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Transition from paediatric to adult care: a qualitative study of the experiences of young adults with type 1 diabetes

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Transition from paediatric to adult care: a qualitative study of the experiences of young adults with type 1 diabetes

Aim: The aim of the present study was to explore how young adults with type 1 diabetes (T1D) experienced the transition from paediatric to adult health care services.

Design: A qualitative, explorative design was used.

Methods: Eleven young adults with T1D receiving adult diabetes care at a hospital in western Norway participated in semi-structured interviews. Data were analysed using Interpretive Description, an inductive approach inspired by grounded theory, ethnography and phenomenology, and specifically designed to explore phenomena in clinical practice aiming to generate new knowledge and skills.

Results: Four main themes regarding the adolescents' experiences of the transfer from paediatric to adult care emerged: (i) limited information about the transition; (ii) transition from frequent, thorough and personal follow-

up to a less comprehensive and less personal follow-up; (iii) the importance of being seen as a whole person; (iv) limited expectations of how the health care services were organised.

Conclusions: The study showed that the existing routines for transfer between paediatric and adult care are not optimal. The participants expressed that they were not prepared for the dissimilarities in follow-up and were predominantly less pleased with the adult care follow-up.

Relevance to clinical practice: The findings support a need for structured transition programmes, that is programmes that contribute to young adults with T1D receiving a safe and positive transition at an otherwise demanding life phase. Young peoples' individual needs for the transition to and follow-up in adult care may be promoted by an approach based on person-centred care.

Keywords: type 1 diabetes, adolescents, young adults, transition to adult care.

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Introduction

Type 1 diabetes (T1D) is caused by autoimmune destruction of insulin-producing beta cells in the pancreas, leading to insulin deficiency and a need for lifelong insulin treatment (1). T1D is most commonly diagnosed in children, adolescents and young adults, but can occur at any age. Approximately 8000 children develop T1D every year worldwide, and it is estimated that more than 500 000 children aged 0–14 years are living with the disease (2). In 2016, the incidence rate of T1D in Norway

was 37.4 per 100 000 person-years for boys and 32.9 per 100 000 person-years for girls aged 0–14.9 years; Norway is among the countries with the highest incidence rates of childhood T1D in the world (3). Living with T1D is demanding, and especially demanding during adolescence and young adulthood when many rapid physical, cognitive and social changes are taking place. During this period, the transition from paediatric to adult diabetes follow-up, also take place.

Background

Insulin treatment and diabetes self-management for people with T1D entail a variety of complex requirements for both the individuals living with the disease and their families (4). They need to identify the body's need for insulin and administer insulin several times a day. Blood

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glucose levels (by finger pricking and a glucometer) or levels of glucose in the interstitial fluid (by a continuous glucose monitoring system) must be measured several times every day, as well (4, 5). The blood glucose level, the individuals' experiences with their need for insulin in different situations, food intake and physical activity are among the issues that require consideration when determining insulin doses. Thus, insulin treatment is complicated. The complex considerations required might partly explain why many adolescents and young adults with T1D do not achieve the recommended treatment goal for blood glucose regulation measured by glycosylated haemoglobin A_{1c} (HbA_{1c}) (6). Poor blood glucose regulation over time increases the risk of long-term diabetes-related micro- and macro-vascular complications (7).

In addition to an often experimental and unstructured lifestyle, the adolescent period includes several important and often demanding changes and transitions. Meleis (8) has described four different types of transitions: developmental transitions (e.g. from adolescent to adulthood), transitions related to health and illness (e.g. from being healthy to being diagnosed with a chronic disease), situational transitions (i.e. from feeling fine to having a hypoglycaemic event) or organisational transitions (e.g. transfer from paediatric to adult diabetes care). The adolescent period most often includes several of these types of transitions: physical, hormonal and mental changes from childhood to adulthood; a transition from being a student to being an employee; and a transition related to moving out of the childhood home. For adolescents with T1D, also the transfer from paediatric to adult care takes place.

