Experience of family function, family involvement, and self-management in adult patients with type 2 diabetes
A thematic analysis

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ABSTRACT

Aim: To describe the patient's experience of family function and its importance in diabetes-related self-management.

Background: Many patients fail to reach the targeted glycemic level due to low self-management adherence. Knowledge is needed regarding the impact of family function on diabetes self-management.

Design: A qualitative descriptive design.

Methods: A purposive sample of 20 patients with type 2 diabetes. Data were collected in March-June 2017 via audio recorded semi-structured interviews, field notes and Eco-maps. Analyzed using thematic framework matrix and thematic analysis.

Results: Four themes were identified: (1) Downplaying disease. The disease was trivialized creating a barrier to family involvement; (2) Second guessing. When diabetes was not discussed, patient and family made their own assumptions; (3) Going it alone. The participants preferred sole disease responsibility to maintain usual family life; (4) No regrets. The participants managed their disease with medications only to maintain family cohesion and "the good life".

Conclusion: The participants in our study downplayed the consequences of type 2 diabetes and chose to control their disease medically rather than by lifestyle changes. They renounced family involvement to maintain their lifestyle and promote family cohesion.

Impact:

- During clinical check-ups, patients should be encouraged to involve their family in lifestyle changes
- Healthcare professionals need to recognize illness- and treatment beliefs and the impact of family function in disease management

Key words: nursing, family function, diabetes type 2, beliefs, self-management, lifestyle, qualitative, HbA1c, glycemic control, patient

1 | INTRODUCTION

Type 2 diabetes (T2D) is a chronic endocrine disease with an increasing prevalence primarily due to increasing incidence and furthermore decreasing complication-specific mortality. To date, T2D is affecting 425 mill people (Cho et al., 2018). T2D is largely the result of an interplay of non-modifiable factors such as age and genetics and modifiable lifestyle factors including overweight, physical inactivity and smoking (American Diabetes Association, 2019c, 2019b). Metabolic control is indicated by glycosylated hemoglobin (HbA1c) levels and has strong predictive value for diabetes complications. Even with a growing selection of anti-diabetic treatment options and patient education including recommendations for diet and physical activity, many patients still fail to reach the targeted HbA1c level (American Diabetes Association, 2019a).

Adherence to self-management is an essential feature of diabetes and is considered to play a central role in treatment effectiveness (Asche, LaFleur, & Conner, 2011). As T2D self-management primarily occurs at home, all family members are likely to be affected by symptoms, treatment, restrictions and complications. Although family members influence illness management, their concerns are rarely voiced (White, Smith, & O'Dowd, 2007; L. M. Wright & Bell, 2009). Self-management adherence is low, inevitably undermining treatment effectiveness, increasing the burden and late complications, decreasing quality of life (QoL) and finally, resulting in higher health care costs (Ahola & Groop, 2013).

2 | Background

Family involvement in T2D management has been widely examined in relation to supportive and harmful behaviors and the complexity of how T2D influences the family system and interactions. (Bennich et al., 2017; Karlsen, Oftedal, & Bru, 2012; Mayberry & Osborn, 2012; Rintala, Jaatinen,

Paavilainen, & Åstedt-Kurki, 2013). Family involvement does not always benefit patient self-management because family members might be uncomfortable or underqualified to share the responsibility of T2D management (Mayberry & Osborn, 2014). Conversely, studies show improvement of QoL, self-management behaviors and HbA1c control in T2D interventions focusing on family involvement (Baig, Benitez, Quinn, & Burnet, 2015; Torenholt, Schwennesen, & Willaing, 2014).

Family function includes communication abilities, problem-solving, task performance and mutual support (Skinner, Steinhauer, & Sitarenios, 2000; Steinhauer, Santa-Barbara, & Skinner, 1984). However, knowledge of the impact of family function on the quality and level of family involvement in T2D self-management is scarce (Batty & Fain, 2016; Bennich et al., 2018)**.** Our study will potentially add to the knowledge on the link between family function and patients' self-management behaviors and will be of value in clinical practice and further research. The theoretical framework of our study is *The Process Model of Family Functioning* (Skinner et al., 2000; Steinhauer et al., 1984). The model describes the overarching goals for a family including a successful process of task accomplishments, development of all family members and providing security and sufficient cohesion to maintain the family as a unit. *The Family Assessment Measure* (FAM) is developed from the model and is a non-disease-specific self-report instrument that provides quantitative indicators of the family functioning's strengths and weaknesses. These are expressed by the respondent's assessment of the process and interrelation of the six domains of *Task Accomplishment*, namely: *Role Performance* (willingness to assume and carry out the assigned roles) *Communication* (achievement of mutual understanding), *Affective Expression* (content, intensity and timing of the feelings involved)*, Involvement (*degree and quality of mutual care of the emotional and security needs and respecting each other's autonomy)*, Control* (the process of influence including persuasion and pressure)*, Values and Norms* (family rules and the flexibility for family members to determine their own attitudes and behavior) (Skinner et al., 2000). The FAM is the theoretical foundation and frame of the interview guide in our study exploring perceptions of family functioning and how the six domains of family functioning individually and in interrelation impact diabetes self-management.

3 | THE STUDY

3.1 | Aims

The aim was to describe the patient's experience of family function and its importance in diabetes-related self-management. The research question was 'How do the participating patients with type 2 diabetes experience and explain the family function as inhibitory, stimulating or insignificant in relation to diabetes self-management?'

3.2 | Design

The study had a qualitative descriptive design using individual semi-structured interviews. It was part of a larger mixed methods investigation exploring the patient perception of family function as a unique factor regarding diabetes self-management, glycemic control and QoL in adult patients with T2D (Bennich et al., 2018). The study was conducted at one-year follow-up after a randomized controlled trial comparing two diabetes care programs (Munch et al., 2016, 2019). We used thematic analysis as described by Braun and Clark (Braun & Clarke, 2013) to investigate the experience of family function by people with T2D.

