

RESEARCH ARTICLE

To Tell or Not to Tell: Disclosure and Self-Management among Adults with Early-Onset Type 2 Diabetes: A Qualitative Study

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Abstract:

Background:

Adults with early-onset Type 2 Diabetes Mellitus (T2DM) are an emerging high-risk population who may experience social challenges related to diabetes management.

Objective:

To explore the disclosure of T2DM and how disclosure affects diabetes self-management and the psychosocial adjustment to life with diabetes among adults with early-onset T2DM.

Methods:

A qualitative study was conducted using Systematic Text Condensation (STC). Data was derived from semi-structured interviews with 15 individuals with T2DM \leq 46 years (10 women and 5 men) recruited from diverse settings using purposeful sampling.

Results:

Most informants disclosed their diabetes to a close relative shortly after receiving the diagnosis. This led to immediate emotional support and overall positive disclosure experiences. However, informants often hesitated to disclose their condition to others due to shame, fear of negative judgement or social exclusion. Over time, the majority of informants became more open about their condition, which often resulted in emotional and practical self-management support. Those most reluctant to disclosing their diabetes struggled with shame and negative diabetes-related emotions, which had negative effects on their diabetes self-management.

Conclusion:

Disclosure of T2DM seemed important for the social, emotional and practical management of diabetes among adults with early-onset T2DM. The disclosure was most often accompanied by feelings of shame and fear of condemnation. Professional guidance to support disclosure and interventions to address stigma may improve well-being and diabetes self-management in this population.

Keywords: Type 2 diabetes, Disclosure, Self-management, Qulitative study, Early-onset type 2 diabetes, Psychosocial adjustment.

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1. INTRODUCTION

Worldwide, Type 2 Diabetes mellitus (T2DM) in younger adults aged 20-45 years is increasing [1 - 4]. Early-onset of T2DM in younger adults is associated with a higher prevalence of cardiovascular risk factors and earlier onset of diabetesrelated complications compared with older adults with T2DM

* Address correspondence to this author at the Department of Public Health, Aarhus University, Bartholins Allé 2, DK-8000 Aarhus C, Denmark, Tel.: + 299 250639, E-mail: majahnielsen1@gmail.com [5 - 7]. A diagnosis with T2DM can be particularly challenging in early adulthood because this stage of life is characterised by several life transitions and numerous external obligations in relation to education, job, family, and social relations [8]. Recent studies have found a high burden of psychosocial problems [9, 10] and sub-optimal diabetes self-management [11, 12] among younger adults with T2DM.

Diabetes self-management involves various tasks such as following a strict diet, increasing physical activity level, taking

medication and attending clinical follow-up. Furthermore, people with T2DM have to cope with the psychological consequences of the condition [13]. Self-management takes place in every-day life and often in social contexts including, e.g., family, friends or colleagues. Brewer-Lowry et al. [14] described a framework of diabetes self-management as intersections between various tasks (e.g., diet and physical activity) and resources (e.g., family and friends). Moreover, previous research has identified social support as critical for diabetes management [15, 16]. The ability and willingness of the individual to share information and feelings about the condition in social contexts, therefore, seems pertinent to obtain social support and could enhance the emotional coping and problem-solving. In line with this, diabetes disclosure has been argued to be a diabetes self-management strategy in itself [17].

Disclosure can be defined as the act of telling others about T2DM and the degree of openness in talking about the condition [18]. Disclosure entails a complex process of 1) deciding to whom, when, what, and how to tell about the condition, 2) the act of disclosure, and 3) outcome or experiences of the disclosure. Both the pre-disclosure consideration and consequences of disclosure are likely affected by the individual's social context and by the individual's own understanding of the condition [19].

Recent research has brought attention to the seriousness of perceived stigma towards people with T2DM and stigmatising language in clinical encounters [20]. Individuals with T2DM report feeling judged and blamed by others for bringing the condition on themselves. Furthermore, they report feeling as subjects to negative stereotyping (*e.g.*, lazy, fat), leading to social exclusion [21]. Being a younger person with T2DM maybe even more stigmatising as it is a rare condition in this age group and thus perceived as out of the "normal" and perhaps perceived as an "old man's condition". This could be an important reason why younger adults may prefer not to disclose their condition. Both non-disclosure and negative disclosure experiences may lead to a lack of social support and a negative impact on diabetes management and emotional wellbeing [18].