Research has shown that paediatric and adult care often have different approaches and different cultures with regard to follow-up and interactions with adolescents and their families (9, 10). The International Society for Paediatric and Adolescent Diabetes (ISPAD) describe dropping out of continuous follow-up in health care as a potential risk after transitioning to adult care (11). Accordingly, studies have indicated that the transition from paediatric to adult care for adolescents with T1D is associated with a lack of continuous follow-up, decreased glycaemic control and an increased risk of acute and long-term diabetes complications (12–16). In a study by Lotstein et al. (15), leaving paediatric care was associated with a 2.5-fold increase in the odds for poor glycaemic control. Further, reviews of intervention studies have indicated that structured transition programmes may be effective to decrease the adverse outcomes, but without clear evidence on which programmes or components of programmes that are most effective (10, 17, 18). Components mentioned as essential in the reviews include starting preparation for transition early (preferably in early adolescence), clarifying expectations for the process and

the skills needed for the transition, assessing the adolescents readiness for change before transition, employing a separate transitional coordinator, establishing specific transition clinics and organising specific transition meetings to allow the adolescents to meet the adult providers in the familiar paediatric setting. A need to develop structures during and after the transition to adult care that also takes into account the role of the parents, and their ability to continue supporting their child into young adulthood, has also been emphasised in the literature (19).

To identify the components of greatest importance for effective transitional care, it is essential to increase the knowledge about the adolescents own experiences and opinions about the transitional care. Few previous studies have emphasised the adolescents' and young adults' own experiences of the transfer from paediatric to adult care. In a qualitative study among young adults in the United States, the participants reported inadequate planning of the transition and insufficient follow-up in adult care (20). Young adults in the United States have also reported challenges related to the establishment of a satisfactory relationship with the adult providers (21). The challenges with identifying the most effective components and interventions for transitional care may partly be explained by differences in health care systems and cultures between countries, and research on transitional care for adolescents with T1D in Scandinavia is scarce. No studies from Norway have been published. Therefore, we conducted a study to expand our knowledge on the transition from paediatric to adult care for adolescents with T1D in a Norwegian care setting.

Aim

The aim of the present study was to explore how young adults with T1D experienced the transition from paediatric to adult health care services.

Methods

Design

We used a qualitative, explorative research design to understand and describe how the young adults experienced the transition from paediatric to adult care. Interpretive Description (ID) was used because the method is specifically designed to explore phenomena in clinical practice for which there is a need to generate new knowledge and skills (22). ID is an inductive approach drawing on elements from grounded theory, ethnography and phenomenology, but departs from these approaches by emphasising the importance of practice implications. The purpose of ID is to gain deeper insight into human experience within the context of the experience (22).

Participants

The participants were recruited from an outpatient clinic at a large hospital in western Norway. Using the clinic's patient list, a diabetes nurse identified all young adults with T1D who transitioned from the paediatric clinic to the adult clinic between January 2012 and November 2015. Individuals who did not speak fluent Norwegian or had cognitive impairment were excluded. In total, 63 eligible participants were identified. Invitations with information and consent forms were sent by regular post from the outpatient clinic to the eligible young adults. Eleven of the 63 eligible young adults agreed to participate and signed the consent form before the interview started. The participants, five young women and six young men, were aged between 19 and 23 years, had been living with diabetes for 9–19 years, and transitioned to adult care between 1 and 4 years before the study took place.

Data collection

We chose individual interviews as the method for data collection since it gave the opportunity to acquire in-depth and rich information. In addition, individual meetings made it easy to arrange the place and time for the interviews according to the individuals' wishes and needs, which we experienced as essential for participation. Eleven individual interviews were conducted between November 2016 and January 2017 by the first author. All but one interview were held in a meeting room at the hospital. The interviews lasted from 19 to 64 minutes and were audiotaped. We used a semi-structured interview guide to cover the main topics related to the aim of the study (Table 1). The scope of the questions was based on previous research on transition from paediatric to adult care. The interview guide was tested in the first two interviews. However, it was not deemed necessary to make any changes in the interview guide as result of these two pilot interviews. The two interviews provided rich information in accordance with the aim of the study and were therefore included in the analysis.

