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# **Conceptions of Diabetes and Diabetes Care in Young People With Minority**

## **Backgrounds**

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## **Abstract**

Adolescents with type 1 diabetes (T1DM) need stable self-care routines for good metabolic control to minimize future cardiovascular health complications. These routines are demanding, and might be particularly challenging in underprivileged groups. The aim of this study was to gain in-depth knowledge on the experience of adolescents with T1DM and a non-Swedish background regarding factors that might influence their ability to take care of themselves, in particular, factors that might influence diabetes management routines; their social situation; and the support they receive from caregivers. We interviewed twelve adolescents with T1DM and minority backgrounds. The results indicated resources and constraints in the adolescents' social context and in the health care organization. The adolescents developed conceptions that helped to explain and excuse their self-care failures, and their successes. These findings highlight the importance of integrating T1DM as part of the individual's personal prerequisites. We discuss implications for the organization of diabetes care for adolescents.

## **Keywords**

adolescents / youth, at-risk; children; diabetes; health behavior; health care

People with type 1 diabetes (T1DM) who fail to take sufficiently good care of their health in regard to their disease can in the long term suffer severe medical complications that can gravely impair quality and length of life (DCCT Research Group, 1993). Such problems also lead to substantial societal costs. Both the ethical and the economic consequences are further aggravated by the fact that T1DM generally appears at an early age. Successful prevention of future medical complications requires self-care in terms of strict and repeated metabolic control of blood glucose levels throughout the day, achieved by taking blood tests and balancing physical activity, food intake, and insulin injections.

When children with T1DM become teenagers, they must take increasing responsibility for the demanding task of self-care. Being in the adolescent phase of physical, psychological, social, and emotional development further complicates this task. Teenagers, whom researchers have indeed identified as the least successful group regarding diabetes metabolic control, are therefore a vulnerable group of patients (Delamater, 2009; Weissberg-Benchell, Wolpert, & Anderson, 2007). Although risks related to diabetes are cumulative and often have delayed health consequences, young people frequently fail to grasp the long-term risks (Slovic, 2000). People tend to favor short-term benefits over long-term ones (Zohar & Erev, 2007). Also important is understanding the negative outcomes versus the benefits of risk taking (Hampson, Severson, Burns, Slovic, & Fisher, 2001).

Povlsen, Olsen, and Ladelund (2005) have shown that belonging to a minority ethnic group might contribute to poor metabolic diabetes control among young people with diabetes, and thus to poor long-term quality of life. The problem might be exacerbated among immigrant adolescents with a background from developing countries where the general knowledge of diabetes is sometimes limited. Patients, parents, and health care staff can thus have different conceptions of sickness, treatment, self-care, and prevention (Hjelm, Bard, Nyberg, & Apelqvist, 2005).

In a systematic literature review Larsman, Eklöf, and Törner (2012) identified age, ethnicity, socioeconomic status, and knowledge regarding risk and health outcomes as covariates of adolescents' risk perceptions in regard to health risks with long-term but delayed health consequences. Larsman et al. (2012) also identified perceived control of risks and stereotyped conceptions regarding susceptibility to negative outcomes as important in relation to adolescents' health behavior. Consequently, these factors need to be considered in communicating risk and in supporting self-care among adolescents with T1DM. To successfully master the responsibility of self-care, these adolescents need strong social and family support, as well as effective support from pediatric specialist care services (Delamater et al., 1999). It is therefore an important and challenging task to improve caregivers' ability to support effective self-care among adolescents with T1DM, not least those with a non-privileged social background.

Larsman et al. (2012) suggested that health care staff should strive to determine each young person's status regarding risk perception, knowledge, and perceived control, as well as perceived benefits and costs of health behavior. This warrants a person-centered care (PCC) strategy. The importance of achieving consensus between the caregivers and the person cared for, to secure personal responsibility for demanding treatment regimens, is increasingly acknowledged (Ekman et al., 2011). This means reducing misunderstandings and improving outcomes from encounters between caregivers and patients (Britten, Stevenson, Barry, Barber, & Bradley, 2000). A premise of PCC is that different people have different views on their medical conditions and assess their situations from a rich context of personal history and social conditions (Ekman et al., 2011).

Brown (2002) has proposed social ecological theory as a useful framework for pediatric research, in which the young person is considered as part of a social ecological context. Structures on the macro level, for example, culture and school organization, and

supportive systems at the meso level, such as friends, diabetes teams, and family, interact with the individual at the micro level (Bronfenbrenner, 1979). To develop person-centeredness in the care of adolescents with T1DM, and particularly those with a minority ethnic background, it is therefore important to gain in-depth knowledge of these adolescents' experiences of their illness, their self-care, their social situation, and the care support offered to them by the pediatric diabetes care teams.

The aim of the present study was to contribute to such knowledge by approaching the following issues from the perspective of teenagers with T1DM and a minority ethnic background: Which factors are important for the adolescents to consistently take responsibility for self-care, and which factors might counteract taking such responsibility? Which factors related to the pediatric diabetes care unit are important motivators or demotivators for the adolescents? What types of support for self-care are available to the adolescents in their social context, and what types of support do they wish for? How do the adolescents perceive their ability to influence their health situations?

