Article

Mutual Involvement in Families Living with Type 2 Diabetes: Using the Family Toolbox to Address Challenges Related to Knowledge, Communication, Support, Role Confusion, Everyday Practices and Mutual Worries

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Abstract: Family involvement plays a key role in diabetes management. Challenges related to type 2 diabetes (T2D) often affect the whole family, and relatives are at increased risk of developing diabetes themselves. Creating family involvement in families living with T2D is a complex matter. This article studies potential effects of working with dialogue tools specifically developed to create family involvement. The data consist of 18 semi-structured family interviews. The data were analyzed using radical hermeneutics and theories on family identity and healthcare authenticity. The analysis revealed five themes: (1) Working with the tools created better and broader intra-familial involvement; (2) the tools enabled new roles and self-understandings for all family members; (3) the tools facilitated mutual insights into each other's thoughts and worries; (4) after working with the tools, it was easier to discover potential challenges and possible behavior change; and (5) gaining new knowledge and the motivation to seek more knowledge was easier after working with the tools. Working with the tools changed how the families perceive themselves and the ways in which they can affect their own T2D-related health behavior together. This has direct implications for healthcare practitioners working with people with T2D.

1. Introduction

The family plays a key role in the management of type 2 diabetes (T2D), and the importance of family approaches has received increasing recognition in recent years (Kovacs Burns et al. 2013; Torenholt et al. 2014). Creating the grounds for genuine family involvement is a complex matter, often characterized by unclear intra-familial relations, difficult family dynamics, and contrasting needs and expectations within the family. Supportive and obstructive behaviors frequently co-occur (Mayberry and Osborn 2014; Khan et al. 2013). For this reason, more family involvement is not always beneficial (Mayberry and Osborn 2014; Stephens et al. 2013).

The majority of diabetes self-management occurs within the family environment. Therefore, the intra-family perspective of supportive and non-supportive interactions should be understood and addressed, as family members are interdependent and affected by each other. Future research assessing the impact of professional support and the family function will have the potential to improve the daily life and well-being of people with T2D as well as the whole family (Bennich et al. 2017).

People with limited resources are especially vulnerable to the harmful aspects of family involvement (Mayberry and Osborn 2012). Close relatives often describe discomfort with the perceived

need to monitor the person with diabetes as well as confusion about their role in diabetes care; these feelings often result in unintended family conflict (Samuel-Hodge et al. 2013). Studies have also shown that relatives tend to have concerns about diabetes that are often not voiced (White et al. 2007).

In families where a member has T2D, relatives have a significantly higher risk of developing T2D themselves (Weijnen et al. 2002; Khan et al. 2003; Pierce et al. 1995). A major obstacle to positive intra-familial communication about prevention, familial risk, and risk reduction is a lack of perceived disease relevance (Myers et al. 2015; Heideman et al. 2015). Motivation to engage in risk-reducing health behaviors or to undergo screening is dependent on awareness of one's susceptibility to a given disease (Godino et al. 2014).

Vongmany et al.'s recent meta-synthesis on family behaviors that have an impact on the self-management activities of adults living with T2D showed that a significant number of familial behaviors are experienced as equivocal. They concluded that it may be possible to encourage adults living with T2D to reframe these behaviors so that they are perceived as enabling their diabetes self-management (Vongmany et al. 2017).

We need to know more about how to approach families in order to support a heightened level of positive involvement and support—while acknowledging that this involvement has to be sensitive to myriad potential family characteristics.

2. Project Background

Based on the challenges mentioned above, we set out to uncover the specific challenges and problems found in a Danish population. Through a rigorous co-creative design-based process, we initially uncovered (through two separate analyses) six challenges (Grabowski et al. 2017) and three main barriers (Grabowski and Andersen 2018) in daily family life with T2D.

The first analysis disclosed six affected domains: Knowledge: Many families have unclear structures for sharing knowledge. Relatives often lack knowledge about T2D and how to provide support. Family members with self-reported adequate knowledge and ways of sharing are more involved in each other's life. Communication: Balancing communication about T2D is difficult. Some families do not talk about T2D and others talk too much about it. Families who find an appropriate balance are more motivated to deal with challenges as a family. Roles: T2D changes roles in the family. It is difficult to accept the role as a person with T2D and the role as a close relative to a person with T2D. Understanding new roles or adjusting existing roles is deeply connected to grasping how T2D affects everyone. Everyday practices: Many families do not want T2D to dominate daily life. They often create inappropriate practices to maintain a sense of normality. This makes positive involvement and constructive support difficult in everyday life. Support: Being supportive without being controlling is a key issue. Conflicts about support or misunderstood support often result in completely opting out of supporting and thereby significantly reducing mutual involvement. Worries: Living with T2D is a source of worries. In many families these worries are left unsaid. People with T2D often worry that bad habits are being adopted by younger generations (Grabowski et al. 2017).

