Participants believed their parents were often worried and stressed. For example, a 17-year-old female with a high HbA1c level said:

> I don't think it has affected them... Basically they are not involved.

Most participants reported siblings were not affected, as reflected in the statement of a female 17-year-old with a low HbA1c level:

> I have some grandparents who don't understand it... No matter how often I try to explain to them.

People outside the family. Participants said people outside the family were often fearful or apprehensive about the condition, as reflected by a 16-year-old female with a low HbA1c level:

> It's kind of annoying because everyone is constantly saying 'oh you can't have sugar'...

In addition, people outside the family often forgot or had limited knowledge about diabetes. In fact, a 16-year-old male with a high HbA1c level said:

> Most people act surprised when they find out I have diabetes.

However, friends often showed concern or made them feel good.

**Health professionals.** Participants felt that many health professionals spoke to them in an authoritative manner and were not supportive. For example, a 20-year-old male with a high HbA1c level said:

> I guess when they try to tell me... that I need to do something different, 'Since I'm the doctor you need to do what I say', [it] just kind of pisses me off...

One 22-year-old low HbA1c female said:

> I never felt close to any of them to where I could open up...

Knowledge about diabetes. Participants recognised their future would be affected if their diabetes was uncontrolled and felt they were responsible for their health. One 18-year-old female who had a high HbA1c level noted:

> And then there are always outcomes... I could go blind and stuff, but if I keep it under control I'll be OK...

Both groups also knew their condition could affect their future careers.

**Differences**

Differences between the two groups of participants related to their perceptions of the illness, parent involvement, self-care, and experiences attending diabetes camp.

**Perceptions.** Most participants with a high HbA1c level believed there would be a cure for type 1 diabetes, whereas most with low HbA1cs did not. A 16-year-old in the groups of participants with a low HbA1c added:

> It will take them a long time... I can't just wait for it. I just, kind of, move on.

Those with high HbA1c levels also perceived their initial diagnosis as difficult; an 18-year-old female said:

> I remember being upset... I didn't really know how bad it would be.

On the other hand, those with low HbA1c levels perceived things differently. One 15-year-old female said:

> I was three years old when I was diagnosed with diabetes... I have just grown up with it.

Parent involvement. Both groups reported they were primarily responsible for their own care, but individuals with high HbA1cs said they cared for themselves independently and did not have much parental supervision. In addition, some had no home meal structure. One 18-year-old female said:

> Well, we don't really have family dinners... I just get my own food.

When asked what she ate, she said:

> Whatever sounds good.

In contrast, participants with lower HbA1c levels reported their parents followed up on glucose testing or food they had eaten.

**Self-care attitudes.** Differences in attitudes towards self-care were noted between the two groups. Participants with low HbA1cs assumed responsibility for self-management and accepted their diagnosis, as reflected by one 22-year-old female, who was 16 when diagnosed:

> Back when I left the hospital my family forgot about most of what we learnt there. It was left to me to figure out myself. So I have learnt how to take care of myself.

However, several participants with high HbA1c levels avoided caring for their disease; one 19-year-old female said:

> I didn't do anything on my own until 13ish or 14ish... then I kind of wanted to do it by myself.

In addition, many participants with higher HbA1cs did not count carbohydrates, and several reported guessing the carbohydrate content of foods eaten and determining insulin based on how they felt.

**Discussion**

**Similarities**

Participants reported their parents were stressed or worried about the condition but that it had little effect on their siblings. However, other studies have found siblings to be involved in dietary management or insulin injections, despite having...
limited knowledge about type 1 diabetes (Adams et al., 1991).

Our study confirmed past findings that extended family and people outside of the family did not remember receiving information and had limited knowledge of the disease (Wennick et al., 2009).

Participants felt relationships with health professionals were important. However, they did not like authoritarian approaches, being threatened about future consequences if their condition was not managed appropriately, or health professionals who were unsupportive. Participants from both groups recognised that their condition would adversely affect their future if they did not properly manage it and knew this was their responsibility.

**Differences**

Participants with a high HbA1c level initially perceived the diagnosis of diabetes as traumatic. There was some suggestion they may not have received support from health professionals or parents and may avoid self-care management strategies; these findings suggest they had some difficulty accepting the condition. These young adults also believed there would be a cure for diabetes in the future—a belief that may make them feel self-care is not important. Conversely, participants with low HbA1c levels were not sure there would be a cure and were diligent in self-care activities.

Almost all parents of participants with a low HbA1c were actively involved in managing their child's condition; they monitored blood-glucose levels and considered carbohydrates when planning meals. Wiebe et al. (2005) found those with low HbA1cs experienced more family support and involvement in diabetes care than those with high HbA1cs. When parents and young people with diabetes have positive and supportive relationships, diets are watched more carefully, blood-sugar levels tested more frequently and HbA1c levels are lower (Fiese and Everhart, 2006).

However, participants with high HbA1c levels seemed to have less parental support, carbohydrate counts were not considered when preparing meals and they did not have regular family meal times. Lewin et al. (2006) discovered metabolic control was worse for young people with diabetes when no family member took responsibility for managing the condition.

Differences were also noted in participants’ experiences when interacting with others who had diabetes. Participants with high HbA1c levels said they could interact with others who understood what it was like and improve their knowledge of self-care activities by attending a camp for children with the condition.

**Study limitations**

Several study limitations are noted. Participants were from similar backgrounds and lived in the same geographical area. Most of them (n = 10) were female. Because participants did not know the interviewer well, there is also a chance that responses may reflect their desire to please the interviewer rather than honestly talk about their experiences of living with diabetes. Interviewing parents and guardians of the participants may have provided useful data.

**Implications**

Psychological interventions should form part of the approach to support young people with type 1 diabetes. These should focus on the skills needed to handle the challenges of living with the condition.

Attending diabetes camps can be helpful, especially for those struggling with self-management issues. Similarly, support groups and websites for young people with diabetes to share experiences and challenges may also be useful. Education needs to be age and developmentally appropriate and include information about the physiology of type 1 diabetes as well as appropriate self-management activities. Education should also involve the main caregivers and emphasise their important role in supporting without micromanaging self-care activities.

Siblings may also benefit from being given information, while support to improve communication and relationships among family members should be offered where possible. Relatives also need to understand how developmental trajectories of young people affect self-management and the decisions they make.

Finally, health professionals play a critical role in helping young people to take responsibility for self-management and motivating them to maintain glycaemic control. A non-threatening, non-authoritarian approach is critical; professionals should observe non-verbal messages and answer questions. It is also important to assess how the individual is coping with self-management activities and involve parents/guardians in routine visits as well as in those that occur when complications or self-management problems develop.

It is essential to provide interventions to help young people with higher HbA1c levels improve their self-care. Future research should look at how to improve young people’s knowledge about diabetes and its management, and young people—as well as parents and guardians—from different socioeconomic groups/ethnicities should be involved in further studies.

**Conclusion**

While we provide some new information, some of our results are similar to those of other studies. Specifically, we discovered participants with high HbA1c levels were more likely to believe a cure for type 1 diabetes was possible compared with those with low HbA1cs. This suggests assessing beliefs related to a cure is a good indicator of how a person will manage their self-care. Parents should be encouraged to actively help their child manage their diabetes. Healthcare providers need to give them information on self-management activities using an open, nurturing approach.”


**References**


