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RESEARCH ARTICLE

A qualitative study of motivation to self-management in pediatric diabetes health care consultations with adolescents with type 1 diabetes.

Rose Marie Teyken^{1*}, Johanne Jeppesen Lomholt², Anders Jørgen Schou³

¹cand. psych., Aarhus University

²cand. psych., ph.d., associate professor, Aarhus University

³cand. med., ph.d., consultant paediatrics, H.C. Andersen Hospital.

*rose.teyken@gmail.com

ABSTRACT

Background. The impact of health care professionals on the motivation for self-management in adolescents with type 1 diabetes has been highlighted as important. It is, however, not well understood how health care practitioners can help increasing motivation to self-management. The aim of the study was to investigate how practitioners can motivate their patients to self-management in consultation and how adolescents with type 1 diabetes experienced that consultation could facilitate motivation to self-management.

Methods. The study triangulated participant observations of 11 consultations at a pediatric health care clinic and 10 interviews of the adolescents (age 15-17) about their experiences of consultations. The analysis showed five categories: 1. Consultation dialogue, 2. Roles in treatment, 3. Assuming consultation-facilitated responsibility for self-management, 4. Relationship in treatment, and 5. Consultation context.

Results. Overall findings showed that the adolescent's developmental process of becoming autonomous in relation to self-management was influenced by consultations, and that the need of feeling related was experienced as valued by the adolescents.

Conclusions. The feeling of relatedness and development of autonomy were experienced as important for how consultations could facilitate motivation to self-management in 15-17-year-olds and may be fundamental to adolescents' experience of competence in relation to self-management.

Keywords: type 1 diabetes, qualitative research, self-management, adolescent, health care professional, consultation, motivation, phenomenological research.

Introduction

Metabolic control and management is an ongoing task for patients with type 1 diabetes (T1D)¹. The Danish Diabetes Database showed that 61% of children with T1D reached the treatment goal of HbA1c \leq 59 mmol/mol in 2019/2020². The patient's self-management is an important part of reaching the treatment goal, thus minimizing diabetes-related complications. Self-management of T1D in youth was defined by Schilling et al.³ as "an active, daily, and flexible process in which youth and their parents share responsibility and decision-making for achieving disease control, health, and well-being through a wide range of illness-related activities"³ (p. 92). Studies show that many children struggle with managing their diabetes and experience psychological stress related to their treatment⁴ and youth with T1D are at a higher risk of experiencing psychological problems compared to their peers⁵. Moreover, even optimal self-management cannot guarantee good metabolic control¹ as adolescents more often experience problems related to reaching an optimal level of HbA1c due to physiological and psychological changes^{6,7}. Health care professionals may play a significant role in motivating patients' self-management. According to the International Society for Pediatric and Adolescent Diabetes (ISPAD), "Developing a trusting and motivating relationship between health care professionals and the adolescent patient and maintaining continuity may result in better patient self-care"⁶ (p. 245). How practitioners can affect their patients' motivation to change behavior has been studied extensively using the Self-Determination Theory (SDT)^{8,9}.

According to the SDT, three innate motivational needs are the foundation for our motivation and integrity in behavioral changes¹⁰: the needs for autonomy, competence and relatedness⁹. According to Ryan et al.⁹, the health care climate is partly accountable for the fulfilment of these needs as practitioners can facilitate the patient's motivation to health-related behavioral changes by creating an autonomy supportive health care climate. Ng et al. compared 184 independent data sets that used SDT in a health care setting and concluded that SDT could be successfully used as a conceptual framework for understanding patients' motivation to behavioral change⁸. However, none of the studies in Ng et al.'s⁸ review investigated SDT in relation to adolescents with T1D.

The aim of the present study was to investigate how practitioners can motivate their patients to self-management during consultation, and how adolescents with T1D experienced that consultations could facilitate motivation to self-management.

Material and Methods

DESIGN

The study used triangulation as a method, collecting participant observations of the adolescents' consultations at a Pediatric Diabetes Care Unit (PDCU), and subsequently interviewing the adolescents about their experiences of the consultation. According to Denzin¹¹, triangulation can help validate theoretical interpretations of the data by giving the participants the possibility to object to the investigator's interpretation of the observational data.