3.3 | Participants

Eligible patients were recruited from the diabetes outpatient clinic at a university hospital in Denmark. The patients were contacted by phone or in person at the outpatient clinic by the first author (BBB). Purposive sampling was used to ensure the perspectives of a wide range of patients with T2D as to familial status, gender, age, marital status and duration of T2D (Braun & Clarke, 2013; Miles, Huberman, & Saldana, 2014). We included 20 adult patients with T2D and incipient complications willing to convey their perspectives on family function and T2D (Table 1). The data collection was guided by the principles of data saturation referring to the process of gathering and analyzing data until a richness of data and meaningful coherence is reached (Morse, 2015).

In the following, we use the terms 'patient' and 'participant' interchangeably. 'Patient' is used as opposed to 'family' and 'participant' is used to stress that our findings are particular to our participants and cannot be generalized. We define family members as individuals with a close relationship and regular contact with the patient and we adhere to the following family construct: "Family members are not necessarily marital or blood-related, but could be neighbours or good friends" (Lorraine M. Wright & Leahey, 2019).

[Insert Table 1 Participant characteristics]

3.4 | Data collection

Data were collected during face-to-face interviews, using a semi-structured interview guide. Medical data (Table 1) of the individual participant were not known by the interviewer prior to each interview to pursue an unbiased approach. The interviews were performed in March to June 2017. The point of departure for the interview guide were by the overarching six domains of the FAM (Skinner, Steinhauer, & Santa-Barbara, 1995; Skinner et al., 2000) although we rephrased all of the questions to fewer and broader questions. The guide consisted of open-ended questions where we non-judgmentally invited the participants to openly communicate their views and experiences regarding the importance of family function in relation to their diabetes self-management. Furthermore, the guide was continually adapted in response to incipient patterns in the data. (Braun & Clarke, 2013). Moreover, Eco-maps were used during the interviews (Hartman, 1978; McCormick, Stricklin, Nowak, & Rous, 2008). An Eco-map is a diagram of the elements of a person's environment and quality of the interactions between those elements. We used Eco-maps to illuminate and verify a shared perception of the participants' family relations, function and interactions of the family overall. Interviews were conducted and audio recorded by the first author at the participant's home (n=9) or at the hospital (n=11) as preferred by the participants. Interviews lasted 49 - 121 min (mean = 86 min). Important features of each participant's responses and initial ideas for data analysis were recorded in field notes. Field notes were taken immediately after each interview to capture body-language, interactions with the participant, emotional reactions and ideas of beginning patterns and intial codes. Initial subthemes were further revised during the analysis process (Table 2). The field notes were analyzed with the interview transcripts and Eco-maps (Braun & Clarke, 2013).

[Insert Table 2 Excerpt of field note]

3.5 | Ethical considerations

The study was approved by the Committees on Health Research Ethics and the Danish Data Protection Agency. We adhered to the General Data Protection Regulation (GDPR) allowing participants to give their consent to certain areas of scientific research. All participants received verbal and written information about the study and provided written informed consent prior to the interviews. Participation was voluntary and participants were given the option of pausing interviews or withdrawing from the study at any time, including after data collection, without giving a reason. No participants withdrew from the study. Participants were given time to debrief after their

interview and were provided with information on clinical supervision and support. We used pseudonyms in the published quotes.

3.6 | Data analysis

Interviews were transcribed verbatim and checked against audio recordings for accuracy. Data were initially summarized, sorted and indexed in a matrix in an ongoing process during the data collection (Miles et al., 2014). We iteratively analyzed, categorized and interpreted our data using Braun and Clarke's (Braun & Clarke, 2013) six stages of thematic analysis. 1. Familiarization with the data by reading the transcripts. We constructed the initial matrix where every participant was allocated a row and columns denoted by separate evolving domains and data were entered in the appropriate cells (Miles et al., 2014). The matrix was used to support coding and analysis, allowing the iterative process between different levels of abstraction without the loss of grounding in the raw data. 2. Generating initial codes driven by the research question. Transcripts were coded line-by-line deductively using pre-set codes informed by the thematic framework matrix but also inductively by open-coding developed by the data itself. Eco-maps and field notes supported this process by maintaining an overview of the relations in the respective interviews. 3. Searching for themes by collating codes that fitted together into initial subthemes and furthermore organizing into broader themes. 4. Reviewing themes by re-reading the entire data set and modifying and developing the preliminary themes. The initial thematic framework matrix, field notes and the Eco-maps supported this process. 5. Defining the 'essence' of each theme developing the four main themes; 6. Writing-up. An analytic software NVivo, version 12 (QSR, 2018) was used to support the organization of data (Table 3). COREQ guidelines are used to strengthen the quality of reporting.

3.7 | Rigor

We used the trustworthiness criteria of dependability, credibility, confirmability and transferability (Lincoln & Guba, 1985; Shenton, 2004). Descriptions of the setting and the sample's demographic characteristics were described to enable readers to put the findings in context and judge transferability to their own practice. All interviews were conducted by the first author (BBB). Dependability and credibility were increased by performing the initial interview with a co-author (DO). The participants verified the interviewer's understanding by reviewing the Eco-map during

and after each interview. Two authors (BBB and HK) coded sections of the first transcript independently and compared their findings to increase trustworthiness. The first author (BBB) coded the following transcripts. The first and last authors (BBB and IE) decided on the final themes. Confirmability was secured by field notes and an audit trail of initial interpretation and decisions before proceeding to the final themes. All authors participated in discussion of the final analysis and themes.

