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Isolated thoughts and feelings and unsolved concerns.

Adolescents' and parents' perspectives on living with type 1 diabetes:

a qualitative study using visual storytelling

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ABSTRACT

AIMS AND OBJECTIVES

To explore and describe the experiences of adolescents and their parents living with type 1 diabetes (T1DM), to identify their needs for support to improve adolescents' self-management skills in the transition from child- to adulthood.

BACKGROUND

Adolescents with T1DM often experience deteriorating glycemic control and distress. Parents are important in adolescents' ability to self-manage T1DM, but they report anxiety and frustrations. A better understanding of the challenges adolescents and parents face, in relation to the daily self-management of T1DM, is important to improve clinical practice.

DESIGN

A qualitative explorative study using visual storytelling as part of individual interviews.

METHODS

A purposive sample of nine adolescents and their parents (seven mothers, six fathers) took photos illustrating their experiences living with T1DM. Subsequently participants were interviewed individually guided by participants' photos and a semi-structured interview guide. Interviews were analyzed using thematic analysis.

RESULTS

Four major themes were consistent across adolescents and their parents: 1) striving for safety, 2) striving for normality, 3) striving for independence and 4) worrying about future. Despite adolescents and parents had same concerns and challenges living with T1DM, they were experienced differently. Their thoughts and feelings mostly remained isolated and their concerns and challenges unsolved.

CONCLUSIONS

The concerns and challenges adolescents and their parents face in the transition from child- to adulthood are still present despite new treatment modalities. Parents are fundamental in supporting the adolescents' self-management-work, however, the parties have unspoken concerns and challenges.

RELEVANCE TO CLINICAL PRACTICE

Health care providers should address the parties' challenges and concerns living with T1DM to diminish worries about future including fear of hypoglycemia, the burden of T1DM and the feeling of being incompetent in diabetes self-management. It is important to focus on supporting both adolescents and their parents, and to provide a shared platform for communication.

SUMMARY BOX

WHAT DOES THIS PAPER CONTRIBUTE TO THE WIDER GLOBAL CLINICAL COMMUNITY?

- The same concern and challenges are consistent among adolescents and parents, but experienced and handled differently.
- Adolescents and parents hesitate or even avoid to share their thoughts and feelings in order to protect each other. Hereby, their concerns and challenges remain unsolved. This leads to misunderstandings, frustrations and feeling alone.
- It is important to focus on the fear of hypoglycemia, worries about future, feeling different and incompetent in diabetes-care and to elucidate both adolescents' and parents' perspectives to successfully strengthen the adolescent/parent-dyad and the adolescents' self-management skills.

KEYWORDS

Adolescence, T1DM, self-management, transition, visual storytelling, qualitative methods.

INTRODUCTION

Adolescence can be a demanding developmental stage that is even more challenging for a person with type 1 diabetes (T1DM) (Luyckx *et al.* 2008). It is a time marked by rapid physical, cognitive, emotional and social changes, including new lifestyles (Court *et al.* 2009). Adolescents with T1DM often experience deteriorating metabolic control and emotional distress (Kovacs *et al.* 1997, Cardwell *et al.* 2005). Approximately 80% of young people with T1DM have an HbA1c higher than recommended (Cardwell *et al.* 2005), and they are more likely than their peers without T1DM to develop serious mental health outcomes like distress, anxiety and depression (Kovacs *et al.* 1997). Deteriorating metabolic control can lead to short-term complications, such as hypoglycemia and extreme hyperglycemia, and long-term complications, such as retinopathy, nephropathy, cardiovascular disease and neuropathy (Inzucchi, SE, Sherwin, RS 2009).

BACKGROUND

Self-management in children and adolescents with T1DM is multidimensional and an evolving process moving from being totally dependent on parents toward a more collaborative relationship where both adolescents and parents perform diabetes-care-activities to the final goal where adolescents assume full responsibility to manage their diabetes (Schilling *et al.* 2009). Schilling *et al.*, 2002 define self-management in the transition from child- to adulthood as “an active, daily and flexible process in which youths and their parents share responsibility and decision-making for achieving disease control, health and well-being through a range of illness-related activities” (Schilling *et al.* 2002). During the last decade, transition guidelines have been developed (Peters *et al.* 2011, NICE February 2016) and transition programs have been implemented in many outpatient clinics to meet the needs of adolescents and parents in the transition from child- to adulthood. Unfortunately, there is still a lack of evidence of the outcome of the programs (Crowley *et al.* 2011).

