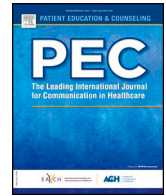




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# Active involvement of young people with T1DM during outpatient hospital consultations: Opportunities and challenges in transitional care services

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## ABSTRACT

**Objective:** Little is known about active involvement of young people (YP) with type 1 diabetes (T1DM) in transitional care. This study aims to gain insight into patient-provider interactions during outpatient hospital consultations.

**Methods:** Semi-structured observations (n = 61) of outpatient consultations with YP with T1DM (15–25 years) treated in 12 hospitals in the Netherlands. The consultations concerned pediatric care (n = 23), adult care (n = 17), and joint consultations (n = 21). Thematic data analysis focused on whether professionals engaged in open, in-depth conversations; used motivational interviewing techniques; involved YP in shared decision-making; and addressed non-medical topics.

**Results:** Apart from some good examples, the healthcare professionals generally had difficulty interacting adequately with YP. They paid little attention to the YP's individual attitudes and priorities regarding disease management; non-medical topics remained generally underexposed. Conversations about daily life often remained shallow, as YP's cues were not taken up. Furthermore, decisions about personal and health-related goals were often not made together.

**Conclusion:** By adopting a more person-centered approach, professionals could empower YP to take an active role in their diabetes management.

**Practice implications:** Using a structured conversation model combined with a tool to encourage YP's agenda-setting and shared decision-making is recommended for more person-centered transitional care in T1DM.

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## 1. Introduction

Type 1 diabetes mellitus (T1DM) is a complex metabolic disorder characterized by lifelong demands of self-care and motivation to adhere to stringent treatment recommendations [1]. The health risks of glycemic variability can be immediate and life threatening and could lead to long-term complications. For young people with T1DM, adolescence is a critical period in their lives, as they have to learn

looking after their own healthcare needs. They must take up responsibility for day-to-day self-management (e.g., daily insulin injections and dietary restrictions) as well as the logistical aspects of diabetes care (e.g., follow-up in healthcare services) in the context of competing developmental life demands [1–5]. For example, they are expected to become more confident and autonomous in managing their own concerns, establish relationships, and get actively involved in decisions affecting them. At the same time, transfer from pediatric to adult diabetes care is imminent, with its risks of fragmentation of care and adverse clinical and psychological outcomes [1, 4, 6, 7]. Diabetes management is not the highest priority of most young people, compared to achieving developmental milestones in other life domains [8]. The process of moving from being a child to become a young adult between 15 and 25 years – known as the transition phase – can, therefore, bring unwanted effects. Studies have

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reported, for example, decreased outpatient clinic attendance, higher loss to follow-up rates in specialist adult care services, elevated glycosylated hemoglobin (HbA1c) levels, and inadequate self-efficacy and self-management skills [9–12].

Given the vulnerability of young people with T1DM in the transition phase, fostering commitment to continuity of diabetes care in this period is an important task for both pediatric and adult care services [4]. Current consensus recommendations in diabetes care articulate the importance of providing developmentally appropriate healthcare and active involvement of young people [3, 4, 6, 13–17]. This concept recognizes that young people develop understanding, coping and self-management skills at varying rates and intervals irrespective of their age, under the influence of individual experiences, capabilities and motivation [3, 16, 18]. One should consider that various aspects of development may impact on other life transitions (e.g., moving away from the family home, education, career, social and intimate relationships) and vice versa [4, 16, 19].

Professionals involved in transitional care are in a core position to set up young people for a lifetime of positive health-related behaviors and relationships with healthcare services [4]. They can help young persons to meet the expectations that the healthcare system places upon them by modelling appropriate relationships, helping them acquiring skills and knowledge, and overcoming barriers to become active participants in care [19]. Consultations in transitional care are crucial for facilitating a young person's autonomy, empowerment, and self-management [20]. These consultations allow healthcare professionals and young people to build a shared understanding of how diabetes care is integrated with what else is going on in these young people's daily lives and what priorities they set at that particular point in their development [1, 19, 20]. Person-centered communication facilitates this by empowering a patient to take an active role and express needs, preferences, values and concerns [21–24]. Previous studies confirmed that providing care from a holistic perspective, investing in building positive relationships with young people, and facilitating an active role of the patients in care are conducive to positive health outcomes [1, 25, 26].

Thus, healthcare professionals will be better equipped to engage with the young people and provide person-centered care when they take into account the young people's developmental context. This will allow to explore how T1DM is impacting on a young person's roles and responsibilities in the broader sense [19]. However, the uptake of recommendations on developmentally appropriate healthcare remains unknown. Research showed that healthcare professionals still spend much time and effort on disease management; i.e., achieving control, minimizing disease progression, and reducing complications [1, 27, 28]. They would do well to pay more attention to person-centered care around transition and transfer [20]. Apart from some studies [29,30] – which both conclude that young people want to be more involved in their care, but also call for more research – little is known about patient-provider interactions in the transition phase (15–25 years).

Hence, this study is unique in that it aims to gain insight into the interactions between young people with T1DM and healthcare professionals during outpatient hospital consultations in the years before and after transfer to adult care. Deeper understanding of these interactions could help unravel how active involvement of young people with T1DM in their care can be promoted, thereby limiting unfavorable health outcomes.

## 2. Methods

### 2.1. Design and setting

Within the framework of a Netherlands-based mixed-methods research and quality improvement program named '*Better Transition in Type 1 Diabetes*' (2016–2018), we carried out semi-structured

participant observations with an overt approach – in which the researcher's role is to undertake research with brief exposure to collect observation data (i.e., "observer-as-participant" approach) [31]. The improvement program aimed to advance transitional diabetes care [32] by supporting healthcare professionals to improve their transitional care arrangements based on findings from the literature, mirror meetings between young people and healthcare professionals, and research. The current observational study focused on gaining more insight into the interactions between young people with T1DM and healthcare professionals during the transition from pediatric to adult care. Professionals' actions, intentions and beliefs were explored in relation to existing knowledge about those young people's needs and preferences. We applied the focused ethnographic method, which is a pragmatic form of ethnography that intends to collect focused data based on a preliminary formulated central question and, therefore, concentrates on specific problem areas [33,34]. Results on the pre-defined topics can be obtained within a short time span in several settings simultaneously [33,34].