The second analysis disclosed three main barriers to intra-familial prevention of T2D: (1) Sole responsibilities and the absence of collective practices: Not incorporating aspects of daily diabetes management into collective practices is a significant barrier to intra- familial prevention of T2D. Not involving any other family members in challenges and frustrations associated with T2D severely affects the possibilities for constructive mutual involvement within the family. The family's self-understanding and social imaginaries of wanting to live what they perceive as a normal family life make it difficult to maintain the perceived reality of being a normal family. (2) Intra-familial differences in perceptions of risks and future health: Most families are to some extent aware of the hereditary risks of T2D; this awareness is, however, rarely transformed into actual preventive action. In many families, there are well-established, generationally defined familial understandings that enable family members to carry out the collective practices that sustain younger generations' unhealthy practices and reduce mutual involvement. This leaves very little room for implementing health behavior changes that affect the

whole family. (3) Lack of perceived disease significance and the ensuing lack of mutual care: In many families, T2D is not deemed important enough to talk about. When no one talks about it, it is difficult to incorporate awareness of being a family with T2D into social imaginaries and understandings of active involvement, care, and support. When T2D is not an active subject, intra-familial prevention is rendered very difficult, as prevention involves as sense of significance and a role in how you imagine your future and your family's future (Grabowski and Andersen 2018).

These analyses were the primary starting points of the co-creational development process that eventually produced The Family Toolbox with four dialogue tools designed to enable healthcare practitioners to generate mutual family involvement in families with at least one person with T2D. The dialogue tools were constructed to address the barriers and problem domains mentioned above; they were given to healthcare professionals who also took a two-day course on how to use the tools most effectively. The four tools are: The Family Mirror: Inviting the participants to construct an image of themselves and a family member using cards with pictures and quotes regarding support, everyday life, worries, roles, communication, and knowledge related to life with T2D. This is intended to help participants reflect on and discuss challenges and opportunities in the family. The Family book: Preparing for interactive reflection on various aspects of daily family life while giving the participants practical knowledge and information about T2D. The book can be read at home or used as a communication tool in patient education for families. The Family Line: Enabling family members to show each other how big a part diabetes plays for them in daily life and how big a part diabetes should play, which can initiate dialogue on T2D in daily life. The Family Plan: Enabling the family to identify challenges and solutions related to T2D, and on that basis to establish specific objectives and plans for how they will improve or positively retain important elements in their daily life.

3. Objectives

Based on the familial problem domains and barriers mentioned above, the primary objective of the present study is to examine potential familial effects in families, living with T2D, who have worked with elements of The Family Toolbox in a healthcare setting.

4. Methods

Setting: In Denmark, many people diagnosed with T2D are offered patient education courses. These courses are typically constructed as a number of weekly meetings with nurses/dieticians/physical therapists who instruct groups of patients on topics such as exercise, diet and general self-management of T2D. These courses rarely include familial involvement, although some of them invite spouses to join the part of the course about healthy cooking. All of the participants in the present interview study took part in a patient education course in which the teachers incorporated tools from the Family Toolbox.

Interviews: The researchers contacted all healthcare practitioners who had attended the training course and asked them whether they had used or were planning to use the toolbox with families. All these families were then contacted and asked whether we could interview them, preferably in their own home. We stopped recruiting and interviewing families after 18 interviews, at which point all researchers agreed that data saturation had been achieved (Malterud et al. 2016). In total, the 18 interviews included 38 family members of whom 36 were couples, where one or both had T2D, and the two remaining interviewees were a daughter and a son-in-law.

We chose to conduct family interviews, as it was deemed the most suitable method for gaining access to the families' backstage and everyday life, while still taking ethical considerations into account (Daly 1991; Åstedt-Kurki et al. 2001). A semi-structured interview guide with questions related to the family's concrete work with the tools as well as questions on family-related health topics was used to focus on how the toolbox-session was experienced and managed by the families (Daly 1991; Reczek 2014; Åstedt-Kurki and Hopia 1996).