Ongoing development of new interventions to support self-management have also dominated the transition-literature, and so have interventions focusing on improving the psychosocial and physiological outcomes in adolescents with T1DM been developed with promising outcomes (Grey *et al.* 2000, Hampson *et al.* 2000, Husted *et al.* 2014b): Grey *et al.* improved glycemic control and quality of life in group sessions with coping skill training (Grey *et al.* 2000) and Husted *et al.* significantly reduced amotivation for diabetes self-management using the Guided Self-determination-Youth intervention in outpatient consultations (Husted *et al.* 2014b). In addition, interventions that provide parents with strategies to build and maintain autonomy supportive relationships with their adolescent have been effective (Burke *et al.* 2012, Van Ryzin & Dishion 2012, Husted *et al.* 2014b): Burke *et al.* combined behavioral family intervention with acceptance-based strategies resulting in significantly lower parental stress (Burke *et al.* 2012) and Van Ryzin and Dishion found that a family check-up intervention was associated with a decline in family conflicts and a rise of parental monitoring (Van Ryzin & Dishion 2012). However, most interventions have been tested outside of usual care and provided in group settings. In addition, many interventions are

characterized by small sample sizes and high rates of drop-out (Grey *et al.* 2000, Hampson *et al.* 2000, Burke *et al.* 2012).

Parenting an adolescent with T1DM can be challenging (Haugstvedt *et al.* 2011). Parents report heightened stress, anxiety, worry and frustration about their parenting role (Haugstvedt *et al.* 2011). However, parents play an important role in adolescents' ability to self-manage T1DM. Too much parental control does not support adolescents to self-manage, whereas lack of parental attention may lead to chaotic self-management behavior (Hanna & Guthrie 2001). Both approaches often result in conflict between parents and adolescents and are associated with poor glycemic control (Tsiouli *et al.* 2013). However, a constructive form of involvement that comprises autonomy support, guidance, dialogue, shared knowledge and responsibility yields growing self-management skills (Viklund & Wikblad 2009a).

Despite the importance of the adolescent/parent-dyad in the transition from child- to adulthood, qualitative interview studies usually focus on adolescents only when identifying the challenges of living with T1DM in the transition from child- to adulthood (Huus & Enskar 2007, Freeborn *et al.* 2013); however, a single study focused on both adolescents' and parents' perspectives, although only one father participated (Marshall *et al.* 2009).

There is a need to elicit more detailed knowledge of the challenges both adolescents and their parents face to inform the content of future interventions as well as clinical practice. The aim of this study was to explore and describe the experiences of adolescents and their parents living with T1DM, to identify their needs for support to improve adolescents' self-management skills in the transition from child- to adulthood.

METHODS

Design

A qualitative explorative study was conducted using visual storytelling (Drew *et al.* 2010) as the basis for individual interviews. Visual storytelling is a photo-based approach inspired from anthropology (Collier 1986) in which participants take photos prior to an interview. We chose the visual storytelling method because photos help participants' to promote and verbalize experiences, reflections, thoughts and feelings but also their actions and context (Mattelmäki 2005, Drew *et al.* 2010). The use of photos in interviews hereby supports participants in telling about their individual perspectives, challenges and choices living with T1DM. This inductive perspective may otherwise be difficult to maintain during the interviews (Mattelmäki 2005, Drew *et al.* 2010). In addition, we needed a flexible method to accommodate the adolescents' range of development-related cognitive skills in regard to reflection and articulation of complex thoughts (McCarthy Gallagher 1981).

Sample/Participants

A purposive sample (Patton 1990) of young people with T1DM and their parents, living in the region of North Zealand, Denmark, was recruited from the pediatric and adult diabetes departments at a single hospital. Participants were recruited from January to July 2014. They were first contacted by letter followed by a phone call by the first author (PCS). Adolescents and their parent(s) were included if the adolescent was 15 to 19 years old and had had T1DM for at least one year. They were excluded if the adolescent or a parent had a psychiatric disorder that made it impossible to accomplish the project. We invited 15 adolescents, 15 mothers and eight fathers to participate in the project. The sampling ensured variation in age, sex, duration of T1DM, ethnicity and whether participants received care in pediatric or adult departments (Patton 1990).

The final sample comprised six dyads (an adolescent and a parent), two triads (an adolescent and two parents), one single adolescent, one single parent and a single parent couple--a total of nine adolescents aged 15-19, seven mothers and six fathers (Table 1). Adolescents' and parents' reasons for not participating in the study included that they were too busy, too private about T1DM, ill, or disinterested in the study or that the other parent in the family was already participating.

Data collection

Photos

Adolescents and parents were given instructions to take photos during a week prior to the interview to capture situations that illustrated how they experienced their life with T1DM.

Participants took photos with their own smartphones or cameras, with the exception of one adolescent who borrowed a mini-tablet. Participants took four to 25 photos, which were delivered to the first author (PCS) and printed. SMS text reminders were sent the day before a photo week, the day before the photos were to be delivered, and the day before interview. Participants were asked to call the first author (PCS) if any questions arose.

