



## Being Facilitators in a Challenging Context—School Personnel's Experiences of Caring for Youth with Diabetes Type 1



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### ABSTRACT

**Purpose:** The purpose of the study was to describe school personnel's experiences of caring for youth with diabetes type 1.

**Design and Methods:** A qualitative design was chosen for this study. Data were collected with individual interviews that were subjected to inductive qualitative content analysis. The sample consisted of 24 school personnel (teachers, principals and school nurses) from Swedish schools. All had experience with youth aged 6 to 18 years old with diabetes type 1.

**Results:** School personnel experienced caring for youth with diabetes type 1 as “*Being facilitators in a challenging context*” and described establishing trusting relationships, finding strategies to support self-care, feeling uncertain and incapable in need of education, and dealing with unclear responsibility.

**Conclusions:** School personnel (teachers, principals and school nurses) are key professionals supporting youth with diabetes type 1 and self-care in school. Lack of education and unclear responsibility created feelings of uncertainty and insecurity for school personnel and a need for mandatory education of school personnel regarding T1DM and self-care, including legislation was identified.

**Implications:** Mandatory education should be provided for all school personnel regarding diabetes type 1, self-care and current legislation. A liaison position in form of a nurse specialist should manage the education.

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### Introduction

School personnel face growing demands within schools. They are expected to provide support and care for youth with a wide variety of chronic illness, including diabetes type 1 (T1DM), in addition to their teaching responsibilities. The incidence of T1DM is increasing (Diamond Project Group, 2006; Patterson et al., 2009). In Sweden, each year approximately 700 youth develop T1DM (SWEDIABKIDS, 2015), therefore, there are more youth in schools with complex health needs, as well as needs for individual adjustments and support with self-care. Youth spend a great deal of their upbringing in school settings, and this means that self-care is to a large extent performed in schools. The standard of care and self-care in schools implies a good metabolic control (i.e. to monitor blood glucose, knowledge of the goals for blood glucose, self-care regarding administering insulin by insulin pumps or multiple daily insulin injections and continual glucose monitors and how to handle an emergency with hyperglycemia or

hypoglycemia) (American Association of Diabetes Educators, 2018). This is crucial for youth's optimal self-care, immediate health and wellbeing, for learning, for academic performance and for future health (Marks et al., 2013). Living with T1DM is a challenge for youth and often requires individual adjustments to manage school (Hill et al., 2007).

#### Swedish School Setting and Self-care

The school system in Sweden consists of nine grades of compulsory school for children between 7 and 16 years of age. Before compulsory school, families are offered a voluntary preschool year for their child from the age of 6. After the ninth grade, families are offered 3–4 years of voluntary high school. Free lunch and an afternoon snack are provided daily in Swedish schools. School nurses are a part of student health and are located at the schools, but according to the legislation, school nurses are not responsible on an individual level for the actual care or self-care of children with chronic illnesses. They shall primarily work with prevention and health promotion and support collaboration and planning regarding self-care and chronic illnesses (Swedish National Agency for Education, 2017). School legislation varies worldwide regarding diabetes care and self-care, and Sweden has one of the

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most far-reaching and most rigorous pieces of legislation to support pupils with chronic diseases at school (Education Act, SFS, 2010:800). The self-care concept was defined in the Healthcare Act (SFS, 2017:30) as care that a legitimate healthcare professional assessed that a patient can perform. In regard to youth, it is more complex. A youth with T1DM often needs support with self-care at home from parents and, while in school, needs support from school personnel. Furthermore, the Swedish legislation requires schools to provide support with self-care for children in school. However, it is a healthcare professional, often the child's diabetes physician, who is responsible for assessing the individual youth's need for support with self-care in school. Youth's need for support in the daily self-care and treatment of T1DM often varies related to individual maturity and developmental level as well as differences in capacities between younger schoolchildren and adolescent students. The physician reaches an agreement with the youth and parents regarding the youth's need for support with self-care in school and collaborates with the principal (representing the school administration) to provide a safe school environment. An individual care plan for self-care is established, and self-care should be carried out accordingly by the youth with support from school and family (National Board of Health and Welfare, SOSFS, 2009:6).