PARTICIPANTS AND DATA COLLECTION

Data was collected in January and February 2018 by first author. The recruitment pool was based on the patients scheduled for appointment and participants were recruited in the waiting room prior to their consultation at the PDCU. Inclusion criteria were: T1D diagnosis, age between 15 and 17, and verbal and mental ability to participate in the interview. One adolescent declined participation in the study. Eleven adolescents agreed to have their consultation observed. Observations were made behind the adolescent and their parents to make as little intrusion as possible on the normality of the consultation, but also to signal to the family that the aim was to take their point of view. The general guidelines for consultations at the PDCU for this age group, focused on a dialogue based on the adolescent's blood measurements and insulin intake since the last

consultation and on a judgement of their HbA1c. Parents are encourage to leave the consultation, so the adolescents will get used to managing the consultations on their own. Interviews were either collected right after the consultation at the PDCU (n=2) or by telephone one of the following days (n=8). Due to miscommunication, one participant was not interviewed. All interviews were recorded and lasted between 19 and 35 minutes. The interview guide was developed to this study and is included as an additional file. The interviews were semi-structured to allow observations made during consultations to be discussed with the interviewee allowing a triangulating validation between observational and interview data¹². All interviews were recorded with consent from the interviewees and deleted upon transcription. Demographic characteristics of the participants are presented in table 1.

Table 1: Participant characteristics

Gender	Mean age	Age median	Mean number of years since onset of diagnosis
Female (n=6)	15.7	15.5	10
Male (n=5)	16.6	17	6.8

DATA ANALYSIS

The data analysis was conducted by the first author according to Giorgi's phenomenological analysis method¹³. This method is based on Husserl's phenomenological philosophical idea of observing phenomena as they are experienced, not as they are objectively speaking¹³. According to Giorgi this is the starting point from which the essence of a phenomenon can be sought and described¹³. In accordance with the method, all data transcripts were read to understand the

overall meaning attributed to the phenomenon. Then units of meaning about the phenomenon were derived from the text. Lastly, these units were changed into phenomenologically and psychologically sensitive expressions that could be generalized into themes. The method was used to analyze both observational data and interview data separately. According to Denzin data triangulation is the use of several different forms of data to illuminate the same phenomenon during analysis¹¹. The present study sought triangulation through

categorization. This was done by including both themes from the observational data analysis and themes from the interview data

analysis in five overall categories. Figure 1 gives a visual example of the analysis process.

