ORIGINAL ARTICLE International Diabetes Nursing, Vol. 14, 2017, 52–59

Partnership in transition: Experiences of adolescents with Type 1 diabetes

Karina Kudahl Hansen and Annesofie Lunde Jensen
Department of Endocrinology and Internal Medicine, Aarhus University Hospital, Aarhus C, Denmark

Aims: Debut of Type 1 diabetes (T1DM) is most common in childhood and adolescence. In late adolescence, transfer from pediatric to adult diabetes care is often associated with poor metabolic control. Knowledge is scarce on transition and on the experiences of adolescents concerning partnership in transition. The aim is to explore how adolescents with T1DM experience partnership in the transition.

Methods: Ten adolescents with T1DM receiving adult diabetes care at the Department of Endocrinology and Internal Medicine at Aarhus University Hospital participated in semi-structured interviews.

Results: Three major themes emerged from the analysis: (1) Transition unawareness. (2) A crucial change in relationship. (3) Partnership without shared decision-making.

Conclusions: Findings highlight the importance of a specific relationship with the health care providers and a planned and prepared transition. Unawareness concerning the transition process leads to a non-reflective transition and does not support the development of health literacy and partnership.

Keywords: Type 1 diabetes, Adolescents, Transition, Partnership, Patient experience, Qualitative methods

Introduction

Youth is generally considered the period between childhood and adulthood. This period is often defined as the gap between puberty and the point at which a person reaches the legal definition of an adult at around 18 years, depending on the national criteria. However, feature of youth are generally not bound by chronological age can extend beyond this legal definition into young adult-life until the social norms of adult life such as an enduring relationship, a career and personal independence are established. This youthful period is often termed adolescence, which the World Health Organization defines as the period of life between 10 and 19 years of age, although again adolescence is a social construct that can vary between cultures. However defined, it is common that at the end of this adolescents period, young people with Type 1 diabetes (T1DM) mellitus transfer from paediatric to adult diabetes care. Transfer is the event of moving from paediatric to adult diabetes services and is often associated with poor metabolic control, loss of follow-up in adult care and risk of adverse health outcomes.[1–4] Transition is defined in this paper as the purposeful, planned transfer of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented health care systems.[5] Studies show that a successful transition is planned and based on good working relationship between the paediatric and adult diabetes departments. This contributes to a greater sense of security, patient satisfaction, quality of life and adherence to self-care.[2,6] In addition, qualitative research has shown that a successful transition also depends on the relationship between the adolescent and the provider. The adolescent should feel encouraged to gain knowledge, skills and confidence to become an active partner in the process.[6]

In Canada, Great Britain and US there are published expert consensus guidelines on health care transition for emerging adults with T1DM.[7,8] Preparation is the key word in ADA's recommendation on transition. Not only preparation on the future transfer, but also a more directed focus on diabetes self-management skills for the adolescents.[7] Despite the importance of a successful transition, there is in general limited empiric data on concrete transition processes and outcomes.[6–9] In Denmark, there are still no joint recommendations or guidelines on transition available.[8] There are local initiatives, but in general, there is a lack of research within the field.[9] At Aarhus University Hospital, the transition process is comparable with the recommendation from the American Diabetes Association.[7]

T1DM is a chronic illness, and debut is most common in childhood and adolescence. T1DM requires lifelong medical follow-up and ongoing intensive self-care.[6] Good metabolic control depends on cognitive ability and the understanding of society in the light of future risks to health.[10] Enhancing the patients active participation in diabetes care, is regarded to be a key factor to outcome improvement.[11] It is in this stage of many developmental changes, the transfer from paediatric to adult

Correspondence to: Karina Kudahl Hansen, Department of Endocrinology and Internal Medicine Aarhus University Hospital, Tage Hansens Gade 2, DK-8000 Aarhus C, Denmark. E-mail: karinhns@rm.dk

DOI 10.1080/20573316.2017.1382182

services takes place. Neurophysiological research has shown that it is not until in the twenties that the brain develops functions such as long-term planning, ability to be attentive, impulse control and ability to think in the abstract.[10] Furthermore, the adolescent is undergoing psychological and social changes.[4,10] It is challenging to transfer from a well known to a new relationship, especially at this stage, where social skills still are undergoing changes.[10,12]