## **Method**

### *Informants*

We invited all first- or second-generation immigrant adolescents, aged between 13 and 18 years and treated for T1DM at a major pediatric hospital in Sweden, to participate in the study, in all, 24 adolescents (17 girls and 7 boys). Of these adolescents, 21 had parents born in a non-European country, and three had parents born in Europe (non-Nordic countries).

Twelve adolescents agreed to participate in the study. Nine of these were born in Sweden, three in Iraq, and one in Somalia. All of them spoke Swedish.

### *Procedure*

The adolescents and their parents received written information about the study, and an invitation for the adolescents to participate. Fifteen families provided written consent for the adolescents to participate. We contacted these adolescents by telephone to determine the time

and location (of the adolescents' choice) for individual interviews. At this stage, three of the adolescents withdrew from participation. When the remaining 12 adolescents next visited their doctor or diabetes nurse at the hospital diabetes clinic, staff provided additional information about the study and its purpose to the adolescent and the accompanying parent or custodian.

Nine of the 12 interviews took place in the adolescents' homes; one interview was conducted at the diabetes clinic, and two at the university. A trained interviewer, a registered nurse with previous experience of interviewing children, performed the interviews. The interviewer was not a member of the diabetes team. The interviews, which took between 35 to 50 minutes to complete, were recorded and we then transcribed verbatim.

#### *Instrument*

The interviews were based on a semistructured interview guide consisting of 14 questions that prompted respondents to share their experiences and thoughts about their attitudes, social norms, and perceived control in regard to their diabetes, self-care, social situation, and medical contacts. We tested the interview guide in a pilot interview study with three ethnic Swedish adolescents receiving T1DM care from another pediatric diabetes clinic in the same region. (No non-Swedish teenagers were available at this clinic). The pilot interviews were recorded and transcribed. The research team, comprising among others a doctor and a nurse, both with extensive experience from diabetes care of children with a non-Swedish background, discussed the experience of the pilot interviews. The interview guide was subsequently refined.

In the main interview study, the interview began with an open question that asked the informant to choose an issue that he or she considered important in relation to being a teenager with diabetes. The interviewer posed follow-up questions until there was no further information forthcoming on this issue. This line of question was followed by open questions

regarding three main domains: self-care, relation to health care providers, and general life situation. Questions in these domains included the following. “Think of a day when you felt that you took care of your diabetes in a way that you think was good. What made that day a good day?” “Who in the diabetes clinic is the most important person to you?” “If you think about your own situation, and your family, what do you think helps you to take care of your diabetes in a manner you think is good?”

### *Analyses*

Our choice of methodology for data acquisition and analysis was inspired by phenomenography. We believe that such analysis does not reveal truth or facts, but rather, how people perceive the world around them. In focus are people’s subjective experiences and their descriptions of the meaning of how the world is constituted. In the analysis we aimed to describe the variation in perceptions by comparing differences and similarities in statements to identify characteristics of different perceptions. An informant might express an experience as reflected or non-reflected; nonetheless, it constitutes the knowledge and the foundation on which people build their reasoning (Marton & Booth, 2000).

The research team performed the analyses in the following five steps. In step one all five researchers read the transcribed interview protocols, which enabled an understanding of the meaning content of each interview. We performed step two to ensure the credibility of the analysis: Two of the researchers, neither of whom had performed the interviews, analyzed two interview transcripts in two different ways, one researcher starting from the questions in the interview guide, and the other with no predetermined questions applied to the text. In both approaches, the readers sought similarities and differences in perceptions in the interview texts. Similar results emerged from the two analyses, and the first form of analysis (using the interview guide) was used thereafter.



The authors formulated categorizations of meaning in themes that reflected similarities and differences in the data and described the major aspects of the respective phenomenon. In step three of the analysis, Boman analyzed four of the interviews, and Bohlin co-judged the emerging themes. The researchers discussed discrepancies and similarities. In step four, we discussed an emerging model of the themes and refined it in consensus within the entire research team. This process continued for the next four interviews, and the model thus continued to emerge and develop. By this stage, a global theme regarding integration/non-integration of the diabetes had emerged (see the Results section). Therefore, in the fifth step of the analysis, when analyzing the four final interviews, we specifically considered the degree of integration of the disease.

As the analysis progressed, we found that signs of differences in the degree of integration evolved in several of the emerging themes, and therefore, we were able to validate the global theme. The analysis procedure resulted in a model based on the informants' statements and Bronfenbrenner's (1979) ecological theory on individuals' involvement in micro, meso, and macro levels of society.