All interviews were carried out in the families' homes and conducted by two trained interviewers, who were unknown to the families prior to the interview. The home as interview setting was chosen to make the

participants comfortable. The home is preferable as an interview setting because it is seen as the family's "natural environment" and positions the researchers in the role of visitors (Åstedt-Kurki et al. 2001). To earn the trust of all family members, the purpose of the study was explained using non-scientific language. Prior to the interviews, all families gave their written informed consent. All workshop sessions were recorded and transcribed verbatim.

The study followed the codes of ethics found in the Helsinki II Declaration. The study was approved by the Danish Data Protection Agency (Rec. No.: NOH-2016–024). According to Danish legislation, interview studies require no approval from an ethics committee.

Analysis: The data were iteratively analyzed and categorized using Rasmussen's (Rasmussen 2004) radical hermeneutics, which are guidelines for content analysis that, by virtue of being a combination of hermeneutics and constructivism, manages to be both empirically true and theoretically complex. Radical hermeneutics focuses on keeping a balance between theory, method and data, as an interconnected process that requires a constant focus on how these elements influence each other.

The methodology entails three steps of analysis. The first step involves a reading of the data with a view to observing how specifically selected guiding differences are observed in the data. This observation in itself constitutes an interpretation rather than a description, and its task is to reduce the complexity of the data. Elements within the scope of the guiding differences selected by the interpreter are extracted from the data. The second step involves making these elements the subject of interpretation as an observation of the differences employed. The third step involves interpreting the sum of these differences. In the concrete analysis, the first reading disclosed the five themes presented below. In the second round, these themes were analyzed and interpreted separately, and in the third round, the findings were analyzed transversely, using the concepts of healthcare authenticity and family health identity, which was also the theoretic construct used for the needs assessment from which the tools were developed.

In the process of the three rounds of analysis, it is important to be aware of the blind spots in the analysis. Making the guiding differences explicit is a way of observing your own observations in the analysis, and as such it is an alternative way of approaching traditional methodological parameters like relevance, validity and reflexivity.

Theory: Contributions to the conceptualization of authenticity largely stem from the education research literature. In a review of authenticity in teaching, Kreber et al. (2007) discussed authenticity as a multidimensional concept based on genuine care. Informed by Taylor's (1991) 'ethics of authenticity', Kreber et al. foregrounded the importance of engaging people in genuine dialogue around ideas that matter. Barab et al. (2000) described authenticity as an emergent process that is actualized through individuals' participation in tasks and practices of value to themselves and to a community of practice. In doing this, they drew upon Dewey's classic theories of experience and of how an idea is always to be located in its consequences (Dewey 1938). To summarize, there are many different (but all related) definitions of authenticity; it is a concept that revolves around realness, relevance, meaning, caring, consistency, ethics, recognition and openness.

The definition of health identity is based on Waterman's (1984) theories on delineated self-definitions, Taylor's (2004) social imaginaries and Luhmann's (1995) concepts of observation and expectational structures. The definition of health identity used in the analysis is: 'People's observations and expectations concerning their own health, their knowledge about health and in what ways their health is related and comparable to the health of others' (Grabowski 2015). People's health identity is developed on the basis of individual observations (and consequent meaning making) of communication and is expressed through expectational structures and social imaginaries that have an impact on health values, health beliefs and health choices. Health identity functions as a way of orienting to and navigating the complexities of health communication, health information, and possible health behaviors (Grabowski and Rasmussen 2014).

In the concrete analysis of the interview data, the concepts provide an analytical strategy that enables us to focus specifically on elements related to different kinds of authenticity, individual family health identities and especially on the relations between the two.

5. Findings

The analysis disclosed the five primary themes enumerated below. The themes are highly interrelated and at times even interdependent. However, they all represent important aspects of potential familial effects of using the Family Toolbox.

5.1. Better and Broader Intra-Familial Involvement

Most families mentioned that the conditions for creating mutual involvement had improved after working with the Family Toolbox. This improved involvement, however, came in many different forms and depended significantly on the family dynamics, the level of intra-familial communication and the degree of self-reference in each family.