During the interviews, the first author aimed to create a good atmosphere and establish trust. Questions were asked in a manner that allowed the participants to control the conversation as much as possible. Follow-up questions were used for clarification and to get a deeper understanding of the content. During the interviews, the participants were encouraged to raise issues that they considered important in relation to the transition, and the interviewer summarised her understanding of what she had heard to confirm that the information was perceived correctly.

Data analysis

Data analysis was guided by ID methodology and was conducted concurrently with the data collection (22).

Table 1 Interview guide

Opening question: Tell me a little about yourself. (Can you tell me who you are?)	
Introductory question: Can you tell me how long has it been since you were transferred to adult care?	
Key questions with possible sub-questions	
What kind of experiences do you have with the transition from paediatric care to adult care?	What thoughts do you have about these experiences? Is there something that immediately comes to your mind?
Did you have any expectations when you were transferred to the adult care?	Can you say something about your expectations?
Can you say anything about the information you received about this transition?	What kind of information did you receive? How did you get this information?
What experiences do you have with the follow-up in adult care?	Based on these experiences, what thoughts do you have?
How did you experience your follow-up in paediatric care?	What is the same and what is different? Good? Bad?
Do you have any thoughts based on your experience on when it would be appropriate to be transferred from paediatric to adult care?	Why? Can you elaborate on that?
What experiences do you have with the communication between you and the health care personnel at paediatric care and adult care?	Can you elaborate on this? Why do you think it is like that?
Closes the discussion with a summary	
Is there anything you think I have forgotten mention here today... anything you want to add?	

The first author transcribed all interviews verbatim, and the analysis started immediately after the first interview. The first author read the transcripts several times to become familiar with the data, with a debriefing with all authors. We discussed the transcripts in the author group as a whole but also the nuances arising from the different pieces of the data. To encourage more creativity and to allow the use of intuition in the analysis process, a detailed coding was avoided, which also prevents premature coding. In accordance with the ID approach, open-ended coding was used to capture the issues, ideas and patterns in the data. Data were grouped in broad groups to avoid premature closure of our interpretation. Groupings emerged through the coding process that helped us organise the data, and a constant comparative method was applied to compare the data and patterns within and between every interview. For example, as the analysis progressed, similarities and differences were explored between the informants' descriptions of paediatric and adult care and their description of the transition process.

Thus, comparison of data was conducted to look for differences, variations and similarities (22, 23). During this phase, in order to avoid being too focused on the details, the attention was shifted by going in and out of the data material and focusing on the overall content. Questions repeatedly asked during this process included: 'What is seen in this data?' 'Why is this seen?' 'What is not seen?' (22). A sense of the whole was developed through the ongoing process, from which the body of transcribed material was more formally coded and organised into themes.

Ethics

The authors had no relationship with the participants in this study. The participants were informed that participation was voluntary and that their treatment and follow-up at the outpatient clinic were not affected by whether they wanted to participate in the study or not. The study was conducted in accordance with the Declaration of Helsinki, the Norwegian Regional Committee for Medical and Health Research Ethics approved the study (2016/1100/REC West), and informed consent was obtained.

Findings

From the analysis of the data, some themes concerning the participants' experiences with and views of the transition from the paediatric outpatient clinic to the adult outpatient clinic emerged:

- 1 Limited information about the transition;
- 2 Transition from a frequent, thorough and personal follow-up to a less comprehensive and less personal follow-up;
- 3 The importance of being seen as a whole person;
- 4 Limited expectations of how the health care services were organised.

Limited information about the transition

Information about the transition from paediatric to adult care before it took place was limited and often absent. None of the participants remembered any written information beyond an ordinary notice letter about an appointment at the adult outpatient clinic. Accordingly, one of the participants said:

I cannot quite remember, but I do not think I received any information. I received a letter about the next appointment at the adult outpatient clinic.