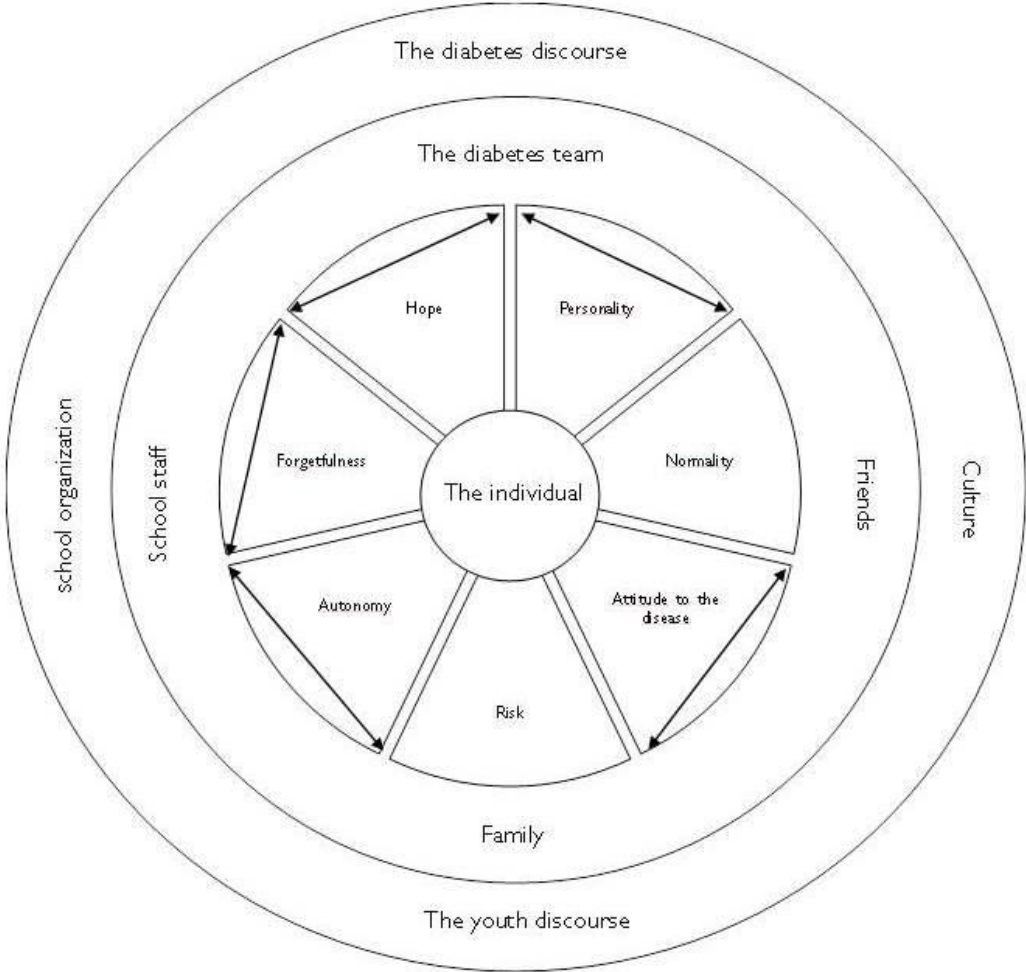
### *Ethical Considerations*

The regional ethics committee in Gothenburg, Sweden, approved the study. The researcher who performed the interviews took care to ensure that all adolescents and their parents were well informed about the purpose of the study (verbally as well as by letter) and that the adolescents were comfortable in the interview situation. The adolescents were informed that their participation was voluntary and that they could terminate their participation at any time. Discretion and confidentiality were guaranteed. After the interview sessions, as well as in the informational letter, we gave the adolescents and their parents the research team's contact data in case they wanted more information about the study. The participants also had ongoing contacts with the diabetes care team. The research team concealed all names and places in the

transcripts to ensure confidentiality of the participants, and archived the recordings and transcripts in a secure place.

**Results**

The influence of factors at the macro and meso levels, on the adolescents’ reasoning in relation to their adherence to the T1DM self-care regimen, is illustrated in an ecological model (Bronfenbrenner, 1979) in Figure 1.



**Figure 1.** Model showing how adolescents with T1DM and a non-Swedish background reasoned regarding self-care, social situation, and care support offered to them by the pediatric diabetes teams.

Of the 12 informants, three (two boys, of 13 and 14 years of age, respectively, and one girl of 16 years) explicitly described themselves as adherent to the treatment regimen, whereas the remaining nine described many difficulties in adhering to the regime. As the analysis evolved, differences between the adherent and the non-adherent groups inductively became apparent in most of the themes that were identified. These differences had common features and resulted in an emergent global theme, integration of the disease, where the adherent group seemed to have integrated the T1DM as part of their personal prerequisites. The non-adherent group tended to view the T1DM as something external over which they had limited control, which both explained and justified not taking constant and full responsibility for self-care. We found differences between the adherent and non-adherent groups in five of seven themes at the micro level, in two of four themes at the meso level, and in two of four themes at the macro level, as illuminated below.