A part of growing up is the ability to form equal relationships with other adults and form a personal identity and vocational capacity.[10,13] The providers have a responsibility to support this development from the beginning to the end of adolescence, and specialized clinical communication skills and knowledge about adolescent development are needed.[10] A recent review found that the most effective interventions are those with a direct approach to support patient participation in diabetes care and self-care behaviour, while interventions, which focus on change of provider behaviour, were less effective.[11] A partnership relationship between patient and provider could be a suitable method to train the adolescent's social skills.[14] With partnership, the aim is to personalize care according to individual patient's needs, values and experiences.[15] The patient is encouraged to be an active competent participant in the consultation, and the providers respect, support and training through adolescence are crucial.[14] Health literacy, meaning the patients ability to obtain, to process and to understand basic health information is fundamental to patient engagement and for the partnership to work.[16] To support the adolescents' health literacy, it is important that the adolescent develop an autonomous behaviour, meaning the ability to act with a full sense of volition and choice because the activity is interesting or personally important.[17]

Studies have shown that a high level of patient involvement increases the quality of the consultation, when the patient is an adult.[16] However, there is only limited data on patient involvement when the patient is an adolescent with a chronic illness, like diabetes.[18,19] When treating adult patients, a partnership relationship is a method that increase the quality of the consultation and patient satisfaction by taking into account the patients preferences, resources and life situation.[16] Preferences are defined as the patients' wishes and needs regarding their health and illness. Treatment choice should be guided by the patients' preferences. The provider's responsibility is to inform about options, communicate risk effectively and respect the patient's choices. This type of partnership is known as shared decision-making and requires health literacy in the patient.[16] Originally, shared decision-making was meant for acute life-threatening diseases.[20] It is not until recently, that the principles of shared decision-making were tailored to account for the routine chronic disease decision-making.[20]

We conducted a study with the aim to investigate how adolescents with T1DM experienced the transition from paediatric to adult diabetes services with a focus on partnership and shared decision-making between the provider and the adolescent. This was in order to expand our knowledge on concrete transition from paediatric to adult diabetes care services in Aarhus, Denmark, and furthermore, on how the adolescents experienced partnership in the transition process.

Research design and methods

An inductive qualitative approach based on semi-structured interview[21] was used for the study, following systematic text condensation.[22] The inductive approach characterizes qualitative studies and the design are more flexible than fixed. On example of the inductive approach in our study, is the analysis, which was an iterative process as well as the focus on specific person and situation.[23]

Participants

The participants in the study were adolescents with T1DM who transferred from paediatric to adult diabetes care. In the spring of 2016, all adolescents ($n = 18$) with T1DM who had transferred from the outpatient clinic at the Department of Pediatrics at Aarhus University Hospital to the outpatient clinic at the Department of Endocrinology and Internal Medicine at Aarhus University Hospital, Denmark one year before (spring of 2015) were asked to participate in the study. The adolescents were invited by phone to join the study. In all 10 adolescents [seven females and three males, mean age 17.2 (17–18)] agreed to participate in the study.

The 10 adolescents who participated in the study received different medical treatment, eight had an insulin pump, and two were treated with insulin pen. One participant was living in a boarding school, and the other participants were living with their parents. Table 1 outlines characteristics of the adolescents in the study.

The eight adolescents, who declined to participate in the study did not differ from the 10 attending participants in any characteristics (Table 1) and had been through the same transition process. The reason why they did not participate in the study was lack of time or they did not connect on the phone.

The content of the transition

The participants in the study went through the same cross-functional transition process, which proceeded over a year, starting in the fall 2014. The transition process aims to contribute to a higher degree of security, patient satisfaction, quality of life and adherence to self-care. This aim is comparable with the goal described by the American Diabetes Association.[7] The transition process is part of a formal practice between the two outpatient clinics and in accordance with the recommendations from the American Diabetes Association.[7,8] Table 2 outlines the transition process.

Table 1 Characteristics of the adolescents in the study.

Participants	Age at transfer	Age at interview	Gender	Occupation	Age at diagnosis	Medical treatment	Housing
U1	17	18	Male	In education	8	Insulin pump	Living with parents
U2	18	19	Female	In education	5	Insulin pump	Living with parents
U3	17	18	Female	In education	11	Insulin pen	Boarding school
U4	17	18	Female	In education	8	Insulin pump	Living with parents
U5	17	18	Female	No occupation	14	Insulin pen	Living with parents
U6	17	18	Female	Working	3	Insulin pump	Living with parents
U7	17	18	Female	In education	10	Insulin pump	Living with parents
U8	18	19	Male	In education	9	Insulin pump	Living with parents
U9	17	18	Male	In education	13	Insulin pump	Living with parents
U10	17	18	Female	In education	6	Insulin pump	Living with parents
Mean	17.2	18.2	7 females 3 males	8 in education 1 working 1 no occupation	8.7	8 insulin pumps 2 insulin pens	9 living with parents 1 in boarding school