A narrative review of the literature by Hinton and Kirk (2015), regarding teachers' perspectives of supporting pupils with long-term health conditions in mainstream schools, suggested that teachers receive little formal training relevant to long-term condition management and that they are fearful of the risks involved in teaching youth with long-term conditions. Communication between families, school and healthcare services appears to be poor. Educational programs developed in conjunction with and/or delivered by healthcare professionals appear to have the potential to increase teachers' knowledge and confidence (Hinton and Kirk, 2015).

The school personnel spend their working hours in the school environment together with the youth. Therefore, they are vital professionals taking part in the daily life of youth with chronic illness. If the care of youth with T1DM is to be improved in school, the experiences of school personnel need to be addressed.

#### Aim

Thus, the aim of this study was to describe school personnel's experiences of caring for youth with T1DM.

#### Method

To describe school personnel's experiences of caring for youth with T1DM in school, a qualitative descriptive approach was chosen for this study. Data were collected with individual interviews (Bates, 2004) and subjected to inductive qualitative content analysis, which means that the analysis remained close to the text and was conducted without preconditions (Graneheim and Lundman, 2004).

#### Participants and Procedure

A purposive sample of 24 school personnel with experience of caring for youth 6–18 years of age with T1DM participated in the study. All participants worked in public schools, in different levels (preschool classes, compulsory school grades 1–9 and high school). The schools were situated in four municipalities in the north of Sweden. The school personnel's prior experience with youth with T1DM ranged from one to twenty years ( $m = 10.5$ ). Characteristic variation was attempted by selecting school personnel who varied in terms of experience, from different levels in the school system, (preschool  $n = 6$ , grade 1–9  $n = 10$ , high school  $n = 8$ ); professions (teacher  $n = 11$ , physical education (PE) teacher  $n = 2$ , principals  $n = 5$ , school nurse  $n = 6$ ); gender (female  $n = 20$ , male  $n = 4$ ); and prior diabetic education ( $n = 4$ ). The head school nurse in each municipality administered letters to school

personnel. The letters contained information regarding the study, a request to participate with a response envelope. Upon receiving response letters, the first author contacted school personnel to arrange a time for interview.

#### Ethical Considerations

The study was conducted in full accordance with ethical principles according to World Medical Association Declaration of Helsinki (2008) and undertaken with the understanding and written consent of each subject and accordingly. This study is a part of a larger study, aimed to obtain more knowledge about youth with T1DM, reviewed and approved by the northern ethical committee. In this specific study, the participants were school personnel, hence, no vulnerable youth or relatives, were included in the interviews. Prior to the interview, written and verbal information regarding the study were given and informed consent was obtained from all participants. The participants were guaranteed confidentiality and confidential presentation of the results.

#### Data Collection

Qualitative individual interviews were conducted and were of a narrative nature with school personnel in a 'natural' environment (e.g., in the school medical room, personnel room, class room or head teacher's office). The interviews were conducted from January to June 2017 by two of the authors in four municipalities in the middle of Sweden. The interviews were conducted in Swedish and analyzed in English.

Participants were encouraged to speak freely without interruption about their experiences, and an interview guide was used to provide consistency and dependability during interviews (Kvale, 1996). The interview guide was structured by using four open questions: *Please, tell us how you experience the school environment for school youth with T1DM. Please, tell us how the school youth's self-care is organized in your school. Please, describe your cooperation with parents, diabetes team, colleagues and other school personnel. Have you encountered any difficulties or possibilities in your work with school youth with T1DM?* A first pilot interview was conducted and judged to be rich in information. Therefore, the interview was included in the study. The interviews were audio recorded, transcribed verbatim by the first author and lasted between 20 and 65 min ( $md = 46$ ).

#### Analysis

The interview texts were analyzed using inductive qualitative content analysis described by Graneheim and Lundman (2004). The unit of analysis focused on the experiences of school personnel encounters with youth with T1DM within schools. The analysis occurred in five steps: (1) the interviews were read through several times by the authors to get a sense of the content; (2) the text was divided into meaning units (i.e., a word, sentences or a paragraph with the same content) and condensed; (3) condensed meaning units were abstracted; (4) abstracted meaning units were then reviewed in relation to the aim of the study; and finally (5) meaning units were compared and sorted into a theme and subthemes based on similarities and differences (Table 1). These five steps were taken to enhance trustworthiness. Clearly describing each step of the research process and presenting verbatim quotes contributes to the trustworthiness of the findings and enables the reader to individual assessment of the validity (Sandelowski, 1994).