### 2.2. Participants

The study population consisted of providers of transitional care to young people with T1DM, working in multidisciplinary diabetes teams in twelve regional and teaching hospitals participating in the '*Better Transition in Type 1 Diabetes*' program. Their self-selection for participation indicated that they were motivated to improve their transitional care. The sample size was not predetermined, but we invited professionals from different backgrounds, resulting in participation of pediatricians, internists, pediatric diabetes nurses, diabetes nurse specialists, dieticians, and psychologists. We aimed to reach variation in settings by studying three different types of consultations: 1) consultations in pediatric care, 2) consultations in adult care, and 3) joint consultations with professionals from pediatric and adult care. All patients involved were aged between 15 and 25 years and had been diagnosed with T1DM. They were asked to provide consent for observation in advance.

### 2.3. Data collection

We observed outpatient hospital consultations in which healthcare professionals, these young people, and in a number of cases parents as well participated. Consultations in each setting were observed for about 4 h in total. The participants were told that the overall aim of the research was to gain a better impression of the working ways, procedures and routines in the consultation room for this specific age group, which might help to further improve transitional care processes. The application of a semi-structured protocol ensured that all these aspects were included in the observations (Table 1) [35]. The boxes in bold in Table 1 indicate the focus of the current study.

The observer – who was present in the consultation room but maintained a neutral stance – took field notes and wrote down the findings in narratives on the same day to ensure that the spoken words during the consultations were well captured. In addition, notes of informal talks with the healthcare professionals, alongside the observations were included in the narratives [36]. The different observers all had a background in health sciences or nursing and were trained prior to conducting the observations. We have no indication that their presence disturbed the interactions.

### 2.4. Data analysis

Data were analyzed by using a constant comparative analysis method [37]. Observation narratives were coded thematically by two researchers (MP & HH), of whom HH is a young person with T1DM who was a youth panel member in the '*Better Transition in Type 1*

**Table 1**  
Observation guide (based on the study protocol of Sattoe and colleagues [35]).

Topic	Aspects addressed
<b>Background information</b>	<b>Hospital</b> <b>Department</b> <b>Setting (pediatric care/adult care/joint care)</b> <b>Healthcare professionals present (disciplines)</b> <b>Young person (gender, age, presence of family)</b>
<i>What is going on in general</i>	Activities Actions Interventions used Reporting Process
<i>Environment and atmosphere</i>	Consultation room layout Attitudes and involvement of attendees (verbal and non-verbal)
<i>Diabetes team</i>	Attendees Task division and coordination Communication between healthcare professionals (verbal and non-verbal)
<b>Interaction*</b>	<b>Division of roles</b> <b>How the young person behaves and how he/she experiences his/her involvement</b> <b>Parent's role and attitude (if present)</b> <b>Healthcare professional's role and attitude</b> <b>Communication (verbal and non-verbal)</b> <b>Topics addressed (content, by whom, and how extensively)</b> <b>Questions asked and how they are responded to (both ways)</b> <b>Shared decision-making</b>

\* Main focus of the current study.

*Diabetes'* program and participated in the mirror conversations with healthcare professionals [32]. For optimal interpretation of the observation narratives, HH participated in the current study as a co-researcher.

MP and HH started by reading the narratives several times independently and considering what the interactions and field notes implied. They wrote memos about the essence of what was happening in the consultation room, and these were discussed within the entire research team, in the light of the central research question [38]. Leading themes deriving from this discussion were focused on interactions between healthcare professionals and young people, and how this affects patient engagement; i.e., whether the healthcare professional: 1) engaged in open and in-depth conversations; 2) addressed psychosocial and other non-medical issues; 3) used motivational interviewing techniques; and 4) involved the young people in shared decision-making. Based on these themes, MP and HH pulled the data together and classified the findings into two contradictory categories: preferable practices versus non-preferable practices (Table 2). The results were discussed until consensus was reached on the final distribution among the categories.

**Table 2**  
Clarification of preferable versus non-preferable practices in patient-provider interactions.

Theme	Preferable	Non-preferable
<i>Person-centered care</i>	Attention to individual attitudes and priorities in diabetes management; open and in-depth conversations	No/little attention to individual attitudes and priorities; shallow conversations
<i>Psychosocial aspects</i>	Both medical and non-medical aspects are addressed	Strict focus on medical aspects
<i>Motivational interviewing</i>	Follow-up on the replies and signals given by the patients (patients' cues <sup>a</sup> )	No follow-up on the replies and signals given by the patients
<i>Shared decision-making</i>	Involving patients in decisions about their care and treatment	Decisions about the patient's care and treatment are predominantly made by the healthcare professional, without patient involvement

<sup>a</sup> Defined as: "a hint, which might be an expression or signal, mostly verbal but also nonverbal, which indirectly indicates an issue of presumed importance for the patient and implies an emotion, worry or uncertainty that the patient would like to bring up, or a move to another topic, that should demand an exploration from the provider" [39].

## 2.5. Ethics approval

The Ethics Review Board of Erasmus MC approved the original study protocol as well as the updated addendum (MEC-2014–246). Ethics approval was also obtained from all local hospital review boards. All participating young people and their parents (in case of minors) had received an information letter about the goals of the study, and they were ensured complete confidentiality and anonymity. All participants provided written informed consent for observation during their consultation(s). Pseudonyms were used in the observation narratives.

