

# Health care to empower self-care in adolescents with type I diabetes mellitus and an immigrant minority background

SAGE Open Medicine  
Volume 5: 1–8  
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DOI: 10.1177/2050312117700056  
journals.sagepub.com/home/smo



Åse Boman<sup>1</sup>, Margareta Bohlin<sup>2</sup>, Mats Eklöf<sup>3</sup>, Gun Forsander<sup>4,5</sup>,  
Christian Munthe<sup>6</sup> and Marianne Törner<sup>7</sup>

## Abstract

**Background:** The pediatric diabetes team aims to support health, quality of life, and normal growth and development among adolescents with type I diabetes mellitus. Adolescents with an immigrant background have been found less successful in self-care. Previous research indicated that adolescents who had integrated the disease as a part of their self-image reasoned differently about their self-care to those who had not.

**Objective:** The aim of this study was to identify elements in the patient–pediatrician consultations that might influence such integration of the disease among adolescents with type I diabetes mellitus.

**Methods:** A total of 12 pediatrician–adolescent consultations were video-recorded and analyzed. The adolescents all had an immigrant background.

**Results:** Integration of the disease appeared enabled when responsibility was shared; when hope, autonomy, and emotions were confirmed; and when the pediatrician asked probing questions. Letting objective data dominate the adolescent's experiences, using risk as a motivator, neutralizing emotions in relation to having diabetes, and confirming forgetfulness, may instead inhibit disease integration.

**Conclusion:** An extended person-centered approach with focus on the adolescent's experiences of everyday life with a chronic disease and less attention on physical parameters in the pediatrician–adolescent consultations may increase integration of the disease.

## Keywords

Adolescents, youth at-risk, diabetes, type I diabetes mellitus, healthcare professionals, phenomenography, self-care, immigrant

Date received: 15 September 2016; accepted: 21 February 2017

## Introduction

Type 1 diabetes mellitus (T1DM) is a common and demanding chronic disease among children and adolescents.<sup>1</sup> Diabetes self-care aims at near-normoglycemia but is not always successful, and chronic hyperglycemia is the primary cause of micro- and macro-vascular T1DM complications. Complications might cause much suffering and even premature death.<sup>2</sup> Self-care is demanding and minority-ethnic youths with T1DM are markedly less successful in self-care.<sup>3</sup> The multi-professional pediatric diabetes teams support their patients through education and counseling to empower the young individual in relation to challenges they meet. In the context of the psychological turbulence of adolescence, this is a recognized challenge.<sup>4</sup> To achieve optimal diabetes self-care, adolescents need to incorporate type 1 diabetes routines

<sup>1</sup>Department of Health Sciences, University West, Trollhattan, Sweden

<sup>2</sup>Department of Social and Behavioral Studies, University West, Trollhattan, Sweden

<sup>3</sup>Department of Psychology, University of Gothenburg, Gothenburg, Sweden

<sup>4</sup>The Queen Silvia Children's Hospital, Sahlgrenska University Hospital, Gothenburg, Sweden

<sup>5</sup>Institution of Clinical Sciences, Sahlgrenska Academy, University of Gothenburg, Gothenburg, Sweden

<sup>6</sup>Department of Philosophy, Linguistics and Theory of Science, University of Gothenburg, Gothenburg, Sweden

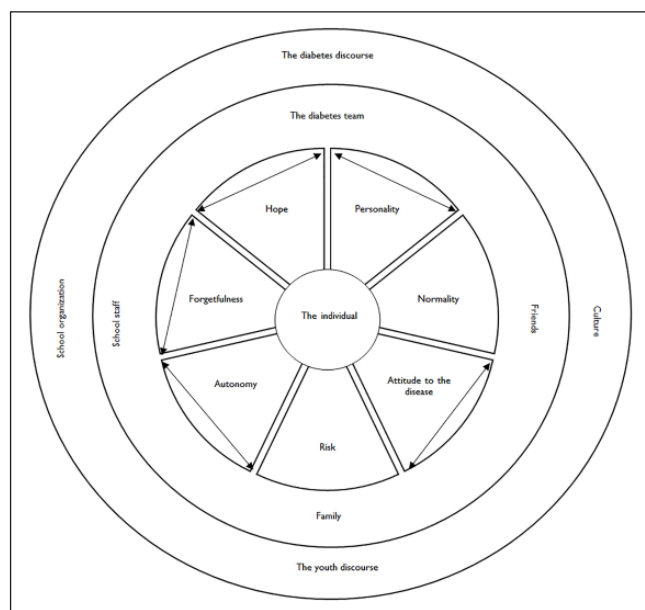
<sup>7</sup>Sahlgrenska Academy, University of Gothenburg, Gothenburg, Sweden

### Corresponding author:

Åse Boman, Department of Health Sciences, University West, Gustava Mellins Gata 2, SE-461 86 Trollhattan, Sweden.