The participants described follow-up consultations every third month at the paediatric clinic, and they expressed a desire for information about the transition to adult care about 9 months before it takes place. In addition, they wanted the information to be repeated several times before the last appointment at the paediatric

outpatient clinic. A meeting with an adult provider while still under paediatric care would be beneficial and helpful for these young people according to their needs. The participants suggested that the adult provider should participate in the last visit at the paediatric outpatient clinic. They also expressed that they would have appreciated an opportunity to visit the adult outpatient clinic before the transition, that is to see where the clinic is located and to receive information about what takes place during visits at the adult clinic. A 'get acquainted appointment' on the first visit was among the suggestions that could clarify expectations. Oral information about the adult clinic seemed preferable, but written information about the adult outpatient clinic was also regarded as positive.

Despite information on the transition being portrayed as limited, it appeared that such information was not necessarily equally important to all; one participant said:

For me personally, it did not matter to me that I did not get that information.

Transition from a frequent, thorough and personal follow-up to a less comprehensive and less personal follow-up

The participants experienced the paediatric outpatient clinic as comfortable, with frequent and thorough follow-ups (every third month), including more examinations and better quality advice and guidance. They felt they were being cared for in the paediatric clinic. Appointments at the adult outpatient clinic were experienced as taking place more randomly and less frequently. The personnel in the adult clinic were experienced as being vague and indifferent, and the young adults expressed feeling that support was less personal. Shorter consultation was one reason why they felt they could not address aspects they were wondering about. Routine and checklists characterised the follow-ups by the physicians.

Yes, because I feel like the doctor is just measuring you, and then you leave again. However, the disease is about so much more than taking insulin. The disease affects you mentally. Therefore, I think the focus on how you are really doing is less evident in the adult outpatient clinic. At the paediatric outpatient clinic, they asked me how I felt and things like that.

A perception of not having clear goals for their diabetes treatment was expressed in the interviews. In addition, the young adults experienced not getting advice nor guidance in relation to specific problems such as fluctuating blood glucose values, which they were used to in the paediatric care. A desire and a need for something more comprehensive than what the adult outpatient clinic offered was expressed. Consultations once or twice a year were perceived as not frequent enough. In addition, the participants requested various examinations:

I do not know how I am going to adjust my blood glucose. Because to measure my HbA_{1c} once a year

is not enough. I do not feel I have control over my HbA_{1c}. I would be more satisfied with follow-ups twice a year.

Some young adults wanted to continue the follow-ups at the paediatric outpatient clinic beyond 18 years of age:

I thought it was tougher to be a diabetic when I was about 18–20 years old compared with earlier, and handling the disease at the same time when I was new at the adult outpatient clinic was hard. I would have preferred to continue at the paediatric outpatient clinic.

The importance of being seen as a whole person

An unpleasant experience among many of the participant's was a feeling of not being seen as a whole person by the physician at the adult outpatient clinic. At the paediatric outpatient clinic, the young adults usually met the same physician and diabetes nurse specialist over time. The health care providers always asked them how they were doing and how they had been since the previous appointment. This contributed to a feeling of having a more personal relationship with the providers and being cared for. Consequently, it gave them a feeling of being seen as a whole person by the providers. Through continuity with the same physician, the participants perceived a bond that they did not experience at the adult outpatient clinic.

The young adults who attended consultations with a diabetes nurse specialist were more satisfied with follow-up in adult care than those who just met the physician, or those who did not know the profession of the health care provider. The diabetes nurse consultations were longer, and the young adults experienced that the nurses provided better guidance and knew them better than the physicians did. Those who met diabetes nurse specialists experienced that the nurses had taken over the role of the paediatrician:

Now, I have had the conversation that I had with the doctor at the paediatric outpatient clinic with the nurse here at the adult outpatient clinic, and that is actually okay.

The participants expressed that they preferred meeting the same health care provider at every consultation because this gave them a feeling of trust:

Now, I feel in a way that talking about diabetes is a personal thing and how I have handled it or are handling it is personal. It would be easier to talk about it with people I have met before than with total strangers.