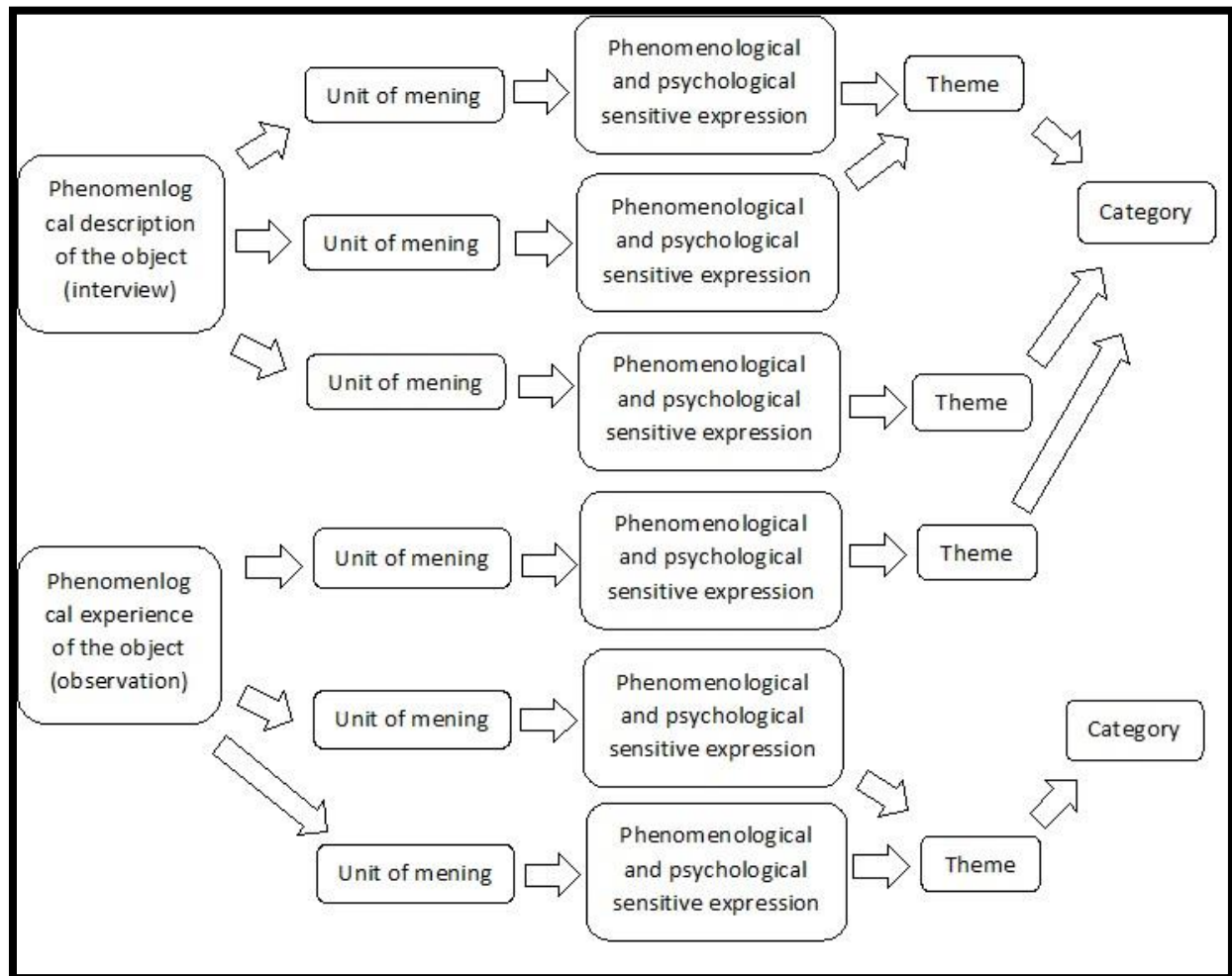


Figure 1: The analysis process

Results

As presented in Table 2, the data analysis revealed that the phenomenological experiences connected with consultation-facilitated motivation to self-management of T1D in 15- to 17-year-olds could be organized in the following five categories:

1. CONSULTATION DIALOGUE

According to the observations, the following characterized consultation dialogues at the PDCU: First, the practitioners generally

praised the patients for their commitment to treatment, especially while controlling the patient's blood sugar measurements since last consultation. Second, the practitioners used part of the consultation to talk with the patients about other things than diabetes like the weather, school, friends, transportation to the hospital, the future, and hobbies. Third, at times the practitioners normalized the difficulties that patients from this age group could experience, such as following treatment plans, remembering to measure blood sugar,

or thinking that it was unfair that they had diabetes. Fourth, at times the practitioners acknowledged that it could be difficult having diabetes or answering practitioners' questions during consultation and, finally, the practitioners generally discussed diabetes-related issues, and future changes in treatment, but also other subjects of interest to this age group, e.g. alcohol intake and transition to adult care.

As illustrated in the quote below, some of the interviewees said that the dialogues about other things than diabetes were important, because it made them feel like they were not just perceived as patients by the practitioners.

It becomes a bit more personal. I feel like I don't just go see a doctor and a nurse, because they try to understand who I am as a person and I like that. (Boy, 16)

According to one interviewee, it also made sense because the things that troubled her everyday life would naturally affect her self-management. To these adolescents, the practitioners' interest in their lives was motivating to self-management. However, one interviewee only experienced the dialogue about other things than diabetes as mere small-talk.

To some interviewees, it was important that the practitioners listened to them, making them feel respected as equals in their diabetes treatment, even though their choices were not always what was best for their HbA1c level.

If they told me "you must eat in the morning or else...", I'd have told them "I don't think it's okay you're telling me that", but I think they respected what I said. (Boy, 16)

The first time we agreed that I should try to manage it myself I just don't think I was old enough, because it didn't look pretty, but the advice and motivation they gave me helped me do what I do today, helping me being good enough at controlling it. (Boy, 16)

According to these statements, the adolescents experienced that the practitioners acknowledged their autonomy and to some interviewees this made it easier for them to adjust to the practitioners' advice as compared to advice from their parents. However, a group of interviewees had experienced that in the past practitioners had spoken harshly to them during consultations. For most of these adolescents, this had made them less motivated to self-management.