Email: ase.boman@hv.se





**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. Published with kind permission from SAGE.

as a part of their daily life and to integrate diabetes into their identity.<sup>5</sup> Four different illness identity dimensions related to T1DM have been identified.<sup>6</sup> *Engulfment* and *rejection* refers to low illness integration where the adolescent's life situation either is invaded or dominated by the disease or the diabetes is rejected as a part of one's identity. This may lead to neglecting self-care.<sup>7</sup> *Acceptance* refers to the adolescent accepting the disease as a part of their identity.<sup>8</sup> *Enrichment*, finally, refers to the diabetes resulting in positive life changes that enables personal growth.<sup>9</sup>

### Diabetes in youths' reality

Based on the results of an interview study with adolescents with T1DM, where most had an ethnic minority background, a social ecological model,<sup>10</sup> Diabetes in youths' reality (DYR) (Figure 1), was presented, illustrating how the adolescents with T1DM reasoned regarding their disease in relation to their social context at the macro-level, that is, culture, societal discourses, and structures; the meso-level, that is, groups of peers and adults with whom they interacted frequently and directly; and (micro-level) themselves and their ability and motivation for self-care.<sup>11</sup>

Regarding the micro-level, the adolescents' reasoning could be categorized into seven themes. In two of these, all interviewed youths reasoned similarly, namely (1) *normality*, that is, the dilemmas in handling their social environment to live a normal life as teenagers, and simultaneously managing their self-care; and (2) *risk*, that is, the awareness of both short-term and long-term risks related to T1DM creating

much worry and anxiety. Concerning the other five micro-level themes, a difference appeared between two sub-groups. One sub-group appeared to have integrated the T1DM as part of their self-image. This sub-group (below called "integrated") also appeared to be more successful in self-care, manifest in a tendency to have a lower HbA1c-level, the standard index of glycemic control over the preceding period of 6–8 weeks. The other sub-group (below called "non-integrated") did not express such integration of the T1DM. Theme 3: *Attitude to the disease*. The integrated youths expressed that T1DM was a part of their life and that they were no different from others. The non-integrated disliked to talk about their disease and were hoping for a cure. Theme 4: *Personality*. The integrated youths described themselves as taking general responsibility for what is theirs, while the non-integrated described themselves as careless or "a bit wild." Theme 5: *Autonomy*. The integrated youths stated a wish to manage self-care in accordance with recommendations, while the non-integrated claimed that they wanted to do things their own way. ("Autonomy" is a notion that appears also in ethical analyses, however, there referring less to a psychological tendency of independence in relation to the biomedical goals of the care, and more to the ability [figuring in bioethical ideals] of patients to make well-founded decisions and perform self-care in accordance with whatever decisions they make [Munthe, Sandman and Cutas, 2012]).<sup>12</sup>

Theme 6: *Forgetfulness*. The integrated youths stated that they did not think about the disease all the time, but never forgot about it, while the non-integrated meant that it is normal and acceptable for youths to forget things, and that forgetting may relieve the burden of being ill.

The non-integrated adolescents' reasoning concerning themes 4–6 might be expressions of an attempt to reduce cognitive dissonance<sup>13</sup> because of lack of perceived control.

Perceived control, an important antecedent of behavioral intentions,<sup>14</sup> was found positively related to risk perception and health behavior among adolescents.<sup>15</sup> In diabetes care measures indicating metabolic control is routinely fed back to patients, and negative feedback may decrease perceived control and induce mental stress.<sup>16</sup>

Theme 7: *Hope*. The integrated youths expressed that what they already did in terms of self-care could always be further improved, while the non-integrated stated that there was hope because there is always room for a second chance to improve self-care.