4 | FINDINGS

Demographics: We interviewed 20 people with T2D, 11 men and nine women with a mean age of 69 years (range 54-83), mean duration of diabetes 9 years (range 1-26), mean HbA1c 51.1 mmol/mol (range 37-70). Eighteen participants were diagnosed with comorbidities and 13 with diabetes complications. Twelve individuals lived with their spouse and eight lived alone (5 divorced, 2 had a partner, 1 widow). Fourteen had children, 13 were retired and seven were in employment. Most were well-educated, employed or retired and all were resourceful with a strong social network and well-established living conditions (Table 1). The interviews showed overall high satisfaction with the family function expressed by gratitude and perception of shared understanding among family members concerning the six domains of task accomplishments. None of the participants recognized a need for family involvement in their diabetes management. Qualitative analysis: We identified four themes answering our research question: (1) Downplaying disease, (2) Second guessing, (3) Going it alone and (4) No regrets. In the following we present the themes identified in our study (Table 3).

4.1 | Theme (1): Downplaying disease

This theme describes how our participants trivialized their disease toward themselves and in interaction with the family. Their disease progressed slowly and in the absence of symptoms, they failed to take the disease seriously. Lack of disease recognition and emotional internalization were major obstacles to family involvement in T2D management:

> *"But diabetes is nothing, really. Nothing happens, you know, diabetes is invisible and you don't feel it like you would a broken arm. I don't feel diabetes affects anything". [Paula]*

Most of the participants judged the severity of the disease and the quality of their diabetes management by the extent of perceptible symptoms and late complications. Family involvement in lifestyle changes was not considered before the onset of symptoms:

"No, I don't discuss my disease with anyone. People at work and in my family are aware of my hypertension, high cholesterol and diabetes, but I don't do much about it because I still haven't experienced late complications". [Ike]

Patients with adult children were torn between their wish to protect them from their parents' ills and their need to engage in the children's problems. While downplaying their own disease they expected to get involved if their child became ill:

"There's a limit to what children should be involved in. I try to hold back. I want to protect her. She has her own issues, but she shares these with me". [Evelyn]

4.2 | Theme (2): Second guessing

This theme describes how patient and family failed to openly discuss the disease. They waited for cues from each other and second-guessed whether they should interfere, thereby tacitly making assumptions regarding each other's reactions and understanding:

"I don't think [diabetes] has any effect on anyone in my family, not even my wife". [Ike]

The family was involved at the time of diagnosis, but mutual support dwindled after a while when the disease lost its novelty and the patient ceased to discuss the disease. The patient gradually became indifferent and, in turn, the family became disengaged. Most patients guessed that their family and friends assumed they were in control of the disease:

"I talked to my two daughters in the beginning but not any longer. When I don't talk about it they don't ask, you know? I think they that when they don't hear anything, all is well". [Jay]

Some of the participants acknowledged the concerns of their family and particularly of their spouse. Nonetheless, they chose not to worry and convinced themselves that this is the right thing to do. They second-guessed what would be best for themselves and the family. This was at odds with their general perception of a close family with shared values and beliefs:

"She [my wife] is a bit more worried and says: 'why aren't you more considerate and think about how I'm doing?' We usually agree on things; she also likes to have a drink or share a bottle of red wine, so ..." [Ike]

Some parents wished to discuss the risk of passing on their disease on to their children. The children had mixed feelings about discussing the disease: while wanting to help the parent by supporting lifestyle changes, they still turned their backs on their own risk of developing diabetes. Second guessing could lead to a strained relationship between parent and child reducing family involvement and support:

"I tell my daughter: 'Now you take care, you know?' [to avoid diabetes] Because it's no fun to have diabetes - but I know it's not easy just losing weight". [Gwen]

Most participants suffered from obesity and many had low self-efficacy resulting in distrust in their ability to make lifestyle changes. They experienced guilt when they lost control and enjoyed non-healthy food and drink. Also, they avoided discussing their feelings with their family on the assumption that they would not understand. Fear of failing discouraged attempts at lifestyle changes and family involvement:

"I can't discuss it with my family, but it affects me because I've always been such a sugar craving glutton. I beat myself up; I caused my diabetes and this gives me a bad conscience".
[Evelyn]

4.3 | Theme (3): Going it alone

This theme describes how participants, knowingly or not, took sole responsibility for diabetes management; it was not considered family business, they would go it alone:

"I don't make much of it and don't talk about having diabetes. I eat some vegetables and add carrots to the potatoes; I guess that's what I should do, you know? I don't take notice of my diabetes and eat a lot of cake. [Rachel]

All the participants described a close relationship with their spouse, children and friends and they found it natural to share personal matters with their network. But some participants were unaccustomed with discussing their fears with others than their spouse. Interestingly, all participants tried to keep disease management to themselves and dissociated from both their disease and their family:

"In fact, I generally don't talk much about illness – this is my illness. I find it boring when other people [discuss illness], really, so it's only if people ask". [Ann]

The participants tried not to burden the family with their disease. They did not wish to impose dietary restrictions on the rest of the family and tried to avoid disruption and conflict:

"It's his (my husband's) job to go grocery shopping, so he decides what we eat. It's not particularly diabetes-friendly". [Holly]

Generally, the participants adhered to their medical regimen and considered this to be the most important factor in T2D management. Consequently, there was no need to involve the family. Moreover, medication adherence legitimized their aversion toward lifestyle changes:

"I don't feel sick. I take my medications and that's it. Of course, I try to eat and do what I have to do, but it probably doesn't concern me too much. Why should I involve my family?" [Nelly]

Most of the participants preferred not to get dietary advice from the family because they focused on their shortcomings, putting a strain on family interaction. Moreover, the patients often distrusted advice from family and friends who lacked knowledge on disease management. Although the patients took care of themselves, they were not unappreciative of the good intentions behind controlling behavior of the family:

"When my wife tells me not to drink too much, I think it's because she rarely touches alcohol herself. And ah ... it might also be because she actually cares for me. But I feel controlled and try to keep a distance because it annoys me. Or, perhaps, because she's right. Perhaps I should drink less". [Morris]

A few of the participants revealed the tacit wish that their family would help them to maintain healthy behaviors. They acknowledged, however, that their family avoided controlling behavior to avoid conflict:

"Actually, I'd rather see him act a little macho and say: 'You shouldn't have any chocolate or pastry' but I would be upset if he did say that". [Evelyn]

The choice not to involve family members in disease management had certain drawbacks for the patient. It gave them 'permission' to maintain poor health habits and made it more difficult to resist temptation when the spouse enjoyed an unhealthy diet, snacks or drinks. Although many

participants failed to acknowledge the interplay between their disease progression and the lifestyle of their family, the family's health behaviors did have a considerable effect on the patient:

"My wife has a sweet tooth and sometimes I eat as much as she does. I think it's hard for people who don't have diabetes to understand the problems of having diabetes. So, I say: 'You know I have to be careful, [Ruth]', otherwise I'll suddenly drop dead". [Kenny]

Patients that had led a healthy life before diagnosis wished to prevent the rest of the family from getting T2D:

"Fortunately, it won't hurt if my husband eats the same as me; less sugar and more greens. He agrees and when I started to swim he joined me. I would like to prevent others from ending up like me". [Dorothy]

Most participants agreed that their disease was their own responsibility, but only few regarded lifestyle changes as a part of the plan:

"The most important thing is the doctor and me and my diet and exercise. You can't really pin it on anybody but yourself". [Billy]

Not all participants wished to combat the disease alone. A few of the participants adapted a healthy lifestyle before diagnosis and were motivated to further improve their diet and exercise to comply with recommendations. They wished to avoid medication dependence and gain control of the disease. In these cases, the spouse collaborated with the dietary changes:

"Well, the numbers [HbA1c] were continuously high and I'm not stupid. I read about the complications and started to take Metformin and eat a healthier diet, with help from my wife.

I exercise more and now the blood sugar is down to 50 and I hope I can stop taking

Metformin". [Louis]

When patients collaborated with their family a spillover effect was seen. When the wife changed her lifestyle, her husband was encouraged to comply even more with diabetes management:

"I haven't done much. Of course, I've eaten a very healthy diet, mostly with support from my

wife, but ah ... then I began to think about exercising more". [Louis]

4.4 | Theme (4): No regrets

This theme describes how participants accepted their previous and present lifestyle even if it prompted the onset of T2D and accelerated late complications. QoL and family cohesion were associated with 'the good life' whereas diabetes was managed by medications:

"I have no regrets, none whatsoever. This is my own fault, I should have thought of this

before, but why?" [Chris]

Most of the participants considered themselves 'bon vivants' regardless of their health-related lifestyle. They loved traveling, theater and fine dining with friends and family. Their choice of lifestyle was deliberate as it encompassed good social and family life:

"It's just a glass of wine. It's so enjoyable. My husband and I always did it together and why

should we abstain from everything? Life should be good and fun. Red wine adds a spice to

life. I love to go out. I have many friends. I have no late complications of diabetes; it's just too

bad". [Paula]

What was most important to the participants was to enjoy life. They were grateful for their family and managed their diabetes in that context. Potential late complications should not stand in the way of "the good life":

"I do my best and I'm still alive. When I eventually experience complications…well, I don't know … I don't want it to ruin my life" [Dorothy]

"What means most is my family … it's the be all and end all". [Sean]

[Insert Table 3 Overview of the themes identified in our study with example quotes]

5 | DISCUSSION

We identified four themes describing how people with type 2 diabetes experience family function and its importance in diabetes-related self-management. Together, the themes formed the following narrative: The patients trivialized their disease and thereby created a barrier to family involvement in diabetes management. When diabetes was not openly discussed, patient and family made their own assumptions regarding disease progression and management. The patients chose to manage their diabetes alone and thereby maintained their 'normal' family function and lifestyle. They accepted their lifestyle choices and managed their disease with medications to sustain "the good life" and family cohesion. As such, the patients largely regarded the family function as insignificant in relation to diabetes self-management.

The findings in our study reflect the participants' beliefs about T2D and self-management behaviors and explain the lack of family involvement. These findings are similar to other studies where patients minimize disease consequences and individualize disease management (Grabowski, Andersen, Varming, Ommundsen, & Willaing, 2017; Myers, Fernandes, Arduser, Hopper, & Koehly, 2015). Studies have demonstrated that family involvement plays a key role in diabetes management linking family identity and healthcare authenticity (Grabowski et al., 2017). Patients do not need moralistic diabetes management but require care consistent with their family identity.

Several health and illness belief models have explained patient and family behavior in relation to illness, coping and self-management. (Duhamel, Dupuis, Turcotte, Martinez, & Goudreau, 2015;

Leventhal, Phillips, & Burns, 2016; L. M. Wright & Bell, 2009). Adherence to self-management is related to a variety of factors, such as age, gender, socio-economic status, self-efficacy, family support and illness beliefs (Adam & Folds, 2014; Bennich et al., 2017). Like numerous studies on lifestyle diseases, our study shows trivialization and lack of awareness of the impact of disease on daily life and family function (Grabowski et al., 2017; White et al., 2007).

Also, in accordance to other studies, our participants avoided discussing their disease with their family to maintain cohesion, well-being and the perception of normal family life (Årestedt, Benzein, & Persson, 2015; Grabowski et al., 2017). The perception of small disease burden and minimal illness severity might explain the lack of shared family responsibility in our study. By contrast, other studies have demonstrated that late and severe complications changed patients' perceptions of the disease to a more threatening and unpredictable condition (Pereira, Pedras, & Machado, 2014). The perceived importance of self-management and family involvement increases with disease acknowledgment (van Puffelen et al., 2015). Some studies have shown that family tends to perceive T2D as more serious than the patient. The dissonance between patient and family regarding the perception of disease severity interferes with normal family life, thus hindering mutual involvement, responsibility and shared beliefs. (Grabowski et al., 2017; White et al., 2007). Resilience is enhanced when couples regard disease management as a collaborative issue increasing mutual understanding and open communication (Årestedt et al., 2015).