The researchers' backgrounds and preconceptions varied, which was useful during the analysis. The first author was a pediatric nurse specialist and a senior lecture, the second author was a critical care nurse and a senior lecturer and the third author was a registered nurse and professor with extensive previous experience in the qualitative research field. Furthermore, the researchers have worked closely during the whole analysis to achieve credibility. Throughout the analysis, there were on-going discussions between the authors to critically reflect on

**Table 1**  
Overview of the data analysis – examples of condensed meaning units, subthemes and theme.

Meaning units	Condensed meaning unit	Subthemes	Themes
“It was a change of roles he taught me... but it was a good talk where I really got to know him and I think he realized that I honestly wanted the best for him and that I was not trying to interfere in his private life. We have had a better relation after that talk”	Teacher and youth changed roles showed concern and will to understand	Establishing trusting relationships	Being facilitators in a challenging context
“I text the parents several times every day and I help to handle the insulin pump and to measure blood glucose. I have the same application on my cellphone as the youth and we count carbohydrates together.”	Teacher support self-care and interacting with youth and parents	Finding strategies to support self-care	
“We tried using the insulin pen and injected water in oranges and that was pretty much it...when I got back to school and faced reality in the classroom I felt I knew nothing I really needed to learn more... I googled... asked parents asked the school nurse”	Teacher experiencing uncertainty and need for education	Feeling uncertain and incapable	
“What will happen to me if I push the wrong button on the insulin pump and accidentally insert too much insulin and maybe the youth dies... Who is responsible then?” (Teacher 2)	Teacher experiencing responsibility uncertain	Dealing with unclear responsibility	

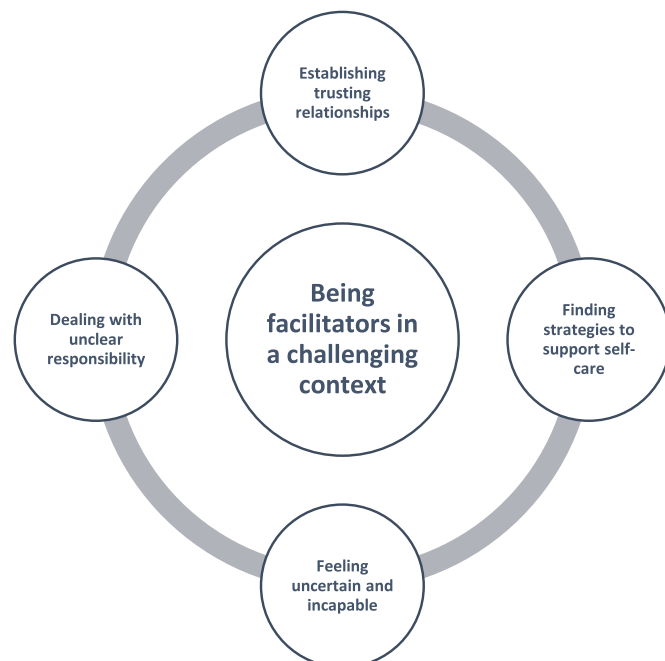
and review interpretations of the findings throughout the analysis. Finally, all authors met and discussed the analysis thoroughly until consensus among the authors was reached (Graneheim and Lundman, 2004).

## Results

The analysis resulted in a theme: *Being facilitators in a challenging context*, and four subthemes: *Establishing trusting relationships*, *Finding strategies to support self-care*, *Feeling uncertain and incapable*, *Dealing with unclear responsibility* (Fig. 1) describing the school personnel's experiences of caring for youth with T1DM. The theme and subthemes, are presented below with referenced quotations from the interviews.

### *Establishing Trusting Relationships*

All participants regardless of found that a good dialogue and communication with the youth and parents was fundamental for establishing trusting relationships with easy interaction. The results did not identify differences regarding the age or maturity of the youth with T1DM but rather differences in the school personnel's approach towards youth with T1DM. School personnel found it important to be responsive



**Fig. 1.** Illustration of school personnel's experiences of caring for youth with T1DM.

to individual needs from both youth and parents. They experienced an association between the youth feeling safe and secure in the school setting and the youth being seldom absent from school and participating in schoolwork in the same way as healthy peers. One teacher described that she asked the youth to tell her about T1DM to better comprehend youth with T1DM in relation to school. She said:

It was a change of roles he taught me... I hadn't understood that it affected his ability to concentrate... I simply didn't have the knowledge... it was a good talk where I really got to know him and I think he realized that I honestly wanted the best for him and that I was not trying to interfere in his private life (Teacher 1, high school).