In some families, members felt the tools had enabled them to talk about many of the things they had already wanted to talk about. Failing to talk had occurred sometimes because they had simply never had the time to sit down and talk and sometimes because they somehow knew that the problem existed but needed the family tools to be able to put the issues into words:

> "Well, I believe that the tools helped us to get to talk about some of the things that we already wanted to talk about—and made us put it into words in a different way than we maybe had done before. The things would probably have come up anyway somewhere down the road, but working with the tools was a good opportunity to just get it done. Because all our evenings are about maybe a child that won't sleep, dishes that have to be done, work we have to finish and all kinds of other practical stuff. So, we rarely get a chance to really talk before bedtime […] maybe people should really do the mirror-thing once a week, really!"
>
> (Man with T2D)

This notion of creating a window of opportunity, where there is room to go a bit deeper into daily frustrations as well as practical issues, was mentioned by many family members as a significant element of working with the tools. Creating this space for communicating meaningfully was apparently something very much in demand among the families that found it difficult to navigate the daily hassles of everyday life with T2D.

In many families, there had been another communicative issue concerning disseminating knowledge and experiences to the rest of the family. In these families, it was often the person with T2D who would go to the doctor alone and be the only participant in diabetes management courses:

> "It [diabetes] affects the whole family, so it would be really nice to be able to take part and to just hear things together. 'Cause it's not just for John, it's for all of us. He must not be alone with this. It's something we're all part of and we always make it work for all of us together. So, it's fantastic, that this is for the relatives as well, 'cause there will always be things I don't know. I want to be involved in more things".
>
> (Wife)

Feeling like a unit was important to the families. Creating a knowledge- and experience-based common ground for the family's self-reference was essential to being and feeling involved in each other's daily lives.

However, this involvement effect from working with the Family Toolbox also had its potential challenges.

> "Overall, I think it was a good process. But I think we were made to talk about really vulnerable aspects of our lives. I think the process needs to be longer. You can't just open a person up and then close everything down without talking it through thoroughly".
>
> (Wife)

When relatives participated in diabetes courses or other diabetes-related activities, it was most often spouses who were involved. In many of our interviews, it came up that the family tools presented a natural opportunity for including the broader family—especially adult offspring:

"We have two daughters who don't live at home anymore. These tools would be fantastic for them to try. It would give them real insight into what diabetes really is and what they need to do, so that they won't make the same mistakes as we did".

(Wife)

Family members generally perceived the tools and the topics generated by the tools to be easy to relate to for all family members—even those not present at the actual toolbox sessions. Thus, the Family Toolbox enabled authentic ways of communicating about T2D and created opportunities for authentic and thereby meaningful intra-familial discussions about issues related to self-identification, social imaginaries as well as everyday life with T2D.

5.2. New Roles and Self-Understandings for All Family Members

In the needs assessment studies we conducted before developing the Family Toolbox, the families often reported role confusion and difficulties regarding intra-familial self-understanding. These themes emerged again when discussing the effects of working with the tools. Especially the peer-to-peer interactions with other families were important in questioning one's own roles, self-understandings and family identity:

"I was actually really surprised that most of the other families didn't seem to be particularly interested in or focused on T2D. They seemed completely indifferent. It was like, they didn't think about it at all—and I think about it many times every day. I think about how many vegetables I should eat, eating low fat, getting enough protein, and basically how to structure my life every day. It's not something that just comes easily".

(Woman with T2D)

Observing peers act and think completely differently from oneself in relation to T2D was something that made a great impression on people with T2D and their families and that was perceived as very real and authentic. When something observed seems very different from what is expected, people tend to question their own approaches and reflect on their own practices. Many families described this process as something that has made the greatest difference as regards changes in their self-understandings and role administration:

"We found out that people take it in very differently and react in different ways. Some people are very anxious and nervous and others just kind of dismiss the whole thing as irrelevant. A third group seem to be completely unsure about how to relate to it at all. When I talked with the others and when they spoke out in the plenary, it became very obvious that they were occupied with very different things in very different ways. Some of it was easy to relate to because it was things I had thought about myself and some of it was things I had never thought about at all".

