

# To integrate and manage diabetes in school: Youth's experiences of living with Type 1 diabetes in relation to school – a qualitative study

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In Sweden, each year approximately 700 children develop Type 1 diabetes. Living with the illness is a challenge for youth and requires adjustments to lifestyle, and to manage school. The aim was to describe youths' experiences of living with Type 1 diabetes in relation to school. A qualitative research design was used and interviews were performed with eight girls and five boys with Type 1 diabetes. The interviews were subjected to qualitative content analysis. Three themes were identified: to be friends with the diabetes, striving for normality and receiving support from others. Results showed a need to increase the understanding of T1D and diabetic competence within the Swedish school system and knowledge of youths' own experiences is vital in this work. Living with T1D was a struggle for normality, independency and the youth needed to be friends with diabetes to handle everyday self-management. Although there are demanding life and school circumstances, it eventually becomes possible for the youth to handle the illness and to integrate and manage diabetes in school.

**Keywords:** Type 1 diabetes, Experiences, Qualitative content analysis, School, Self-management, Youth

## Background

Type 1 diabetes (T1D) is a common childhood diseases worldwide and influences daily lives of youth affected to a great extent.<sup>1</sup> Youth is a time of life characterized by wide changes, i.e. physically, mentally, socially, striving for independence and developing an adult identity. Having a chronic illness such as T1D influences this process.<sup>2</sup> Young people spend almost half of their waking hours in school, and for youth with T1D, school is an important arena for self-management.<sup>3</sup> However, the schools cannot always meet the youths' needs, and schools have different procedures for self-management. Youth with T1D missed school more frequently than healthy children and schoolwork and concentration was disrupted when they had to manage their diabetes and, as a consequence, their learning may be impaired.<sup>4–6</sup> The legislation regarding self-management in schools differ nationally.<sup>4</sup> In Sweden, it states that during school time the responsibility for self-management is transferred from the parent to the municipality(schools).<sup>7</sup> By regarding the youth's experiences as valid, helpful insights could be gained for school- and healthcare personnel, parents and youth with T1D, and other chronic illnesses. To the best of our knowledge, there is a lack of studies describing youths' experiences of living with T1D in relation to school in a Swedish context. Thus, the aim of this study was to describe youths' experiences of living with T1D in relation to school.

## Methods

### Design

This study has a qualitative design, as the aim was to describe youths' experiences of living with T1D focusing on the school situation. Data were obtained from individual interviews (cf.<sup>8</sup>).

### Participants and procedure

A purposive sample of eight girls and five boys with T1D participated in the study. Characteristic variation was attempted by selecting youth from four municipalities, variation in terms of age, gender, family structure, living conditions, prior diabetic experience, length of diabetic onset, insulin pump or pen, diagnosis of gluten, and ethnicity. The criteria for participation were age 13 and experience of T1D for at least 2 years. The participants' ages ranged from 13 to 20 years (md = 16 years) with a length of onset ranging from 2–14 years (md = 7 years). Three participants had prior diabetic experience from parents or grandparents' T1D and T2D. Nine were born in Sweden and four in Europe; 10 lived in families, two in separated families, and one youth lived alone. Two participants preferred insulin pen, while the rest used insulin pumps. Three participants had diagnosis of gluten intolerance.

The school nurse were informed about the study at several meetings and through dialogue with the school nurses and the head of school health services, informative

