



Experiences of follow-up and dietary guidance among young adults diagnosed with type 1 diabetes as children: a qualitative study

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Abstract

Background: Type 1 diabetes (T1D) is an autoimmune disease that can affect people at any age, but usually develops in children or young adults. T1D involves a life-long treatment with insulin therapy and self-monitoring of blood glucose levels. To avoid long-term complications in adulthood, appropriate dietary guidance is an important pillar in the care of children with T1D. The transition from pediatric diabetes care to adult care may imply challenges related to self-monitoring and empowerment. The purpose of this study was to explore experiences of follow-up and dietary guidance among adolescents diagnosed with T1D in young age (>16 years).

Participants and methods: 11 participants (8 women, 3 men; 18–25 years) were purposely recruited from two outpatient diabetes clinics in Southeast Norway. Individual, semi-structured interviews were conducted from September 2021 to January 2022. Interviews were transcribed and analyzed using thematic analysis. Mean age when diagnosed with diabetes was 10 years (4–14).

Results: Participants perceived information about the diabetes management in pediatric care as more targeted towards their parents and expressed a wish to be involved in their follow-ups. They reported that their care mainly focused on the medical aspect with little focus on dietary guidance. They expressed dissatisfaction with the transfer to and follow-up in adult care and asked for more individually tailored nutrition information.

Conclusion: Patients diagnosed with T1D at a young age wished to be more involved in their follow-ups already when they were children. Dietary guidance should to a greater extent focus on their individual food habits and preferences.

Keywords

type 1 diabetes, children, adolescents, dietary guidance, experiences

Key findings

- Patients diagnosed with T1D at a young age wished to be involved in their diabetes care from the beginning.
- Participants found it challenging to be transferred from pediatric to adult care.
- Participants reported that their diabetes care mainly focused on the medical aspect with little focus on dietary guidance.

Introduction

Type 1 diabetes (T1D) is an autoimmune disease and caused by destruction of insulin-producing beta cells, leading to insulin deficiency and a need for lifelong treatment with insulin therapy and self-monitoring of blood glucose levels (1). The prevalence of T1D among children increases worldwide and Norway is among the countries with the highest prevalence of T1D among children and adolescents (2, 3). In Norway, children and adolescents up to 18 years of age, receive education in self-management of T1D and follow-up at an outpatient pediatric clinic, held by a pediatrician and a nurse, and sometimes a clinical dietitian. The availability of a clinical dietitian varies depending on the hospital at which children and adolescents are followed-up (4–6). Dietary guidance is an important pillar in the follow-up and enables people with T1D to optimize insulin treatment. Children are accompanied by their parents. Adolescents can come to the follow-up on their own (5).

Although advances in technologies, such as insulin pumps and continuous glucose monitors have improved self-management of T1D, only 36 % of children and adolescent with T1D achieve the recommended treatment goal of hemoglobin A1c (HbA1c) of <48 mmol/mol (1, 4). Appropriate dietary guidance is an important element of diabetes care to prevent long-term complications (7).

The dietary recommendations for children and adolescents with T1D are based on the general recommendations for healthy

eating (8). Knowledge of carbohydrate content of the diet is important as it is the primary nutrient affecting blood glucose postprandially (6, 8). For most patients, specific training in carbohydrate assessment is required to be able to estimate or measure portions and read food labels to adjust mealtime insulin doses accordingly (9). Thus, it is important that children and adolescents with T1D and their parents receive comprehensive education at diagnosis and ongoing, with a healthy diet and its impact on insulin requirements playing a central role (5, 6).

The transition from pediatric care to adult care implies more self-management of T1D. Previous studies have identified barriers in the communication between children, adolescents and their health care professionals (10–12). Adolescents and young adults with T1D have experienced challenges related to gained responsibility, self-management, follow-up, and transition from pediatric to adult care (10–12). Only a few studies focus particularly on the patients' experiences with diabetes care from the transition from childhood to adulthood (11, 13). Thus, the aim of this study was to explore how young adults diagnosed with T1D as children experienced dietary guidance and follow-ups from healthcare professionals during this transition.

Material and methods

Setting and participants

Seven participants were recruited purposely by clinical dietitians and nurses at two outpatient clinics in Southeast Norway. One participant contacted the first author

after reading a recruitment page shared on Facebook. Three participants were recruited by the first author through snowball sampling with the help of other participants. Inclusion criteria were between 18 and 25 years; diagnosed with T1D before age 15; no other concurrent diet-related diseases or any current or previous eating disorders. Recruitment was carried out until we experienced informational power in the

conducted interviews. Sufficient information power depended on the quality of dialogue with the participants about the aim of the study. Participants' background characteristics are presented in **Table 1**. The mean age of the participants was 21 years. Five of the participants were diagnosed with T1D before they were 10 years old. All participants received diabetes care by pediatricians, nurses and clinical dietitians.