The participants in our study did not wish to burden the family with unwanted lifestyle changes. Other studies have shown how patients keep up the illusion of good health to maintain normal family life (Grabowski et al., 2017; Leventhal et al., 2016; L. M. Wright & Bell, 2009). This behavior is explained by the patient's wish to avoid stigmatization due to low self-esteem after failed attempts of lifestyle change and accusations that their diabetes is self-inflicted by poor eating habits (Oftedal, 2014). These insights reflect the participants' expectations regarding the negative and limiting aspects of T2D and family involvement. Conversely, none of our participants discussed the opportunity to share diabetes management as seen in other studies (Bennich et al., 2017; Mayberry & Osborn, 2014).

Studies find that self-management behavior is more strongly associated with beliefs about treatment behavior than with beliefs about the disease (Aujla et al., 2016; French, Wade, & Farmer, 2013) making treatment beliefs important predictors of self-management behavior. (Mann, Ponieman, Leventhal, & Halm, 2009). Similarly, our participants had strong beliefs regarding the

effectiveness of medications compared with lifestyle changes (Broadbent, Donkin, & Stroh, 2011). These assumptions have not been confirmed in relation to long-term reduction of late complications (Haw et al., 2017). These beliefs are a major challenge for health professionals to convince asymptomatic patients of the importance of self-management as to healthy diet and exercise in collaboration with their family. Psychological and family-focused interventions have been shown to change illness perceptions and improve glycemic control. Thus, the importance of family involvement in T2D management and adherence to self-management behaviors should be acknowledged (Ismail, Winkley, & Rabe-Hesketh, 2004; Martinez, Lockhart, Davies, Lindsay, & Dempster, 2018).

Most of our participants were overweight or obese, representing one of the most powerful risk factors of T2D (Leitner et al., 2017)**.** Although our participants were well-educated and resourceful, they displayed ignorance of the benefits of lifestyle changes and family collaboration. In fact, most of them were more likely to engage in self-management requiring the smallest effort. Modern healthcare is dominated by a preference for pharmacological solutions for T2D with an individualized disease-centered focus (Funnell, 2004; Holstein, 2016). Further research on how the approach by the healthcare professionals affects the patients' treatment beliefs, sense of responsibility and self-management behaviors is important, as the effectiveness of T2D management ultimately depends on the patient's adherence with treatment recommendations.

5.1 | Strengths and limitations

The sample in our study was a selected group of T2D patients at risk of or with incipient late complications. Although this selection has a wide range as to complications, a sample including patients with severe late complications might have produced different results. The group is similar with reference to age, HbA1c levels, a healthy perception of family functioning and lack of burden of diabetes. Furthermore, the participants were found to be well-educated and resourceful, which might be a limitation to the transferability to other settings. However, the study contributes importantly to the understanding of family function in families with T2D as the knowledge of interactions, self-management behaviors and beliefs in families with resourceful T2D patients is scarce. We collected data on an individual level from the patient perspective only. The study would have been more complete with the perspectives of families. Furthermore, concealed or misunderstood needs and perceptions of the patient and family might have been illuminated in

dyadic interviews. However, Individual interviews might be better suited to explore patient experiences without interference of family members. Trustworthiness of the study was increased by using well-established methods of data collection and analysis and by investigator triangulation during analysis.

6.0 | CONCLUSION

Our study reflects the participants' beliefs about T2D as to the trivialization of the disease and the insignificance of family involvement in self-management behaviors. By maintaining usual lifestyle, the participants promote family cohesion by sharing 'the good life'. The beliefs of the superiority of controlling T2D by medications rather than healthy lifestyle further justified the choice of disease management. Future research should take into consideration the different beliefs of patient and family when planning interventional studies. Furthermore, the findings suggest that a healthy family function is related to a lower sense of burden of T2D. Hence, interventions and clinical care assessing family function and involving the family actively according to the assessment are likely to improve the patients' self-management behaviors as to healthy lifestyle and thus has a beneficial impact on diabetes control and well-being.

REFERENCES

Adam, J., & Folds, L. (2014). Depression, Self-efficacy, and Adherence in Patients With Type 2 Diabetes. *The Journal for Nurse Practitioners*, *10*(9), 646–652. https://doi.org/10.1016/j.nurpra.2014.07.033

Ahola, A. J., & Groop, P.-H. (2013). Barriers to self-management of diabetes. *Diabetic Medicine*, *30*(4), 413–420. https://doi.org/10.1111/dme.12105

American Diabetes Association. (2019a). *6. Glycemic Targets: Standards of Medical Care in Diabetes—2019*. S61–S70. https://doi.org/10.2337/dc19-S006

American Diabetes Association. (2019b). 10. Cardiovascular Disease and Risk Management: Standards of Medical Care in Diabetes—2019. *Diabetes Care*, *42*(Supplement 1), S103–S123. https://doi.org/10.2337/dc19-S010

American Diabetes Association. (2019c). 11. Microvascular Complications and Foot Care: Standards of Medical Care in Diabetes—2019. *Diabetes Care*, *42*(Supplement 1), S124–S138. https://doi.org/10.2337/dc19-S011

Årestedt, L., Benzein, E., & Persson, C. (2015). Families Living With Chronic Illness: Beliefs About Illness, Family, and Health Care. *Journal of Family Nursing*, *21*(2), 206–231. https://doi.org/10.1177/1074840715576794