Interview and analysis

Interview as method was chosen to access the adolescents' individual experiences and perceptions on transition in relation to their developmental stage.[21] The interviews were audiotaped and conducted at the outpatient clinic at the Department of Endocrinology and Internal Medicine ($n = 9$), or in the participants' home ($n = 1$). An interview guide was conducted prior to the interviews. The interview guide had four themes: (1) Before Transfer, (2) The transition process, (3) The experience of Partnership and shared decision-making and (4) After transfer. During the interview process the questions were further developed according to the participants' individual situation, e.g. in relation to family structure. The interviews took on average 54 min (49–74).The first author conducted and transcribed the interviews verbatim (150 pages transcribed interviews).

Data analysis was an inductive process, using systematic text condensation.[22] The software program NVivo 10 supported the organization and analysis of data.

Systematic text condensation offers the researcher a process of intersubjectivity, reflexivity and feasibility, while maintaining a responsible level of methodological rigour.[22] Systematic text condensation consists of four analytical steps. Table 3 outlines the analytical process in the study. The analysis led to three main themes, which reflect the significant patterns, description and concept of the adolescents' experience of the transition with a focus on partnership between the provider and the adolescent.

Study ethics

The study was approved by the Danish Data Protection Agency (ID no. 1–16–02–101–16) and followed the principles of the Helsinki declaration.[24] The patients who agreed to participate in the study signed informed consent forms. It was emphasized that taking part in the study was voluntary, and declining participation would not affect their treatment.

Results

In the following, we present the main themes; (1) Transition unawareness, (2) a crucial change in relationship with health care providers and (3) partnership without shared decision-making.

Transition unawareness

Overall, the adolescents were not aware that they were a part of a predetermined cross-functional transition process, but considered it as a natural unavoidable shift of care. They remember being informed about some of the elements of the transition process, but did not perceive it as a planned process, they could influence. The adolescents' role in the process was not something the adolescents remembered having discussed with the paediatric providers before the process was initiated.

> U10: I don't think it was something we talked about. I think it was perhaps the last consultation or the one before that, they mentioned, that it was time for me to move. There wasn't been any communication about it. I don't think, there was

The adolescents described the time of transition to be predetermined and the providers' decision. Most of the adolescents had the same age at transfer. They did not have the perception that maturate or big educational changes were taken into account. The adolescents believed it to be a natural process towards being of legal age.

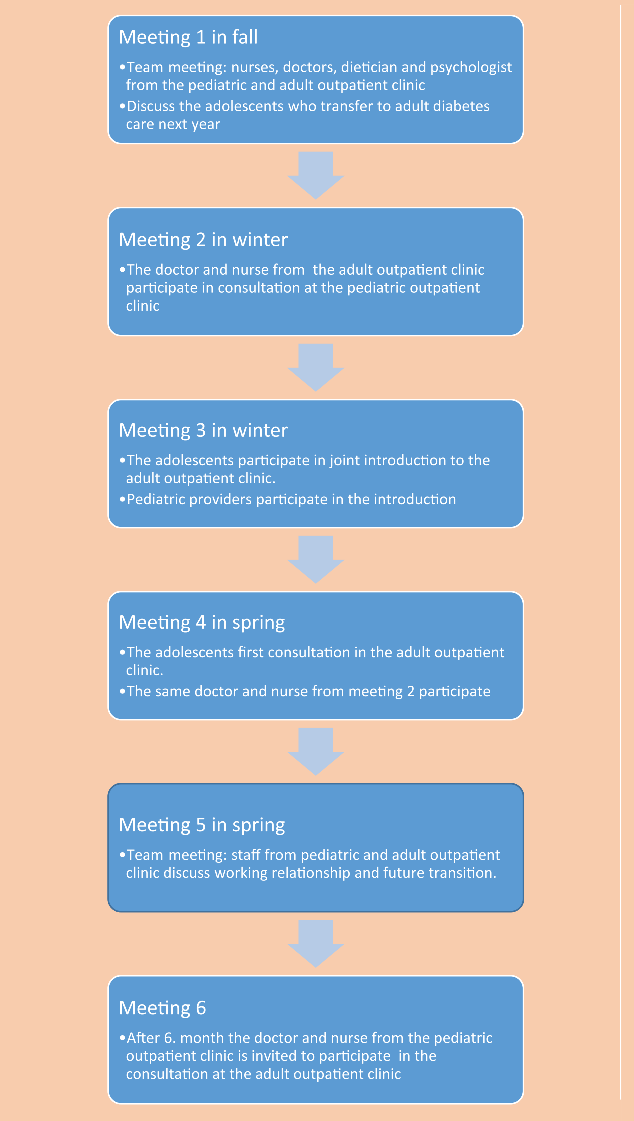
> U1:I turned 18 and then I had to move. I think it was coincidental, but I think in most cases it is a good idea that it occurs before further education.