(Man with T2D)

Intra-familial observations while working with the Family Toolbox also played a significant role in family members' self-understandings:

Woman with T2D: *"Personally, I've started focusing more on myself. I used to be the one helping everyone else all the time and always making sure that everyone was OK. But now I've turned it around to thinking that it is important that I focus on being OK myself. Because I learned that it is really difficult for my family to see me constantly working hard for them while maybe struggling a bit with my diabetes. So, I hope it'll make them feel better to see me doing something for myself for a change. What do you think?*

Husband: *"Well, yes [. . .] You've definitely started to think about yourself more."*

Woman with T2D: *"Yes, I've never done that before."*

These reflections and the ability to observe oneself from the outside were the concrete results of working with the Family Mirror and learning about how the rest of the family feels about having T2D in their family. The reflections and ensuing decision to do something for herself in order to do something for her family are good examples of the meta-reflective self-referencing occurring through intra-familial observation and communication.

Some of the families experienced that working with the tools confirmed that their intra-familial roles as well as their role understandings were fine—especially when they compared themselves to other participating families:

I think we've got confirmation in that we're pretty good when it comes to talking about the important stuff. Some of these tools kind of assumed that everyone has trouble communicating, so maybe we weren't the main target group, really? It was obvious that some of the other families hadn't talked as much about these things. And that was actually really great. It's important for us to know that we communicate well".

(Man with T2D)

The confusion of having a T2D diagnosis in the family had disrupted the family identity, causing existing roles to no longer fit as well as creating new interdependent familial roles. These roles became very clear-cut and easy to mutually observe when working with the family tools—especially in settings where several families worked with the tools together. Families and the individual family members could identify with other families and their ways of dealing with challenges, and they often mentioned getting confirmation for the ways they already dealt with things.

These processes of identifying with peers as well as observing and reflecting on others and themselves in the context of T2D involved getting to know and coming to understand new roles or making old roles fit with the new circumstances. The tools can potentially play a significant part in this process by making the health identification process easier and appear more relevant and authentic.

5.3. Mutual Insights into Each Other's Thoughts and Worries

One of the main challenges for families living with T2D was the lack of insight into each other's thoughts and worries. Very often things remained unsaid and thereby unshared within the family relations, and this constituted a very concrete barrier to intra-familial communication.

"Well, I thought it was nice to hear what Philip actually thought about me having diabetes. Because that's not something we really talk about at all. It's not like I just sit there and ask, 'what do you think about my diabetes'. So that was really nice, and I also think it was nice for him to hear what I think about it".

(Woman with T2D)

This very basic issue of not having talked about thoughts and worries at all was a recurring theme when developing the tools—and in the current interviews, it was something that most families had reflected on after working with the tools. Most of the families had not created this non-communication because they did not want to talk about diabetes. It was more often a case of it not being a natural topic of conversation.

"My husband is a very quiet man and he rarely talks about his feelings or about what is on his mind. It was really nice to have it confirmed that he has some of the same thoughts I have".

(Wife)

Knowing that your spouse or another close relative shares your thoughts or worries was considered very important by most participants. In many cases, this was not something they had given a lot of thought to before the toolbox session; instead, they had merely accepted this state of things. After realizing that thoughts and worries related to diabetes were something one could actually share with others, many of the family members expressed a desire to achieve the same effect with their offspring or other family members.

> "They basically only know that their dad has diabetes and that's it, really! So I think it would reduce their worries if they learned more about diabetes and how I feel about it. Then they'd know that it isn't as bad as they might think. I don't know if they think that I'm gonna die in a year […] I hope they don't".

(Man with T2D)

Many participants also commented on how they had observed other families in the toolbox sessions being really worried and how they did not want to end up like that. Being able to relate directly to similar families that were experiencing similar problems made the toolbox activities and diabetes topics appear contextually relevant and authentic. Other families' problems or challenges were seen as directly applicable to their own circumstances, as most of the families identified with each other because of the shared disease.

This direct identification is both a potential challenge and a potential resource for the families. Many participants observed other families performing poorly in their diabetes management, and they often reacted with both surprise and a fear of ending up in the same negative circumstances. If handled well, such observations could potentially be used constructively by the observing families. However, we also talked to families that were frightened after seeing how other families were handling diabetes in very negative ways:

> "I know they're worried. They keep an eye on me. We saw the same thing with that other girl at the course. She was worried to a point where she was actually worried sick. She was worried that her mom was gonna die […] and that scared me and made me fear that my girls could end up in that place".