Despite the potentially important role of disclosure in early-onset T2DM, there is little knowledge about how T2DM disclosure is unfolded and experienced and how disclosure may affect the well-being and management of T2DM in their everyday life. The present study aimed to explore how adults with early-onset T2DM disclose their condition, and how disclosure affects their diabetes self-management.

2. MATERIALS AND METHODS

2.1. Research Design and Methodology

A qualitative study was conducted using Systematic Text Condensation (STC) in accordance with Kirsti Malterud's strategy for qualitative analysis [22]. Data was retrieved from semi-structured interviews providing an in-depth understanding of the experiences and perspectives [23] among members of the target group. All informants gave written informed consent to participate and for results to be published.

2.2. Sampling and Recruitment

Individuals were eligible for participation if they had a T2DM diagnosis, were 18 to 45 years of age, and if they were able to speak and understand Danish and currently resided in Denmark. Informants were selected purposefully to achieve a variation in gender, age, diabetes care provider (general practitioner or specialist hospital clinic), geographical residence and duration of T2DM [24]. The 15 informants (10 women and 5 men) were recruited from municipal healthcare centres, at general practitioners, through public announcements and by snowballing [25]. Arrangements concerning time and place for the interviews were made by email or phone.

2.3. Data Collection

2.3.1. Interview

Data collection was performed between March 2016 and February 2017 (11 months). The interviews were conducted in non-clinical settings, primarily at the informant's own home: Interviews lasted on average 61 minutes (Minimum and maximum duration: 39; 99 min). Before the interview, informants received information about the study as an investigation of 'experiences and needs of living with T2DM among younger adults'. In-depth interviews with all informants were carried out using a semi-structured interview guide focusing on the following areas: Experiences with being diagnosed, and with disclosure, social support and stigmatisation. The interview guide contained research questions in accordance with Kvale & Brinkmann [26]. All interviews were audio-recorded and transcribed verbatim by the interviewer (first author). Examples of research and interview questions are shown in Table 1. Furthermore, the informants completed a short questionnaire on demographic and diabetes-related issues [26].

Table 1. Examples of research questions and questions asked by interviewer.

| Research Questions | Interview Questions | | | |
|--|---|--|--|--|
| How did the patient feel about the time of diagnosis? | What did you do in the weeks after being diagnosed and how did you feel? Who did you tell? | | | |
| How does the concept disclosure unfold in different relations and settings among adults with early- onset T2DM? | Do you tell about or talk with others about your diabetes? When you meet new people, what can make you tell about your diabetes? Do you keep it a secret to some people? Is it easier for you to live with your diabetes when your social network knows about it? Will you describe yourself as open or closed about your diabetes? Why/why not? How do you experience that people react when they find out about your diabetes? | | | |

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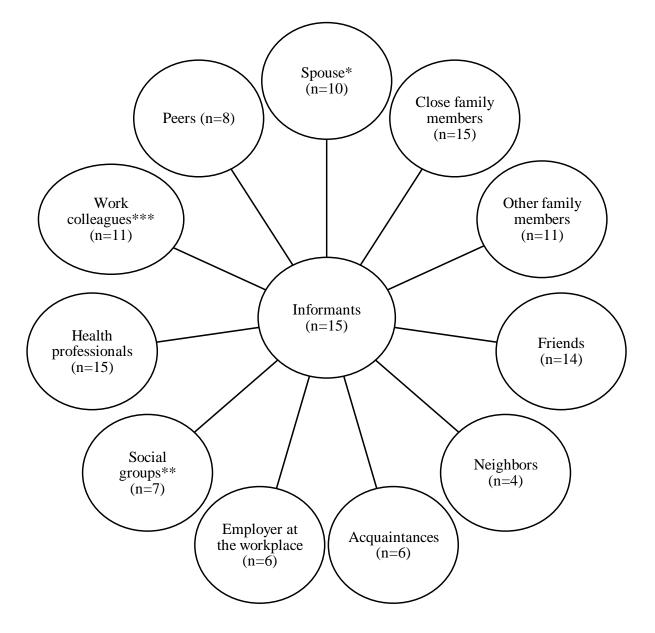


Fig. (1). Ecomap depicting social relations identified as important for diabetes management by 15 adults with early-onset T2DM. The number (n) represents the total number of times each of the social relation types was selected by the 15 informants which were important for informants to their diabetes management.