Helping adolescents with T1DM to accept and integrate their disease as part of the self appears as an essential task for caregivers and custodians.<sup>11</sup> This is particularly so for youths with an immigrant background, since they often have less access to supportive resources; therefore are particularly vulnerable; and, in general, are less successful in their self-care. An empowering approach, with the aim to enable these patients to take control over their own health, helping them to identify their resources, and recognize their knowledge of everyday life with the disease, would then be fruitful.<sup>17</sup> This

**Table 1.** Median age, origin and gender.

Participants	Girls	Boys	Total
Non-European	6	3	9
Median age	15	15	15,5

means focusing on patient participation and collaboration in the patient–healthcare professional meeting.<sup>18</sup> In the study by Boman et al., the adolescents with T1DM experienced the pediatric diabetes team as supportive, but also much anxiety in relation to visits to the diabetes clinic, due to anticipation of non-satisfactory HbA1c levels. The HbA1c level is a strong and reliable indicator of the success of self-care but may provide negative feedback on the adolescent’s ability, especially among the non-adherent youths. This might invoke defensive reactions and counteract acceptance and integration of the disease as part of the self-image.

This study is following up on the results acquired in the previous study,<sup>11</sup> relating the findings presented in the DYR model to concrete elements in the actual consultations between teenagers with an immigrant background and their pediatrician.

The aim of this study was to identify concrete elements in the patient–pediatrician consultations at the pediatric diabetes outpatient clinic that might promote or inhibit empowerment and thus integration of the disease as part of the self-image among adolescents with T1DM. The study specifically focused on adolescents with an ethnic minority background.

## Methods

The study had a qualitative design with a phenomenographic approach. In all, 12 regular patient–pediatrician consultation meetings (December 2010 to December 2011) between caregivers and adolescent T1DM patients at the pediatric diabetes outpatient clinic at a major pediatric hospital in Sweden were studied to identify (1) existing elements that might be elaborated to promote integration of the disease, (2) hints or attempts from the adolescents that might provide cues to promote integration of the disease, and (3) disempowering elements.

### Participants

In this study, patient–physician appointments with two teenaged boys and one girl treated for T1DM and with parents born in Sweden were audio- and video-recorded in a pre-study aiming to identify any technical or recording problems. Subsequently, all adolescents 13–18 years old with parents born in a non-Nordic country were invited to participate (n=24). Nine accepted (see Table 1). The teenagers in the pre-study and the full-scale study all lived in the same catchment area. At the time of the study, there

were 400,000 inhabitants in the catchment area, of whom 118,000 were born abroad. The nine participating immigrant adolescents of non-Nordic origin, of whom six were girls, had a mean age of 15 years and a HbA1c-value of 61.8 mmol/mol (standard deviation (SD), 12.7). The mean value of all of the patients at the clinic (N=505) was 64.6 mmol/mol. Five of the patients used continuous subcutaneous insulin infusion (CSII), and the others used multiple daily injections (MDI) as insulin treatment regimen. No one showed any sign of micro- or macro-vascular complications. Four pediatricians participated. All adolescents and medical staff spoke Swedish. A parent was present at 11 of the consultations.

### Procedure

Parents and adolescents were contacted by the clinic. After receiving written information about the study, both parents and the adolescents themselves consented to participation. Regular appointments with their physician (0.5–1 h) were audio- and video-recorded, but in a room specially prepared to facilitate the recordings. The videos were observed several times by the research team and the audio and video recordings were also transcribed verbatim.

### Instrument and analysis

Phenomenography was chosen for the analysis, as it aims to reveal variations in peoples’ perceptions and experiences.<sup>19</sup> In focus were people’s subjective experiences and their descriptions of the meaning of how the world is constituted. An informant might express an experience as reflected or non-reflected; even so, it constitutes the foundation on which people build their reasoning.<sup>20</sup> In the analysis, we aimed to describe the varying differences and similarities in statements. First, all members of the research team watched the video recordings. The first two authors watched them together and took systematic notes of the patient–pediatrician interactions and statements. The themes in the DYR model were used as an observational protocol, with a particular focus on the five micro-level themes *hope, forgetfulness, personality, attitude to the disease, and autonomy*. Subsequently, the entire research team discussed the systematic notes, until consensus was reached on the thematic interpretation of the data. Second, the first two authors once again watched the video recordings and specifically noted empowering and disempowering interactions related to each identified theme that could support or impede integration of the disease as part of the self-image (Table 2). Empowering and disempowering interactions were identified by the use of statements in the interview, the earlier study by Boman et al.<sup>11</sup> and processes in social interactions in relation to the human ecological model by Bronfenbrenner.<sup>10</sup> Finally, the entire research team discussed the results, and the analysis was developed further until consensus was reached and that