Personally, I don't feel like doing it when I'm told off, as compared to when they say: "we believe you can do it". (Girl, 15)

One adolescent said, however, that it made her realize she needed to do more.

It made me sad, which they also realized, but it wasn't because of the way they said it, it was because I hadn't done a better job. I was disappointed with myself because I thought I was doing okay... well, it was a good kick to make me do more. (Girl, 16)

Therefore, the majority experienced a harsh tone as negative for motivation but it could also be considered motivating to self-management. The difference may depend on how the adolescents perceive their own autonomy in management.

2. ROLES IN TREATMENT

According to the participant observations, the doctor and the nurse each had different roles in treatment during consultations. During consultations, the doctor was spokesperson,

meaning that they initiated the dialogue, either by asking the patient what they wanted to talk about or by presenting the agenda of the dialogue. The doctor was an authority who decided whether the parents were to participate in the whole consultation or only in part of it. The doctor gave diabetes-related advice, calmed the patients and their parents if they had diabetes-related concerns, decided, often in consultation with the nurse, how treatment should proceed, and set the date for the next consultation. The doctor also distributed tasks to the nurse. Based on the observations, the nurse's role in consultation was to measure HbA1c and report the result, to handle the pump, e.g. printing diagrams with information about blood sugar measures and insulin administration, to adjust the pump to treatment changes, and to give advice regarding pump related problems, e.g. change of batteries. The nurse also advised patients and families about carbohydrates, transition of treatment and management of the pump, made new appointments for consultations, and invited patients to an informal youth arrangement at the hospital.

Although the observational data showed differences as to which tasks were handled by the doctors and nurses, respectively, interview data indicated that, the adolescents did not differentiate between the two professions and considered them as a team. However, the adolescents had different opinions about the roles of these teams. A few interviewees explained that the practitioners were trying to help them, hence acknowledging their personal, sensitive questions, e.g. about pregnancy. Communicational relations were thereby characterized by a knowledge about the practitioners' good intentions. Others

experienced the practitioners as authorities, who had the final say in future treatment.

I feel like they know what's the best thing to do, so I want to do what they tell me to, because I'm also counting on and hoping that it'll help me. (Girl, 17)

To perceive practitioners as experts could be helpful in maintaining self-management tasks but also a surrender of the responsibility for self-management, thus undermining autonomy. In relation to this point of view, being praised during the dialogues for their level of HbA1c was experienced as important in figuring out what the adolescents needed to do better and what they did well.

If there's something I need to do better, they are always good at pointing out the things I'm doing good. (Girl, 17)

However, to some interviewees the practitioners' judgement of the blood sugar diagrams and HbA1c was a negative experience because it forced them to face realities. The practitioners were also expected to tell whether or not the adolescents took care of their diabetes.

It's not like I don't dare, I'm just nervous because I know I have to face the truths in a way and being told again: you have to do this better. (Girl, 17)

This point of view gave the practitioners a more judging role in treatment and possibly the adolescents less of a feeling of autonomy.

3. ASSUMING CONSULTATION-FACILITATED RESPONSIBILITY FOR SELF-MANAGEMENT

The practitioners acknowledged the patient's problems with assuming responsibility for self-management and accepted their refusals of treatment-related changes. The doctors had dialogues with their patients about becoming

wiser than the pump. One doctor recommended patients to think independently in relation to the pump instructions regarding insulin administration, whereas another doctor advised a patient to follow the pump instructions more carefully. The practitioners involved their patients in the consultation dialogue by asking them questions, e.g. regarding future treatment. Parents were not always asked to leave the consultation room and only left if the doctor asked them to. In some cases, the parents or the nurses withdrew the patient's responsibility for treatment by changing the setting of the pump without the patient's knowledge. In seven consultations, the patients assumed responsibility for self-management, in two cases the parents were reproved for suggesting changes to future treatment, both times in connection with parents having been asked to leave the consultation for a period of time. The practitioners generally supported the adolescent's suggestions for assuming responsibility, e.g. going to future consultations without their parents.