Interviews

Individual interviews took place within four weeks (range: 1-4) after finishing the photo session and were conducted by the first author (PCS) in the participants' homes (n=7), at school or work (n=4) or at the hospital (n=11) from March to August 2014. To begin the interviews, participants were asked to select and elaborate on the photos most important to them. Interviews were guided primarily by participants' photos (Drew *et al.* 2010) and secondarily by a semi-structured interview guide with open-ended questions (Table 2a and 2b). Interviews lasted 55 to 82 minutes and were digitally recorded and transcribed verbatim. According to qualitative methodology (Denzin, NK and Lincoln, YS 2000), transcripts were checked for accuracy (e.g. spelling, punctuation, correction of words) by first author (PCS), who re-listened to the digital records while comparing the

transcripts. The transcripts were uploaded to Nvivo software (QSR International 10) to organize data and support the entire analysis.

The study was approved by The Danish Data Protection Agency (no. 02249 HIH-2013-016), and performed in accordance with the ethical recommendations of the Helsinki Declaration. Written consent was obtained from all participants and in addition from parents if adolescents were younger than 18 years old. After each interview, the first author (PCS) spent some 'cool-down' time with participants asking how they felt about sharing their photos, thoughts and feelings. All participants were subsequently contacted by phone, one to two weeks after the interview, to evaluate the process. Psychological support was available if desired by participants; none made use of it. Confidentiality and anonymity were assured and pseudonyms are used. Ethical approval of interview studies by Research Ethics Committee is not necessary in Denmark (no. 15000468).

Data analysis

In a six-phase thematic analysis, described by Braun and Clarke (Braun & Clarke 2006), first and last authors (PCS and GRH): 1) read and re-read the transcripts; 2) generated initial codes; 3) searched for themes; 4) reviewed themes; 5) defined and named themes; and 6) produced the report. To ensure trustworthiness and transparency (Denzin, NK and Lincoln, YS 2000), reflexivity was addressed throughout the research process by first and last authors (PCS and GRH) through constant critical reflection of possible blind spots by sharing their assumptions and preconceptions and how these could affect the research analysis. All interviews were coded independently by first and last author (PCS and GRH), who afterwards discussed the codes and themes until consensus was reached. The final themes were presented and discussed with the co-authors before producing the final report. Memos were written during the analysis to document the process of category conceptualization (e.g. reflections, initial codes, defining and naming themes) (Denzin, NK and Lincoln, YS 2000).

RESULTS

The analysis identified four major themes: 1) striving for safety, 2) striving for normality, 3) striving for independence and 4) worrying about future (Table 3). Adolescents, mothers and fathers overall faced the same concerns and challenges living with T1DM. However, adolescents and parents often experienced it differently; some hesitated while others avoided to share their thoughts and feelings with each other, mainly because they wanted to protect each other. The consequences of this behavior were that their concerns and challenges remained unspoken and led to misunderstandings and frustrations between and within the parties. In the following section, the findings are detailed in each of the four major themes; quotes identified with A, M, and F are from adolescents, mothers and fathers, respectively.

Striving for safety

Adolescents and parents had many thoughts and strategies on how to avoid situations where the adolescents were not able to manage their T1DM. The parties need for safety was related to the wish of being in control of T1DM, and in striving for safety, adolescents and parents often tried to create an ongoing “safety net”. For instance, adolescents used parents as a hotline, knowing that they were always ready to help with issues concerning diabetes-care, and adolescents and parents ensured that friends knew how to react if episodes, like hypoglycemia, occurred.

Adolescents and parents had an ongoing fear of hypoglycemia. This fear was especially present when the adolescents were away from home: Both parties were afraid that the adolescents would lose control or, in the worst case, not wake up from sleep. A mother to an 18-year-old boy describes her fear:

(M5) ... if he doesn't wake up fairly early in the morning, I go check on him - it (the fear of hypoglycemia) is there and it will always be there.

Adolescents and parents often used a lot of energy and different strategies to control or minimize the fear, here exemplified by a 19-year-old boy:

(A3) ... I always carry around glucose, gel or a juice and I always make a sandwich before I go to a party, and I measure my blood sugar fairly often, when I am out ...

In situations where it was not always possible to get help, like during sports or at parties or work, some adolescents deliberately chose to have a higher blood sugar to avoid hypoglycemia, as exemplified here by a 19-year-old boy:

(A3) If I am at scouts, and there are twenty kids standing around a campfire ... and I suddenly have low blood sugar ... - that's dangerous. I am driving a car, my blood sugar is too low - that's dangerous ... that is also why I prefer to have slightly elevated blood sugar ...

Some parents also encouraged their adolescents in having a slightly elevated blood sugar in situation where they were not sure if their adolescents could get help if they should get hypoglycemia. As a mother to a 15-year-old girl stated:

(M2) ... that's why we feel, better to have her a little high ... because that is not as alarming, as if she is low.