## 3. Results

### 3.1. Background characteristics

Sixty-one outpatient hospital consultations with young people with T1DM in the transition phase, with a mean age of 19 years, were observed. The consultations lasted between 15 and 30 min and included consultations in pediatric care (n = 23), adult care (n = 17), and joint consultations (n = 21). Involved professionals were pediatricians (n = 25), internists (n = 17), pediatric diabetes nurses (n = 27), diabetes nurse specialists (n = 21), dieticians (n = 8), and psychologists (n = 3). Parents were present in 23 of the consultations (38%); mostly in pediatric care (n = 11) and during joint consultations (n = 9). Two patients brought their partners to the consultation and one came with her grandmother (all in pediatric care).

### 3.2. General impression

Analysis of the observation narratives revealed different patterns of interaction. Some healthcare professionals took a directive attitude towards the young people and actually started the conversation without first asking them a question (non-preferable practice), while others adopted a coaching approach and made the young people active partners in their own care (preferable practice). The distribution among preferable and non-preferable practices was somewhat skewed. In most cases, an alternation of preferable and non-preferable examples on the themes mentioned in Table 2 was observed. This pattern was alike in the pediatric and adult care settings, and was also found in the setting of joint consultations.

Box 1 and Box 2 present composed cases illustrating the differences in preferable versus non-preferable patient-provider interactions in the transition phase. Both cases are intended to give an impression of how a consultation can proceed, from the beginning to the end.

### 3.3. Person-centered care

The central focus of many consultations appeared to lie on monitoring young people's diabetes management, so as to ensure

**Box 1**

Composed case of non-preferable interactions in the consultation room.

An 18-year-old girl, Lynn, has just made the transfer from pediatric to adult care and visits the internist for the first time. She has brought her mother. Right after they enter the consultation room and sit down, the internist starts talking about high blood glucose levels. She says: *"The values have never been so bad before!"* No further questions are asked about how Lynn is doing in daily life activities. On the contrary, the internist continues the conversation by asking her what she has done recently to prevent the "bad" values. She is also wondering whether the pediatrician's recommendations have been taken up and what she wants to do about the high values herself. Lynn seems to be uninterested; she does not really care. She says she has never had a really bad day and that she is not going to change anything. Her mother, who did not say much until then, looks somewhat frustrated and states that she almost hopes that things will go wrong so that her daughter finally becomes more alert about her condition. Then, the internist starts to explain the importance of structural measurements for a type 1 diabetes patient. However, she does not try to unravel the reasons behind Lynn's behavior. She urges her to measure more frequently and advises her to do this at fixed times. *"Blood sugar should be tested at least twice a day,"* the internist declares. Lynn shows little concern; she still seems to be uninterested and pays little attention to the doctor's instructions. She says that she never experiences hypos and has not been admitted to hospital in recent years: *"I am fine with that."* Even when the internist explains that the consequences of poor therapy adherence may not become apparent until years later, Lynn remains indifferent. One last time, the doctor stresses the importance of behavior change, after which the consultation is over.

that they follow the treatment recommendations. At the same time, the healthcare professionals often paid little attention to the young person's individual attitudes and priorities regarding his or her diabetes management (Box 1). It is evident that patients' priority given to the management of blood sugar levels widely differs. Although the importance of controlling values and preventing outliers is widely supported by both diabetes healthcare professionals and patients, it is not always the main priority in a young person's daily life. An 18-year-old patient illustrated this: *"It does not interest me that my values are high as long as I am feeling good."* General instructions and treatment recommendations did not seem fit into personal life goals of these patients and, therefore, did not make any sense to them (Table 3). In such cases, a more profound exploration of how patients dealt with the diabetes seems warranted, but such exploration was not often observed during the consultations.

### 3.4. Psychosocial aspects

To obtain a comprehensive view of the young patients, it is important for healthcare professionals to pay attention to psychosocial aspects such as school, work, social and intimate relationships, and leisure activities. For example, a 19-year-old woman asked her internist for advice on alcohol consumption, as this interferes with blood sugar levels. Together they explored the risks and a suitable solution (Table 3). Furthermore, showing interest in one's personal life instead of being asked questions about the diabetes at the beginning of a consultation can help to make the patient feel comfortable and to establish partnership (Box 2). Observations like these,

however, were relatively exceptional. Psychosocial themes were often not addressed during the observed consultations.

### 3.5. Follow-up on the cues given

Although psychosocial aspects were not always addressed, most of the professionals did ask the young persons how they were doing. However, these conversations often remained shallow, as professionals often did not follow-up on the cues given by the young persons. Thus, the young persons were generally not supported in integrating structural diabetes management into daily life. A more preferable situation is, for example, the conversation between an internist and a young adult, during which possible explanations for the patient's high HbA1c values were explored together (Table 3).

### 3.6. Shared decision-making

The young people's expected involvement in shared decision-making was often limited due to inadequate follow-up. Some professionals even stressed this explicitly, such as an internist did during his first contact with the patient in adult care: *"I will be a strict coach, I expect you to follow-up on my treatment recommendations as much as possible."* A more preferable practice in the light of shared decision-making was the conversation between a pediatrician and a patient about blood glucose monitoring. The pediatrician did not only provide information and advice, but also asked the patient about his own ideas to prevent outliers. The patient indicated that he should count carbohydrates better, upon which the pediatrician specifically asked how he was going to do this. In this

**Box 2**

Composed case of preferable interactions in the consultation room.