Overall, the practitioners supported their patients in taking over responsibility for self-management from their parents, for instance by inviting the patients to participate in the dialogue and, in some cases, by managing part of the consultation without their parents' participation. Most interviewees had opinions about their parents leaving the consultation room. One interviewee experienced it as positive that his parents did not leave the consultation, because he felt reassured by their presence. Another said that he felt neutral about his parents staying or leaving. However, most interviewees experienced it as

positive that their parents left the consultation room for a period of time. Handling the consultation on their own made these adolescents feel more responsible.

I get to speak about the way I see things, so it's not just my parents' point of view that's discussed. (Boy, 16)

The adolescents may also have felt more confident in assuming responsibility and disagreeing with their parents when they had had consultation time alone with the practitioners. The practitioners may therefore be able to enhance the process of assuming responsibility for self-management between parent and adolescent. However, in relation to the process of assuming responsibility for self-management between patient and practitioners, observations were more mixed as shown in the example of becoming wiser than the pump. One interviewee told that, the practitioners told him to be more autonomous regarding the pump instructions, but also encouraged him not to.

4. RELATIONSHIP IN TREATMENT

In the participant observations, the relationship between patients and practitioners was observed as follows: First, in case of conflict between the diagrams from the pump and the patient's experience, the practitioners chose to believe in their patient's view of things, thereby respecting the patient's experiences and their problems related to self-management. Second, the practitioners, especially the nurses, knew their patients well. They would ask their patients about hobbies and everyday life, have inside jokes, and have a way of comparing self-management tasks with the patient's areas of interest. The way the practitioners knew their

patient's hobbies and tried to connect with them showed that the patient-practitioner relationship was more than just a formal relation and could have a positive effect on the motivation to self-management. Most interviewees told that they experienced the treatment relation as positive, especially their relationship with the nurse, who was the same in every consultation. Two interviewees said that they did not mind not seeing the same doctor in every consultation, as long as the nurse was the same, whereas one adolescent thought it was strange.

There has been a new doctor with [the nurse] every time it's a bit ... a bit weird in my opinion. I don't know why ... I think I can be open and I'm not afraid of talking to them, because they have their oath of silence. (Boy 16)

Overall, the adolescents mostly used the practitioners' names when talking about them instead of calling them by their title. This gave the impression that the relationship with practitioners was familiar and important to the adolescents, making them feel safe in consultation. One interviewee said that if the nurse was present in consultation, she did not need her mother's presence. Two interviewees said that the relationship mattered to the motivation to self-management, because the practitioners knew that the adolescents were not bad diabetics in case the blood sugar measurements were not optimal, and that they just had had a rough period. Overall, the analysis showed that the relationship to the practitioners mattered to most of the adolescents and affected their experience of feeling safe in consultation and motivated to self-management.

5. CONSULTATION CONTEXT

Looking across the interviews, several adolescents expressed feeling safe during consultations and that they appreciated the dialogue. No interviewee expressed dissatisfaction with the consultation context. However, the interviewees expressing satisfaction with the consultation context gave different explanations for their satisfaction: First of all the quality of the consultation dialogue and time of day for consultations, secondly the PDCU location being close to home, and finally the feeling of safety in consultation.

The dialogues and relationships with practitioners were considered to have influenced some interviewees' experiences of having diabetes. Consultation could influence their daily lives in negative as well as positive ways as illustrated in the quotes below.

It doesn't affect how I treat my diabetes, but more how I feel, psychologically, about myself. (Boy, 17)

Even though I come there with the purpose of checking up on my diabetes they make it feel very relaxed and very "easy to live with if you only want to", because that's how it is really. (Girl, 17)

The interviewees' experiences of consultations as motivating to self-management were divided. To some of the interviewees the check-up control of their HbA1c and blood sugar values since last consultation was motivating, where the relationship with the practitioners was mentioned as important to these adolescents' motivation to self-management:

They don't say "you should do this and this and we'll see you next time". I think that's a

really nice experience so I'm looking forward to going, because I feel like: "I'm going to show you how good I am", exactly because I feel like I know them. (Girl, 17)

Some interviewees experienced that the motivation to self-management was primarily an inward need for feeling good and thus not affected by experiences in consultation. They described it as important that practitioners understood that the adolescents wanted to

take care of their blood sugar level and feel normal. However, one interviewee explained that consultation-facilitated motivation was not enough for her to change her habits.