Several principals expressed that a key to success was to arrange a meeting with the youth and parents as soon as possible after diagnosis. These meetings were initiated by the principal or by the school nurse and the agenda for the meeting was to discuss information from the healthcare providers, go through the school day and identify and designate one teacher to be primary responsible. It was described as important by school personnel, to have one person in charge and responsible for communication with the family. The school nurse, PE teachers and kitchen staff often participated in these meetings, and sometimes also healthcare providers (diabetes nurse). To establish trust and interaction, it was also vital to make agreements regarding how to handle acute situations, who to contact and to adhere to the agreements. The care plan from the healthcare provider was an important issue to discuss and implement. After these meetings, the principals experienced youth and parents as being more safe and secure and school personnel being less stressed.

### *Finding Strategies to Support Self-care*

The school personnel expressed that they supported youth's self-care in various ways. Teachers described that they supported youth's self-care directly in the classroom when interacting with the youth during the school day. For many, it was a new task to support self-care, and some expressed that they found themselves in the middle of expectations from the parents and the principal as well as their own ambition of being a good teacher. Teachers described strategies of how they supported youth to count carbs, to check blood glucose, to manage the insulin pump, to eat a snack or to contact parents.

I text the parents several times every day and I help to handle the insulin pump and to measure blood glucose. I've the same application on my cellphone and we count carbohydrates together... it's practical math (Teacher 7, grade 1–9).

The principals described how they supported youth's self-care mainly at an organizational level, where they initiated adjustments based on information from healthcare providers, care plans, parents and youth. Information from the healthcare providers was valuable

information for the principals. The adjustments could include providing extra resources in form of personnel, adjusting the schedule or the school lunch. One principal had organized the school lunch for all in a successful way to meet the needs for a youth with T1DM and said:

What's good for youth with T1DM is good for all (Principal 4, grade 1–9).

Several school nurses described their work as similar to a lobbyist to affect the school environment to be more conscious of the needs of youth with T1DM. The nurses saw themselves as a bridge between youth and parents, school, and between the school and the healthcare provider. School nurses cooperated with the school kitchen regarding individual needs for school lunch. School nurses provided healthy snacks or fruit, and cooperated with PE teachers by administering dextrose, informing and supporting regarding physical education, and how to handle an emergency with hypoglycemia or hyperglycemia.

The school nurses supported the principals who had no formal medical education. Nurses added a medical competence to the school and described an important task to initiate and write care plans in dialogue with parents and healthcare providers. They implemented and evaluated the care plans in school in collaboration with the principal and teachers.

#### *Feeling Uncertain and Incapable*

Teachers expressed that caring for youth with specialized healthcare requirements in the classroom was challenging and reported lack of academic education for this task. They expressed need for more knowledge and competence. Several teachers in primary and middle school had participated in education offered by the healthcare provider or from parents, but only a few teachers working with older youth had participated in any education. The teachers experienced great uncertainty and felt incapable and found offered education positive but too basic, though it did not prepare for the situation they had to address in school.

It was positive to meet the diabetes nurse who really explained what diabetes means but when I got back to school and faced reality in the classroom I felt I knew nothing... I really needed to learn more... I googled... asked parents, asked the school nurse (Teacher 9, grade 1–9).

Teachers all expressed the need for more education later when they had more experience and questions. There were positive experiences of inviting the diabetes nurse to the school where the focus was practical issues such as food, counting carbonates and physical activity. However, these visits were rare due to lack of resources.

#### *Dealing with Unclear Responsibility*

Several teachers experienced the responsibility for the school youth's self-care as a responsibility that never ends. Regardless of schedule, they were always on call and some chose to be present in the classroom during the entire school day to be close to the youth. This caused much stress, especially for teachers who worked with younger youth and teachers who did not have any co-workers to talk too. Teachers reported that they had to manage the situation even though they were not comfortable with it. Some teachers experienced work dissatisfaction and they were looking for other employment. Teachers feared making mistakes and this created anxiety and uncertainty. One teacher described an incident she could not forget.

It was on a walk and suddenly the youth with T1DM was all pale and didn't feel well. I checked blood glucose and it indicated low. We were 1.5 km from the school I was alone with nine or ten kids and I didn't have Dextrosol with me. I panicked and ran to a house, knocked on the door and asked for something sweet to eat. I got

some Coca-Cola, and it was alright. But it was a terrible feeling, it still haunts me sometimes, I keep thinking what if. I never want to experience that again, I felt so helpless and out of place (Teacher 3, grade 1–9).