A 22-year young man, Alex, has a regular follow-up visit with his diabetes nurse specialist. He came alone and the conversation starts with small talk about his study, internship, and future career goals. Then, the nurse asks Alex what he would like to discuss today, upon which he says that he's concerned about his high blood glucose values. Together they look at Alex's pump details and glucose results, and discuss how Alex deals with his values at work, in the evenings and on the weekends. The nurse asks about Alex's preferences in dealing with his high values. She suggests more physical activity, but Alex says that he is too busy with work at the moment. Therefore, a new insulin is proposed, and the nurse explains how this works. Alex responds openly. The nurse asks whether it would be helpful to write down what she has just explained, and Alex agrees. The conversation continues about Alex's eating habits and, especially, the carbohydrates intake. Alex says that he sometimes eats cookies in the evening, but that he wants to adjust his eating pattern. The nurse tries to gauge what is feasible for him. She explains that in case he does not want an extra insulin injection, he could opt for reducing his carbohydrates intake. Alex finds this is a good idea. *"The cookies are just for the hunger pangs,"* he says, after which the nurse explains what could cause these hunger pangs and how to prevent this. The nurse summarizes what has just been discussed and performs some medical checks. Finally, she asks Alex if there are any questions left and reminds him that it is always possible to contact her between the regular follow-up consultations that take place every six months, for example to adjust his insulin regimen.



**Table 3**

Examples of preferable versus non-preferable interactions between young people and healthcare professionals.

Theme	Preferable	Non-preferable
<i>Person-centered care</i>	A patient visits her diabetes nurse in adult care for the first time after transfer. The nurse introduces herself and then asks the patient what she does in daily life; school, hobbies, holidays and sports are discussed. They talk about when the diabetes was diagnosed and how she has dealt with it in recent years. The patient seems to feel comfortable and continues to signal that it does not really interest her that her values are not good, as long as she feels good. They discuss about what the patient is doing about her diabetes so far. (F; 18   AC*; nurse)	Directly at the start of the consultation, a dietician tells her patient: "A HbA1c of 60, last time it was 53. That's really high for someone who doesn't eat carbohydrates." Then, she asks the patient to take a look at his recent values and starts explaining about the working of glucose, fructose, and granulated sugar. (M; 22   AC; dietician)
<i>Psychosocial aspects</i>	A patient asks her internist about drinking alcohol and how to prevent hypoglycemia. The internist emphasizes that she should be open about what and when she's consuming. Then, the internist can see when and how much her blood sugar levels drop, and then give adequate advice. The internist explains: "Of course it is better not to drink or to drink small amounts, but if you want to do so, we must discuss how this can be done as safely as possible." (F; 19   AC; internist)	"How are you?" asks the diabetes nurse, who meets the patient for the first time in adult care. "Could be better," he answers. The nurse does not follow-up on this, but talks about adult care: "Consultations will be shorter, less frequent, and probably less personal here." Then the conversation continues with discussing medical aspects such as blood sugar levels, hypoglycemia, and measurements. Finally, she asks whether the patient smokes, drinks alcohol or uses drugs, and when the last eye and foot checks were performed. She writes everything down and, after asking the patient if he has any questions, the nurses end the consultation. (M; 22   JC*; pediatric nurse & adult care nurse)
<i>Follow-up on patients' cues</i>	A patient shares his struggles with measuring, especially in combination with sports and work. The internist tries to gain more insight into this by asking: "What do you find difficult about it; do you mind that people see you measuring?" The patient answers that the problem is that he does not always remember to measure, after which the internist asks how he can help with this. He emphasizes that the young adult should do it on his own, but that he can take on a coaching and guiding role. (M; 19   JC; pediatrician & internist)	A nurse asks his patient how often she measures her blood glucose levels, upon which the patient says: "That differs, I actually do not know." It turns out that the patient sometimes does not measure for a whole week. The nurse reports this in the patient's medical record but pays no further attention. He only asks: "Are you going to try to do better from now?" (F; 20   AC; nurse)
<i>Shared decision-making</i>	During a joint consultation with two diabetes nurse specialists from pediatric and adult care, respectively, the conversation turns to the patient's wish to participate in Ramadan. The adult care nurse strongly discourages this, because of the high risks involved for people with T1DM. The pediatric nurse seems to be more open to the patient's values and religious considerations, although she recognizes the associated risks. She tries to think about solutions and suggests looking for alternatives that give a satisfying sense of participating; e.g., shorter fasting times or preparing different meals. In this way, the pediatric nurse tries to follow-up on the expressed wishes of the young person and involved her in shared decision-making. (F; 18   JC; pediatric nurse & adult care nurse)	A young person visits the pediatrician for a regular follow-up consultation, together with his father who still plays a big role in his diabetes management. "Let us see how you can become more independent," says the pediatrician to the young person. She instructs him to measure every time before eating and before going to bed from now on. "That will give dad a better night's sleep," the pediatrician says. "And do not forget to send us your data more often. So, go for it!" (M; 17   PC*; pediatrician)

\*PC=pediatric care; AC=adult care; JC=joint care.

way, the treatment decisions were not only supported, but even suggested by the young person himself.

## 4. Discussion and conclusion

### 4.1. Discussion

Our study revealed a wide variety in interactions between young people with T1DM and healthcare professionals during outpatient hospital consultations in the transition phase. We certainly observed good practices, but nevertheless also a variety of non-preferable practices, indicating that some healthcare professionals had difficulty to adequately interact with these young patients. In fact, we noticed that most of the observed consultations presented examples of both preferable and non-preferable practices. This would imply that there was often still room for improvement to actually get young people involved. Furthermore, parents' influential role in young people's health and development – and so the importance of appropriate parental support in transitional care – should not be underestimated [40]. This was not the focus of our study, but future research into the parents' role during transition is recommended.

It is widely known that healthcare professionals treating adolescents and young adults do not always acknowledge and address their patients' development and health-related issues [28,32]. Our observations confirmed this medical focus in transitional care for young persons with T1DM, and revealed that the healthcare professionals often inadequately responded to the patient's replies and cues. Although routine attention for psychosocial aspects is

identified as a core element in transitional care, these aspects are still not always covered in practice [32,41]. There even seems to be a significant discrepancy between professionals and young people regarding the discussion of psychosocial issues, raising the issue of the efficacy of the communication strategies being employed by professionals [28].