**Table 1** Overview of the data analysis – examples of condensed textual units, categories and themes.

Meaning units	Condensed meaning unit	Categories	Themes
'I go shopping and I'm always open that I've a pump attached to my belly. Gloat all you want; I don't care! To have diabetes is nothing to be ashamed of!'	Youth go out public with viewable insulin pump. Refuses to feel ashamed	To be open about the diabetes	To be friends with the diabetes
'I like the responsibility and the feeling that I'm in control of myself and my body. I'm the master'	Youth like to be in charge and in control	To be the master in control	
'I could have killed my mother when she tried to force me to sleep in the teachers' tent when we were at camp! I refused to go unless I could sleep with my friends. Dad agreed with me and I slept with my friends'	Youth frustrated with overprotecting care from parents and school staff. Wants to be treated like everyone else	To be treated like everyone else	Striving for normality
'It was as if I was transformed when I came back to school. I just wanted to scream, 'I'm just like before; I'm just ill.' I'm the same person!'	Youth frustrated with feeling of transformation when returning to school	To be different and still the same	
'I've always had good friends who helped me in school, and told me things that I missed. My friends know me so well and how I behave, and then they say, 'Let's go eat something. Maybe you need to eat something now.'	Youth experience good friends as valuable and gets support from friends	Support from family and friends	Almost adult but still needing help
'When I got back from the hospital, my teacher showed me a drawer in her desk and said, I always keep dextrose here for you. It was a small thing to do but it made me feel safe.'	Youth experiences good support from school staff in small actions	Support from significant others	

letters was sent to each school nurse accordingly to the number of youth with T1D at the actual school. A total of 100 letters was sent to the school nurses including extra letters due to separated families with two home addresses. The school nurses sent letters to parents of youth who met the inclusion criteria. The letters contained information about the study, a request to participate with a response envelope, and information about consent to the study. After receiving response letters the first author contacted the youth and arranged individual interviews at a preferred location of the participant (research room at the university, community centre or library).

### Data collection

Personal interviews with a narrative approach were conducted between January and September 2016 by the first author. The interview guide consisted of four open questions: *Please, tell me about the onset, when you got diabetes? What was it like when you returned to school? How do you experience the school situation and the management of diabetes in school? How do you experience your self-management today?* Follow-up questions were asked, such as: 'Can you give an example?' 'What were you thinking then?' The interview guide and the interview technique had been tested in two pilot interviews which were not included in the study. There were no earlier relationships with any of the authors and the participants. All interviews were digitally recorded, transcribed verbatim and lasted between 37 and 73 minutes (md = 52 minutes).

### Data analysis

The interviews were analysed using qualitative manifest content analysis. The analysis was carried out using the following steps: First the interviews were read through several times to get a sense of the content, second the text was divided into meaning units (i.e. one or more

sentences related by their content), condensed and abstracted third, the abstracted meaning units were compared and sorted into themes and subthemes based on similarities and differences. The second author performed a second analysis of one of the interviews in order to validate the findings. Finally, all authors discussed the analysis and agreed on the findings (cf.<sup>9,10</sup>) (Table 1).

### Ethical considerations

Written consent was obtained from participating adolescents and their parents if the adolescents were not 18 years old. The participants were informed that participation was voluntary and they could withdraw anytime without explanation. Confidentiality and an anonymous presentation of the findings were assured. The study was approved by the Regional Ethical Review Board (Dnr 2015/416-31Ö).

### Results

The analysis revealed three themes with six subthemes (Table 2).

#### To be friends with the diabetes

*To be open about the diabetes* Youth described that to be open about diabetes involved feeling comfortable taking insulin injections, checking the BG in front of others and that everyone at school knew about T1D. They did not want to feel ashamed of their illness. If an acute situation occurred, the friends knew how to act and this made the youth feel safe. Youth mentioned that young celebrities with T1D increased the youth's motivation to be open about the diabetes. 'I go shopping and I'm always open that I've a pump attached to my belly. Gloat all you want; I don't care! To have diabetes is nothing to be ashamed of!' (girl 15 years).

**Table 2** Themes ( $n = 3$ ) and categories ( $n = 6$ ) constructed from the analysis of the interviews with youth with D1T.