Some of the adolescents felt immature and would have preferred to continue in the paediatric outpatient clinic and reluctant to leave the safe environment and trusting relationship in the paediatric outpatient clinic. However, they did not argue against the transfer, they accepted it as unavoidable.

One adolescent in the study was involved in discussion about age of transfer, and his preference was to wait a year based on the relationship he had with the providers in the paediatric outpatient clinic. He said:

> U8: I could have transferred, when I became 17, but since I had a really good doctor and nurse at the pediatric ward, we waited till last minute. They

Table 2 The transition process from paediatric to adult diabetes care at Aarhus University Hospital, Denmark.



Meeting 1 in fall
- Team meeting: nurses, doctors, dietician and psychologist from the pediatric and adult outpatient clinic
- Discuss the adolescents who transfer to adult diabetes care next year

Meeting 2 in winter
- The doctor and nurse from the adult outpatient clinic participate in consultation at the pediatric outpatient clinic

Meeting 3 in winter
- The adolescents participate in joint introduction to the adult outpatient clinic.
- Pediatric providers participate in the introduction

Meeting 4 in spring
- The adolescents first consultation in the adult outpatient clinic.
- The same doctor and nurse from meeting 2 participate

Meeting 5 in spring
- Team meeting: staff from pediatric and adult outpatient clinic discuss working relationship and future transition.

Meeting 6
- After 6. month the doctor and nurse from the pediatric outpatient clinic is invited to participate in the consultation at the adult outpatient clinic

> said they could easily transfer me right away because I had no problems, so I could transfer, when I wanted. But we waited on account of the good doctor and nurse.

Preparation of a written transition plan was not something the adolescents had participated in, and they did not feel that the adult providers had any knowledge about them prior to the consultation in the paediatric outpatient clinic. The adolescents were happy to have met their new adult providers prior to transfer. This made the first consultation in the adult outpatient clinic safer and foreseeable.

The adolescents in this study did not have the perception of being involved in the transition. They were informed about the elements of the transition process and were prepared on the cultural differences. They did not have the perception of dialog or that the transition process was based on maturate and individual needs and wishes. Nor did they reflect on their responsibility or opportunity to influence the content of the transition.

A crucial change in relationship with health care providers

The relationship between the adolescents and their providers showed to be of great importance to the adolescents and it was crucial that the relationship was based on the adolescents' preferences in order for the transition to be successful.

Especially preferences in relation to health and illness were very important to the adolescents, meaning the general knowledge about their personal interest, education and daily activities in relation to diabetes. The adolescents felt more involved and comfortable if the providers showed genuine interest, respect and knowledge about their everyday life. They wanted the providers to understand how aspects of young adult-life such as school, work and social demands, impact diabetes management. This made the relationship between them and their providers better and more genuine.

The adolescents valued two types of relationship, either a personal or a professional relationship. The adolescents who valued a personal relationship felt that the consultations in the adult outpatient clinic were standardized. For example, one adolescent described the first consultation like this:

> U8: At the first consultation, the doctor and the nurse were present. They asked many personal questions, more than they do now, so that they could decide properly which treatment would be the best. The consultation was extended - I think it took about 45 minutes. Today it only takes 10 minutes.

The adolescents experienced that the focus was on the professional content, hence a shallower relationship. The adolescents felt that the provider at the adult outpatient clinic did not have the general knowledge about their everyday life. They missed the safe environment, small talk and the familiar connection with the provider, which characterizes the personal relationship in the paediatric outpatient clinic. After transfer, it was difficult for the adolescents, who valued the personal relation, to establish the same connection with the adult providers.

The personal relationship, which was characteristic at the paediatric outpatient clinic, could, on the other hand also be restraining. As one of the adolescent said:

> U10: So it was assumed, even though we didn't talk about it, that the reason for me not checking my blood sugar after school was because I was together with my friends. So they reach conclusions based on the knowledge they felt they had of me as a person.

Table 3 The analytical process in the study — using systematic text condensation (Malterud).