The question of accountability was highlighted by several teachers who were not familiar with the legislation regarding supporting self-care in school. Many teachers were unsure of what was required of them and what would occur if something went wrong. A teacher posed the question:

What will happen to me if I push the wrong button on the insulin pump and accidentally insert too much insulin and maybe the youth dies. Who is responsible then? (Teacher 2, pre-school)

On the other hand, principals were all clear about the responsibility and the legislation. Even though the principals had no formal medical education, they were responsible for making decisions affecting health and wellbeing of youth with T1DM. Principals experienced this challenging and found school nurses to be valuable partners and support in this work.

As the head of the school I'm the one in charge and I've to answer for what happens. In health matters it is reassuring to have a qualified nurse to talk to (Principal 5, high school).

## **Discussion**

### *Trusting Relationships with Teachers*

This study suggests that participants experienced that good dialogue and communication with the youth and their parents were fundamental to creating trusting relationships to interact easily. Furthermore, school personnel expressed being a facilitator for youth with T1DM in school as a challenge, nevertheless teachers were identified as key professionals for supporting youth with T1DM.

As possible after diagnosis, the principals and the school nurse often initiated meetings with the youth and parents and one vital factor during these meetings was to designate one person often a teacher, to be in charge for the self-care and the communication with the family. These meetings could be regarded as a starting point for creating trusting relationships and the designated teacher often had daily contact with the youth as well as the parents often by cell phone. Teachers spent most of their working day together with youth with T1DM and assumed responsibility for supporting the daily self-care and wellbeing of the youth. The participants experienced an association between the youth being safe and secure in the school setting and youth seldom being absent from school work as were healthy peers. It is possible that the school personnel's work to establish trusting relationships could have contributed to the positive association that school personnel described. In this work, they emphasized the need to create a safe environment for the youth. The results shows that when school personnel in collaboration with youth and parents identified support needs, developed and implemented the care plan, and designated one teacher to be primary responsible, youth and parents were more content and had more secure feelings towards the school and school staff. This corresponds well with earlier research where youth experienced support from teachers when the teachers knew about the illness, and also knew what to do in an acute situation as well as daily by reminding youth to check their blood glucose (Holmstrom et al., 2017). Another study showed that self-care in Swedish schools improved during 2008–2015 with respect to metabolic control of children with T1DM. The proportion of children with designated school personnel available to provide self-care support increased as did the proportion of care plans (Sarnblad et al., 2017).

Furthermore, earlier research found a positive environment important for youth with T1DM to feel safe and included, as well as effective

collaboration and communication between child, parent and school (Kise et al., 2017; Marschilok et al., 2011), whereas poor communication between teachers and students with chronic illnesses was found to be major barrier for adequate support (Boden et al., 2012; Hinton and Kirk, 2015).

It could be argued that when school personnel established trusting relationships and supported youth's self-care, this promoted school attendance and prevented youth with T1DM from being marginalized at school. Earlier research showed adequate support, both social and medical, improved outcomes of treatment (Moore et al., 2009; Wodrich et al., 2011). The aim of this study was not to explore associations between school support and outcomes of treatment, but it is logical to assume that when school personnel established trusting relationships it could also affect the outcome of the treatment.

#### *Education for Teachers*

The results show that school personnel agreed as to a need and demand for more education concerning T1DM to increase their knowledge and competence, as they found themselves ill-prepared to address the needs of the youth with T1DM. Furthermore all teachers participating in this study reported lack of academic education regarding management of school children with chronic illnesses, and several of the teachers reported not receiving any formal training or education in the workplace, even though the number of children with chronic illnesses in school increased (Diamond Project Group, 2006; Patterson et al., 2009). Lack of education for school personnel regarding T1DM has been shown in earlier studies (Boden et al., 2012; Clay et al., 2004; Hinton and Kirk, 2015; Kise et al., 2017; Marschilok et al., 2011; Moore et al., 2009; Olson et al., 2004; Wodrich et al., 2011) and should be considered as an area in need of development. Most teachers regarded the healthcare provider as vital for diabetes education, but at the same time as inflexible, hard to reach, and with limited resources (for example to visit schools). Information was gathered from available sources that were convenient to access such as the school nurse, parents and googling.