2.3.2. Ecomap

During the interview, informants were asked to draw an ecomap to guide them in visually expressing the quality of their social relations [27]. By drawing the ecomaps, the informants identified various social relations, which they found to be important for their diabetes management. These social relations included spouses, close relatives, other family members, friends, colleagues, employers, acquaintances, neighbours, healthcare professionals, peers and other social connections such as teammates. The ecomap was used to guide the interview about how each of the identified social relations influenced disclosure situations in the informant's everyday life. Fig. (1) provides an overview of all ecomaps.

2.4. Data Analysis

The total data material consisted of 256 pages of transcribed text based on interviews and 15 ecomaps. Immediately after each interview, the interviewer wrote down notes and reflections contributing to the understanding of the interview during the analysis. The analysis strategy was based on STC [22], which is inspired by phenomenology and consists of four steps [25]. In step 1, data was explored with an open mind and themes were identified based on a general impression. In step 2, the themes were converted into codes. The identified meaning units were marked with a code and subsequently sorted. In step 3, the content was condensed, and the codes were transformed into meaningful units. The meaning content was summed up in step 4 and the condensation implied that well-known concepts arose [22].

Finally, quotations illustrating the well-known concepts were selected [25]. Data analysis was supported by the software programme NVIVO 11.

3. RESULTS

The demographic and diabetes-related characteristics of the 15 informants (10 women and 5 men) are outlined in Table **2**.

Data analysis entailed four distinct themes: 'Aspects of disclosure, 'Disclosure strategies', 'Disclosure and adjustment to living with T2DM', and 'Disclosure and self-management'. The first three themes outlined aspects of how people with early-onset T2DM disclose their condition; the last theme related the identified disclosure aspects to self-management. Fig. (1) shows social relations identified as important for diabetes management. These included the partner or other close family, close friends, distant friends and family, colleagues, health care professionals, peers with T2DM, and finally, "the media" as an un-personified social context.

3.1. Aspects of Disclosure

The analysis revealed four different aspects of disclosure: 1) Telling others about the diagnosis; 2) Having conversations with others about the condition; 3) Keeping the condition a secret; and 4) Sharing thoughts with peers.

Most informants had shared information about the diabetes diagnosis to a close relative shortly after diagnosis, but a few did not share information about the new condition with anyone for up to four weeks. Those who were in a relationship told it to their partner right after they received the diagnosis. Those who lived alone typically told it to their parents or a close friend, but sometimes waited for a long time before telling others about the condition. Experiences with the first disclosure to close relations were generally positive, and informants reported experiences of immediate emotional support after disclosure:

"I cried on the phone when I called him (her husband). And then he asked what was wrong. And then I just said that the doctor told me that I had diabetes. And my husband's reaction was 'No, I'm so sorry. But we will take care of it. We will take care of it together.' And I think it was just what I needed to know." (IP15)

Informants generally experienced that sharing their feelings about diabetes helped them cope with the emotional and practical challenges in life with diabetes. This was, for example, talking about their fear of complications or other

| Table 2. Demographic and | diabetes-related characteristics of | of patients with early-onset diabetes, N= 1 | 5. |
|--------------------------|-------------------------------------|---|----|
| | | | |