In general, patients appear to assess the quality of their care largely through the perceived quality of the communication process; i.e., whether professionals listen to them carefully, understand their needs and preferences, and provide clear and sufficient information [23]. Especially in the care for young people with chronic conditions, a person-centered and holistic approach seems essential to support them in their transition towards independence, empowerment, and involvement [32]. This requires professionals' attention to go beyond medical aspects, also addressing developmental and psychosocial challenges, so that these young patients can make choices in their care that best fit their individual circumstances [23,32]. Additionally, there is sufficient evidence for the importance of effective communication for patient outcomes [1, 25, 26], also specifically for young people with diabetes [20,42].

Experienced gaps in transitional care following the principles of developmentally appropriate care, may be explained by the notion of epistemic injustice as a common, possibly pervasive feature of healthcare [43]. Based on this notion, young persons' experiences and interpretations may be heard and considered by professionals, but judged irrelevant or insufficiently articulated, as they do not always recognize that taking their young patients seriously is of potential therapeutic value. As a consequence, the improvement of

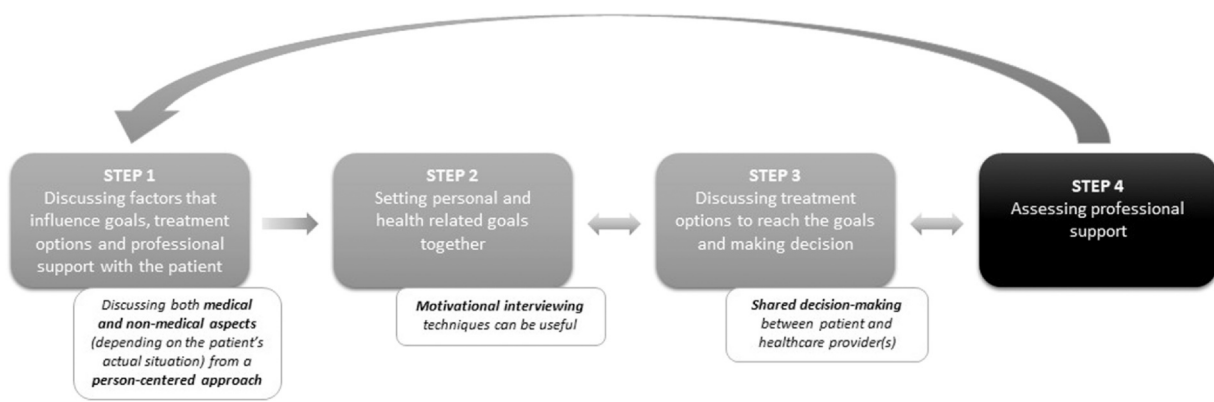


Fig. 1. Structured conversation model of Rutten and colleagues [47].

communication skills as part of professionals' continuous learning process is not self-evident. Many professionals assume they are already performing well in this area and, consequently, focus on the acquisition of new technical information, insights and skills [23]. Furthermore, they are concerned that listening to patients' worries and addressing their individual difficulties and needs requires too much time, which they do not have because of the pressure to see as many patients as possible in a day [23].

Another important aspect, specifically in diabetes care, are choices in language. Person-first, strengths-based, and empowering language is expected to improve patient-provider interaction and enhance a patient's motivation, health, and well-being [42]. In contrast, words or phrases that have potentially negative connotations can contribute to stress and feelings of shame and judgement in T1DM patients – e.g., 'nonadherent', 'poorly controlled' and 'bad values' – and our observations confirm that this still occurs in daily practice.

To give healthcare professionals more insight into the potential therapeutic value and needed improvements of the transition and transfer experiences, mirror meetings with young people are highly recommended [44]. In the 'Better Transition in Type 1 Diabetes' program, such group discussions with healthcare professionals served as an eye opener for diabetes teams on the different aspects of interaction (Table 2), and encouraged them to listen to young people's voices [32]. Concrete preferences or recommendations appearing from these conversations, such as choices in language, are relatively easy to apply.

In addition to the individual factors associated with person-centered care, Luxford, Safran and Delbanco [45] argue for adopting a strategic organization-wide approach for successfully advancing person-centered care with a focus on patients as 'customers' of the healthcare service. It appeared from our study that the provision of person-centered care and the use of effective communication strategies still seems challenging for professionals from all diabetes teams, regardless of their organization of transitional care or whether they were working in the pediatric or the adult setting. Also in joint settings, healthcare professionals were still searching for best practices, which could be a consequence of poor collaboration and communication between pediatric and adult healthcare professionals [46]. Professionals sometimes appeared to feel a bit uncomfortable as such a joint setting is also new for them.

Implementing a structured conversation model, such as the diabetes consultation model of Rutten and colleagues [47], which is supported by the Dutch Diabetes Federation [48], could perhaps help improve interactions between young people and healthcare professionals. Fig. 1 shows how this stepped model fits with the themes that emerged from our observations.

In step 1, the diabetes healthcare professional addresses both medical and non-medical aspects with attention to individual

attitudes and priorities of the young person. This means that the choice of topics to be discussed is not protocolled, but that the choice depends on the patient's actual situation and agenda-setting. In step 2, personal and health-related goals are set together, where motivational interviewing techniques can be useful. In step 3, shared decisions related to personalized health goals and treatment options are made. Lastly, the consultation is completed in step 4 with an assessment of the experienced professional support. We hardly observed this step in our study, although it is considered important for follow-up. The model seems well applicable and is expected to result in more patient involvement including shared decision-making, which is appreciated from a patient perspective [47,48]. In the end, a more person-centered approach is expected to facilitate patient empowerment and self-management [24]. A possibly useful tool to bring the model into practice is the Self-Management Web, which facilitates an open and patient-led conversation about various life areas [49]. The Self-Management Web ensures a holistic view and encourages shared decision-making between patients and healthcare professionals; the patient is in charge of selecting an area to work on if support is desired.