Sometimes you are told you really must change, but you quickly go back to your everyday life where you have to think about other things. That's why it's difficult to actually do what they recommend. (Girl, 16)

Table 2: Overview over categories, themes and sub-themes with the responding number of units.

Overall category, interview themes, and observation themes and subthemes		Number of units	
Category 1: Consultation dialogue		83	
Observation themes	1.1. Praise	15	
	1.2. Dialogue about other things than diabetes	10	
	1.3. Normalization	5	
	1.4. Acknowledgement	4	
	1.5. Diabetes-related dialogue	15	
Interview themes	1.1. Experience of dialogue	10	
	1.2. Experience of communication	16	
	1.3. Effect on motivation to self-management	8	
Category 2: Roles in treatment		84	
Observation themes and subthemes	2.1. Doctor	2.1.1. Spokesperson	13
		2.1.2. Authority	8
		2.1.3. Judgement and guidance	15
	2.2. Nurse	2.2.1. Calendar	10
		2.2.2. Blood sugar	4
		2.2.3. Advice	10
		2.2.4. Devices	11
Interview themes	2.1. They are trying to help me	4	
	2.2. They are in charge	3	
	2.3. They are judging me	6	

Overall category, interview themes, and observation themes and subthemes		Number of units
Category 3: Assuming consultation-facilitated responsibility for self-management		41
Observation themes	3.1. Acknowledgement	5
	3.2. Encouragement	5
	3.3. Involvement	14
	3.4. Denial of responsibility	5
	3.5. Initiative	7
Interview theme	3.1. Assuming responsibility for self-management	10
Category 4: Relationship in treatment		33
Observation themes	4.1. Respect	16
	4.2. Familiarity	5
Interview theme	4.1. Relationship	12
Category 5: Consultation context		22
Interview themes	5.1. Judgement of context	6
	5.2. Effect on everyday life	6
	5.3. Effect on motivation to self-management	10

Discussion

The purpose of this study was to gain a better understanding of the link between consultation, motivation, and self-management in adolescents with T1D. This qualitative study revealed five categories of themes (consultation context, consultation dialogue, roles in treatment, assuming consultation-facilitated responsibility for self-management, and relationship in treatment) relevant for how consultations could facilitate motivation to self-management in adolescents with T1D.

According to the SDT the needs for autonomy, competence and relatedness are fundamental for motivation⁹. The results from our study will be discussed in relation to these needs below.

The ISPAD guidelines recommend that adolescents gradually assume more responsibility for the diabetes management

tasks, in agreement with their parents¹⁴. Overall, the practitioners were in our study observed to support the patients' involvement in consultation-facilitated treatment and thereby autonomy. In the present study, observations were made of the practitioners acknowledging their patients' problems related to assuming responsibility for self-management, accepting refusals to treatment related changes, involving patients in the consultation dialogue, and asking parents to leave the consultation room. However, some observations also showed that practitioners did not involve patients in self-management decisions, e.g. changes in pump settings. Based on the present study, we argue that the development of autonomy in self-management in adolescents with type 1 diabetes can be regarded as two simultaneously ongoing processes: one between parents and child, and one between

practitioners and child. In this study, practitioners generally supported their patient's autonomy in relation to their parent's involvement. However, the practitioners may have found it more difficult letting the adolescents become autonomous in relation to self-management tasks previously controlled by the practitioners.

A recent study found that if health care providers' use of confronting and persuading in their communication with the adolescents it had a negative impact on the youth's engagement in adherence behavior¹⁵. This was also the case for some of the interviewees in our study. However, one interviewee had experienced a harsher tone as motivating to self-management, possibly because the other motivational needs were fulfilled during consultations. The patient's assessment of the practitioners as an authority may be important to autonomy. According to Ryan et al., the more regulation a doctor asserts over his patient, the less likely the patient is to feel autonomy and thus motivation to self-management⁹. In the present study, some interviewees told that they experienced the practitioners as authorities, who decided their future treatment and were able to judge whether the patients adhered to their treatment. This may have a negative impact on their feelings of autonomy in treatment, making motivation to self-management less likely. It is important to support the adolescent's need for autonomy to facilitate motivation. The sense of autonomy in relation to self-management are also highly important in the adolescent's transition to the adult health care system. The development of autonomy were in our study experienced as important for how consultations could

facilitate motivation to self-management. Being autonomous in consultation-facilitated motivation to self-management are to be considered as an ongoing developmental process in which the individual patient's need for independence and skills in self-management should be taken in to consideration, both in relation to parents and practitioners.