Parents longed for being in control of their adolescents' diabetes-care, to reduce the risk of complications. For example, they tried to make agreements about the number of blood sugar measurements, about taking insulin and about calling home. However, the parties did usually not share their concerns, and the parents "nagging" were often misunderstood by the adolescents, who became frustrated instead. Here exemplified by an 18-year-old boy:

(A6) ... it pisses me off when my parents interfere ... It sometimes pisses me off, so I don't care to take insulin.

When agreements were not kept by their teenager, mothers felt distrust and had difficulty letting go, often leading to frustrations and increased concerns. A mother's frustration is illustrated below:

(M1) ... if I could be a constant miniature glucose monitor in her tiny vein, that would be great ... if she took responsibility and I knew that things were under control ... if she, for Pete's sake, just was willing to measure her blood sugar.

Striving for normality

The adolescents experienced that the demand for self-management of T1DM was a burden. They felt different from their peers and experienced that they had difficulties in acting like their peers. For instance, it was hard to do activities spontaneously. They felt that their condition had to be on their mind every minute, and they had to plan their activities beforehand such as bringing extra food, insulin etc. One described T1DM as an "extra piece of luggage" pointing out the extra "duties" which T1DM brings and the mental burden of this as they "stroved for normality". The adolescents had different ways of coping with T1DM to try to feel normal and minimize the burden of T1DM in daily life. They had all tried to keep life and disease apart by hiding T1DM from friends or work or simply ignoring routine care by taking a "time off" from T1DM (e.g. not testing blood sugars, hiding injections and not talking with anyone about it). This may indicate that they had not integrated T1DM into their lives and had not become a part of their identity yet. Striving for normality is exemplified by a 15-year-old girl:

(A2) ... I stopped measuring my blood sugar ... you just get tired of it, and then I choose to forget, that I have diabetes and just ignore it ... I thought, that I have a right to be like the others too.

The parents felt sorry for their children living with the burden of T1DM and therefore, some parents supported the adolescents if they assessed they needed a time off period. In striving for normality, some parents chose not to pay attention to healthy food. A mother to a 15-year-old girl described it this way:

(M2)... because it (diabetes) is so invasive and with stuff like diet, we don't take many considerations ... it ... shouldn't be a nuisance, that food also becomes a factor on top of her having her diabetes under control, but if she also has to be scolded every time she eats something wrong ...

The parties hesitated or even avoided to share their thoughts and feelings in order to protect each other from further concerns and challenges. Hereby, they were not aware of the reasons for each other's actions directed towards normality. The time-off often resulted in adolescents feeling alone with their T1DM, while some parents found it hard to accept their adolescents' way of managing T1DM.

Other adolescents had finally integrated and accepted T1DM as part of their lives. They did not hide T1DM nor did they need time off from it. When parents had chosen to integrate T1DM as part of the whole family, living and coping with T1DM had become a natural part of the adolescents' and their families' daily routines. Here exemplified by a mother to an 18-year-old boy:

(M5)... we all eat healthy food ... to us, it has been important, that the whole family has adopted a very healthy lifestyle.

For some adolescents, the feeling of normality first occurred when they spent time with other peers with T1DM. This situation gave them a chance to share their thoughts and challenges in integrating T1DM into their lives. A 19-year-old boy who had attended a diabetes camp described it this way:

(A6) ... I stood there watching those other kids (with diabetes), and they looked perfectly normal, you really could not see it on them, and then I thought, that must be the way I look too.

Striving for independence

All adolescents wanted to be able to self-manage T1DM, but were often faced by several obstacles such as lack of knowledge, skills and parental support. Instead, they felt embarrassed and struggled to hide their incompetence from their parents and health care providers. Parents also longed for their adolescents to be independent in managing T1DM. The father of an 18-year old boy described it this way:

(F6) ... it is ... by far the best, that he himself knows the most about it (T1DM) ... that it is he, that knows what is best for him, and that he is best at it. It wouldn't be good if we were the ones who knew the most and he didn't have a clue.

Both adolescents and parents were aware of challenges that prevented autonomy and independence in T1DM management: It was evident that some of the adolescents did not feel they had the knowledge to self-manage T1DM. They had, for instance, trouble counting carbohydrates, and they were unsure about how to regulate their blood sugars when drinking alcohol or exercising. Some adolescents expressed that they received good advice and support from the hospital, as stated by a 15-year-old girl:

(A2) ...they (doctor and nurse) are good at giving some good advice as to how and what you can do ... what is best for yourself ... The fact that you are a part of the discussion about what is a help to you ... instead of just being scolded.