(Man with T2D)

The most significant finding related to observing each other's worries and thoughts was how surprised the families often were when they found out what they actually thought about diabetes and about each other:

> Woman with T2D: "It surprised me how interested you actually were. I thought that I was the only one thinking like that. But it was really interesting that you were interested."

> Husband: "But of course I'm interested. We should all feel well. It's always been like that with us. I don't feel well if you don't feel well."

Getting to know each other's thoughts and worries helped a lot of families to incorporate T2D into the ways they would usually share thoughts and worries in other domains of everyday life. Talking about the issues within their own family as well as with other families made T2D part of their family identity in a natural and authentic way.

As well as observing each other within the individual family, the observations of other families' connectedness also generated many reflections among the participants. Observing other families one did not know caused many families to reflect on their own roles, and several reported that they automatically felt closer together after watching other families who seemed to not know much at all about other member's feelings and worries:

> "On that night, we experienced how some of the other couples surprised each other again and again. And that tells me that the tool really works and that there is a real need for it. You could hear that some of the couples didn't know each other at all".

(Wife)

The general feedback from the families was that the tools were effective and that they addressed real needs in the families.

Woman with T2D: *"I don't know if Paul actually knew how much I think about diabetes?"*

Husband: *"I didn't know. But it was made very clear at the session."*

Woman with T2D; *"We weren't in the same place at all. I felt that it was on my mind constantly and Paul didn't think about at all. He just saw that I seemed to be doing OK and didn't give it a second thought."*

This couple had used the experience of not being in the same place at all as a reason to work with the way they shared things; this was something several families talked about. The ways diabetes was contextualized when working with the tools turned the disease into something relevant that was integrated positively into identities and self-understandings in new ways. The perceived authenticity of this contextualization seems to have generated feelings of genuine caring that, in turn, generated instant identification among the participating families.

5.4. Easier to Discover Potential Challenges and Possible Behavior Change

Many families told us that they felt that working with the tools helped them to perceive possible areas of potential action and in some cases to be aware of possible future complications in new and more personally relevant ways.

"The questions and quotes were actually very good in terms of making us think about things that could potentially be challenges. That really helped me in the talks with my husband about me wanting him to be a bit more engaged in my diabetes than he is at the moment. It really helped me a lot".

(Woman with T2D)

"My thoughts started racing a bit when we sat there listening to the others. I mean, my dad has diabetes, Johan(husband) has diabetes—so it's in both families which means the kids have a potentially heightened risk of getting it. I never really thought about that before".

(Wife)

This quote illustrates a potential challenge when working with the tools. Some participants told us that they got new insights and/or knowledge that caused them to worry more about things like complications and heredity. These families, however, also stated that they were happy that these issues had come up.

When doing the planning exercise, most families came up with basic plans about changes in diet or physical activity. Although these plans seemed rather trivial, they nevertheless represented an eye-opener in the families; the family members had never even considered making joint plans about anything related to health or T2D, as these things were mostly seen as every individual's own responsibility—and health problems and lifestyle diseases were seen as basically the person's own fault and responsibility in terms of making changes.

"When we did that planning thing we agreed to really focus on writing down some achievable goals. We want to exercise more together. We want to eat healthier than we do right now and we really need to get rid of the cookies. Our goal is to grow old together and to play football with our grandkids".

(Man with T2D)

Another thing that kept coming up in the interviews was the reflection that the families felt that working with the tools simply presented an opportunity to talk to each other about things they knew were there—but had never had a real reason to discuss in depth.

"It just basically gave us a window of opportunity to discuss some things about; what can we do? What can I do? What can you do? So now we've had all the important talks about finding the best ways to get through this".

(Wife)

Discovering potential areas for health-behavior change or communicative change was an eye-opening process for most of the families. These families had never had joint approaches to diabetes or healthy behavior, as it had never been part of any of their collective practices, resulting in diabetes becoming the sole responsibility of the person with T2D. It was clear in the interviews that T2D only very rarely was an integral part of the family identity and that because of this, issues related to diabetes were deemed inauthentic by the family as a whole and only seen as relevant to the person with diabetes. Working with the family tools would seem to be an effective way of making diabetes a relatable issue on which collective practices can be based.