#### 4.1.1. Strengths and limitations

A strength of this study is the participatory observational design that provided deep insights into patient-provider interactions during outpatient consultations in the transition phase. Furthermore, the study was conducted among members of fifteen diabetes teams in various outpatient settings (pediatric care, adult care, and joint care) and across a wide range of disciplines. Unfortunately, we could not make systematic comparisons among these disciplines as they were not equally distributed in our data collection. Moreover, healthcare professionals were present in many different combinations during consultations. Apart from that, our study did not reveal any trends in performance, neither by type of professional (i.e., doctor, nurse, or allied healthcare professional) nor by setting (i.e., pediatric or adult care). Unique in our study was the participation of a young person with T1DM in our research team, which enabled to achieve optimal interpretation of the observation narratives.

Our study results were limited by its cross-sectional design, which could only provide a momentary snapshot of the interactions between young people with T1DM and their healthcare professionals in the transition phase. Longitudinal studies are required to facilitate a developmental perspective in research by gaining insight into follow-up and interactions over time; e.g., how personal and health-related goals and decisions have been evaluated [50]. Furthermore, since the observation narratives contained only limited direct quotations, we could not in all cases link findings to the actual data. Nevertheless, we preferred a participatory observational design above video recordings, because we wanted to disturb the natural process of interactions in the consultation room as little as possible.

After all, it is not uncommon for others to be present during a consultation.

#### 4.2. Conclusion

Healthcare professionals treating young people with T1DM in the transition phase are challenged to empower these young people to take an active role in their own treatment, by exploring their individual norms, values and priorities regarding the management of T1DM in daily life more in depth. Deeper understanding of attitudes and motivation may enable healthcare professionals to tailor self-management support and treatment recommendations. By adopting a more person-centered approach, young people are expected to become owners of their diabetes management and care. This might help to limit the risks of unfavorable health outcomes, thereby improving their future prospects.

#### 4.3. Practice implications

First of all, encouragement of active patient involvement on a higher organizational level with a culture supportive of change and learning, can help diabetes teams to make their transitional care service more person-centered. On the healthcare team level, the use of a structured conversation model to support interactions between young people with T1DM and healthcare professionals could possibly contribute to more person-centered transitional care and is, therefore, highly recommended. Combined with the use of the Self-Management Web to facilitate patients' agenda-setting and shared decision-making, the application of such a conversation model seems promising in advancing the quality of transitional care for young people with T1DM. In addition, systematic attention for judgmental versus non-judgmental language choices is required. Mirror meetings could be a valuable tool to reveal such hidden realities among young people with T1DM.

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#### CRedit authorship contribution statement

**Mariëlle A.C. Peeters:** Conceptualization, Methodology, Formal analysis, Investigation, Resources, Data curation, Writing – original draft, Writing – review & editing, Visualization. **Hielke G. de Haan:** Formal analysis, Resources, Writing – review & editing, Visualization. **Roland A. Bal:** Conceptualization, Methodology, Formal analysis, Resources, Writing – review & editing, Visualization, Supervision. **AnneLoes van Staa:** Conceptualization, Methodology, Formal analysis, Resources, Data curation, Writing – review & editing, Visualization, Supervision, Project administration, Funding acquisition. **Jane N.T. Sattoe:** Conceptualization, Methodology, Formal analysis, Resources, Data curation, Writing – review & editing, Visualization, Supervision, Funding acquisition.

#### Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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#### References