Other adolescents experienced a lack of advice from the hospital. Here illustrated by a 16-year-old girl:

(A4) ... it can be difficult (to do sports) because when it (the blood sugar) starts to drop or if it is too high when I start to work out, if I need to take insulin at all or if I shouldn't ... I haven't received any support on the matter. I still have trouble with it.

Knowing how to manage T1DM did not always lead to self-management. The adolescents claimed that it was difficult to incorporate T1DM-related routines into their busy, sometimes unpredictable, lives. The adolescents found it easier to manage and incorporate T1DM-related routines when the day was structured and activities were familiar. Some adolescents struggled trying to self-manage T1DM by themselves. They used a lot of energy in hiding their incompetence in self-management, when they felt they were not able to meet the expectations of their parents and health care providers: Some avoided confrontation by staying away from clinic visits; others chose not to tell their parents how they were doing. A 15-year-old girl illustrates this:

(A2)... I am one of those, that easily get sidetracked, and I don't take care of it (diabetes) for a while... then it sits at the back of your head all the time, because I am actually hiding it from my mother, until she finds out.

Some parents were very aware of how they could support their adolescents to self-manage T1DM. These parents had decided to act as role models. They changed their way of living, incorporating behaviors such as eating healthy, exercising and counting carbohydrates even when the adolescents did not bother. A father described the effort he had made to support his 19-year-old son to self-manage T1DM by acting as a role model:

(F2) So have you through the way you have eaten, through your own behavior, have you instilled the basic skills or haven't you. And you can hope you have.

Worrying about future

All parties expressed worries about the future, such as how it would be to transfer to an adult diabetes clinic, if it was possible to get a boy- or girlfriend, an education and establishing a family. However, in order to protect each other and lessen the burden of T1DM, they hesitated to share their concerns about future challenges, which they might have to face due to T1DM. This left both adolescents and parents alone with their worries and frustrations. In addition, they were all aware of the risk of long-term complications, and some adolescents regarded the future as uncertain. Both parties became frightened when reading the Diabetes Association's newsletter and when facing elderly people with T1DM with visible complications in the waiting room. The adolescents felt guilty when their blood sugar tended to increase, exemplified here by a 15-year-old girl:

(A1) I get an extremely guilty conscience towards my body ... I feel ... it
(high blood sugar) is destroying ... my body ...

Adolescents avoided talking about their concerns, because they did not want their parents to feel sorry. Instead, they felt alone with their worries. Here exemplified by an 18-year-old boy:

(A5) ... well, every time you get high blood sugar, it affects your life expectancy at some point ... (voice breaking slightly). I just try not to think too much about (it) ... we don't want to get into that. I just think it would make my father sad ...

Parents often thought that their adolescents did not care or worry about future, and parents usually chose not to share their thoughts about the risk of complications to protect and avoid worrying their children. However, parents were frustrated and concerned that their children would not be able to live normal lives. A mother to a 15-year-old girl described her frustration this way:

(M1) ...man, I think this is tough. However, she is my daughter...but sometimes I also need to....paint the whole picture, what are the consequences of her letting go for long periods of time, and the fact that she doesn't take responsibility.

To summarize, adolescents and parents were faced by several challenges and concerns when trying to improve adolescents' self-management skills. Worries, fear, the burden of diabetes and the feeling of being incompetent in managing T1DM, dominated their lives and resulted in strategies that led to misunderstandings, frustrations and the feeling of being alone.

DISCUSSION

This study is the first, as far as the authors know, to use visual storytelling to elucidate both adolescents' and parents' perspectives living with T1DM. Four major themes regarding living with T1DM emerged: 1) striving for safety, 2) striving for normality, 3) striving for independence and 4) worrying about future. The parties' fear of complications, as well as the burden of T1DM and the feeling of not being competent in self-managing T1DM, forced adolescents and parents to use different strategies not always compatible with successful self-management. For example, some adolescents chose to maintain an elevated blood sugar to avoid hypoglycemia, some ignored diabetes-routine-care to feel normal, while some avoided clinical visits to hide their incompetence in self-managing T1DM. These approaches were often supported by parents who faced the same concerns and challenges and felt sorry for their child carrying the burden of T1DM.

The fact that adolescents and parents chose to maintain an elevated blood sugar in certain situation is a very important finding, highlighting that the parties still use this approach even though they are all aware of the potential risk of complications later on (Inzucchi,SE, Sherwin,RS 2009). Being aware of this strategy, clinicians should speak more openly with adolescents and parents about how to overcome this fear in order to improve glycemic control, but also focus on educating adolescents as well as parents in how to manage and avoid future episodes of hypoglycemia. The strive for safety and approaches to avoid hypoglycemia have previously been identified in adults with diabetes as well as parents (Haugstvedt *et al.* 2010, Sakane *et al.* 2015) .