#### *Micro level*

*Personality.* The adolescents explained their management of the disease as an outcome of their personalities. They referred to their personalities as something unchangeable and beyond their control. They described personality as a law of nature that determined their ability to manage the disease. This conceptualization differed between the two groups. The adherent group attributed their adherence to their responsible personalities, and the non-adherent group perceived personality as limiting their room to maneuver. Adherent: “I’ve always been that kind of person. All that is mine is mine, and I’ll take care of it” (13-year-old boy [13, B]). Non-adherent: “They [the diabetes team] have recommended the insulin pump to me, but I said no. I’m pretty wild as a person, you know, so it doesn’t work” (18, B).

*Normality.* To obtain normality in social situations, the adolescents’ strategies varied from hiding the disease but actually taking care of it, to ignoring the disease. No differences were identified here between the adherent and the non-adherent group. The adolescents

expressed a wish to do the things their friends did. When practical self-care tasks demanded attention, and the adolescents perceived them to be in conflict with the peers' intentions, they chose either to ignore the disease or to redefine their actions as a strategy to do what was required from a medical perspective, without standing out from the crowd. "So, if I have low blood sugar, for example, I say 'I am hungry.' I don't tell them [friends] that I have low blood sugar." (17-year-old girl [17, G]) The adolescents also stressed their unwillingness to be perceived as abnormal in their peer group, and their reluctance in intimate situations to admit to having diabetes. "Yeah, like when you're on a date, then you can't bring out the appliance [blood glucose tester] and keep on, like, thousands of times" (18, B).

*Attitude toward the disease.* In the adherent group, the adolescents had accepted the disease to the degree that they did not perceive themselves as sick; they stated they felt the same now as before being diagnosed. The disease did not infringe much on their lives, and they did not think it was difficult to talk about their illness with other people. They perceived themselves as the same as everybody else, despite the disease. Adherent: "Even if I have diabetes, I'm like everyone else. I'm not sick" (14, B). The non-adherent group dissociated from the disease and wished that the disease and the injections would disappear. They hoped that science would come up with a cure, and some put their faith in God, praying for the disease to disappear. They also declared their unwillingness to talk about their disease in their social network. Non-adherent: "That's what I want most; I really wish they could wipe it [the disease] out. That would be the best" (16, G).

*Risk.* We identified no difference between the groups in regard to the adolescents' awareness of the risks associated with the disease. The risk awareness emerged in two ways. First, there was an awareness of what could happen at any time, and second, there was an awareness of the risks in the longer perspective. Both risk perspectives seemed to be associated with stress and anxiety, even though the adolescents formulated a solution to the

problem: if you take care of yourself and the disease, you minimize the risks. “I’m a little scared when it [metabolic glucose level] is high or not good, if my eyes are not good, or my feet are bad. I think of all these things” (17, G).

*Autonomy.* The adolescents stressed their need for autonomy. They expressed a wish to be independent and strongly disliked interference from other people in their disease management. They articulated positive feelings when they were responsible for their diabetes management and stated that they felt better when taking the initiative themselves. Autonomy was stressed differently in the adherent and the non-adherent groups. The adherent group exhibited a proactive self-determination and described how they took responsibility for themselves and appreciated doing so. Adherent: “I think of everything myself; I like to take more responsibility” (13, B).

The non-adherent group stated that they disapproved of other people interfering with their management of the disease. Non-adherent: “I do not like to get advice from others. I have a sense that they want to try to make decisions about me so I usually do not listen to advice. I do what I want” (14, G). One non-adherent adolescent declared that he had found ways to manage the disease other than those recommended by the diabetes team.

*Forgetfulness.* To forget, or not forget, was a central concept in the adolescents’ descriptions of how they related to their disease. The theme of forgetfulness ranged from being impossible to forget, to forgetting it because it was something beyond the individual’s control. It could refer to being conscious of having a chronic disease, without letting it constantly occupy one’s thoughts; the adherent group used this explanation. Adherent: “I’m taking my tests and so on, but it’s not like I go and think of diabetes, diabetes, diabetes all the time” (15, G).

In the non-adherent group, forgetfulness was used to explain the lack of adherence. The individuals’ explained the failure to manage their diabetes as non-conscious and caused

by external factors, and they were therefore liberated from the responsibility of remembering. Non-adherent: “I don’t know. It just happens. I just forget to take tests” (16, G). For the non-adherent group, forgetting could also be a means of escaping anxiety. They expressed that the burden of having diabetes was sometimes too heavy, and that the disease was therefore disregarded.

*Hope.* The adolescents expressed hope as an ever-present possibility for improving their management of the disease. There was always a second chance for the individual to put the diabetes discourse into better practice. All adolescents expressed a desire to manage their disease in an acceptable way, but if HbA1c (a standard index of glycemic control over the preceding period of 4 to 12 weeks) increased to undesirable levels, there was always a possibility of adjusting and improving the treatment at a later stage.