- [1] Dovey-Pearce G, Doherty Y, May C. The influence of diabetes upon adolescent and young adult development: a qualitative study. *Br J Health Psychol* 2007;12:75–91. <https://doi.org/10.1348/135910706X98317>
- [2] Agarwal S, Raymond JK, Schutta MH, Cardillo S, Miller VA, Long JA. An adult health care-based pediatric to adult transition program for emerging adults with type 1 diabetes. *Diabetes Educ* 2017;43:87–96. <https://doi.org/10.1177/0145721716677098>
- [3] Saxby N, Beggs S, Kariyawasam N, Battersby M, Lawn S. Do guidelines provide evidence-based guidance to health professionals on promoting developmentally appropriate chronic condition self-management in children? A systematic review. *Chronic Illn* 2020;16:239–52. <https://doi.org/10.1177/1742395318799844>
- [4] Sandler CN, Garvey KC. A practice in maturation: current perspectives on the transition from pediatric to adult care for young adults with diabetes. *Curr Diab Rep* 2019;19:126. <https://doi.org/10.1007/s11892-019-1247-x>
- [5] Bronner MB, Peeters MAC, Sattoe JNT, van Staa AL. The impact of type 1 diabetes on young adults' health-related quality of life. *Health Qual Life Outcomes* 2020;18:137. <https://doi.org/10.1186/s12955-020-01370-8>
- [6] Cameron FJ, Garvey K, Hood KK, Acerini CL, Codner E. ISPAD clinical practice consensus guidelines 2018: diabetes in adolescence. *Pediatr Diabetes* 2018;19(Suppl 27):250–61. <https://doi.org/10.1111/pedi.12702>
- [7] White PH, Cooley WC. Transitions Clinical Report Authoring Group. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics* 2018;142:e20182587. <https://doi.org/10.1542/peds.2018-2587>
- [8] Vallis M, Willaig I, Holt RIG. Emerging adulthood and type 1 diabetes: insights from the DAWN2 study. *Diabet Med* 2018;35:203–13. <https://doi.org/10.1111/dme.13554>
- [9] van Staa AL, Jedeloo S, van Meeteren J, Latour JM. Crossing the transition chasm: experiences and recommendations for improving transitional care of young adults, parents and providers. *Child Care Health Dev* 2011;37:821–32. <https://doi.org/10.1111/j.1365-2214.2011.01261.x>
- [10] Clements MA, Foster NC, Maahs DM, Schatz DA, Olson BA, Tsalkian E, et al. T1D Exchange Clinic Network. Hemoglobin A1c (HbA1c) changes over time among adolescent and young adult participants in the T1D exchange clinic registry. *Pediatr Diabetes* 2016;17:327–36. <https://doi.org/10.1111/pedi.12295>
- [11] White M, O'Connell MA, Cameron FJ. Clinic attendance and disengagement of young adults with type 1 diabetes after transition of care from paediatric to adult services (TrAcED): a randomised, open-label, controlled trial. *Lancet Child Adolesc Health* 2017;1:274–83. [https://doi.org/10.1016/S2352-4642\(17\)30089-5](https://doi.org/10.1016/S2352-4642(17)30089-5)
- [12] Farrell K, Fernandez R, Salamonson Y, Griffiths R, Holmes-Walker DJ. Health outcomes for youth with type 1 diabetes at 18months and 30months post transition from pediatric to adult care. *Diabetes Res Clin Pract* 2018;139:163–9. <https://doi.org/10.1016/j.diabres.2018.03.013>
- [13] Sawyer SM. Developmentally appropriate healthcare for young people with chronic illness: questions of philosophy, policy, and practice. *Pediatr Pulmonol* 2003;36:363–5. <https://doi.org/10.1002/ppul.10369>
- [14] Peters A, Laffel L. American Diabetes Association Transitions Working Group. Diabetes care for emerging adults: recommendations for transition from pediatric to adult diabetes care systems: a position statement of the American Diabetes Association, with representation by the American College of Osteopathic Family Physicians, the American Academy of Pediatrics, the American Association of Clinical Endocrinologists, the American Osteopathic Association, the Centers for Disease Control and Prevention, Children with Diabetes, The Endocrine Society, the International Society for Pediatric and Adolescent Diabetes, Juvenile Diabetes Research Foundation International, the National Diabetes Education Program, and the Pediatric Endocrine Society (formerly Lawson Wilkins Pediatric Endocrine Society). *Diabetes Care* 2011;34:2477–85. <https://doi.org/10.2337/dc11-1723>
- [15] National Institute for Health and Care Excellence (NICE). Transition from children's to adults' services for young people using health or social care services, Guideline 43. London: NICE; 2016.
- [16] Farre A, McDonagh JE. Helping health services to meet the needs of young people with chronic conditions: towards a developmental model for transition. *Healthcare* 2017;77.
- [17] Dutch Diabetes Federation, Healthcare Standard Diabetes [in Dutch]. <https://www.zorgstandaarddiabetes.nl/type-1/>, 2021 (accessed 12 March 2021).
- [18] Modi AC, Pai AL, Hommel KA, Hood KK, Cortina S, Hilliard ME, et al. Pediatric self-management: a framework for research, practice, and policy. *Pediatrics* 2012;129:e473–85. <https://doi.org/10.1542/peds.2011-1635>