**Table 2.** Length of video recordings (VR) and themes consistent with the DYR-model that emerged from each session.

Themes	Pre-study			Main study									
	VR1	VR2	VR3	VR4	VR5	VR6	VR7	VR8	VR9	VR10	VR11	VR12	VRm
Duration (min) counseling	30	19	42	52	35	58	40	53	47	37	58	61	44
Micro-level themes integrated													Sum themes
Hope	x	x		x			x		x		x	x	7
Forgetfulness				x	x					x		x	4
Personality	x	x			x					x			4
Attitude dis	x				x		x	x					4
Autonomy										x	x		2
Micro-level themes non-integrated													
Risk	x	x	x	x		x	x	x	x	x	x		10
Normality										x	x		2
Meso-level themes													
Family	x	x			x	x				x	x	x	7
Diabetes team			x		x		x			x	x		5
School staff				x				x					2
Friends													0
Macro-level themes													
Diabetes discourse	x	x	x	x	x	x	x	x	x	x	x	x	12
Youth discourse	x			x			x			x			4
School org.					x						x		2
Culture						x							1
Sum themes	7	5	3	6	7	4	6	4	3	9	8	4	

no utterances were disregarded. The data were considered saturated by the research team.

### Ethical considerations

The Swedish regional ethics review board in Gothenburg approved the study (registration number 532-10). The researchers took care to ensure that all adolescents and their parents were well informed about the purpose of the study and that the adolescents were comfortable with the set-ups of the caregiver/patient sessions. The adolescents and their parents were informed that their participation was voluntary and that they could terminate their participation at any time. Discretion and confidentiality were guaranteed. After the sessions, as well as in the informational letter, we gave the adolescents and their parents the research team's contact data in case more information about the study was desired. The researchers concealed all names and places in the transcripts to ensure confidentiality of the participants and archived the video recordings and transcripts in a secure place.

### Results

In all consultations, the pediatrician initiated and led the conversation. The themes at the meso-level could all be discerned but were sparingly mentioned and will not be further presented. In the three pre-study video recordings, with Swedish adolescents, eight themes emerged: hope, personality, attitude to the disease, risk, family, the diabetes team, the

diabetes discourse, and the youth discourse. No differences were found in how these themes emerged in the pre-study and the full-scale study.

### Macro-level

*The diabetes discourse*, that is, salient knowledge on what diabetes is and how it should be managed, was a theme in all consultations. It dominated the dialogues and was introduced by the pediatricians. It was presented in a normative way, and three variations were identified: (1) education and knowledge control; (2) responsibility for the disease outcome, where often the responsibility was attributed to be the young person; and (3) an emotional valuation of having the disease. The latter emerged in few situations and was initiated by the doctor or the parent, who then generally confirmed and legitimized the adolescent's emotions. In most consultations, however, the subject of emotions toward the disease was not introduced.

### Micro-level

*Risk* was the most dominating theme, and three variations were identified: (1) education and knowledge control, where the adolescents were asked to present their knowledge of hazards that might occur later in life, and their eating, smoking, and alcohol habits were probed; (2) the adolescents' experience of physical complications since the last meeting; and (3) consequences of risk behavior. The situations were

discussed and related to the context in which they had occurred, mostly by the parents and the doctors. One adolescent had a pronounced non-adherent behavior and the doctor explicitly announced possible consequences.

*Hope* was the second most frequent micro-level theme. Some adolescents expressed reassurance of their ability and motivation to improve their self-care and reach goals set by themselves and the doctor. Hope was expressed in terms of positive physical improvement related to the biomedical treatment goals, and the patients' own ability to take responsibility for achieving these. Sometimes these opportunities were seized by the pediatrician responding reassuringly.

When the adolescents expressed hope, or lack of such, the doctors acted by: (1) confirming the hope, and expressing belief in the adolescent's capacity: Doctor 4 (D4): "Yes. This is definitively right. You are absolutely on the right track, good work."; (2) confirming hope by suggesting technical equipment as a possibility for improvements: D2: "You're doing well, this will be OK but it will also improve when we introduce the pump."; or (3) disconfirming hope by letting data from the physiological parameters dominate over the adolescents' statements: Girl 2 (G2): "Well, anyway, today's [values] are better than before, aren't they? D3: "According to the graph, it has not worked so well."

*Forgetfulness* was brought up in four consultations, where the adolescents used it as an explanation for not having performed successful self-care. When forgetfulness emerged, the doctors acted either by (1) discussing memory as rationally controllable, and focus on devices that could help the adolescent to remember or by (2) considering forgetfulness as the result of complex psychological processes. The doctors then asked probing questions about situations and distractions: D1: "When do you forget, in what situations? Why do you think you forget?"