Adolescents in the adherent group expressed a belief in the possibility of continuously becoming better at regulating their HbA1c values, whereas adolescents in the non-adherent group expressed hope as the possibility of starting afresh in taking personal responsibility for their unsuccessful self-care. Thus, the concept hope was used either as the potential for improvement or as the constant possibility of a fresh start. Adherent: “There are always opportunities for improvement” (13, B). Non-adherent: “I can be dissatisfied [with HbA1c], but then I think I’ll go home and fix it. I’m starting over again. You can always fix it. I don’t have to do it now; I can do it later” (16, G).

### *Meso Level*

*The pediatric diabetes team.* The adolescents stressed the significance of the staff at the pediatric diabetes clinic. The personnel there were described as “the light in the darkness”; they listened, they cared, and they tried to make things easier for the adolescents. The adolescents commented that the pediatric teams supplied them with the help and the technical equipment they needed to manage their disease. There was also an atmosphere of familiarity

at the clinic, which they experienced as positive. One non-adherent girl expressed gratitude to the staff because they had stood by her and offered her many chances, but believed that she had let the staff down by not taking them. The degree of the adolescents' codetermination at the clinic was, however, expressed as low: you did as you were told. Non-adherent youths expressed a wish for the conversation at the clinic to be more about the youth as a person and about one's life situation. An adherent girl wished for more consultative support, rather than being told what to do.

All adolescents stressed that the doctor is the most important professional at the clinic. They attributed this to the doctor's knowledge of the disease and how to control it. They stated that the doctor knows everything about the body and how to treat the disease. He or she asks a lot of questions, and the adolescent poses questions in return. The doctor gives information and help on how to do things. Most of the dialogue at the clinic visit is with the doctor. Several of the informants expressed the importance of always seeing the same doctor.

The adolescents associated the nurses less with the disease, and described the nurses' function more in terms of socializing and relieving anxiety. The nurses were referred to as welcoming, nice, laughing, and helping out in taking blood tests such as HbA1c. Social workers and dieticians were described according to their functions, and many of the adolescents could not recall the last time they had consulted any of them. They referred to the psychologist as someone to consult when more severe problems were identified. In general, they considered the social workers, dieticians, and psychologists to have reactive roles, whereas the doctors and nurses had proactive functions.

The adolescents described the clinic visits as emotionally permeated by the outcome of the HbA1c level. Expectations of the test values ruled the emotions in regard to an upcoming visit. Adolescents in the adherent group looked forward to the visit, but for the non-adherent group, the upcoming visit was a cause for anxiety. If they suspected their HbA1c

values to be unsatisfactory, they hesitated to visit the clinic. Adolescents in the non-adherent group expressed an unwillingness to visit the clinic and declared that they could manage by themselves. They found it hard to discuss the disease with the diabetes team and to hear the HbA1c results from the doctor.

The adherent group described themselves as feeling the same as usual when meeting the diabetes team; it was a part of their everyday life. They did not express specific feelings about receiving HbA1c results at the clinic visits, whereas the non-adherent group described negative feelings, and sometimes shame, when HbA1c levels were unsatisfactory, and great relief when they were not. Adherent: “It feels normal when I go there [to the clinic]. I know what will happen: they will weigh me and measure me, and they’ll be talking about my diabetes, and then I get to go home again” (13, B).

Non-adherent: You have taken bad care of yourself and you are reminded of it; you’ll see the values. They are not as good as you hoped and imagined maybe, and then when it happens, you become angry and disappointed in yourself (14, G).

Strategies to handle the negative feelings were to withdraw and avoid talking about the visit to the clinic, or to make resolutions to make a fresh start. The adherent group stressed that the health care teams should explicitly point out the delayed complications that might occur as a consequence of high HbA1c levels, because this would help to motivate them in their self-care. This wish was not expressed in the non-adherent group. Common to all adolescents was their conviction that, regardless of the HbA1c result, they only had themselves to blame or credit.

*School staff.* Whether or not the school was informed about the adolescent’s diabetes varied, but this variation was not linked to adherence. In some cases, all relevant school staff members were informed, and in others, just the adolescent’s main teacher. In the first case, support from the school was considered important, whereas the latter group did not find



support from school important at all. Staff members who were identified by the adolescents as supportive were teachers, mentors, and school nurses. The type of perceived support was described either as prompting the adolescent about diabetes routines or as being prepared for hypoglycemia emergencies. “My mentor is very good, she is there, she is prepared if I’m low, every time I’m low she has something for me to eat. She has thought about it for me” (14, B).

*Family.* The adolescents perceived various members of the family, such as mothers, fathers, siblings, and cousins, as supportive. They identified two kinds of positive support: first, a complementary memory, meaning that another person helped them to remember routines, and second, access to information, with the family acting as a knowledge bank and providing information in an educational way. They identified support given by the family as loving and caring. They could, however, also perceive the family as non-supportive. This was a result of the parents’ lack of time or their temporary absence. The perception of a lack of support could also be because of some parents’ disinclination to watch their child giving himself or herself injections, because injections were identified as a sign of severe illness. Furthermore, they associated lack of support with the parents’ repeated reminders about the physical complications that are a consequence of the lack of self-care. In one family, the disease was not discussed at all.