Seeing the same person gave the young adults and the providers an opportunity to get to know each other better. Subsequently, this contributed to a more open and equitable dialogue. In the young adults' characterisation of the aspects they did not experience as satisfactory,

they expressed a worry about criticising specific providers instead of the system. They clarified this by pointing out that the health care providers at the adult outpatient clinic were all nice people.

Limited expectations of how the health care services were organised

Before the transfer from paediatric to adult care took place, the participants expected that the follow-ups at the two clinics would be similar. They recognised that this was not the case. However, the young adults conveyed that they had not asked for nor required any of the reported shortcomings in the follow-up, and they expressed a low degree of criticism of the system. Moreover, the participants expressed a belief that the issues they perceived as not optimal probably had explanations.

The young adults had few expectations for how the health care services should be organised, and they described how they just show up to the appointments and accept what is offered. One of the participants, who received only one annual check-up at the adult outpatient clinic, described additional follow-ups at his general practitioner (GP). He said:

I did not feel I had any other choice really. Because at the GP you can get check-ups more often. I was told that there would not be as many follow-ups after the transition to the adult outpatient clinic, so I should get a GP where I could get my mean blood glucose checked more often.

When asking the participants about the most appropriate age for transitioning, most found 18 years of age as suitable. Nevertheless, several voiced that the age for transition ought to be based on an individual assessment.

Discussion

Overall, the findings in this study indicate that young adults with T1D were not fully satisfied with how the transition from paediatric to adult care was organised. Throughout the interviews, it became clear that the young adults received limited information before the transition. They were not prepared for the differences between paediatric and adult care and expressed a feeling of not being seen as a whole person in the adult outpatient clinic. Furthermore, the participants spoke of limited expectations regarding how the health care services were organised.

Regarding limited information before the transition, some reported that they received information concerning the transition from their parents. This may indicate that health care providers had delivered information, but that the young adults did not absorb it. One could question whether the information had been communicated satisfactorily. Lack of information in connection with

transition between paediatric and adult care has also been highlighted in a previous study from Germany (24). The participants in the study considered information about the transition process as essential and reported insufficient information as a major problem. In a recently published study from Denmark, the ten participating adolescents did not perceive the transition as a planned process that they were able to influence (25). The study by Garvey et al. (20), also reported a lack of planning before the transition. Therefore, they recommended better information from the paediatric team about the transition. Similar to the present study, participants described unexpected differences between the paediatric and adult teams, and problems and challenges related to inadequate diabetes follow-up in adult care. Once adolescents approach the age for transition, it would be beneficial if the clinic had greater focus on the transition itself and a more structured approach in the delivering of information. Weissberg-Benchell et al. (26) recommend that health care providers, patients and families collaborate in developing individual written plans for the transition about 2 years before the planned transition. Garvey et al. (14) describe increased attendance rates in the adult clinic among adolescents prepared for the transition to adult care compared with those who were not prepared.

The participants in the present study assumed that follow-up in adult and paediatric care would be similar. However, they experienced that this was not the case. The perception of different approaches and cultures in the two care units has also been described previously. In the study by Garvey et al. (20), the young adults expressed words like 'shock' or 'surprise' after attending the adult outpatient clinic for the first time. Like our participants, young adults communicated a need for improved preparation to ensure realistic expectations about adult care follow-up. Cadario et al. (12) reported that attending a structured transition programme, including a meeting with health care providers from adult care, resulted in better attendance and improved glycaemic control (HbA_{1c}) among the participants 1 year after the transition compared with a group not attending the programme. This highlights the need for structured approaches for the transition from paediatric to adult care for young adults with T1D, and that meeting the adult outpatient clinic's health care providers ahead of the transition may have positive effects. According to Schumacher and Meleis (27), a degree of knowledge regarding a transition is essential for the transition process because it often affects the quality of the transition experience. In addition, describing plans and expectations are considered essential for success in transition processes.