Theme: To be friends with the diabetes	Theme: Striving for normality	Theme: Almost adult but still needing help
Category: To be open about the diabetes	Category: To be treated like everyone else	Category: Support from family and friends
Category: To be the master in control	Category: To be different and still the same	Category: Support from significant others

*To be the master in control* The youth described that they knew what worked and what did not related to diabetes. They knew all about healthy habits and diabetes routines. The youth expressed taking full responsibility, and reported relief of being in control of their body and life, 'I like the responsibility and the feeling that I'm in control of myself and my body. I'm the master.' (girl 16 years).

The youth described that good control enabled them to do almost everything they wanted. At the onset, the illness controlled their whole life. It was common that parents had been very engaged at the onset, but this changed when they became more accustomed to the condition. Youth reported feeling more mature than their healthy friends because of self-management of the illness. 'I'm more mature than some of my friends, but I had no choice. I just had to deal with it and take control' (boy 15 years). To be the master in control was not a quick fix, it was a constant challenge. They reported handling pressure daily, being prepared for managing BG getting low or high, and keeping up with schoolwork in order to get good grades. To do well in school could be hard especially when the BG was unstable. Youth described a strategy to have a 'little higher BG than recommended' in order to feel safe. Several youth reported a fear of dying in their sleep. The fear of low BG without waking up made them strive for higher BG than recommended at bedtime. 'The first three years with diabetes, I was afraid to fall asleep every night. I thought I would be low, die and never wake up' (girl 15 years).

Youth described problems with poor sleep due to fluctuating BG, and this influenced the performance in school. Sometimes they were too tired, and it was hard to keep up with the schoolwork. In order to master the illness, youth expressed a need for new modern self-management tools, which were incredibly valuable especially in the school.

#### Striving for normality

*To be treated like everyone else* The youth wanted to be treated like before. They got upset when mistreated and not included in decisions regarding them. 'I could have killed my mother when she tried to force me to sleep in the teachers' tent when we were at camp! I refused to

go unless I could sleep with my friends. Dad agreed with me and I slept with my friends' (boy 14 years). The youth strived hard to fit in, and sometimes during lessons in school when the BG was getting low, they described how they ate something sweet and choose not to tell the teacher. They experienced it as easier not to draw attention to themselves 'I usually take dextrose and just sit through the lesson ... I don't usually tell the teacher that I'm now low (boy 15 years).' The most embarrassing thing was incidents of hypoglycaemia and to lose control in front of the whole school, and to avoid this, they allowed their BG to be little higher than recommended.

*To be different and still the same* Youth described a huge transition when returning to school after the onset of diabetes. They felt that teachers, friends and parents regarded them differently from before, 'It was as if I was transformed when I came back to school. I just wanted to scream, "I'm just like before; I'm just ill." I'm the same person!' (girl 18 years). The youth accepted that diabetes required adjustments in life, but except for necessary adjustments, they wanted everything to be as normal as possible. 'All my friends know about my diabetes. I'm the same person as before I got sick. My friends accept me for who I'm.' (boy 13 years).

#### Almost adult but still needing help

*Support from family and friends* Youth described parents to be their greatest support. When growing older, they gradually took over the responsibility for their illness, but the parents were still there. All youth had parents who had visited the school and educated the personnel about diabetes. Siblings played an important role. Friends were of great importance because they shared the experiences of everyday life in school, 'I've always had good friends who helped me in school, and told me things that I missed. My friends know me so well and how I behave, and then they say, 'Let's go eat something. Maybe you need to eat something now.' (girl 17 years).

*Support from significant others* Youth experienced support from teachers who knew what to do in an acute situation. School staff reminded the youth to check their BG, take insulin, and noticed when they were absent from school. They reported that there was a big difference if a teacher was interested in their well-being or just controlling school absences. They did not believe that most of their teachers had adequate diabetes skill and had 'favorite teachers' if they needed help in school, 'When I got back from the hospital, my teacher showed me a drawer in her desk and said, I always keep dextrose here for you. It was a small thing to do but it made me feel safe.' (girl 13 years).