Members of the family could be perceived as understanding the adolescents’ situation and knowing what to do in specific situations. When this was the case, the adolescents expressed trust and security within the family. This was the case with the adherent group.

Adherent: I guess it’s the help, you have access to the help you need. You feel safe with the family. They have lived with you since you got the disease, so they know how to do things, and they are always there. (15, G)

An adherent girl appreciated that her mother had applied an empowering parental style, helping her daughter to gradually assume responsibility for her self-care. This girl also expressed appreciation for her mother's present consultative supportive style. In contrast, several of the informants in the non-adherent group expressed frustration and discontent with the type of support they got from their families. The support was then largely in terms of reminding, nagging, and controlling, and one of the informants expressed a wish for a more consultative type of support.

Non-adherent: I want my mother to know that I can, that I can do it by myself; she doesn't need to nag all the time. I do understand that all she wants is to take care of me, but she doesn't need to nag. (18, G)

*Friends.* The adolescents had various approaches to how to relate to friends regarding the disease, but the variation was not identified in relation to adherence. Many expressed a wish to have the opportunity to talk to a friend who shared their experience of having T1DM, and those who presently had access to this type of supportive relationship greatly appreciated it. Some described their friends as an integrated part of their care routine, because they provided reminders, rejoiced about good HbA1c values, and gave comfort when the values were bad. When friends were excluded, some adolescents rationalized this through the perception that friends were unable to understand the situation. Others excluded their friends from their disease management so as not to burden them, and even expressed a fear of losing them, if they did. Some expressed a reluctance to disrupt social activities for illness-related care.

For example, if I go out with my friends and I have to stop and take test and so on, I don't want to spoil the fun at the moment, I don't want to interrupt my mates. They might think it's annoying, or something like that (14, G).

### *Macro Level*

*The diabetes discourse.* No variation was found in how the diabetes discourse was perceived. All adolescents expressed awareness of how self-care should ideally be performed and gave detailed descriptions of the necessary balance between food, insulin, tests, and physical activity. “I’m supposed to take the test, inject insulin, eat, and a few hours later take a new test” (14, G). The adolescents also showed awareness of the self-care discourse by stressing that the responsibility for the disease outcome was their own and nobody else’s.

*School organization.* The non-adherent adolescents described diabetes management problems because of the school organization, issues that did not appear within the adherent group. They described toilets, where some sought privacy to take their injections, as dirty and disgusting. At scheduled lunchtimes, their schoolmates would rush to the school cafeteria, and the adolescent with diabetes would have to choose either to be left behind or to refrain from taking glucose tests. The adolescents also pointed out that too little time was scheduled for lunch to allow them to take the tests, queue up, be served, and eat. Non-adherent: “I don’t have time to eat, and I also have to queue, terribly boring” (17, G). Pupils with diabetes were allowed to bypass the queue, but this interfered with keeping the disease a private matter. Finally, the adolescents outlined the lack of food alternatives as a problem; if the food offered was not to their taste, they ate less, and their insulin balance was disturbed.

*Culture and the youth discourse.* Two cultural affiliations were identified: the ethnic culture and the youth culture. According to the first affiliation, the adolescents perceived problems related to cultural perspectives on disease and disease management. When visiting their parents’ home countries, they had to deal with ignorance regarding the disease and comments to the effect that taking injections is not for young people. It is something that only

old and seriously ill people do. This attitude greatly impaired their ability and motivation for self-care, but emerged only in the non-adherent group.

Non-adherent: Once, when I was in my home country, it was—everybody looked at me when I injected, and it was something totally different to them that a young person injected. They said: “What is she doing? What kind of disease is that? Is it serious?” And I was a little embarrassed and thought, No, I’m not going to inject. So I did put my syringe away, I didn’t want it. (18, G)

The youth discourse was identified in the non-adherent group and expressed as adolescents having more responsibilities than children—that stress is inevitable for young people, and that all adolescents are somewhat irresponsible and have days when they do not take care of themselves. Non-adherent: “All youths have such days when they don’t take care of it [the disease]. Children have their parents who help, but youths have more responsibility by themselves” (18, G).

## **Discussion**

### *The Individual’s Integration of the Disease*

The adolescents who considered themselves as adherent differed from the subjectively non-adherent adolescents in five of seven themes. These were attitude to the disease, personality, autonomy, forgetfulness, and hope. The adherent group’s attitude to the disease indicated that they had integrated the disease into their lives; they had accepted or tolerated the fact that the disease was inevitable and impossible to avoid. Consequently, they considered and performed self-care as a part of their daily routines, and forgetting the disease was not used as a way to escape feelings of guilt for neglecting self-care.