It should be noted, that teachers working with younger children had received education in a larger extent compared to teachers working with older children. Educational programs offered for school personnel has shown increased knowledge and increased confidence of school staff among teachers caring for students with T1DM, as well as improved health and quality of life for students (Pansier and Schulz, 2015; Smith et al., 2012).

#### *School Personnel Feeling Uncertain with Unclear Responsibility*

Many of the school personnel experienced feeling uncertain and they worried about not understanding an acute condition/situation (Boden et al., 2012; Tolbert, 2009), and about legal liability. Olson et al. (2004), found teachers to be concerned about risk of classroom emergencies and death in youth with chronic illness, as well as about legal liability. The question regarding responsibility is complex and involves several professions. According to the Swedish school legislation, SFS, 2010:800, all youth have the right to education and the care they need in school; schools must provide services to ensure youth are medically safe while having the same access to educational opportunities as others (SFS, 2010:800). This applies for youth with T1DM. They should not be excluded or discriminated against in any way because of their illness.

According to the Swedish legislation, SFS, 2010:800, the principal (as representative for the school administration), is responsible for insuring the youth's right for education, supporting self-care in school as well as the safety in school (SFS, 2010:800). A healthcare professional, (SFS, 2017:30; SOSFS, 2009:6) often child's diabetes physician, is responsible for assessing the individual need for support with self-care in school; the physician is responsible for collaboration with the school (i.e., the

principal) to ensure the youth's self-care (SFS, 2017:30; SOSFS, 2009:6). The principals in this study were identified as very important professionals though they enabled support and self-care at an organizational level by initiated adjustments and individual needs. The principals were quite clear about the legislation, but they also expressed that the healthcare provider was more competent in healthcare issues. Principals found working collaboratively with the healthcare providers positive but also challenging, though the healthcare providers lacked flexibility and resources, for example to provide education to school personnel and to visit schools.

School nurses in Sweden are situated at the schools are easy to access and are identified as resources because of their health care competence. Earlier research outside of Sweden showed school nurses to be resources on-campus for youth with chronic illness, and school nurses were available to support both youth and school personnel, as well as the professionals being responsible for self-care in school (Marschilok et al., 2011; Olson et al., 2004; Wodrich et al., 2011). In the Swedish context, school nurses are not in charge for the active care or self-care of youth with chronic illnesses, such as T1DM. However, the school nurses are responsible for promoting the collaboration between the youth-family, school principal, teachers and the healthcare provider. In this study, school nurses reported that they advocated for the student with T1DM in each area of concern, especially in initiating and promoting education of teachers who often provide care to youth with T1DM. Furthermore, it has been showed that the strengthened Swedish legislation regarding self-care improved the support for self-care in school (Sarnblad et al., 2017). Nevertheless, the results in this study showed that, among school staff, the knowledge regarding the legislation is still imperfect and is a source for many worry and anxiety among school staff. With this in mind, there is a need for school staff to be well-educated regarding T1DM as well as for better cooperation between school and healthcare providers.

In order to enhance trustworthiness of the study, the authors have clearly described each step of the research process and presented verbatim quotes to contribute to the trustworthiness of the findings (Sandelowski, 1994). However the study was conducted in a Swedish context (i.e the Swedish health-care, educational system and legislation), and with limited numbers of school personnel from each discipline and grade level; this is an important limitation especially regarding transferability. Nevertheless, the results describing the experiences of school personnel caring for youth with T1DM could be similar for school personnel caring for youth with different chronic illnesses and in Sweden and in other countries with similarities in the health-care, educational systems and legislation.

#### *Implications*

Lack of education and unclear responsibility creates feeling of uncertainty and insecurity for school personnel and this study shows that there is a need for mandatory education of school personnel regarding T1DM and self-care, including legislation.

The authors suggests the content of the mandatory education for school personnel should be developed in cooperation with education and health-care professionals, and families (youth and parents) with experiences of T1DM. The mandatory education should be in line with, clinical practice consensus guidelines (American Association of Diabetes Educators, 2018), and with the Swedish legislation (SFS, 2010:800; SFS 2017:30; SOSFS 2009:6), to ensure quality and equality for youth with T1DM in Swedish schools. A diabetes nurse specialist in form of "a liaison position" could be the professional in charge of the mandatory education and to enable a more flexible and accessible support to school facilitators is also suggested.