Our participants communicated an experience of not being seen as a whole person by the physicians in adult care. The relationship with the physician was described as being largely impersonal compared with the

relationship with the paediatrician. Hilliard et al. (21) describe similar findings: the participants expressed a feeling of being just 'a number' among patients in the adult clinic. This is quite contradictory to the ideals of person-centred care whereby it is essential to consider each patient individually and respect the patients' values, preferences and expressed needs (28). According to Ekman et al. (29), a person-centred approach will put the person's view of his/her situation in the centre of care. The person's own narrative forms the basis for person-centred care and provides the basis for the development of a good relationship between the physician and the patient.

An approach based on the philosophy of person-centred care seems to meet many of the shortcomings that the young adults in our study experienced during and after the transfer from paediatric to adult care. Although there were perceived shortcomings, the young adults were careful in their criticism of the system. Overall, they expressed limited expectations of the health care services. This may indicate the normal insecurity among young people, but it may also indicate a great trust in the system. However, diabetes follow-up may not be the most prominent topic of interest in the lives of young people with T1D. Therefore, safeguarding the interests and needs of young adults with T1D is a major responsibility for the health care system.

Strengths and limitations

The study has strengths and limitations. The research team included members with both in-depth knowledge regarding clinical diabetes care and extensive knowledge regarding the ID methodology, which strengthened the study's credibility. However, a pre-understanding of the study phenomenon can be both a strength and a limitation. Preconceptions can help the researchers in collecting rich and adequate data, but may also affect the analysis negatively. To avoid the latter and to strengthen dependability, a reflective open-minded discussion of the data among the researchers took place during the analyses. In addition, we used quotations to illustrate the participants' different perceptions.

Many young adults declined participation in the study, and the sample size might be a limitation. However, we obtained rich data from the sample that included approximately equal numbers of men and women and participants who transitioned 1, 2, 3, and 4 years ahead of the interviews. Thus, the span in the sample was satisfactory, which is a strength. Because some participants transitioned to adult care 3–4 years before the study took place, we cannot exclude recall bias. However, the information provided by those who transitioned 1 year before the interview and those who transitioned 3–4 years before the study did not differ substantially regarding for

example memory of the information received ahead of the transition.

All participants were transferred from paediatric to adult care at the same hospital. Including participants from several hospitals might have been an advantage in providing complementary information. Inclusion of young adults not fluent in Norwegian or with cognitive impairment might also have provided complementary information, but we consider it as practically difficult and in some cases unethical to perform interviews with these groups of young people. Further, the participants expressed few expectations concerning the organisation of the health care services, which may be a result of the individual interview situation. Focus group interviews could have resulted in a more open discussion of the perceived shortcomings regarding the transition and follow-up in adult care.

Conclusions

The study has identified differences between follow-up in a paediatric clinic and an adult outpatient clinic with consequences for young people with T1D regarding transfer between the clinics. The participants were not prepared for the dissimilarities in follow-up and were predominantly less pleased with the adult care follow-up. Unlike paediatric care, the young adults experienced adult care as being less personal and described a feeling of not being seen as a whole person. The study indicates that the existing routines for transfer between paediatric and adult care are not optimal.

Relevance to clinical practice

The findings support a need for structured transition programmes, that is programmes that contribute to young

adults with T1D receiving a safe and positive transition at an otherwise demanding life phase. Young peoples' individual needs for the transition to and follow-up in adult care may be promoted by an approach based on person-centred care.

Acknowledgement

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Conflicts of interest

None.

Author contributions

EI designed the study, collected the data, analysed the data and drafted the manuscript; BCHK contributed to data collection, assisted in the analysis and contributed to the manuscript; JM assisted in the analysis and contributed to the final manuscript; IH contributed to the analysis and the manuscript; AH designed the study, analysed the data and contributed to the manuscript. All authors read and approved the final manuscript.

Ethical approval

The Norwegian Regional Committee for Medical and Health Research Ethics approved the study (2016/1382/REC West), and informed consent was obtained from participants.

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