Table 1. Background characteristics of the participants.

	Male (n = 3)	Female (n = 8)
Mean age (years)	22	21
Mean age at diagnosis (years)	8	11
Mean duration of being diagnosed with T1D (years)	14	10
Close relatives with T1D (number of participants)	1	2

The authors developed a semi-structured interview guide focusing on participants' experiences of 1) receiving T1D at a young age; 2) general follow-up of T1D by health care professionals; 3) dietary guidance from health care professionals. The interview guide was pilot tested with a patient with T1D who fulfilled the inclusion criteria for the study. The individual interviews were conducted from September 2021 through January 2022 by PEC, a master student in Public Health Nutrition, supervised by the last author, professor in health communication experienced in qualitative methods. Since we only made minor adjustments in the interview guide (e.g., changes of wording), we included the pilot interview in the study. The interviews were conducted using Zoom (n = 10) and by meeting physically (n = 1). The interviews had an average duration of 34 minutes (16–67 minutes) and were audiotaped using 'Dictaphone-app' (14).

Data analysis

The first author listened to the audiotapes and transcribed verbatim on a computer without internet connection. The last author read the transcribed interviews. We used thematic analysis based on Braun and

Clarke's six-step analysis (15), which included: reading and re-reading the transcripts; developing initial codes by identifying and highlighting meaningful text relevant to our research purpose; grouping codes into sub-themes, and sub-themes under main themes; reviewing sub-themes and main themes; evaluating main themes and its relation to the other themes; and writing the results. The analysis was carried out by EPC and LGH and reviewed by the other authors. The analysis and citations presented are translated from Norwegian to English.

Ethics

The Ethical Guidelines for Research at OsloMet were followed (25). The study was approved by the Norwegian Centre for Research Data (NSD), (26) (Nr 901451). All participants received a consent form by e-mail and gave a verbal consent prior to the interviews. Participants were also informed that they could withdraw their consent at any time.

Results

We have identified three main themes: *Experience of being diagnosed and the following responsibility*; *Experiences of focus and changes in general follow-up of T1D with*

increased age; Need for more dietary information from health care professionals; Main- and sub-themes are presented in Table 2.

Experience of being diagnosed and the following responsibility

Participants' experiences of being diagnosed varied. Some remembered their parents as most affected. Participants who perceived themselves as not familiar with the diagnosis experienced little or no reaction at the time of their diagnosis, as expressed by a male participant, diagnosed with T1D at the age of 11:

I had never really heard about the disease before (...) I did not really have a big reaction that I can remember ... without knowing like what the disease involved or anything at that time – P10

Most participants expressed parents as being supportive and helpful with self-management in the beginning. As they got older, all participants experienced that they had to take more responsibility themselves

and that their parents got less involved in diabetes management. This was expressed by one participant, who was 4 years when diagnosed with T1D, as:

At a young age, my mom was coming in and measuring me during the night ... but then, when I became six years and then I got a pump ... then I became a bit better ... and so from eight nine years of age I started to take control myself (...)... I got still help and so on ... but it gradually passed more and more on to myself... and it was probably from when I started middle school, when my parents were not involved in my diabetes – P11

At the time of the interview, participants perceived to have good knowledge to self-manage T1D. When asking our participants where they felt they had acquired the information and their knowledge about diet, several mentioned personal experiences in addition to clinical dietitians or use of the internet. Some of our participants mentioned getting further

Table 2. Main and sub-themes identified from the thematic analysis.

Main themes	Sub-themes
Experience of being diagnosed and the following responsibility	<ul style="list-style-type: none"> • Did not understand the scope of the diagnosis • Experienced the parents as most affected • Experienced a negative, emotional reaction at the notice of the diagnosis • Experienced a lot of responsibility early on and reduced involvement of the parents with increasing age
Experiences of focus and changes in general follow-up of T1D with increased age	<ul style="list-style-type: none"> • Experienced health care professionals and parents as key sources of information in the beginning • Felt opportunity to raise questions during the follow-ups at the pediatric outpatient's clinic • Experienced more communication with HCP with increasing age and absence of parents • Less follow-up and personal relationship with HCP at the adult clinic • Experienced focus as mainly related to blood sugar, insulin doses and complications
Need for more dietary information from health care professionals	<ul style="list-style-type: none"> • Experienced receiving little or no dietary advice from HCP • Experienced dietary information from health care professionals as limited to carbohydrates and mealtime insulin doses • Experienced that health care professionals provided information on diet in the beginning, but little afterwards • Did not experience the appointment with a clinical dietitian as useful

help related to carbohydrate assessment and mealtime insulin doses in adult age, which was highly appreciated. We have not identified differences in experiences of being diagnosed with T1D between participants who were diagnosed at a young age (<10 years) compared to older age (>10 years).