To our knowledge, this is the first study to elucidate that parents used different approaches in order to make their adolescents feel and act like their peers. For example, some parents actively tried to lessen their adolescents' burden of T1DM by not focusing on T1DM at home, such as avoiding talking about it or not paying attention to healthy food. However, this approach resulted in the adolescents struggling alone with their T1DM. Our findings can contribute to improved clinical practice by supporting the adolescent-parent management-work by speaking

openly about the importance of sharing the work of managing T1DM – also in regard to their daily lives.

In our study, both adolescents and parents had difficulties in accepting T1DM and normalizing it as part of daily life. The adolescents' feeling of being different from their peers and taking a 'time-off' from the daily T1DM-routines is supported by previous studies (Marshall *et al.* 2009, Freeborn *et al.* 2013, Babler & Strickland 2015). Babler and Strickland described the process of integrating diabetes into one's life as a "shift in the adolescent's mental framework" which helps adolescents understand that diabetes is part of who they are and helps them to accept and realize that their life with diabetes is their "new normal" (Babler & Strickland 2015). However, we found it just as important to support parents in integrating T1DM into their everyday life to improve the management-work, a fact that is also supported by the study of Young *et al.* (Young *et al.* 2014). One way the adolescents in our study expressed feeling normal was being with other adolescents with T1DM. This finding is similar to other studies where attending diabetes camps improved quality of life (Cheung *et al.* 2006) and self-confidence (Rasmussen *et al.* 2011). Peer support may be the way to help the parties create a "new normal" life living with diabetes like identified in adult care (Joensen *et al.* 2016). However, parental groups with focus on how to provide autonomy support may also be a novel initiative, taking previous studies' recommendations into account (Viklund & Wikblad 2009b, Husted *et al.* 2014b).

Another important finding in our study is that both adolescents and parents were quite concerned about their future health, but none of the parties were aware of each other's concerns. This resulted in both adolescents and parents feeling alone with their concerns. Our findings are in line with the results from Carroll and Marrero's study (Carroll & Marrero 2006) who found that parents do not consider that their children worry about long-term complications. The parties' worries about future, such as the risk of long-term complications, are, however, also known from previous studies (Carroll & Marrero 2006, Freckleton *et al.* 2014), and the fact that the parties have difficulties in sharing these worries are also identified elsewhere (Husted *et al.* 2014a).

However, contrary to this study, Luyckx and Seiffge-Krenke found that parents perceived their child's T1DM more serious than the child did (Luyckx & Seiffge-Krenke 2009). Our findings emphasize that it is important to identify potential concerns about the future in clinical practice and to help the parties share their concerns and challenges. This will support their understanding of each other's actions and strategies and improve their collaboration in managing T1DM.

Despite the last decades' ongoing actions to support adolescents and parents in self-manage T1DM (e.g. new technologies, pump treatment, analog insulin, interventions) (Garvey & Wolfsdorf 2015, Pillay *et al.* 2015) not much seems to have changed in regard to the major concerns and challenges adolescents and parents face living with diabetes during the transition from child- to adulthood. There is an urgent call for new kinds of support to adolescents and parents to improve adolescents' self-management skills. Foremost, this study reveals the importance of health care providers to get a more in-depth understanding of the individual families' needs and worries and to routinely assess for instance fear of hypoglycemia, worries about future, feeling different and incompetent in self-management and also assess the parties' strategies in relation to these challenges. At Steno Diabetes Center, Denmark, The PAID-1 scale is being used with great success in adults to assess current challenges – this could be a tool for HCP to implement in outpatient settings (Glindorf *et al.* 2014). In this study, visual storytelling (Drew *et al.* 2010) was used as a way to set the agenda, promote reflections and talk about issues that would otherwise be difficult to raise and talk about. This method may not only be useful as a data collection method, but could also prove fruitful as a communication tool in clinical practice to help identify and pronounce the hidden concerns and challenges.

Our study stresses that the collaboration between adolescent and parents is fundamental and of highest importance during the transition from child- to adulthood to succeed in self-managing T1DM. Like previous studies, we found that parents have major influence in both facilitating autonomy and in being a barrier to independence in diabetes self-management (Hanna &

Guthrie 2001, Palmer *et al.* 2011). However, our study also highlights that adolescents and parents mainly kept their thoughts about living with T1DM by themselves, resulting in the parties struggling alone with their concerns and challenges. This often led to frustrations and conflicts due to misunderstanding of each other's intentions. The findings are of crucial importance to health care providers to improve their work with adolescents with T1DM and their families. The adolescents' and parents' similarly lived experiences can be used in future outpatient clinic to provide a platform for communication around concerns and challenges in order to strengthen the collaboration of the adolescent/parent-dyad to improve the adolescents' self-management. The life skills intervention, Guided Self-Determination-Youth may be a communication tool for health care providers to implement in usual outpatient setting. It has previously proved useful in facilitating the communication and collaboration between adolescents and parents, by helping them to share thoughts, concerns and challenges by using different semi-structured reflection sheets during common outpatient clinic visits (Husted *et al.* 2014b). This approach has shown to improve the fundamental and important management-work required to share responsibility and decision-making for diabetes-care (Husted *et al.* 2014b).