*Personality* was identified in four consultations. In one, the adolescent referred to it to explain non-successful self-care:

B5: I inject insulin after meals, I have always done so and that is how I do it. It's my way to do it.

In three, the doctors initiated the theme and sometimes actively used it to become better acquainted with the adolescents on a deeper level and to investigate how to improve motivation for self-care. This is displayed in attempts to become better acquainted with the adolescents on a deeper level by asking them to describe themselves and link that to their motivation for self-care:

D1: What is it that could make you more interested in taking more tests? What are your interests? What do you want to do?  
B3: I'm a soccer player, I like soccer. D1: Are you good? B3: Yes. D1: Do you want to perform better? B3: I always want to improve myself, I train several times a week.

*Attitude to the disease* was identified in four consultations, expressed on the spectrum from experiencing no problems at all, to exasperation. When the adolescents expressed exasperation with being ill and being compelled to follow specific routines, the doctors acted in three different ways: (1) using open and probing questions to capture the specific problems, and the adolescent's thoughts; (2) normalizing the feeling of exasperation: D3: "You know, a lot of young persons with this disease think like that, it is very common. I hear it all the time"; and (3) confirming emotions and showing empathy: D4: "I do understand you, I know a lot about diabetes but I don't know what living with it is like, but I really do understand your situation."

*Autonomy* was identified in two consultations. In both, the adolescents declared able to manage their self-care, by trying to prove this to the doctor, or by a mere statement of autonomy: G5: "I like to do things my way, I want to have the control, and I want to know I'm in control." In one of these consultations, the adolescent was successful in her self-care and the doctor confirmed her autonomy: D4: "Yes, you're old enough now. You can do it by yourself, that's for sure." In the other, the adolescent was less successful in his self-care. The doctor pointed out the risk for long-term complications and tried to convince him to be more adherent to treatment. This caused the boy to even more assert his right to autonomy (Again, note that this use of "autonomy" differs from that in healthcare ethical ideals. What the boy insists on is what in ethics would be termed *independence*—whether or not he uses that for making and adhering to well-founded decisions (that is act in accordance with ethical ideals of autonomy) is an open question): Boy 5 (B5): "I do it my way. It's my will and my life. I do what I want."

## Discussion

### *The diabetes discourse, risk, and responsibility*

The diabetes discourse and risk dominated and impregnated most of the consultations, both by content and time. The adolescents were taught the physiology of the disease and how to handle different disease-related conditions. The patients' self-care knowledge was also controlled within such a perimeter. This concurs with previous research, where T1DM management guidelines were found to emphasize a medical discourse rather than the patient perspective.<sup>21</sup> Patients' HbA1c-values are reported to national registers used for comparison between clinics of the patient outcome data, which may enhance the domination of biomedical issues. The young patients seemed able to intellectually understand what they were told, but to have problems to situate such knowledge in their own lives. Little time was left over for probing the adolescents' needs in relation to such integration and supporting cognitions and emotions that might be essential for such progress. Positive emotional feedback to promote the internalization of care goals, and the sense of ability to manage self-care, is hindered if risk dominates the agenda.<sup>22</sup> If the threat to future health is not mastering

self-care is understood, but the individual feels unable of such mastery, this may induce cognitive dissonance.<sup>12</sup> To reduce stress, the person may deny the risk, or own inability to control it, and thereby legitimize refraining from active and persistent self-care. In contrast, improving perceived control is likely to empower the youths. Self-care is demanding and minority-ethnic youths are, generally, less resourceful and therefore in greater need of empowering support from the healthcare team. The young person's responsibility must then be balanced with perceived ability, giving more room for reassurance and positive feedback and careful and piecemeal allocation of responsibility for the self-care. The custodians are important here. Although a major goal of adolescence is to achieve a sense of autonomy,<sup>23</sup> shared responsibility between parent and adolescent is associated with better psychological health, good self-care, and metabolic control.<sup>24</sup> Low perceived control may be reinforced by the dominance of the risk theme where central needs of the young person are not acknowledged, for example, if attainment of social goals is perceived as incompatible with prescribed self-care. Increased pressure to adhere is then likely to invoke even more pronounced resistance. This emphasizes the need to allocate time and attention to issues highlighting the young person's life, interests, and thoughts, reducing the conflict between self-care and social needs.<sup>22</sup>