1 step	*2 step*	*3 step*	*4 step*
Total impression — from chaos to preliminary themes	Identifying and sorting meaning units — from preliminary themes to coding themes	Condensation — from code to meaning	Synthesizing — from condensation to descriptions and concepts to code groups
Preliminary teams	*The tree coding themes*	*Example of a condensate*	*Example from result*
• User involvement • Relations The adolescents' • Social condition • The transition process • Cultural difference • Study or employment	• Transition process (R: 209, S: 10) • Relationship (R: 325, S: 10) • Involvement (R: 240, S: 10) Subgroup: Co-management (R: 168), Concrete advice (R: 77), Involving every day life in treatment (R: 95)	An condensate related to the coding theme Involvement: • The nurses and doctors have the answers to what to do. Normally, we try to find a solution together but I think they know best. You make sure, you agree and usually that is what you do.	The code theme Involvement is analyzed and renamed with the category heading: • Partnership without shared decision-making Example of the analytic manuscript: • None of the adolescents in the study had tried to disagree with the providers regarding their treatment, but in theory, if they did, the provider would have the final word.
The analytical task	*The analytical task*	*The analytical task*	*The analytical task*
Getting an overview of data based on the participants' voices. Asking which preliminary themes can be identified?	Based on the preliminary themes to identify interview text, which is relevant for the study in question. We coded the interview text into coding groups and subgroup relevant for the research question. Asking which commonalties and differences appear within and across the code groups and subgroups? What are the distinctive and original patterns?	Interpreting and summarizing the content of the code group. We hereby decontextualize and reduce the content of the coding groups and subgroups in order to condensate and select quotation, which illustrates the condensate. Asking what is the thematic content of the code groups?	Elaborating analytic manuscript based on the condensate and related quotation. This led to the description, concepts and category headings, which define the code groups. Then we look back into data, challenge our conclusion and make reconsolidation. Asking how can we interweave and sum up the code groups?

Abbreviations:
R, Reference which refers to a meaning unit, which is a piece of interview text containing a specific meaning related to the coding themes. In NVivo, a coding theme is named 'a codes', and the meaning units are named 'codes'.
S, Source, which is the different kinds of data material. In this study, the transcribed interviews came from ten different sources.

If, the providers pre-understanding of the adolescent's diabetes management characterized the personal relationship in the paediatric outpatient clinic, the adolescent was looking forward to the change in relationship and wished to start over. They did not find the transfer to be a problem.

The adolescent who valued a professional relationship valued effectiveness and professional content in the consultation. The adolescents did not find the personal relationship between them and the providers as important. Instead, they found it important that the providers had a knowledge about their education and daily activities in relation to diabetes, because it would make the consultation more effective. If the adolescent did not feel that diabetes management kept them from living their everyday life, the need to discuss it was limited. The relationship was professional and the adolescent expected the providers to be effective, competent and able to answer relevant questions, nothing more. Hence, the adolescents were not interested in small talk. As one of the adolescent described:

> U1: What's relevant for me and for you is my diabetes and my insulin pump. If I have any other questions and questions on my blood sugar. That's what relevant. In the pediatric ward, it was more like; what are you doing in your vacation and so on. There is less of that here, and that's fine by me

In general, it was important to the adolescents, that their preferences regarding their personal interest, education and daily activities in relation to diabetes were a topic in the consultation. The adolescents' preferences regarding a personal or professional relationship with the providers were important for the transition to be a success.

Most of the adolescents found it to be a natural process to transfer to the adult outpatient clinic, and they felt it natural that their parents participated less in in the consultation. However, few of the adolescents still depended on their parents' support to such a degree that they did not feel responsibility or had the sense of ownership of their illness. As one adolescent explains:

> U5: My mom and I discuss any questions we might have, or if I have any myself. Therefore, she writes the questions down and it's usually her who asks them. Then I just hear what the doctor has to say, and what I should do, if it has anything to do with me

The adolescents who depended on their parents' support, found it most difficult to transfer and establish a good relationship with the adult providers.

Partnership without shared decision-making

In order for the adolescents to feel involved in the transition, it was important that their preferences regarding their health and illness were respected and taken into account by the providers. However, being involved in treatment choices, for example discussing insulin was not something the adolescents felt competent to do. Hence, they did not feel it would increase the quality of the consultation to participate in shared decision-making.