- [19] Dovey-Pearce G, Hurrell R, May C, Walker C, Doherty Y. Young adults' (16–25 years) suggestions for providing developmentally appropriate diabetes services: a qualitative study. *Health Soc Care Community* 2005;13:409–19. <https://doi.org/10.1111/j.1365-2524.2005.00577.x>
- [20] Manalastas G, Noble LM, Viney R, Griffin AE. Patient autonomy in the consultation: how signalling structure can facilitate patient-centred care. *Patient Educ Couns* 2020;103:2269–79. <https://doi.org/10.1016/j.pec.2020.05.020>
- [21] Epstein RM, Franks P, Fiscella K, Shields CG, Meldrum SC, Kravitz RL, et al. Measuring patient-centered communication in patient-physician consultations: theoretical and practical issues. *Soc Sci Med* 2005;61:1516–28. <https://doi.org/10.1016/j.socscimed.2005.02.001>
- [22] Epstein RM, Street Jr. RL. The values and value of patient-centered care. *Ann Fam Med* 2011;9:100–3. <https://doi.org/10.1370/afm.1239>
- [23] Levinson W. Patient-centred communication: a sophisticated procedure. *BMJ Qual Saf* 2011;20:823–5. <https://doi.org/10.1136/bmjqs-2011-000323>
- [24] Castro EM, Van Regenmortel T, Vanhaecht K, Sermeus W, Van Hecke A. Patient empowerment, patient participation and patient-centeredness in hospital care: a concept analysis based on a literature review. *Patient Educ Couns* 2016;99:1923–39. <https://doi.org/10.1016/j.pec.2016.07.026>
- [25] Hibbard JH. Commentary on “Refining Consumer Engagement Definitions and Strategies”. *J Ambul Care Manag* 2017;40:265–9. <https://doi.org/10.1097/JAC.0000000000000217>
- [26] Sacks RM, Greene J, Hibbard J, Overton V, Parrotta CD. Does patient activation predict the course of type 2 diabetes? A longitudinal study. *Patient Educ Couns* 2017;100:1268–75. <https://doi.org/10.1016/j.pec.2017.01.014>
- [27] Suris JC, Akre C, Rutishauser C. How adult specialists deal with the principles of a successful transition. *J Adolesc Health* 2009;45:551–5. <https://doi.org/10.1016/j.jadohealth.2009.05.011>
- [28] Boisen KA, Hertz PG, Blix C, Teilmann G. Is HEADS in our heads? Health risk behavior is not routinely discussed with young people with chronic conditions. *Int J Adolesc Med Health* 2016;28:429–35. <https://doi.org/10.1515/ijamh-2015-0015>
- [29] van Staa AL. On Your Own Feet Research period behind Group Unraveling triadic communication in hospital consultations with adolescents with chronic conditions: the added value of mixed methods research. *Patient Educ Couns* 2011;82:455–64. <https://doi.org/10.1016/j.pec.2010.12.001>
- [30] Betz CL, Lobo ML, Nehring WM, Bui K. Voices not heard: a systematic review of adolescents' and emerging adults' perspectives of health care transition. *Nurs Outlook* 2013;61:311–36. <https://doi.org/10.1016/j.outlook.2013.01.008>
- [31] Jones J, Smith J. Ethnography: challenges and opportunities. *Evid Based Nurs* 2017;20:98–100. <https://doi.org/10.1136/eb-2017-102786>
- [32] Van Staa AL, Peeters MAC, Sattoe JNT. On Your Own Feet: a practical framework for improving transitional care and young people's self-management. In: Betz CL, Coyne IT, editors. *Transition from pediatric to adult healthcare services for adolescents and young adults with long-term conditions: an international perspective on nurses' roles and interventions* Switzerland: Springer; 2020. p. 191–228. <https://doi.org/10.1007/978-3-030-23384-6>
- [33] Bikker AP, Atherton H, Brant H, Porqueddu T, Campbell JL, Gibson A, et al. Conducting a team-based multi-sited focused ethnography in primary care. *BMC Med Res Methodol* 2017;17:139. <https://doi.org/10.1186/s12874-017-0422-5>
- [34] Lundin CS, Danielson E, Ohn I. Handling the transition of adolescents with diabetes: participant observations and interviews with care providers in paediatric and adult diabetes outpatient clinics. *Int J Integr Care* 2007;7:e05. <https://doi.org/10.5334/ijic.178>
- [35] Sattoe JNT, Peeters MAC, Hilberink SR, Ista E, van Staa AL. Evaluating outpatient transition clinics: a mixed-methods study protocol. *BMJ Open* 2016;6:e011926. <https://doi.org/10.1136/bmjopen-2016-011926>
- [36] Pope C. Conducting ethnography in medical settings. *Med Educ* 2005;39:1180–7. <https://doi.org/10.1111/j.1365-2929.2005.02330.x>
- [37] Strauss A, Corbin J. *Basics of qualitative research: techniques and procedures for developing grounded theory*. 2nd ed., Thousand Oaks: Sage Publications Inc.; 1998.
- [38] Dierckx de Casterlé B, Gastmans C, Bryon E, Denier Y. QUAGOL: a guide for qualitative data analysis. *Int J Nurs Stud* 2012;49:360–71. <https://doi.org/10.1016/j.ijnurstu.2011.09.012>
- [39] Piccolo LD, Goss C, Zimmermann C. The third meeting of the Verona Network on sequence analysis. Finding common grounds in defining patient cues and concerns and the appropriateness of provider responses. *Patient Educ Couns* 2005;57:241–4. <https://doi.org/10.1016/j.pec.2005.03.003>
- [40] Heath G, Farre A, Shaw K. Parenting a child with chronic illness as they transition into adulthood: a systematic review and thematic synthesis of parents' experiences. *Patient Educ Couns* 2017;100:76–92. <https://doi.org/10.1016/j.pec.2016.08.011>
- [41] Stinson J, Kohut SA, Spiegel L, White M, Gill N, Colbourne G, et al. A systematic review of transition readiness and transfer satisfaction measures for adolescents with chronic illness. *Int J Adolesc Med Health* 2014;26:159–74. <https://doi.org/10.1515/ijamh-2013-0512>
- [42] Dickinson JK, Guzman SJ, Maryniuk MD, O'Brian CA, Kadohiro JK, Jackson RA, et al. The use of language in diabetes care and education. *Diabetes Care* 2017;40:1790–9. <https://doi.org/10.2337/dci17-0041>
- [43] Carel H, Kidd IJ. Epistemic injustice in healthcare: a philosophical analysis. *Med Health Care Philos* 2014;17:529–40. <https://doi.org/10.1007/s11019-014-9560-2>
- [44] de Wit F, Mul M, Bal RA. *Leren van patiënten: Spiegelbijeenkomsten leveren zorgverleners nuttige feedback* [Learning from patients: mirror meeting provide useful feedback to healthcare professionals]. *Med Contact* 2008;63:990–3.
- [45] Luxford K, Safran DG, Delbanco T. Promoting patient-centered care: a qualitative study of facilitators and barriers in healthcare organizations with a reputation for improving the patient experience. *Int J Qual Health Care* 2011;23:510–5. <https://doi.org/10.1093/intqhc/mzr024>
- [46] Zhou H, Roberts P, Dhaliwal S, Della P. Transitioning adolescent and young adults with chronic disease and/or disabilities from paediatric to adult care services - an integrative review. *J Clin Nurs* 2016;25:3113–30. <https://doi.org/10.1111/jocn.13326>
- [47] Rutten G, van Vugt HA, de Weerd I, de Koning E. Implementation of a structured diabetes consultation model to facilitate a person-centered approach: results from a nationwide Dutch study. *Diabetes Care* 2018;41:688–95. <https://doi.org/10.2337/dc17-1194>
- [48] Dutch Diabetes Federation, Dutch Diabetes Federation Conversation Model Personalized Diabetes Care feasible and applicable. <https://diabetesfederatie.nl/nieuwsberichten/675-ndf-gespreksmodel-personalized-diabetescare-buikbaar-en-toepasbaar>, 2018 (accessed 12 March 2021).
- [49] Beck D, Been-Dahmen J, Peeters M, Grijpma JW, van der Stege H, Tielen M, et al. A nurse-led self-management support Intervention (ZENN) for kidney transplant recipients using intervention mapping: protocol for a mixed-methods feasibility study. *JMIR Res Protoc* 2019;8:11856. <https://doi.org/10.2196/11856>
- [50] van Staa AL. *On Your Own Feet: adolescents with chronic conditions and their preferences and competencies for care*. Rotterdam: Erasmus University Rotterdam; 2012.