### *Affirming and normalizing*

The analyses showed many examples of the doctor affirming and normalizing the young person's negative emotional response to having a chronic disease, offering emotional support. This helps the crisis management necessary for reaching acceptance of the disease. Compassion relieves the pressure on the young person and may thereby reduce the urge to achieve cognitive consonance through risk denial. When, instead, the doctor fails to affirm the fears and other negative feelings toward the disease, the emotions of the patient are blocked from the conversation. This would discourage the adolescent to bring up existential questions and the integration process might be inhibited. Research by Erickson et al.<sup>25</sup> suggests that adolescents with a chronic illness are more inclined to engage in destructive behaviors and may have lower self-esteem and more feelings of emptiness. From an existential perspective, people need to be able to actively influence their lives. Powerlessness may cause anxiety, a feeling of alienation and attempts to remedy feelings of emptiness in a destructive way.<sup>26</sup>

The results of Erickson et al.<sup>25</sup> also indicate that feedback interventions should be managed with great care for patients with low self-esteem and anxiety because such interventions may worsen these problems.

### *To motivate and empower*

The focus on physiological parameters was prominent when it came to motivating the adolescents to adapt and adhere,

and pedagogical approaches as a ground for change in health behavior were less common. This imbalance is in line with previous research. Both Grey<sup>27</sup> and Savage et al.<sup>28</sup> have identified educational interventions in pediatric diabetes healthcare to focus on the content rather than the pedagogic performance and seldom being based on motivational theory. The type of motivational strategy used by the caregivers should be adjusted to each individual, requiring mapping, probing, and understanding of the type of factors indicated above.<sup>22</sup> It should also, in accordance with the trans-theoretical model,<sup>29</sup> be attuned to the specific stages of a behavioral change process. While stressing risks of future complications might result in withdrawal and resignation in youths who do not perceive to be able to control the risks, such information can motivate those who do. Lack of knowledge about risks does not seem to explain inadequate self-care,<sup>11</sup> but the group of adolescents in the study, who performed more successful self-care, appreciated reminders from the doctor of the risk of long-term complications. This motivated them for sustained effort. Successful self-care will increase the sense of self efficacy<sup>30</sup> and control. Emphasizing risk, but always in step with perceived control, might thus motivate those who are progressing well in self-care. Increasing risk perception in those who are less successful is, instead, likely to demotivate and further disempower them.

Empowerment was promoted when the doctors acknowledged the young individual's personal resources<sup>17</sup> and reassured the adolescents that the physiological parameters were possible to improve through the young person's abilities and efforts. However, even if being reassured of the good work done (e.g. keeping up good levels of HbA1c), other reassurance is necessary, especially by acknowledging the existential questions that follows a chronic disease. Sometimes the adolescent actively sought for positive feedback and reassurance. Such invitations present good opportunities for the caregivers to offer encouragement to sustain and intensify the strive for improvement.

When hope was legitimized and confirmed, this appeared to promote empowerment. This, in turn, would promote the integration of the disease. Previous research showed that adolescents who had integrated the disease in their self-image expressed hope as a potential to further improve the quality of already successful self-care.<sup>11</sup> When, instead, the physiological parameters dominated the consultations, hope was diminished. In letting biological facts dominate over the person's subjective experience of the situation, the adolescent might become objectified, and thereby less enabled to take control over the own health and life situation.<sup>18</sup>

Forgetting, as an explanation for less successful self-care, was used by doctors, parents, and adolescents. By normalizing forgetfulness as an insusceptible trait of youths in general, the adolescent might be deprived of the opportunity to act. Also, by confirming forgetfulness as an adequate explanation, the doctor indicates the disease as something external that might be forgotten. This could inhibit integration of the

disease in the self-image. When instead probing questions were posed about the type of situations when the youth forgets and the young person's reasons for forgetting, the doctor opened up for empowering support, identifying the young person's own psychosocial skills.<sup>31</sup>

When the adolescent's personality was explored, searching ways to increase self-care quality, this was empowering. Making efforts to know the young person, to provide opportunities to engage the adolescent as an active partner, means a person-centered approach. This has shown to improve concordance between care provider and patient regarding treatment plans.<sup>32</sup> However, to be effective for patients who are initially less in control, such an approach also requires emotional support.<sup>22</sup>

In some consultations, the adolescent wished to prove own achievements to the doctor. Non-adherence to the self-care regimen induced regrets of having let the caregivers down. This is obviously something the caregivers need to be observant to. Feelings of guilt and shame are not likely to support a good patient-caregiver relation. Common to all consultations were the adolescents' reluctance to speak and to actively participate in the meetings. This may be due to not feeling entirely comfortable in the artificial situation of video recording, but it may also be an expression of disempowerment, experiencing little opportunity to influence the situation. According to Aujoulat et al.,<sup>31</sup> empowering methods of education in healthcare of patients with chronic conditions are necessarily person-centered, and the provider-patient relationship needs to be continuous and self-involving on both sides.