The youth described different school approaches, a positive approach which automatically enabled self-management through schedules, serving healthy school lunches and providing dextrose. Contrary, there were schools with a more negative approach, unwilling to

understand youths' need for individual adjustments due to T1D. All youth reported a strong anxiety not knowing if school personnel knew how to handle an acute situation. The school nurse was experienced as supportive and youth liked to talk to the nurse. The nurse could help to find solutions for self-management and contacted parents, teachers, and the diabetic team if needed. 'It's not a big issue, but it helps me to have lunch scheduled at the same time every day because I sometimes forget my insulin. This way I can set a reminder on the pump at lunch' (girl 15 years).

The diabetic team was experienced as a competent support. After going back to school, the contact with the diabetic team was during check-ups. At the check-ups there was focus on the HbA1c (blood test) and some missed that the team did not take the youths' concerns seriously with self-management in school. They wanted to talk about their well-being, 'I would like the diabetes team to ask how I'm doing in school and how I feel about life, how I'm managing diabetes, not only caring about HbA1c. I always have good HbA1c values but my BG swings every day. I would like to talk about this; not just hear that I'm doing well' (girl 17 years).

Youth reported getting advice regarding healthy food choices, and applications for smartphones from dieticians. Smartphone applications were found useful, but most of them thought they were complicated. Instead, they learned to listen to their bodies and knew what foods to eat. The lunch situation at school was experienced as stressful and eating good diabetic foods was not always easy. A quiet place to check their BG or administer insulin was hard to find, so they chose to skip lunch or to eat unhealthy food with friends. However, several participants reported getting support from the school nurse, the diabetes nurse, and the dietician who visit schools, and support the schools in finding a solution problems regarding lunch.

## Discussion

The youth's knowledge was important, and influenced how T1D was integrated and managed in school. Learning about the demands of T1D, knowledge of how the body reacts in different situations, and self-managing in school were part of a process to gain knowledge. Earlier research<sup>11,12</sup> has showed in order to live a normal life youth needed to have knowledge of their body, and good control of T1D. Good control enabled youth to be master in control and do almost everything they wanted. It increased their self-esteem to be in charge, and helped them to accept the impact of T1D in life and school as a 'normal mode'. This is in line with studies<sup>13–16</sup> showing that it was important for youth to accept the illness as a natural part of life. By doing so, the youth created their own unique T1D-competence.

The youth described managing fear of dying in a hypoglycaemic episode by regulating BG a little higher than

recommended, especially in school. This gave control of the situation and a way of controlling BG corresponds with earlier research<sup>16</sup> where youth made a conscious decision to 'run high' as a way of controlling fears for hypoglycaemia. The youth reported problems with poor sleep due to fluctuating BG, and this affected their school performance. The youth reported feeling stressed about keeping up in order to get good grades. A negative effect on schooling and grades has been showed in research,<sup>17</sup> and supports the experiences from the youth.

The youth strived for normality, but at the same time, they experienced being different. This was a contradictory experience and is in line with studies<sup>13,18</sup> where youth experienced being treated differently because of the diagnosis. Striving for normality sometimes made youth ignore the symptoms of T1D and the diabetes routine even though they knew it was good for their health. Furthermore, youth reported incidents of hypoglycaemia in school as the most embarrassing thing that could happen, and to avoid this, the youth aimed for a higher BG during the school day. This is in line with research<sup>13</sup> where adolescents understood that the diabetes treatment would make them feel better, but they choose not to follow the treatment because they did not want to be different. There is also research<sup>16</sup> showing that being different from peers caused social conflicts and was related to fears of social embarrassment. To strive for normality even with a chronic illness was important for the youth. Keeping in mind that adolescence itself is a crucial time in life, where most youth want to be just like everybody else, it is important to remember that youth with T1D are first and foremost youths (cf.<sup>15</sup>).