According to Bonanno (2004), resilience following trauma is more common than previously supposed and can follow multiple pathways. The adherent group’s integration can

be a sign of progress in the adjustment and post-traumatic growth process, in which the individual who has integrated the disease has been able to move forward from the trauma—in this case, being informed about having a serious and chronic disease—and begun to feel an increasing sense of purpose and mastery. This is additionally supported by the non-adherent group's dissociated attitude to the disease, which indicates that these adolescents were in an earlier developmental stage of the adjustment process (Salick & Auerbach, 2006).

The adherent group's integration of the disease is moreover supported by their attributing their adherence to their responsible personality, their satisfaction at taking responsibility for themselves, and their inability to forget the disease, even though they were not continually thinking about it. This indicates that helping adolescents with T1DM to accept and integrate the disease as a part of their personal prerequisites is an important task for caregivers and parents. This requires supporting these children through the existential crisis of acknowledging not only that they have a chronic disease but that it is potentially lethal if mismanaged, and that they themselves, in time, must shoulder the entire responsibility for managing their disease. This demands strong, persistent, and high quality support from both parents and caregivers, and the results of our study clearly indicate the need, as well as possible directions, for improvements.

The expressions of personal responsibility for adequate self-care among the adherent adolescents might also reflect an internal locus of control (Rotter, 1966), which has been identified as a predictor of lower Hb1Ac levels (Nabors, McGrady, & Kichler, 2010). Locus of control is generally considered a personality trait and, as such, is difficult to influence. However, it has been argued that children with poor glycemic control can develop an external locus of control over time, because their self-management behaviors do not result in success (Nabors et al., 2010). Avoiding such negative feedback, and instead facilitating positive

feedback through experiences of successful self-care activities, is thus an essential task for health care professionals.

### *Supportive Environment*

Our results strongly indicate that the focus on the Hb1Ac levels permeated the adolescents' emotions and experiences before, during, and after their clinic visits. For the non-adherent group, the clinic visits provided much negative feedback, whereas the adherent group reported that the motivational function of the diabetes teams reminded them of the long-term risks of non-adherence, maintaining their motivation for adherence. The adolescents' experience of the nurses as welcoming and sociable, and as being not as connected to the disease as the doctor, might be rooted in the fact that the nurses' tasks did not include a review of the adolescent's adherence behavior. This helped to relieve anxiety.

The type of reference to hope was found to differ between the groups. The non-adherent group's argument, that there was always the possibility of a fresh start, is in line with optimism bias, a positive illusion being negatively related to risk perception (Larsman et al., 2012). Some researchers have suggested that optimism bias is important in the delicate balance between psychosocial well-being and adherence to treatment. Unrealistic optimism might have beneficial effects on psychological well-being, while, at the same time, this might be at the cost of compromised treatment (Schur, Gamsu, & Barley, 1999). It might also, however, be a condition for taking on at all the heavy burden of lifelong, strict T1DM self-care adherence (Larsman et al., 2012). Consequently, supportive environments for adolescents with diabetes, especially within pediatric diabetes teams and schools, should take this balance into account. One possible way to do so is through a PCC strategy, because such an approach is based on the individual's context, history, family, and personal strengths and weaknesses (Ekman et al., 2011).

The adolescents identified family and friends as either supportive or non-supportive. These diverse perceptions of which people and what actions were considered supportive or not indicated the adolescents' need for better tailored support. Previous findings have illuminated the complexity of peer support. Diabetes treatment problems most frequently occur in the context of social situations with peers, although, conversely, acceptance and encouragement from peers can secure the incorporation of self-care behavior into daily routines (Palladino & Helgeson, 2012). The identification of what each young person finds supportive should therefore be based on the particular social and cultural references, and hence calls for a PCC strategy (Ekman et al., 2011).

### *Structural Level*

The discourse of personal responsibility for disease outcome was dominant. In this respect, both the adherent and the non-adherent adolescents explicitly and implicitly stated that metabolic control, and thereby the disease outcome, was their own responsibility and no one else's. This becomes a dilemma regarding the structural level and the practical one (Bronfenbrenner, 1979) among non-adherent adolescents, who have not integrated the disease into their lives. The non-adherent adolescents also referred to the youth discourse, namely, that for a young person it is normal to occasionally divert from rules prescribed by the adult world—in this case their regimen of diabetes management.

Moreover, because the adolescents had immigrant backgrounds, they also inhabited cultural discourses where disease perceptions sometimes differ from the dominant Swedish one. The adolescents had to relate both to medical knowledge and norms presented by the pediatric diabetes team, and to parents' and relatives' perceptions of the disease. The results clearly illuminated the tension that some adolescents experienced between normative diabetes care and the ethnic culture's perception of sickness and treatment, a tension identified also in previous research (Hjelm et al., 2005). This should be considered in the light of the identified

increased risk of metabolic control problems among adolescents with T1DM with an immigrant background (Delamater et al., 1999).

Belonging to an identified vulnerable group does not necessarily mean that it is the membership in itself that is causing the vulnerability. People's assessment of their lives and medical conditions is a complex web built on their personal histories and social conditions (Ekman et al., 2011), of which an immigrant background is one part. This complexity could explain why only a few of the non-adherent adolescents related their adherence to their migrant and ethnic background. They did not explain their non-adherence by way of culture; rather, their inhabitation of the diabetes discourse led them to take individual responsibility and to use personality and autonomy as explanations. However, it can also be difficult to acknowledge and articulate relevant aspects of one's own culture, because these are implicit and taken for granted.