Asche, C., LaFleur, J., & Conner, C. (2011). A review of diabetes treatment adherence and the association with clinical and economic outcomes. *Clinical Therapeutics*, *33*(1), 74–109. https://doi.org/10.1016/j.clinthera.2011.01.019

Aujla, N., Walker, M., Sprigg, N., Abrams, K., Massey, A., & Vedhara, K. (2016). Can illness beliefs, from the common-sense model, prospectively predict adherence to self-management behaviours? A systematic review and meta-analysis. *Psychology & Health*, *31*(8), 931–958. https://doi.org/10.1080/08870446.2016.1153640

Baig, A. A., Benitez, A., Quinn, M. T., & Burnet, D. L. (2015). Family interventions to improve diabetes outcomes for adults. *Annals of the New York Academy of Sciences*, *1353*, 89–112. https://doi.org/10.1111/nyas.12844

Batty, K. E., & Fain, J. A. (2016). Factors affecting resilience in families of adults with diabetes. *The Diabetes Educator*, *42*(3), 291–298. https://doi.org/10.1177/0145721716637124

Bennich, B. B., Munch, L., Egerod, I., Konradsen, H., Ladelund, S., Knop, F. K., … Overgaard, D. (2018). Patient Assessment of Family Function, Glycemic Control and Quality of Life in Adult Patients With Type 2 Diabetes and Incipient Complications. *Canadian Journal of Diabetes*. https://doi.org/10.1016/j.jcjd.2018.09.002

Bennich, B. B., Røder, M. E., Overgaard, D., Egerod, I., Munch, L., Knop, F. K., … Konradsen, H. (2017). Supportive and non-supportive interactions in families with a type 2 diabetes patient: An integrative review. *Diabetology & Metabolic Syndrome*, *9*, 57. https://doi.org/10.1186/s13098-017-0256-7

Braun, V., & Clarke, V. (2013). *Successful Qualitative Research: A Practical Guide For Beginners* (First edition). Los Angeles: SAGE Publications Ltd.

Broadbent, E., Donkin, L., & Stroh, J. C. (2011). Illness and treatment perceptions are associated with adherence to medications, diet, and exercise in diabetic patients. *Diabetes Care*, *34*(2), 338–340. https://doi.org/10.2337/dc10-1779

Cho, N. H., Shaw, J. E., Karuranga, S., Huang, Y., Fernandes, J. D. da R., Ohlrogge, A. W., & Malanda, B. (2018). IDF Diabetes Atlas: Global estimates of diabetes prevalence for 2017 and projections for 2045. *Diabetes Research and Clinical Practice*, *138*, 271–281. https://doi.org/10.1016/j.diabres.2018.02.023

Duhamel, F., Dupuis, F., Turcotte, A., Martinez, A.-M., & Goudreau, J. (2015). Integrating the Illness Beliefs Model in Clinical Practice: A Family Systems Nursing Knowledge Utilization Model. *Journal of Family Nursing*, *21*(2), 322–348. https://doi.org/10.1177/1074840715579404

French, D. P., Wade, A. N., & Farmer, A. J. (2013). Predicting self-care behaviours of patients with type 2 diabetes: The importance of beliefs about behaviour, not just beliefs about illness. *Journal of Psychosomatic Research*, *74*(4), 327–333. https://doi.org/10.1016/j.jpsychores.2012.12.008

Funnell, M. M. (2004). Overcoming obstacles: Collaboration for change. *European Journal of Endocrinology*, *151 Suppl 2*, T19-22; discussion T29-30.

Grabowski, D., Andersen, T. H., Varming, A., Ommundsen, C., & Willaing, I. (2017). Involvement of family members in life with type 2 diabetes: Six interconnected problem domains of significance for family health identity and healthcare authenticity. *SAGE Open Medicine*, *5*, 2050312117728654. https://doi.org/10.1177/2050312117728654

Hartman, A. (1978). Diagrammatic Assessment of Family Relationships. *Social Casework*, *59*(8), 465–476. https://doi.org/10.1177/104438947805900803

Haw, J. S., Galaviz, K. I., Straus, A. N., Kowalski, A. J., Magee, M. J., Weber, M. B., … Ali, M. K. (2017). Long-term Sustainability of Diabetes Prevention Approaches: A Systematic Review and Meta-analysis of Randomized Clinical Trials. *JAMA Internal Medicine*, *177*(12), 1808–1817. https://doi.org/10.1001/jamainternmed.2017.6040

Holstein, B. E. (2016). *Forebyggende sundhedsarbejde* (6th ed.). Denmark: Munksgaard.

Ismail, K., Winkley, K., & Rabe-Hesketh, S. (2004). Systematic review and meta-analysis of randomised controlled trials of psychological interventions to improve glycaemic control in patients with type 2 diabetes. *Lancet (London, England)*, *363*(9421), 1589–1597. https://doi.org/10.1016/S0140-6736(04)16202-8

Karlsen, B., Oftedal, B., & Bru, E. (2012). The relationship between clinical indicators, coping styles, perceived support and diabetes-related distress among adults with type 2 diabetes.

Journal of Advanced Nursing, *68*(2), 391–401. https://doi.org/10.1111/j.1365-2648.2011.05751.x

Leitner, D. R., Frühbeck, G., Yumuk, V., Schindler, K., Micic, D., Woodward, E., & Toplak, H. (2017). Obesity and Type 2 Diabetes: Two Diseases with a Need for Combined Treatment Strategies - EASO Can Lead the Way. *Obesity Facts*, *10*(5), 483–492. https://doi.org/10.1159/000480525

Leventhal, H., Phillips, L. A., & Burns, E. (2016). The Common-Sense Model of Self-Regulation (CSM): A dynamic framework for understanding illness self-management. *Journal of Behavioral Medicine*, *39*(6), 935–946. https://doi.org/10.1007/s10865-016-9782-2

Lincoln, Y., & Guba, E. (1985). *Naturalistic Inquiry*. SAGE Publications Ltd.