The results could be interpreted as a teacher retention issue if teachers are feeling so burden and stressed by the responsibility regarding youths' illnesses in school, that they may search for different positions, and therefore there is a need for future research regarding

teachers' experiences from different grade levels, personnel and discipline.

## Conclusions

Principals are key professionals for enabling support and self-care for youth with T1DM at an organizational level; school nurses are key professionals for advocating needs and support for the youth with T1DM in each area of concern; teachers are key professionals actively supporting self-care for youth with T1DM at an individual level.

There is a need for mandatory education of school personnel regarding T1DM and self-care, including legislation.

We argue that school personnel need to know the basics regarding T1DM and metabolic control (i.e., how to monitor blood glucose, the goals for blood glucose, self-care regarding administering insulin and how to handle an emergency with hyperglycemia or hypoglycemia) (American Association of Diabetes Educators, 2018; Lange et al., 2014). We also argue that an important health and educational policy issue is a mandatory education regarding T1DM and self-care to fill this gap of knowledge.

This education should also entail the possibility for follow-up visits at the school, for example, by a liaison position in the form of a diabetes nurse specialist to coordinate diabetes self-care as well as to bridge between the educational and the health-care systems.

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## Conflict of Interest

The authors declare no conflicts of interest.

## Author Contributions

Study design: MRH, MH, SS data collection: MRH and MH; analysis: Lead by MRH with support from MH, SS; manuscript preparation: MRH, MH, SS and all authors have contributed to development and revision of article.

## Ethical Approval

The study was approved by the Regional Ethical Review Board, Umeå, Sweden (Dnr 2015/416-31Ö).