Experiences of focus and changes in general follow-up of diabetes with increased age

All participants acknowledged either health care professionals and/or parents as their main sources for information related to management of T1D in the beginning. Even though many participants felt that they could ask their health care professionals for advice, some expressed a lack of understanding of their condition, as illustrated by the statement of a female participant who was diagnosed at 9 years of age:

I feel they only understand if they have diabetes themselves (mild laughter) ... but it was sometimes that I ... took up things ... – P2.

Participants often felt that communication from health care professionals at the pediatric outpatient clinic was more targeted at the parents during the follow-ups, which led to some feeling not being included during the follow-up appointments. Some mentioned experiencing better communication with the health care professionals with increasing age and/or without the presence of their parents. Some experienced that their relationships with health care professionals at the diabetes outpatient clinic for adults were not as close and personal as their relationships with healthcare professionals at the pediatric outpatient clinic. Some experienced less efficient consultation in the transfer to adult care, as explained by a male participant who was diagnosed with T1D at 11 years:

... it does not turn out as good ... since they need to use time to go through the

journals, they do not know you ... like they must get familiarized with a new person again ... – P10

A few also mentioned the follow-ups being shorter and feeling rushed through in adult care, described by a female participant diagnosed at 14 years of age:

I think it was shorter and shorter time for every time I was in consultation really ... but I felt that I did not get as much follow-up when I came to the adult clinic as I did in the pediatric clinic – P5

Participants expressed that the focus, both in pediatric and adult care, were most often related to blood glucose control (like HbA1c or regulation), insulin doses (like adjustments of the basal insulin or settings on the insulin pump), and/or long-term complications. Some of the participants also expressed that they felt this took away the focus from other aspects to life or the disease, expressed by a female participant who was diagnosed at the age of 12 years:

I felt that it was a lot of focus on HbA1c and the numbers and all of that, so then the whole thing around it sort of disappeared ... – P7

Need for more dietary guidance from health care professionals

Participants often experienced to receive scarce dietary guidance from health care professionals in pediatric care, as indicated by a female participant diagnosed at the age of 11 years:

I was never asked about what I ate ... I was just asked about how much insulin I gave to the meals – P8

When asking our participants where they felt they had acquired the information and their knowledge about diet, several mentioned

personal experiences or use of the internet. A female participant, diagnosed at the age of 7 years, pointed out that closer follow-up and more individually tailored dietary guidance would be necessary to get something proper out of the consultations:

I think that if one is supposed to get something proper out of an appointment with a clinical dietitian, then one need a bit closer follow-up ... and have a very individual focus on it ... - P1

Even though clinical dietitians were often mentioned as an important source for dietary guidance, participants described dietary guidance received by health professionals as mainly being related to carbohydrates and mealtime insulin doses e.g., how many units one needed for two slices of bread. Participants often expressed a need for more dietary guidance several years after being diagnosed, as they experienced that health care professionals focused on dietary guidance only in the beginning. They also asked for dietary guidance focusing on their individual food habits and preferences.

Several participants experienced receiving sufficient support regarding determining mealtime insulin doses from clinical dietitians or other health care professionals. Participants mentioned that they at some point had seen a clinical dietitian, one or several times. However, a few expressed that they did not find the appointment(s) useful. One mentioned seeing a clinical dietitian several times to repeat carbohydrate-counting, however, expressed feeling like their approach did not work:

I feel that since I have gone to a clinical dietitian so many times ... and you see that it does not work, or at least that procedure, it obviously does not work for me ... then maybe they should have changed strategy or tried to hear from me, or (sigh) why I think it is difficult, or like ... it obviously did not work so then ... - P2

Discussion

Taken together, this study indicates that patients diagnosed with T1D at a young age wished to be involved in their diabetes care from the beginning. Participants also expressed a need for more dietary guidance. Our findings are comparable to previous studies among young children and adolescents, reporting barriers in the transition from childhood to adulthood (11–13). In our study, parents and health care professionals were considered key sources for dietary guidance, however, communication from health care professionals at the pediatric clinic was by some young patients experienced as more targeted towards parents, leading to some feeling excluded. The use of complicated words made children and adolescents experience despair and exclusion, and not see the point of attending. Whereas easy understandable guidance by health care professionals led to appointments becoming a learning opportunity and promoted both patients and parents' confidence in diabetes management. Lambert et al. found communication between children and health care professionals depended on whether children were perceived as active or passive (16). When health care professionals perceived children as passive, the communication was more targeted towards parents, and health care professionals did not relay information to the patient or used terminology that was incomprehensible to children.