Mann, D. M., Ponieman, D., Leventhal, H., & Halm, E. A. (2009). Predictors of adherence to diabetes medications: The role of disease and medication beliefs. *Journal of Behavioral Medicine*, *32*(3), 278–284. https://doi.org/10.1007/s10865-009-9202-y

Martinez, K., Lockhart, S., Davies, M., Lindsay, J. R., & Dempster, M. (2018). Diabetes distress, illness perceptions and glycaemic control in adults with type 2 diabetes. *Psychology, Health & Medicine*, *23*(2), 171–177. https://doi.org/10.1080/13548506.2017.1339892

Mayberry, & Osborn, C. Y. (2012). Family support, medication adherence, and glycemic control among adults with type 2 diabetes. *Diabetes Care*, *35*(6), 1239–1245. https://doi.org/10.2337/dc11-2103

Mayberry, & Osborn, C. Y. (2014). Family involvement is helpful and harmful to patients' self-care and glycemic control. *Patient Education and Counseling*, *97*(3), 418–425. https://doi.org/10.1016/j.pec.2014.09.011

McCormick, K. M., Stricklin, S., Nowak, T. M., & Rous, B. (2008). Using Eco-Mapping to Understand Family Strengths and Resources. *Young Exceptional Children*, *11*(2), 17–28. https://doi.org/10.1177/1096250607311932

Miles, M. B., Huberman, A. M., & Saldana, J. (2014). *Qualitative Data Analysis*. SAGE.

Morse, J. M. (2015). "Data Were Saturated. . . ." *Qualitative Health Research*, *25*(5), 587–588. https://doi.org/10.1177/1049732315576699

Munch, L., Bennich, B., Arreskov, A. B., Overgaard, D., Konradsen, H., Knop, F. K., … Røder, M. E. (2016). Shared care management of patients with type 2 diabetes across the primary and secondary healthcare sectors: Study protocol for a randomised controlled trial. *Trials*, *17*(1), 277. https://doi.org/10.1186/s13063-016-1409-y

Munch, L., Bennich, B. B., Overgaard, D., Konradsen, H., Middelfart, H., Kaarsberg, N., … Røder, M. E. (2019). Management of people with Type 2 diabetes shared between a specialized outpatient clinic and primary health care is noninferior to management in a specialized outpatient clinic: A randomized, noninferiority trial. *Diabetic Medicine: A Journal of the British Diabetic Association*. https://doi.org/10.1111/dme.13896

Myers, M. F., Fernandes, S. L., Arduser, L., Hopper, J. L., & Koehly, L. M. (2015). Talking About Type 2 Diabetes: Family Communication From the Perspective of At-Risk Relatives. *The Diabetes Educator*, *41*(6), 716–728. https://doi.org/10.1177/0145721715604367

Oftedal, B. (2014). Perceived support from family and friends among adults with type 2 diabetes. *European Diabetes Nursing*, *11*(2), 43–48. https://doi.org/10.1002/edn.247

Pereira, M. G., Pedras, S., & Machado, J. C. (2014). Family variables as moderators between beliefs towards medicines and adherence to self-care behaviors and medication in type 2 diabetes. *Families, Systems, & Health*, *32*(2), 198–206. https://doi.org/10.1037/fsh0000029

QSR. (2018). NVivo qualitative data analysis Software. (Version Version 12 Pro). Retrieved from https://www.qsrinternational.com/nvivo/nvivo-products/nvivo-12-pro

Rintala, T.-M., Jaatinen, P., Paavilainen, E., & Åstedt-Kurki, P. (2013). Interrelation Between Adult Persons With Diabetes and Their Family. *Journal of Family Nursing*, *19*, 3–28. https://doi.org/10.1177/1074840712471899

Shenton, A. K. (2004). Strategies for Ensuring Trustworthiness in Qualitative Research Projects. *Education for Information*, *22*(2), 63–75.

Skinner, H., Steinhauer, P., & Santa-Barbara, J. (1995). *FAM-III™—Family Assessment Measure-III™ | Multi Health Systems (MHS Inc.)*. Retrieved from https://www.mhs.com/MHS-Assessment?prodname=famiii

Skinner, H., Steinhauer, P., & Sitarenios, G. (2000). Family Assessment Measure (FAM) and Process Model of Family Functioning. *Journal of Family Therapy*, *22*(2), 190–210. https://doi.org/10.1111/1467-6427.00146

Steinhauer, P. D., Santa-Barbara, J., & Skinner, H. (1984). The Process Model of Family Functioning. *Canadian Journal of Psychiatry. Revue Canadienne De Psychiatrie*, *29*(2), 77–88.

Torenholt, R., Schwennesen, N., & Willaing, I. (2014). Lost in translation--the role of family in interventions among adults with diabetes: A systematic review. *Diabetic Medicine: A*

Journal of the British Diabetic Association, *31*(1), 15–23.

https://doi.org/10.1111/dme.12290

van Puffelen, A. L., Heijmans, M. J. W. M., Rijken, M., Rutten, G. E. H. M., Nijpels, G., & Schellevis, F. G. (2015). Illness perceptions and self-care behaviours in the first years of living with type 2 diabetes; does the presence of complications matter? *Psychology & Health*, *30*(11), 1274–1287. https://doi.org/10.1080/08870446.2015.1045511

White, P., Smith, S. M., & O'Dowd, T. (2007). Living with Type 2 diabetes: A family perspective. *Diabetic Medicine: A Journal of the British Diabetic Association*, *24*(7), 796–801. https://doi.org/10.1111/j.1464-5491.2007.02171.x

Wright, L. M., & Bell, J. M. (2009). *Beliefs and Illness: A Model for Healing* (First edition). Calgary: 4th Floor Press, Inc.