Competence is described by Ryan et al. as facilitated by autonomy because the willingness to act is fundamental to becoming competent⁹. The need for competence was not clearly identified in our analysis. The fact that the responsibility for self-management, and thus the autonomy in relation to this, is relatively new to adolescents may indicate that competence is not yet obtained. According to Ryan et al., practitioners can help facilitate competence by offering skills and tools for change and by supporting their patient's choices⁹. In the present study, some interviewees expressed feelings of becoming more knowledgeable about self-management during their consultations and many observations were made of practitioners praising their patient's efforts and making suggestions as to how to improve on self-management tasks. A recent study found that adolescents wanted to take over responsibility for self-management tasks, but lacked the knowledge, experience and skills to succeed. The support of practitioners, parents and friends was considered important during this transition¹⁶. The relationship between health care professionals and the patient is not just important for the transition of responsibility. According to ISPAD, the relationship between the health care professionals and the adolescent patient is important for the patient's self-management in general⁶. In line

with the ISPAD guidelines, our study found that the relationship between patient and practitioners is important for how consultations can facilitate motivation to self-management. In relation to this, the consultation dialogue was important to the interviewees' experience of the relationship with their practitioners. The interviewees felt especially connected with the nurse, who was the same in every consultation. This made some interviewees experience that they trusted the nurse's advice more profoundly. This indicates the importance of stability in which health care professionals attend the consultations to increase the adolescents' feeling of relatedness. The feeling of relatedness was in line with development of autonomy experienced as important for how consultations could facilitate motivation to self-management in our study. Relatedness and autonomy may be fundamental to adolescents' experience of competence in relation to self-management. This study supports further investigation of consultation-facilitated motivation to self-management. The next step could be to use the study design with a planned recruitment process and consultation context in several countries or counties thus investigating the findings generalizability. Another possibility is to create an intervention study investigating whether clinician can help facilitate motivation to self-management in adolescents if they focus on the motivational needs. By using triangulation, this study tries to strengthen the verification of its findings; however, triangulation has its limitations¹². By choosing to observe consultations before interviewing the participants, the first author could be biased in the questions asked¹². It should also be stressed that the same

researcher conducted both interviews and observations, which could contaminate the data. Another limitation with this study is the lack of knowledge about the practitioners' phenomenological experiences of how consultation can facilitate motivation to self-management. Third, it is a limitation to this study that the sample was a convenience sample. Thus, we do not know whether the sample is representative of the whole population. Fourth, the analysis was not sensitive to the motivational need for competence. Fifth, the strength of the current study is the focus on a certain type of consultation context, but this limits the generalizability of the findings to other consultation contexts¹⁷.

Conclusions

How consultations can facilitate motivation to self-management in adolescents with T1D is influenced by their experience of relatedness and autonomy, two of the three motivational needs proposed by SDT⁹. In relation to competence, the third motivational need proposed by SDT, the analysis used found no conclusive support; however, it does suggest that the needs for autonomy and relatedness are important to the adolescents' experience of competence in relation to how consultations can facilitate motivation to self-management. To our knowledge, this is the first study investigating consultation-facilitated motivation in relation to adolescents' self-management of T1D. The findings support the guidelines proposed by ISPAD. However, as this is a preliminary study, more research is needed to support the findings.

Conflict of Interest:

The authors declare that they have no competing interests.

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Author contribution

RT designed the study, collected and analyzed the data, and drafted the manuscript. JL substantially participated in the study conception and design, and in editing the manuscript. AS has substantially participated in recruitment of patients,

acquisition of the data and manuscript editing. All authors read and approved the final manuscript.

Ethical consideration

The National Science-ethics Committee was consulted and the families received oral and written information. Written consent to participation was collected for the participants and their parents, if the parents attended the consultation. However, according to the regional science-ethical regulations, no parental consent is required in studies like the present because the adolescents are between 15 and 17 years of age. The participants were assured that participation was voluntary and information would be treated confidentially.

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