The diabetes outpatient clinic is often characterized by measurements and numbers (e.g. HbA1c, reading the pump, height, weight, blood pressure), which are all important parts of diabetes care. However, little or no time is left for contemplation in the daily challenges and concerns faced by adolescents and parents. Moreover, many health care providers have a hectic workday and may deliberately choose not to reveal in-depth feelings because of time pressure or lack of communication-skills (Stuckey *et al.* 2015). In future practice, it may be necessary to allocate time for the psychosocial issues and to educate health care providers in talking about in-depth experiences, since only few have been trained and have the skills to help parents and adolescents to manage fear (Vallis *et al.* 2014).

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Finally, previous interventions may have failed to support adolescents and parents to self-manage T1DM during the transition from child to adulthood, because the parties have been omitted in the development process of the interventions. Participatory design is a well-documented and recommended method to increase the chance of developing interventions which mirror the users' need and wishes and increases the chance of successful implementation (Olsson & Lau 2015). It is therefore essential to use input from the adolescents, parents and health care providers to ensure that future interventions meet the users' needs and can be implemented into practice.

Limitations and strengths

The present study has several strengths: First, the interviewer (PCS) was not known to the families, which encouraged them to be open and speak freely. Second, the study included heterogeneous families and roughly equivalent involvement of both mothers and fathers. Third, the study used a rigorous qualitative methodology (Braun & Clarke 2006, Drew *et al.* 2010) to explore the experiences of both adolescents and their parents—an area of limited research.

However, the study had some limitations: First, the participants lived in the same geographical area in Denmark and were recruited from one hospital. Second, they were interviewed at different settings, which could have influenced their openness about thoughts and feelings. Interviews at home or school may have resulted in less privacy than at the hospital, due to the risk of interference from other family members or classmates. Finally, despite the fact that photos supported most adolescents and parents in articulate thoughts and feelings and were described as “reminders”, some adolescents and parents found it difficult to portray feelings visually.

CONCLUSION

This study provides new insight into the concerns and challenges adolescents and their parents face living with T1DM. It reveals four major themes consistent across adolescents and their parents: striving for safety, striving for normality, striving for independence and worrying about the future. It elucidates adolescents and parents strategies when living with T1DM in the transition from child- to adulthood; but underlines that their thoughts and feelings remain isolated, and both parties often feel alone, worried and frustrated and their concerns and challenges remain unsolved.

RELEVANCE TO CLINICAL PRACTICE

These findings highlight the importance to support both adolescents and their parents to talk about and share thoughts, feelings and concerns about life with T1DM. Health care providers especially need to address the parties' perspectives and strategies to diminish the worries about future including the fear of hypoglycemia, the burden of T1DM, but also the lack of competence in T1DM self-management, to successfully improve adolescents' self-management skills. These findings should be integrated into new intervention programs to support adolescents and parents in finding new ways to manage living with T1DM during the transition from child- to adulthood.

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CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

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Table 1. Participant characteristics

Adolescents (n = 9)		
Female gender, no. (%)	5 (56)	
Participating parent, no. (%)	8 (89)	
Divorced parents, no. (%)	4 (44)	
Acute diabetes-related hospitalizations within the last year, no. (%)	1 (11)	
Non-Danish ethnicity ^a , no. (%)	1 (11)	
Patients attending pediatric care, no. (%)	5 (56)	
Mean age, years (range)	17 (15-19)	
Mean HbA1c, mmol/mol (range)	79 (56-120)	
Mean age at diagnosis, years (range)	11 (8-16)	
Mean duration of diabetes, years (range)	6 (2-10)	
Parents (n = 13)		
Females, no. (%)	7 (54)	
Both parents participating, no. (%)	4 (31)	
Non-Danish ethnicity ^a , no. (%)	1 (8)	
Parents whose child is attending pediatric clinic, no. (%)	9 (69)	
Mean age, years (range)	49 (37-59)	^a First or second-generation immigrants.

Table 2a. Interview guide for adolescents





Theme	Main question	Supporting questions
Introduction	<i>Explanation:</i> We really wish to improve our service for young people with diabetes. Therefore, it is very important for us to get to know your thoughts and feeling regarding living with T1DM.	
Photos	What photos are most important for you to talk about today?	Tell me, why did you choose these photos? Can you give me some examples? What support do you miss? –from whom? What makes your everyday life with diabetes easier?