Wright, Lorraine M., & Leahey, M. (2019). *Nurses and Families: A Guide to Family Assessment and Intervention* (7th ed.). F.A. Davis Company.

Table 1 Participant characteristics

Participants	Age years	Gender	Marital status	Adult children	Employment	Years T2D	BMI kg/m²	HbA1c mmol/mol	Comorbidity	Diabetes complications
Ann	54	Female	Divorced, lives alone	Daughter	Retired	1	32,8	40	Obesity, fibromyalgia	
Billy	54	Male	Married	Son <18	Employed	11	31,8	59	Obesity	Neuropathy
Chris	56	Male	Married	Two sons and one daughter	Employed	3	33,7	50	Hypertension, obesity	Neuropathy
Dorothy	57	Female	Married	Two sons	Employed	6	21,2	57		Neuropathy
Evelyn	63	Female	Married	Son and daughter	Retired	18	45,2	60	Obesity, multiple sclerosis, rosacea	
Frankie	63	Male	Partner, lives alone	Two sons and one daughter <18	Self-employed	4	24,5	70	Hypertension	Neuropathy
Gwen	67	Female	Married	Two daughters	Retired	26	32,4	57	Hypertension, obesity, arthritis	Neuropathy
Holly	69	Female	Married	Two daughters	Retired	5	31,7	56	Hypertension, obesity	Neuropathy
Ike	69	Male	Married	None	Self-employed	4	32,7	46	Hypertension, obesity	
Jay	69	Male	Divorced, lives alone	Two daughters	Retired	15	29,3	50	Hypertension	
Kenny	70	Male	Married	None	Retired	20	31,6	53	Obesity	Neuropathy, Retinopathy
Louis	70	Male	Married	None	Retired	10	25,9	43	Hypertension	
Morris	71	Male	Divorced, lives alone	None	Retired	4	27,2	46	Chronic atrial fibrillation	Neuropathy

Nelly	73	Female	Divorced, lives alone	Daughter	Employed	9	34,9	37	Hypertension, obesity, cardiomyopathy	
Oscar	74	Male	Married	Son and daughter	Retired	18	25,6	65		Neuropathy
Paula	74	Female	Widow, lives alone	Two sons	Retired	6	30,4	44	Hypertension, obesity	
Rachel	75	Female	Divorced, lives alone	Son and daughter	Retired	6	33,9	49	Hypertension, obesity, COPD	Neuropathy
Sean	78	Male	Married	Two sons and one daughter	Retired	3	37,0	52	Obesity, Heart disease	Neuropathy
Tanya	82	Female	Married	Son	Retired	1	32,4	39	Obesity	Neuropathy
Umar	83	Male	Partner, lives alone	Son and daughter	Self-employed	1	25,7	49	Hypertension, Celiac disease	Neuropathy

Table 2 Excerpt of field note

Interactions, reactions, initial reflections	Initial patterns to pursue	Initial subthemes
When asked about the family's involvement and emotions toward T2D, the participant's first reply was that the family was not involved at all and had no feelings connected, and why should they? However, the question seemed to puzzle the participant as seen with prior participants. The participant told me he had never thought of the family being affected by his diabetes. He was obviously disturbed by the thought by crossing his arms over his chest and looking pensively out the window. After some time sitting in silence, he told me that thinking about it, his wife was probably more worried than he was, but he had not thought about it before and never asked.	The participants neglect their families and especially their spouses' potential needs and worries about T2D I am surprised because it seems like the participants have close relationships with their family, but why they do not share T2D with them needs to be explored more thoroughly in the following interviews.	Downplay T2D Want to handle T2D alone Neglect the family's needs

Table 3 Overview of the themes identified in our study with example quotes

Examples of patient quotes	Subthemes	Themes	Overarching themes
"But diabetes is nothing, really. Nothing happens, you know, diabetes is invisible, and you don't feel it like you would a broken arm. I don't feel diabetes affects anything". [Paula] "No, I don't discuss my disease with anyone. People at work and in my family are aware of my hypertension, high cholesterol, and diabetes, but I don't do much about it because I still haven't experienced late complications". [Ike]	Diabetes is invisible Do not feel sick No worries of diabetes No restrictions Late complications	Trivialization of diabetes Lack of concern about the risk of disease Lack of concern about late complications	Downplaying disease
"I don't think [diabetes] has "any effect on anyone in my family, not even my wife". [Ike] "I talked to my two daughters in the beginning but not any longer. When I don't talk about it they don't ask, you know? I think, they think that when they don't hear anything, all is well". [Jay]	No talk about diabetes Communication need of family Involvement of children Effect on family Guilt	Lack of perceived seriousness of the disease Absence of mutual involvement	Second guessing
"I don't feel sick. I take my medications and that's it. Of course, I try to eat and do what I have to do, but it probably doesn't concern me too much. Why should I involve my family?" [Nelly] "The most important thing is the doctor and me, and my diet and exercise. You can't really pin it on anybody but yourself". [Billy]	Understanding diabetes Meals with the family Health advices Exercise Diet Sole responsibility Normal family life	Sole responsibility for diabetes management Maintaining a normal family life	Going it alone
"I have no regrets, none whatsoever. This is my own fault, I should have thought of this before, but why?". [Chris] "It's just a glass of wine. It's so enjoyable. My husband and I always did it together, and why should we abstain from everything? Life should be good and fun. Red wine adds a spice to life. I love to go out. I have many friends. I have no late complications of diabetes; it's just too bad". [Paula] "What means most is my family … it's the be all and end all". [Sean]	No regrets Hedonist Diabetes controlled by medications Importance of family	No regrets concerning previous and present lifestyle Medication controls the T2D management Values in life	No regrets