In this study, we focused on adolescents with a non-Swedish background because immigrants have proven to be less successful in metabolic control.<sup>33</sup> The teenage period is a dynamic and demanding time for most. Families with an immigrant background have often sought refuge from oppression and war. Often these families struggle with trauma and are socio-economically underprivileged. Teenagers in such families are particularly vulnerable, and have less supportive resources available, than their peers. The results of the study indicate several concrete ways in which the healthcare team may empower these adolescents, to believe in their own ability to improve their diabetes self-care. The results are, however, likely to be relevant also to native adolescents with T1DM or other chronic illnesses demanding active self-care.<sup>14</sup>

### *Strengths, limitations, and ethics*

Both adolescents and pediatricians were aware that their conversations were video-recorded which might have influenced the dialogue and the openness under the sessions. We tried to minimize this bias by meticulous information about ethics and by explaining the purpose of the study.

As the age of the participants varied between 13 and 18, they were in different stages of their development. The size

of the present sample did not allow stratification according to age, and the aim of the study was not to describe a developmental process over time.

The sample comprised patients and pediatricians in one clinic only, although with a large catchment area. However, the aim of the study was not to describe pediatric diabetes consultations in a representative manner, but to capture elements of such consultations that can support or impede integration of T1DM as part of the adolescents' self-image.

## **Conclusion and practice implications**

Adolescents with T1DM with an immigrant background are often particularly vulnerable and in extra need of support from the healthcare team to master their self-care. Empowering the youths, to feel able to successfully take on the demanding T1DM self-care, is essential to support integration of the T1DM into their self-image. Concrete ways for the pediatrician to support empowerment and the young person's ability to be an active partner in the consultations were identified as: sharing the responsibility for care with the adolescent, requiring the young patient, in a stepwise manner, to take on self-care tasks that they perceive as being within their ability; affirming existential brooding and feelings related to having a potentially lethal, chronic disease; keeping the focus on the adolescent's experience of living with diabetes type 1, and not letting biomedical data dominate the dialogue; bringing up risks in the consultation only to the extent that the adolescent feels able to control them; confirming hope; asking probing questions about the adolescents' personal situation and experience of having diabetes; and confirming the young persons' autonomy.

## **Acknowledgements**

We thank Ann-Katrine Karlsson for invaluable practical research support.

## **Declaration of conflicting interests**

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## **Ethical approval**

Ethical approval for this study was obtained from the Swedish regional ethics review board in Gothenburg, registration number 532-10.

## **Funding**

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by The Swedish Child Diabetes Foundation, the University of Gothenburg Centre for Person-centred Care (GPCC), Sweden. GPCC is funded by the Swedish Government's grant for Strategic Research Areas, Care Sciences (Application to Swedish Research Council nr 2009-1088), co-funded by University of Gothenburg, Sweden, and the Swedish Research Council (VR)

and the Swedish Research Council for Health, Working Life and Welfare (FORTE), contract no. 2014-4024, for the project Addressing Ethical Obstacles to Person Centred Care.

### Informed consent

Written informed consent was obtained from all subjects before the study, and verbal informed consent was obtained from all subjects before the study.