However, some of our participants experienced that increased age and less presence of parents during follow-ups led to improved communication with health care professionals. Eighteen adolescents (7 boys and 11 girls, aged 16–18 years) from five Norwegian pediatric diabetes centers reported in a qualitative study that the transition to adolescence led to more responsibility. Simultaneously, they experienced that health care professionals addressed them directly instead of the parents (12). Communication between adolescents and health care professionals, rather than parents, was found in another

qualitative study to increase the ability to independently manage their diabetes (17). Strand et al. outlines the importance of involvement of patients with T1D at an earlier age to strengthen self-management of the disease as adolescents (12).

Our participants described dissatisfaction with the transfer from pediatric care to adult care. Coherent with our study, Iversen et al. and Montali et al. found that appointments were experienced as less frequent and shorter, and the relationships with health care professionals felt less personal in adult care, compared with the pediatric ward (11, 18). Participants perceived having different health care professionals from one appointment to another challenging. A Norwegian qualitative study found that young adults preferred meeting the same health care professionals at every appointment as it improved the relationship and communication (11). According to Epstein et al, knowledge of patient-as-person and duration of relationship between patients and providers are factors improving patient-centered communication (19), that might be a useful approach for young patients with T1D.

Similar to other studies (10, 18), participants perceived that follow-ups mainly focused on the medical aspect, in both pediatric and adult care. Participants experienced a lack of focus related to other topics e.g., everyday life and coping with diabetes. Participants in the DiaProm trial found that young adults experienced a focus on biomedical outcomes (10). Also, Italian patients with T1D (15 women; 10–30 years old; 2–24 years from diagnosis) felt that health care professionals focus on the medical aspect leading to scarce consideration of the psychological aspects related to their condition (18). In a study investigating experiences of health care professionals of different professions providing for adults with diabetes, doctors expressed being more concerned with the medical aspects and treatment goals, than other health care

professionals (20). Our participants were in contact with different health care professionals. Even though they did not seem to prefer any particular group of health care professionals, they outlined the importance of continuity of care by the same health care professional.

Participants expressed a need for more dietary guidance from health care professionals. This was also found in other studies mentioned previously (11, 12). In similarity with Strand et al., some of our participants were diagnosed many years ago, where parents might have received most of the diabetes education (12).

It is important to acknowledge that some participants expressed receiving sufficient help and guidance related to insulin doses. As carbohydrate assessment can be done with different methods, it is important to find a suitable approach for each individual (6, 8). In a recently published Norwegian qualitative study by Ullah et al., the experiences of adolescents related to self-management and use of carbohydrate counting was investigated (13). Some participants articulated that carbohydrate counting was appreciated as a suitable tool for dosing insulin and optimizing glycaemic control. Others did not use carbohydrate counting at all and described rather using their own experience. In line with our findings, Ullah's study supports the importance of individualizing diabetes follow-up and to adapt the training in treatment tools to everyone's situation and preferences. When asking our participants where they felt they had acquired the information and their knowledge about diet, several mentioned personal experiences in addition to clinical dietitians or use of the internet. Some of our participants appreciated being offered further help related to carbohydrate assessment and mealtime insulin doses in adult age. This offer may have contributed to some participants perceiving to currently have good knowledge related to this.

Strengths and limitations

This study was conducted among a sample size that is appropriate for qualitative research. Data saturation was achieved when new interviews did not result in novel sub-themes (15). It is important to emphasize that the results are not necessarily transferable to other settings as they are based on subjective experiences. The interviewee had little experience with conducting qualitative interviews and received close follow-up by an experienced supervisor (last author). The researchers had personal and professional experiences and knowledge related to T1D as well as qualitative methodology. Researchers' backgrounds may have helped to ask relevant follow-up questions; however, it could also have affected the analysis. Thus, the analysis was completed by two of the researchers. Interviews were conducted digitally, which might have affected participants' openness (21). However, digital interviews made it possible to conduct this study during the Covid-19 pandemic.

Conclusion

Patients diagnosed with T1D at a young age wished to be involved in their follow-ups already when they were children. Dietary

guidance should also be addressed in adult care and to a greater extent focus on individual food habits and preferences.

The authors declare no conflict of interest.

About the article

Author contributions: PEC, AMA, KB and LGH designed the research. PEC and LGH performed the analysis. PEC and LGH drafted the manuscript. AMA and KB critically reviewed the manuscript. All authors read and approved the final manuscript.

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