The results indicated aspects of the school organization as obstacles to adolescents' self-care adherence. The Swedish Education Act (SFS 2010:800) declares that consideration should be given to children's different needs. Organizing schedules to allow adequate time for meals, as well as offering alternative menus, would not only benefit children with diabetes, it would probably improve most pupils' health and well-being.

The results of the analysis generated the hypothesis that integration of the illness can be essential for taking on the responsibility for self-care, and adhering to the treatment regimen as a part of daily life. This hypothesis motivated comparison of the mean HbA1c values of the three informants in the adherent group, who appeared to have integrated the disease, with those of the non-adherent group, who did not seem to have done so. With the obvious reservation that the sample was very small, this comparison supported the hypothesis, because the HbA1c values of the adherent group during the preceding two years were



considerably lower than those of the other informants, even when controlling for age ( $p = .083$ ).

### *Strengths, Limitations, and Ethics*

Adolescents constitute a relatively vulnerable group, for reasons that are specific to their development phase (e.g., existential and social concerns about life and death), and they therefore need to be paid particular attention during the research process. For example, young people are more willing to participate in research than adults. It is important to recognize and balance the power dynamics between the researcher and the young participant and to respect autonomy and social agency (Heath, Brooks, Cleaver, & Ireland, 2009). In this study, the issue of power balance was taken into consideration by asking the adolescents to participate in consultation with their parents. The most important consideration for data production is that the adolescents are allowed to make their voices heard concerning important aspects of their lives, in this case having diabetes. Tiller (1991) points out that adopting children's and adolescents' perspectives in research on young people is indispensable. Hence, conducting individual interviews with the adolescents was considered the appropriate methodology for gathering in-depth data to understand the adolescents' experiences of their diabetes care.

The interview guide was piloted with Swedish adolescents only. This is a shortcoming, because there might be relevant differences between Swedish and non-Swedish adolescents. However, the questions posed were of an open character, and some were specifically directed toward the informants' life situations. This left room for each informant to choose the issues that were relevant to him or her. Also, there are aspects of being a teenager that cut across cultural differences. Furthermore, before revising the interview guide, the results of the pilot testing were discussed with members of the research team holding medical and nursing expertise from treating non-Swedish children with diabetes.

Another concern is that the age of the participants varied between 13 and 18. These adolescents are in different stages of their development, both psychically and psychologically. The present sample was not large enough to allow stratification according to age. It should also be noted that the adolescents who were found to have integrated their diabetes as part of their personal prerequisites did not differ in age from the rest of the informants.

Our sample is a clinically based convenience sample; that is, we chose to interview adolescent patients of one clinic. It is possible that this procedure had an effect on the results, because patients in one clinic often live in the same area and have similar backgrounds. However, this clinic was a specialist children's diabetes clinic with a large catchment area. Also, the informants had backgrounds in several different countries.

Researchers always influence their object of study. As stated by Dahlberg, Drew, and Nyström (2001), it is also impossible to repress all influence from assumptions that a researcher can have. However, researchers are constrained to handle their own previous knowledge when data are analyzed. By the use of open questions, through applying a phenomenographic approach, and by involving several researchers with different academic backgrounds in the different stages of the analysis process, we strived to constrain this type of bias.

The present article focused on the meaning of the adolescents' experiences and their lifeworld (Marton & Booth, 2000). Although the subjective perceptions and the differences in these perceptions were in focus, some kind of essence of these phenomena can be captured because of the adolescents' shared experiences and interests. In future research, the validity of the findings should be further tested in a larger sample, as well as in diverse populations.

### **Conclusion and Implications for Practice**

Integration of the diabetes into daily life appears to be crucial for adolescents' adherence and sense of responsibility for self-care. Helping adolescents with T1DM to accept and integrate

their disease as part of their personal prerequisites is an essential task for caregivers. The fact that only a small portion of the informants showed signs of having integrated their diabetes indicates the need for improvements in the type of support from the caregivers, both to the adolescents and to their parents. The pediatric diabetes team's focus on HbA1c levels emotionally permeated the adolescents' perceptions of the clinic visits, specifically among the non-adherent group, and provided much negative feedback on their ability for and success of self-care. The focus on HbA1c levels in the clinic consultations with the adolescents might therefore impair the development of self-efficacy (Bandura, 1977) and thus be counterproductive to efforts to help them integrate the diabetes into their lives and assume control over self-care.

The model presented in Figure 1 promotes a PCC strategy. Pediatric diabetes teams can be helped by using the model as a basis for their discussions with the adolescent to identify and highlight the young person's supportive network and the constraints and opportunities for integrating the diabetes into everyday life.

**Author's note:**

No part of this article has been presented elsewhere.

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