The adolescents had high expectations concerning the providers' expertise and thought of the providers as very competent. Hence, they did not find it necessary to contradict their decisions. Often a small negotiation would take place, they could discuss insulin doses with the provider, but they relied on the provider to come up with a suggestion and solution. None of the adolescents in the study had tried to disagree with the providers regarding their treatment, and in theory, if they did, the provider would still have the final word:

> U1: Usually you agree with the doctors. They know what is best, besides yourself, of course. Usually you agree. I have never tried to say no – I don't think that's a good idea. You make sure, you agree and usually that's what you do

Regardless of whether the adolescents had diabetes management issues or just came to have a routine 'check-up' without having any problems or questions, the adolescent's valued clear instructions and specific advice about treatment. If the terms of the partnership were not discussed with the adolescent, shared decision-making could be confusing and interpreted as lack of goodwill.

One of the adolescent explained:

> U5: I had so many problems, it wasn't funny at all. I wanted some help, but when I came to the adult outpatient clinic and told the nurse what the problem was, she didn't want to help me and tell me what to do. It was up to me, what I would do. I hadn't expected to be told to figure it out by myself because I was in an adult clinic. I thought she could help me. But it didn't feel like she wanted to

Overall, the adolescents did not want to be involved in decisions about treatment, and they did not find it relevant to express their preferences regarding treatment.

Discussion

This study was designed to gather information about the adolescents' experiences with transition and partnership. Furthermore, it provides information on whether the adolescents experienced being prepared on transition or not. They participated in elements of the transition process, but they did not have the perception that it was an individual process based on maturate or individual needs and wishes. Nor did they have knowledge about the reasons why a planned and prepared transition was important. However, the reasons why the adolescents did not recall being prepared for the transition, could be many and not necessarily based on lack of information and education. A further study based on participant observation through the transition process could provide knowledge on preparation prior to transfer, and on how the adolescents are involved in the process. In this study, the adolescents perceived the transition as a natural transfer of care when coming of legal age, and it was not something they had reflected upon further. The goal of transition is to focus on easing the transfer process and minimizing the risk of loss-to-follow-up care and poor health outcomes.[7] Recommendations from the American Diabetes Association point out the importance of early preparation, at least a year prior to transfer, and likely during the early adolescent years.[7,8] Preparations according to the American Diabetes Association include information about the transition, development of diabetes self-management skills and preparation of a written transition plan in corporation with the adolescents and their family.[7,8] A written transition plan, including personal interest, education and daily activities in relation to diabetes combined with preferences regarding relationship, may increase the adolescent's involvement in the transition. Furthermore, a written transition plan enhances the sense of security and partnership in the relation, and the adolescents would have the perception that the providers in the adult outpatient clinic had knowledge about them prior to transfer.[25]

Another significant theme of this study was the adolescents' preferences regarding relationship with the providers and its consequences on the transition experience. Two different types of relationship were pointed out as being important, namely a personal relationship or professional relationship. The adolescents who valued a personal relationship were reluctant to leave the safe environment in the paediatric outpatient clinic, and often, they did depend on more support and guidance from their parents and providers and autonomous behaviour was not fully developed. The adolescents who, on the other hand, preferred a professional relationship, valued effectiveness in the consultation and competence from the providers. They did not find the change in relationship through the transition to be complicated. This supports the importance of the providers' communication skills and their interest in getting to know the adolescents preferences regarding relationship. Furthermore, it is crucial that the health care providers have training and knowledge about adolescent development in order to support the development tasks from early adolescence to late adolescence.[10] It is challenging to communicate with adolescents undergoing changes, who may not share an adult cognitive ability to long-term planning, abstract thinking and the ability to be attentive.[10] The HEADSS protocol (home, education, eating, activities, drugs, sex, safety and self-harm) is an internationally acknowledged method to take a full adolescent psychosocial history, which can be a helpful tool when communicating with adolescents.[8,10] The HEADSS protocol helps the providers to gather knowledge about the adolescent's psychological and social development, which is important knowledge in proportion to supporting the adolescent's health literacy and autonomous behaviour. Examining the effectiveness of the HEADSS protocol in relation to the transition process at Aarhus University Hospital could be an interesting study in the future.

Studies show that it is important to support the adolescents on their way to autonomy, based on their competences and developmental stage.[17] Regardless of which type of relationship the adolescents preferred, the adolescents still valued being active partners regarding management and support options. This study showed that they valued specific advice on treatment from the providers. The adolescents, who preferred a professional relationship and had developed a higher degree of social and psychological autonomy thought of the providers as very competent, but still appreciated the 'check-up'. The adolescents who valued a personal relationship depended on concrete support, and they interpreted it, as lack of goodwill if they did not receive specific advice from the providers but instead were encouraged to solve problems on their own. They depended on guidance and misinterpreted the provider's intension to support social autonomy. Development of autonomous behaviour increases the adolescents health literacy and thereby their ability to form a partnership with the providers. Self-determination theory describes the motivationally facilitative environment as one that supports individuals inherent needs for autonomy by providing choice, and minimizing the use of control.[17] A review concluded that competent adolescent decision-making depends on parent and health care provider attitudes rather than on age and emphasizes the importance of communication skills and knowledge on adolescent development.[26] Other studies have shown that securely attached children exhibit a greater desire to seek challenges in their environment[15] The results of the study also show the importance of a good working relationship between the paediatric- and the adult outpatient clinic, were knowledge and experience on adolescent development from two different views, is fertile soil for the most beneficial transition.