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## References

- American Association of Diabetes Educators (2018). Management of children with diabetes in the school setting. *The Diabetes Educator*, 44(1), 51–56. <https://doi.org/10.1177/0145721718754810>.
- Bates, J. A. (2004). Use of narrative interviewing in everyday information behavior research. *Library and Information Science Research*, 26(1), 15–28. <https://doi.org/10.1016/j.lisr.2003.11.003>.
- Boden, S., Lloyd, C. E., Gosden, C., Macdougall, C., Brown, N., & Matyka, K. (2012). The concerns of school staff in caring for children with diabetes in primary school. *Pediatric Diabetes*, 13(6), e6–13. <https://doi.org/10.1111/j.1399-5448.2011.00780.x>.
- Clay, D. L., Cortina, S., Harper, D. C., Cocco, K. M., & Drotar, D. (2004). Schoolteachers' experiences with childhood chronic illness. *Children's Health Care*, 33(3), 227–239. [https://doi.org/10.1207/s15326888chc3303\\_5](https://doi.org/10.1207/s15326888chc3303_5).
- Diamond Project Group (2006). Incidence and trends of childhood type 1 diabetes worldwide 1990–1999. *Diabetic Medicine*, 23(8), 857–866. <https://doi.org/10.1111/j.1464-5491.2006.01925.x>.
- Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, 24(2), 105–112. <https://doi.org/10.1016/j.nedt.2003.10.001>.
- Hill, M., Bacon, C., Cropper, J., Exall, J., Gelder, C., Mullier, C., ... Sewell, G. (2007). A new approach to managing type 1 diabetes in school. *Journal of Diabetes Nursing*, 11(9), 328–337.
- Hinton, D., & Kirk, S. (2015). Teachers' perspectives of supporting pupils with long-term health conditions in mainstream schools: A narrative review of the literature. *Health & Social Care in the Community*, 23(2), 107–120. <https://doi.org/10.1111/hsc.12104>.
- Holmstrom, R. M., Haggström, M., Audulv, Å., Junehag, L., Coyne, I., & Soderberg, S. (2017). To integrate and manage diabetes in school: Youth's experiences of living with type 1 diabetes in relation to school – A qualitative study. *International Diabetes Nursing*, 1–6.
- Kise, S. S., Hopkins, A., & Burke, S. (2017). Improving school experiences for adolescents with type 1 diabetes. *Journal of School Health*, 87(5), 363–375. <https://doi.org/10.1111/josh.12507>.
- Kvale, S. (1996). *Interviews: An introduction to qualitative research interviewing*. Thousand Oaks: Sage.
- Lange, K., Swift, P., Pańkowska, E., & Danne, T. (2014). Diabetes education in children and adolescents. *Pediatric Diabetes*, 15(S20), 77–85. <https://doi.org/10.1111/ pedi.12187>.
- Marks, A., Wilson, V., & Crisp, J. (2013). The management of type 1 diabetes in primary school: Review of the literature. *Issues in Comprehensive Pediatric Nursing*, 36(1–2), 98–119. <https://doi.org/10.3109/01460862.2013.782079>.
- Marschloek, C., Silverstein, J., & Greenberg, R. (2011). Managing diabetes effectively in the school setting: Case studies and frequently asked questions. *NASN School Nurse*, 26(4), 218–220. <https://doi.org/10.1177/1942602x11411053>.
- Moore, J. B., Kaffenberger, C., Goldberg, P., Kyeung Mi, O., & Hudspeth, R. (2009). School reentry for children with cancer: Perceptions of nurses, school personnel, and parents. *Journal of Pediatric Oncology Nursing*, 26(2), 86–99. <https://doi.org/10.1177/1043454208328765>.
- Olson, A. L., Seidler, A., Goodman, D., Gaelic, S., & Nordgren, R. (2004). School professionals; perceptions about the impact of chronic illness in the classroom. *Archives of Pediatrics & Adolescent Medicine*, 158(1), 53–58. <https://doi.org/10.1001/archpedi.158.1.53>.
- Pansier, B., & Schulz, P. J. (2015). School-based diabetes interventions and their outcomes: A systematic literature review. *Journal of Public Health Research*, 4(1), 467. <https://doi.org/10.4081/jphr.2015.467>.
- Patterson, C. C., Dahlquist, G. G., Gyürüs, E., Green, A., & Soltész, G. (2009). Incidence trends for childhood type 1 diabetes in Europe during 1989–2003 and predicted new cases 2005–20: A multicentre prospective registration study. *The Lancet*, 373(9680), 2027–2033. [https://doi.org/10.1016/S0140-6736\(09\)60568-7](https://doi.org/10.1016/S0140-6736(09)60568-7).
- Sandelowski, M. (1994). Focus on qualitative methods. The use of quotes in qualitative research. *Research in Nursing & Health*, 17(6), 479–482. <https://doi.org/10.1002/nur.4770170611>.
- Sarnblad, S., Akesson, K., Fernstrom, L., Ilvered, R., & Forsander, G. (2017). Improved diabetes management in Swedish schools: Results from two national surveys. *Pediatric Diabetes*, 18(6), 463–469. <https://doi.org/10.1111/pedi.12418>.
- SFS 2010:800. *Education Act*. Accessed April 9, 2018 from The Swedish Parliament, [http://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/skollag-2010800\\_sfs-2010-800](http://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/skollag-2010800_sfs-2010-800)
- SFS 2017:30. *Healthcare Act*. Accessed April 9, 2018 from The Swedish Parliament, [https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/halso-och-sjukvardslag\\_sfs-2017-30](https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/halso-och-sjukvardslag_sfs-2017-30)
- Smith, C. T., Chen, A. M., Plake, K. S., & Nash, C. L. (2012). Evaluation of the impact of a diabetes education curriculum for school personnel on disease knowledge and confidence in caring for students. *The Journal of School Health*, 82(10), 449–456. <https://doi.org/10.1111/j.1746-1561.2012.00721.x>.
- SOSFS 2009:6. *The assessment of whether a health care measure can be performed as self-care*. Accessed April 9, 2018 from, National Board of Health and Welfare, <http://www.socialstyrelsen.se/sosfs/2009-6>
- SWEDIABKIDS Annual report 2015. National register of diabetes in children and adolescents. Accessed June 15, 2018 from, <https://swediabkids.ndr.nu/DocumentsAnnualReport.aspx>
- Swedish National Agency for Education 2017. *The Swedish education system*. Accessed April 9, 2018 from, <https://www.skolverket.se/skolformer>
- Tolbert, R. (2009). Managing type 1 diabetes at school: An integrative review. *The Journal of School Nursing*, 25.
- Wodrich, D. L., Hasan, K., & Parent, K. B. (2011). Type 1 diabetes mellitus and school: A review. *Pediatric Diabetes*, 12(1), 63–70. <https://doi.org/10.1111/j.1399-5448.2010.00654.x>.
- World Medical Association Declaration of Helsinki (2008). Ethical principles for medical research involving human subjects. Retrieved from <https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/>, Accessed date: 9 April 2018.