### References

- Fowler MJ. Microvascular and macrovascular complications of diabetes. *Clin Diabetes* 2008; 26: 77–82.
- Nathan DM, Cleary PA, Backlund JY, et al. Intensive diabetes treatment and cardiovascular disease in patients with type 1 diabetes. *N Engl J Med* 2005; 353: 2643–2653.
- Hoey H. Psychosocial factors are associated with metabolic control in adolescents: research from the Hvidoere Study Group on Childhood Diabetes. *Pediatr Diabetes* 2009; 10: 9–14.
- Wolpert HA and Anderson BJ. Young adults with diabetes: need for a new treatment paradigm. *Diabetes Care* 2001; 24: 1513–1514.
- Silverstein J, Klingensmith G, Copeland K, et al. Care of children and adolescents with type 1 diabetes: a statement of the American Diabetes Association. *Diabetes Care* 2005; 28: 186–212.
- Oris L, Rassart J, Prikken S, et al. Illness identity in adolescents and emerging adults with type 1 diabetes: introducing the illness identity questionnaire. *Diabetes Care* 2016; 39: 757–763.
- Tilden B, Charman D, Sharples J, et al. Identity and adherence in a diabetes patient: transformations in psychotherapy. *Qual Health Res* 2005; 15: 312–324.
- Morea JM, Friend R and Bennett RM. Conceptualizing and measuring illness self-concept: a comparison with self-esteem and optimism in predicting fibromyalgia adjustment. *Res Nurs Health* 2008; 31: 563–575.
- Helgeson VS, Reynolds KA and Tomich PL. A meta-analytic review of benefit finding and growth. *J Consult Clin Psychol* 2006; 74: 797–816.
- Bronfenbrenner U. *The ecology of human development: experiments by nature and design*. Cambridge, MA: Harvard University Press, 1979.
- Boman Å, Bohlin M, Eklöf M, et al. Conceptions of diabetes and diabetes care in young people with minority backgrounds. *Qual Health Res* 2015; 25: 5–15.
- Munthe C, Sandman L and Cutas D. Person centred care and shared decision making: implications for ethics, public health and research. *Health Care Anal* 2012; 20: 231–49.
- Festinger L. *A theory of cognitive dissonance*. Palo Alto, CA: Stanford University Press, 1962.
- Ajzen I. The theory of planned behavior. *Organ Behav Hum Dec* 1991; 50: 179–211.
- Larsman P, Eklöf M and Törner M. Adolescents' risk perceptions in relation to risk behavior with long-term health consequences; antecedents and outcomes: a literature review. *Safety Sci* 2012; 50: 1740–1748.
- Kluger AN and DeNisi A. The effects of feedback interventions on performance: a historical review, a meta-analysis, and a preliminary feedback intervention theory. *Psychol Bull* 1996; 119: 254–284.
- WHO. *Ottawa charter for health promotion*. Geneva: WHO, 1986.
- Zimmerman MA. Empowerment theory. In: Rappaport J and Seidman E (eds) *Handbook of community psychology*. New York: Springer, 2000, pp. 43–63.
- Marton F. Phenomenography—describing conceptions of the world around us. *Instr Sci* 1981; 10: 177–200.
- Marton F and Booth S. *Om lärande*. Lund: Studentlitteratur, 2000.
- Boman Å, Borup I, Povlsen L, et al. Parents' discursive resources: analysis of discourses in Swedish, Danish and Norwegian health care guidelines for children with diabetes type 1. *Scand J Caring Sci* 2012; 26: 363–371.
- Herlitz A, Munthe C, Torner M, et al. The counseling, self-care, adherence approach to person-centered care and shared decision making: moral psychology, executive autonomy, and ethics in multi-dimensional care decisions. *Health Commun* 2016; 31: 964–973.
- Shaffer D and Kipp K. *Developmental psychology: childhood and adolescence*. Boston, MA: Cengage Learning, 2013.
- Helgeson VS, Reynolds KA, Siminerio L, et al. Parent and adolescent distribution of responsibility for diabetes self-care: links to health outcomes. *J Pediatr Psychol* 2008; 33: 497–508.
- Erickson JD, Patterson JM, Wall M, et al. Risk behaviors and emotional well-being in youth with chronic health conditions. *Child Health Care* 2005; 34: 181–192.
- May R. Anxiety and values. *Series in Clinical & Community Psychology: Stress & Anxiety* 1982; 8: 13–21.
- Grey M. Interventions for children with diabetes and their families. *Annu Rev Nurs Res* 2000; 18: 149–170.
- Savage E, Farrell D, McManus V, et al. The science of intervention development for type 1 diabetes in childhood: systematic review. *J Adv Nurs* 2010; 66: 2604–2619.
- Prochaska JO and DiClemente CC. Transtheoretical therapy: toward a more integrative model of change. *Psychother* 1982; 19: 276.
- Bandura A. Self-efficacy: toward a unifying theory of behavioral change. *Psychol Rev* 1977; 84: 191–215.
- Aujoulat I, D'Hooore W and Deccache A. Patient empowerment in theory and practice: polysemy or cacophony? *Patient Educ Couns* 2007; 66: 13–20.
- Ekman I, Swedberg K, Taft C, et al. Person-centered care—ready for prime time. *Eur J Cardiovasc Nurs* 2011; 10: 248–251.
- Borschuk A and Everhart R. Health disparities among youth with type 1 diabetes: a systematic review of the current literature. *Fam Syst Health* 2015; 33: 297–313.