Entering a partnership with the providers and sharing decisions were difficult for the adolescents in this study. In shared decision-making, the patient is involved as an active partner in clarifying acceptable treatment, management or support options, discussing goals and priorities and together planning and implementing a preferred course of action.[16,27] This demands an adult's cognitive ability, and not all adolescents can be expected to be able to enter a partnership under those demands. The adolescent's appreciation of specific advice regarding treatment does not make shared-decision-making beneficial to them. Another perspective is the providers' role in shared decision-making. Studies have shown that providers experience a conflict between their responsibilities to deliver evidence-based diabetes care, and to respect patients' rights to make decisions.[20] It is important that the providers are aware of their responsibility in caring out shared decision-making in spite of the adolescent's reluctance. Still we lack knowledge on the effect on patient-centred practice like the use of shared decision-making in relation to the adolescent with T1DM. This and if there are any specific concerns regarding the use of shared decision-making and adolescent with T1DM. Like our study suggest, todays understanding of shared decision-making[27] may need a revision regarding adolescent with T1DM.

The need for knowledge, support and training through the transition in becoming active partners, and being able to participate in decisions about treatment is crucial and must be according to the adolescent's developmental stage.[10] The providers have an important role in supporting the adolescent's autonomous behaviour and thereby their health literacy.[1] Guided self-determination is a shared decision-making and mutual problem-solving method, which aim to develop life skills in adults with T1DM. The method involves reflection sheets and advanced communication skills. Guided self-determination was later adjusted for use in adolescent–parent-health care provider triads.[28] Research on guided self-determination in adolescence shows that use of a life skills approach made outpatient visits person-specific and improved cooperation patterns.[28]

Study limits

In this study, the interviews were conducted a year after transfer, and the adolescents experiences were retrospective. The adolescents could have difficulties recalling the complete transition process, which could be a limitation to the study. However, the transition process proceeds over a year, and it was not possible to conduct the interviews at an earlier stage. The study still offers an understanding of adolescents' experiences with transition and partnership. In relation to age and gender, the participants in our study were representative compared to the average group of adolescents who go through the transition process at Aarhus University Hospital each year.

It is a limitation of our study that it investigates a specific transition process. However, by outlining a comprehensive description of the content of the transition process (Table 2), we have made it possible to compare with other transition processes. This strengthens the usability of the results to other clinical settings.

Our study did not provide knowledge on the effect of different kinds of transitions and if possible the impact of the different parts of the transitions process. Still we need to gain knowledge in this area e.g. does the use of a written transition plan have an impact on metabolic control and loss of follow-up.

Conclusion

This study highlights the importance of a specific relationship with the health care providers and a planned and prepared transition. In addition, a good working relationship between the paediatric- and the adult outpatient clinic, were knowledge and experience on adolescent development from two different views, is fertile soil for the most beneficial transition. The providers have an important role in supporting the adolescent's autonomous behaviour and thereby their health literacy. The adolescents' unawareness concerning the transition process results in a non-reflective transition and does not support the development of health literacy, and thus the ability to form a partnership with the providers. The adolescents appreciate specific advice regarding treatment and do not find shared-decision-making beneficial.

Acknowledgements

We thank all the young people for participating in this study. We would like to acknowledge Peter Peck for editing support.

Conflict of interest

Karina Kudahl Hansen and Annesofie Lunde Jensen declare that they have no conflict of interest.

Source of support

We thank Aarhus University Hospital for funding this study.