		<p>What challenges your everyday life with diabetes?</p> <p>I have noticed a photo, which made me curious. What does this picture mean to you?</p>
Self-management	<p>Imagine a young person, who just got diabetes, confronted you, wanting to know how to manage his diabetes himself. What would you answer?</p>	<p>In what situations do you feel capable to manage your own diabetes?</p> <p>How did you reach this state?</p> <p>In what situations is it challenging to manage your diabetes?</p> <p>Please give me an example.</p> <p>What do you need to manage diabetes all by yourself?</p>
The method	<p>How was it to take the photos?</p>	<p>What kind of reflections did you have before the interview?</p> <p>How do you think this interview would have been for you without the photos?</p> <p>How was it to share your thoughts with me?</p>
Ending	<p>Is there something important you want to add?</p>	<p>Can I call you if I have further questions?</p>

Table 2b. Interview guide for parents

Theme	Main question	Supporting questions
Introduction	<i>Explanation:</i> We really wish to improve our service for young people with diabetes. Therefore it is very important for us to get to know your thoughts and feeling regarding being a parent to an adolescent with T1DM.	
Photos	What photos are most important for you to talk about today?	Tell me, why did you choose these photos? Can you give me some examples? What support do you miss? –from whom? I have noticed a photo, which made me curious. What does this picture means to you?
The method	How was it to take the photos?	What kind of reflections did you have before the interview? How do you think this interview would have been for you without the photos? How was it to share your thoughts with me?
Ending	Is there something important you want to add?	Can I call you if I have further questions?

Table 3. Themes

Themes	Adolescents' photos	Parents' photos
<p>Striving for safety</p> <p>Adolescents and parents longed for being in control of T1DM to avoid situations where the adolescents were not able to manage T1DM. The parties tried to create a “safety net”, such as having a T1DM-hotline, always bringing a juice, and preparing friends. As an example, some adolescents chose to have a high blood sugar to prevent hypoglycemia and some parents supported this approach. Parents longed for control of the T1DM-care to be sure nothing bad happened, often leading to frustrations and conflicts instead.</p>	 <p><i>“You must ... always keep some sugar with you, especially when you ride the train, because on the train it is even harder to get a hold of some sugar ... can I risk it (the train ride)?”</i></p> <p>A5, 18-year-old boy</p>	 <p><i>“She (my wife) hasn't heard from her (the daughter) for some time and she gets worried and it is on her mind a lot...it is ... powerlessness, because you can't do anything, you ... can't force the young people to do it ...”</i></p> <p>Father to a 15-year-old girl</p>
<p>Striving for normality</p> <p>Adolescent experienced the demand for self-management of T1DM was a burden. They all felt different from their peers. Some tried to be normal by keeping life and disease apart and some parents felt sorry for their child supporting these “breaks” from diabetes. Others had integrated and accepted diabetes as part of their life, not spending much effort on</p>	 <p><i>“As a diabetic ... I can't keep Ramadan ... that has ... made me very sad ... I feel ... I become separated from my own family ... feel ... I am not like them.”</i></p> <p>A8, 17-year-old girl</p>	 <p><i>“I want ... for her to have the experience, that she isn't restricted because of her diabetes. That is actually the most important thing for me ... that she has a normal youth and normal journeys.”</i></p>

daily routines. Peers with diabetes helped many feel normal.		Mother to a 15-year-old girl
Striving for independence Both adolescents and parents longed for the adolescents to be independent in managing T1DM. However, the adolescents were faced by several obstacles such as lack of knowledge, skills and parental support. When not succeeding in self-management, adolescents felt shame.	 <p><i>"During ... your teens, many things happen ... You want ... to have ... more freedom and you want to decide ... for yourself ... but in reality you need a little more help ... like ... how many carbohydrates is this? "</i></p> <p>A8, 17-year-old girl</p>	 <p><i>" Time has ... always been controlling ... when you have a child with diabetes ... how much time do we have ... she (my daughter) asks, when are we going to eat?"</i></p> <p>Mother to a 17-year-old girl</p>
Worrying about future Both adolescents and parents worried about the future, such as the risk of long-term complications. High blood sugars caused a guilty conscience for adolescents and frustrated parents. Many parents thought their child did not worry about future consequences and chose not to talk with their children to avoid worrying them. Many adolescents were alone with their worries, not sharing them with anyone.	 <p><i>"... I get an extremely guilty conscience towards my body ... I feel it's somewhat destroying ... my body ... with high blood sugar ... I feel that when you take a shower you can wash all the bad things away ... you feel in "a fresh start" kind of way.</i></p> <p>A1, 15-year-old girl</p>	 <p><i>" When I am alone... when you are in the car ... you let you mind wander... it is mostly concerning his future ... it worries me."</i></p> <p>Father to a 15-year-old boy</p>