Support from parents and siblings represented a basic security. This is in line research<sup>19</sup> where youth described family support as essential for their well-being, and communication from families were associated with higher levels of self-participation, lower impact of diabetes and fewer school absences.<sup>20</sup>

To be a youth and dependent on support from others was experienced as frustrating, but they strived for independence. Karlsson et al.,<sup>21</sup> found teenagers transition towards autonomy in self-management as a process where teenagers needed to distance from others but still to retain the support. In the school situation, support makes a difference in the youths' feelings of self-management. Research<sup>19</sup> has shown friends' acceptance facilitates T1D self-management, and was important for the safety of the youth. Research<sup>22</sup> indicates that youth who received help were found to have a significantly higher quality of life in school.

Support from teachers was important. However, some of the youth expressed concerns regarding teacher's diabetic competence. This concerns regarding lack of diabetic competence in school was also reported earlier (cf.<sup>23,24</sup>). School lunch with healthy friends was sometimes challenging. Youth had to stick to the meal plan and this was difficult in school. Research regarding adolescents transitioning to successful diabetes self-

management indicated that managing diet independently was a great challenge, especially when the youth were eating with healthy friends.<sup>15</sup>

The school nurse was experienced as supportive. This agrees with Kyngas and Rissanen<sup>24</sup> who found support from nurses as a crucial predictor for good compliance of adolescents with a chronic disease. The youth described support from the diabetic team during check-ups (cf.<sup>20</sup>), and when the diabetic nurse visited the school and supported the organization of self-management. It was important for the youth to discuss self-management in the school with the diabetic team. Other studies<sup>25</sup> found need for child-centred contexts with possibility for youth to freely ask questions and problem-solve. The youth reports of schools child-centred contexts differed, there were positive reports of schools fully accepted and facilitated self-management. However, there were also reports of schools with a negative approach. This identifies a need to increase the understanding of T1D and diabetic competence within the Swedish school system.

### Methodological considerations

Different steps were taken throughout the study to enrich trustworthiness in line with Lincoln and Guba (1985), i.e. credibility, dependability, confirmability and transferability.<sup>26</sup>

Clear inclusion criteria were used and the participants were diverse, which increases to shed light on the research question based on a variety of aspects (cf.<sup>9</sup>). This was an expression for supporting credibility of the study. One limitation is the number of participants; the results might have been different with more participants. On the other hand, qualitative inquiry focuses in depth on a relatively small sample selected purposefully. Dependability was supported in the way that two of the authors performed the analysis of data and at the end of the analysis process; the second author performed a second analysis of one of the interviews in order to validate the findings. Finally, all authors met and discussed the results of the analysis and agreed the findings. Giving a clear description of each step of the research process and presenting quotes from the interviews enable the reader to judge the confirmability of the findings. Transferability includes the extent to which the study is transferable to other groups. Results from this study cannot be generalized, but can be cautiously transferred to others in similar situations.

### Conclusion

A need to increase the understanding of T1D and diabetic competence within the Swedish school system was identified and knowledge of youths' own experiences is needed to improve diabetes care in schools. Living with T1D was a struggle for normality, independency and the youth needed to be friends with diabetes to handle everyday self-management. Although there are demanding life and school circumstances, it eventually becomes

possible for the youth to handle the illness and to integrate and manage diabetes in school.

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### Conflict of interest

The authors declare no conflicts of interest.

### Notes on contributors

Study design and data collection were done by MRH and MH, analysis led by MRH with support from MH, IC, LJ, AA, SS. Manuscript preparation was done by MRH, MH, IC, LJ, AA, SS. All authors have contributed to development and revision of article.

Malin Rising Holmström contributed for children and adolescents's health and illness.

Marie Häggström contributed for organizational models and intensive care.

Åsa Auduly contributed for self-management and chronic illness.

Lena Junehag contributed for child health life with chronic illness.

Imelda Coyne contributed for child-centred care, family centred care, transition to adult healthcare services.

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