5.5. Gaining Knowledge and/or Motivation to Seek More Knowledge

A significant challenge in many families living with T2D is the problem of disseminating knowledge within the family. In many families, daily life with the disease was laden with stigma, shame and guilt, resulting in almost no constructive diabetes-related communication. The issue of acquiring new knowledge and of generating motivation for acquiring it is therefore of central concern:

"On the way home from the workshop, I realized that I now really want to learn more about diabetes. To read about it and try to get a better understanding about what it really is and about what the diet does and what the exercise does and what the medicine does and [. . .] just basically understand how these things affect each other. Unfortunately, we had to drive home in separate cars, so we couldn't discuss it right then and there—but I really wanted to".

(Wife)

Presenting knowledge in subtle ways with a focus on relational aspects and dialogue worked well with most of the families. Many of them seemed to gain motivation from being briefly introduced to bits of knowledge as part of a dialogue with peers. Topics seemed to be made instantly relevant and authentic by being introduced directly into relatable, recognizable everyday contexts:

"After working with the tools and talking to all the others, I thought about buying a book or something. In any case I think I need more knowledge about potential complications and what the medicine does and how the blood glucose really affects the body [. . .] Things like that".

(Husband)

This quote illustrates a general tendency among the families. The peer-to-peer dialogues did not necessarily generate any concrete new knowledge, but hearing authentic everyday stories and anecdotes from the other families very often led to an awareness of potential important issues as well as a general awareness of the need to share knowledge in the families.

"In one of the other families, they were a lot of people. I really understand their kids—there are a lot of questions. But with a game like this they could really sit there in a nice way and just spread out all the knowledge".

(Man with T2D)

Sharing knowledge and exploring the need for further knowledge has been a totally new experience for many families. These families had become used to not sharing knowledge, thoughts and experiences related to T2D for so long that it had been accepted as the normal way of doing things. These families expressed being impressed with how great a difference simply sharing knowledge made in the family.

"Well, now we really have a knowledge base in common, so now it is hopefully easier to support each other, right? So Rita doesn't have to sit there alone with everything. That's really nice, I think!".

(Husband)

In many families, there was a lack of diabetes knowledge among the relatives. They had never really talked about the disease and therefore information and general knowledge had not been disseminated in any way. The majority of participants liked the informal way in which the tools generated a relaxed setting for sharing experiences and knowledge about daily life with diabetes. They said they felt motivated by the genuine and authentic caring that was generated. When information is presented in authentic ways, acquiring knowledge is less demanding and easier to relate to—especially when the participating families can identify with each other.

6. Discussion

The families had generally positive attitudes towards the dialogue tools, and the analysis showed that all of the six interconnected problem domains identified in the needs assessment (Grabowski et al. 2017) were affected (albeit to varying degrees) by working with the tools: Domain (1) unclear structures for sharing knowledge: After working with the tools, families reported having gained knowledge and motivation to seek more knowledge. More importantly, they also reported that working with the tools represented a simply way of disseminating the information among family members. Several families asked whether they could take the tools home in order to create a space at home where they could share with the broader family. Domain (2) difficulties balancing T2D communication: The families felt that the family tools created a space for the family to communicate meaningfully without feeling that the T2D-related topics were taboo or out of order. In many cases, they were now able to talk about things they already wanted to talk about—but never felt comfortable with before. Domain (3) intra-familial role confusion: Working with the tools in a peer-to-peer setting created a multitude of opportunities for observing similar role structures in other families. This caused many families to re-contextualize their self-understandings and begin to identify with their new family situation. Communicating in new ways about T2D-related issues basically affected intra-familial self-referencing in constructive ways. Domain (4) frustrations with everyday practices: By observing and communicating with other families about their experiences with T2D in their daily life settings, the issues automatically tended to revolve around everyday issues—mostly concerning how to balance a sensible health behavior regarding diet and exercise. This peer-to-peer effect often inspired health behavior change through the families sharing with each other little tricks for implementation of healthy behavior. Domain (5) trying to work out how to give support: Heightening the level of mutual involvement and communication automatically made it easier to support each other in better and more mutually motivating ways. Several families mentioned that being supportive now comes easier. Domain (6) mutual worries remain unspoken: Perhaps the most important problem to address was reducing the constant worrying about each other in the families. Most families mentioned the surprise they felt when they realized that family members had a multitude of worries about each other. Working with the family tools often gave them instant insights into each other's worries—which then gave them the opportunity to start working with the problems.