ORCID

Annesofie Lunde Jensen http://orcid.org/0000-0003-2025-6663

References

1. Garvey KC, Markowitz JT, Laffel LM. Transition to adult care for youth with type 1 diabetes. Curr Diab Rep. 2012;12:533–41.
2. Crowley R, Wolfe I, Lock K, McKee M. Improving the transition between paediatric and adult healthcare: a systematic review. Arch Dis Child. 2011; 96:548–53.
3. Ritholz MD, Wolpert H, Beste M, Atakov-Castillo A. Patient-provider relationships across the transition from pediatric to adult diabetes care: a qualitative study. Diabetes Educ. 2014;40:40–7.
4. Price CS, Corbett S, Lewis-Barned N, Morgan J, Oliver LE, Dovey-Pearce G. Implementing a transition pathway in diabetes: a qualitative study of the experiences and suggestions of young people with diabetes. Child Care Hlth Dev. 2011;37:852–60.
5. Blum RW, Garell D, Hodgman CH, Jorissen TW, Okinow NA, Orr DP, *et al.* Transition from child-centered to adult health-care systems for adolescents with chronic conditions. J Adoles Health. 1993;14:570–6.
6. Garvey KC, Beste M, Luff D, Atakov-Castillo A, Wolpert H, Ritholz M. Experiences of health care transition voiced by young adults with type 1 diabetes: a qualitative study. Adoles Health Med Ther. 2014;5:191–8.
7. 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. Diabetes Care. 2011;34:2477–85.
8. Boisen KA, Teilmann G. Transition – more than a transfer. Ugeskr Laeger. 2011;173:725.
9. Kipps S, Bahu T, Ong K, Ackland FM, Brown RS, Fox CT, *et al.* Current methods of transfer of young people with Type 1 diabetes to adult services. Diabet Med. 2002;19:649–54.
10. Christie D, Viner R. Adolescent development. BMJ. 2005;330:301–4.
11. van Dam HA, van der Horst F, van den Borne B, Ryckman R, Crebolder H. Provider–patient interaction in diabetes care: effects on patient self-care and outcomes. Patient Educ Couns. 2003;51:17–28.
12. Hilliard ME, Perlus JG, Clark LM, Haynie DL, Plotnick LP, Guttmann-Bauman I, *et al.* Perspectives from before and after the pediatric to adult care transition: a mixed-methods study in type 1 diabetes. Diabetes Care. 2014;37:346–54.
13. Roisman GI, Masten AS, Coatsworth JD, Tellegen A. Salient and emerging developmental tasks in the transition to adulthood. Child Dev. 2004; 75:123–33.
14. Riiskjær E. Patienten som partner: en nødvendig idé med ringe plads. Odense: Syddansk Universitetsforlag; 2014.
15. Pomey MP, Ghadiri DP, Karazivan P, Fernandez N, Clavel N, Bayer A. Patients as partners: a qualitative study of patients' engagement in their health care. PLoS One. 2015;10:e0122499.
16. Coulter A, Ellins J. Effectiveness of strategies for informing, educating, and involving patients. Br Med J. 2007;335:24–7.
17. Deci EL, Ryan RM. Handbook of self-determination research. Rochester (NY): University of Rochester Press; 2002.
18. 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.
19. Valenzuela JM, Smith LB, Stafford JM, D́Agostino Jr RB, Lawrence JM, Yi-Fraiser JP, *et al.* Shared decision-making among caregivers and health care providers of youth with type 1 diabetes. J Clin Psychol Med Settings. 2014;21(3):234–43.
20. Shortus T, Kemp L, McKenzie S, Harris M. Managing patient involvement: provider perspectives on diabetes decision making. Health Expect. 2013; 16:189–98.
21. Kvale S. Interviews: an introduction to qualitative research interviewing. Thousand Oaks (CA): Sage, 1996.
22. Malterud K. Systematic text condensation: a strategy for qualitative analysis. Scand J Public Health. 2012;40:795–805.
23. Maxwell JA. Qualitative research design: an interactive approach. Thousand Oaks (CA): Sage; 2013.
24. World Medical Association. World Medical Association Declaration of Helsinki: ethical principles for medical research involving human subjects. JAMA. 2013;310(20):2191–4; 2011.
25. Rosen DS, Blum RW, Britto M, Sawyer SM, Siegel DM, Society for Adolescent Medicine. Transition to adult health care for adolescents and young adults with chronic conditions: position paper of the Society for Adolescent Medicine. J Adolesc Health. 2003;33:309–11.
26. Mårtenson EK, Fägerskiöld AM. A review of children's decision-making competence in health care. J Clin Nurs. 2008;17:3131–41.
27. Elwyn G, Frosch D, Thomson R, Joseph-Williams N, Lloyd A, Kinnersley P, *et al.* Shared decision making: a model for clinical practice. J Gen Intern Med. 2012;27:1361–7.
28. Husted GR, Esbensen BA, Hommel E, Thorsteinsson B, Zoffmann V. Adolescents developing life skills for managing type 1 diabetes: a qualitative, realistic evaluation of a guided self-determination-youth intervention. J Adv Nurs. 2014;70:2634–50.