The barriers to intra-familial prevention—identified in the second round of analysis (Grabowski and Andersen 2018) of the needs assessment informing the development of the tools—were also addressed by the Family Toolbox: 1st barrier—Sole responsibilities and the absence of collective practices: Finding themselves communicating with each other about things related to T2D made a big difference for the families. They learned about each other's worries and discovered that they often worried about the same things; this enabled them to address these worries more directly than before. All families reported that working with the tools had made their intra-familial involvement both broader and better, which in turn created effective ways of making diabetes a relatable issue on which collective practices could be based. 2nd barrier—Intra-familial differences in perceptions of risks and future health: Even though many of the participating families were represented by husband

and wife at the toolbox-sessions, the tools generated thoughts about cross-generational involvement. It was mentioned several times that they wanted to use the tools with their offspring to create a natural setting to discuss T2D, in general, and the risk of passing it on, in particular. 3rd barrier—Lack of perceived disease significance and the ensuing lack of mutual care: Many of the relatives participating in the toolbox sessions saw it as an eye-opening experience. They simply did not know the potential seriousness of the disease and had no idea how other family members were affected mentally. Several of the people with diabetes had similar eye-opening experiences owing to their previous lack of knowledge and motivation. In any case, the tools helped all of the participants to gain a more varied and complete knowledge base from which to take further action.

Our findings on all of the various elements in play when studying family dynamics in relation to living with T2D are in line with the existing literature. The present data confirm the findings of Mayberry and Osborn (2014) and Khan et al. (2013) showing that contrasting needs and expectations make intra-familial communication and support complex and very difficult to navigate.

The family members' discomfort with issues related to T2D, owing to the risk of family conflict [8], was shown in the present interviews to be one of the things the tools in the Family Toolbox is able to address by making these issues easier to relate to naturally and, thereby, easier to talk about. Most families told us they had experienced both discomfort and conflicts in the past. This is also in line with White et al.'s (2007) findings on relatives' unvoiced concerns about diabetes—and the present analysis clearly shows that using the tools provides a potential way of voicing these concerns.

Perhaps the most significant finding from the analysis concerned the malleable nature of the intra-familial health behavior and communication about diabetes. This is very much in line with Vongmany et al.'s (2017) findings on the equivocal nature of intra-familial behavior and on how it seems possible to encourage the individual living with T2D to reframe these behaviors so that they are perceived as enabling their diabetes self-management. This is exactly what many families talked about when describing how working with the tools had changed how they perceive intra-familial dynamics related to diabetes.

Applying theories of healthcare authenticity and family health identity to the analysis and interpretation of the data was a natural step, as this theoretical construct was also used to analyze the data during the development phases of the project (Grabowski et al. 2017; Grabowski and Andersen 2018). Looking at how individuals are able to relate to elements of a more or less authentic healthcare system can be viewed as individual family health identities being able to relate to different kinds of authenticity—based on how the family members are able to relate to T2D, in particular, and health, in general. In the present analysis, being able to focus on the connection between identities and authenticities in the context of experiences with working with the concrete tools gave the analytical process a clear focal point. Having worked with the same theoretical construct in the development phase and in this ensuing study of potentials made it easier to focus on whether and how the developed tools managed to address the challenges and needs uncovered in the initial studies.

Apart from the solid and pre-tested theoretical foundation, one strength of the present study was the comprehensive dataset consisting of 18 thorough family interviews, which provided us with ample data on which to perform a thorough analysis in three steps.

When recruiting interview families, there is a tendency for families that volunteer to be the ones with mostly positive experiences. We were, however, aware of that when planning the interviews and when doing the analysis. In the interviews, we made an effort to encourage the participants to reflect on potential downsides of working with the tools, and in the analysis, we gave negative statements increased analytical and interpretive value even though they were relatively few and far between. It is, however, not our main objective to study the broad effect of the tools, but rather to study the potential effects among a substantial number of families who have worked with the tools. An effect study needs to be carried out once the tools have been used by more healthcare professionals and more families.

The present study focused exclusively on the families and how they experienced working with the tools. It is important to also study whether and how the tools are implementable in healthcare practice on both the individual and organizational level.

The present findings have direct implications for healthcare practitioners working with people with T2D in a Danish setting. There is, however, a need for further studies as well as adjustment and probably re-development if the tools are to be used in other settings. As regards further research, the connection between family health identity and healthcare authenticity needs additional theoretical and empirical refinement.

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