| Interview Person Id | Age | Gender | Occupation | Living Alone | Children | Educational Background | T2DM Duration (years) | BMI (kg/m ²) | HbA1c (mmol/mol) | Family History of Diabetes | Attended Diabetes Education | Treatment |
|------------------------|---------------|--------|-------------|-----------------|----------|---------------------------------|-----------------------------|-----------------------------|---------------------|-------------------------------------|-----------------------------------|-------------------|
| IP1 | 45 | М | Full-time | - | + | MSc | 6 | 27.4 | 55 | - | - | Oral |
| IP2 | 44 | М | Full-time | + | - | MSc | 1 | 30.3 | 43 | - | + | None |
| IP3 | 21 | F | Full-time | + | - | Vocational school | 3 | 30.0 | 66 | + | - | Oral |
| IP4 | 43 | М | Full-time | - | + | MSc | 1 | 26.5 | 53 | + | + | Oral |
| IP5 | 41 | F | Retired | - | - | MSc | 3 | 29.2 | 63 | - | - | None |
| IP6 | 41 | F | Full-time | - | + | Short extensive education | 2 | 26.3 | 58 | - | + | Oral |
| IP7 | 31 | F | Full-time | - | + | BSc | 0.5 | 33.6 | 40 | + | - | Oral |
| IP8 | 38 | М | Full-time | + | + | BSc | 1.5 | 35.9 | 68 | + | - | Oral |
| IP9 | 41 | F | Full-time | - | + | Vocational school | 0.5 | 28.7 | 63 | + | + | Oral |
| IP10 | 38 | F | Full-time | + | + | BSc | 0.5 | 32.0 | 37 | + | + | Oral |
| IP11 | 32 | F | Student | - | + | Primary school | 4 | 28.1 | 60 | + | - | Oral + insulin |
| IP12 | 36 | М | Full-time | - | - | BSc | 0.5 | 33.1 | 37 | + | + | Oral |
| IP13 | 37 | F | Part-time | - | + | BSc | 0.5 | 26.5 | 42 | + | + | Oral |
| IP14 | 43 | F | Full-time | + | + | BSc | 22 | 41.1 | 55 | - | - | Oral + insulin |
| IP15 | 36 | F | Un-employed | - | - | Primary school | 1 | 36.9 | 43 | + | + | Oral |
| Mean (SD) | 37.8 (6.2) | | | | | | 4.7 (6.7) | 31 (4.4) | 52.2 (10.9) | | | |
| Median(IQR) | 38 (6.0) | | | | | | 3 (3.0) | 30 (5.6) | 55 (15.0) | | | |

Abbreviations: Treatment with *e.g.* metformin (*Oral*), Master's degree (*MSc*), Professional bachelor's degree (*BSc*)

T2DM= type 2 diabetes mellitus

F=Female, M=Male

worries and frustration or solving practical issues in relation to food preparation, keeping medical appointments. However, the interviews also indicated some concerns that talking about their condition would be a burden to their social relations:

"I do it (talk to my husband) all the time. And he also promised me that he will kick me, when he gets tired of hearing about it. But now it has been six months, and he has still not kicked me. He is a fantastic help." (IP13)

Some informants kept their diabetes diagnosis a secret to most of their social network, except closest relatives. This was explained by feelings of shame and self-blame or because they did not want to be perceived as different or sick. Some also expressed a fear of condemnation and negative reactions to disclosure due to the negative and incorrect way they felt T2DM was portrayed in the media. Almost all informants felt that T2DM is associated with negative stereotypes, which made disclosure of their condition difficult. Many expressed how T2DM was linked with the term lifestyle condition meaning that the disease is "just" due to your lifestyle. Some of the most commonly described negative stereotypes were fat, lazy, not doing any exercise, being a bad person and having less value as a human. An informant explained how she was open to others in her social network and how she felt guilty about her condition:

"I am open to family and friends and the people I kind of know; I'm quite closed about it to those I don't know and I don't really want them to know. And it's, you know, you feel so guilty about it and if people just know a little, they could think it's because you're overweight and all..." (IP3)

Others kept the condition a secret because they did not want to be of inconvenience or to be treated differently:

"Many know about my diabetes, but there are also many that don't know about it... And that is because I don't want to cause any trouble. I feel I'm causing trouble if I ask them to take precautions in relation to my diabetes, when they are cooking. I want them to make the food they want, and then I have to adjust it on my own." (IP15)

The last aspect concerned sharing thoughts with peers. The informants felt they could only discuss difficulties related to T2DM and self-management with another person with diabetes. They described that they felt a need for opening up to equals. They felt connected as equals and often had the same knowledge and experiences. An informant said:

'My friends don't understand how it is (to live with T2DM) ... Therefore, it could be nice to have someone to write with, when everything is just annoying, and you don't think you can manage it.' (IP3)

In summary, aspects of disclosure included telling about the condition after the diagnosis, sharing feelings about the condition or keeping the condition a secret to new and existing relations in every-day life, and finally the aspect of sharing thoughts with peers. While some of the informants were open about their condition because they experienced social support, others were primarily closed about their condition, because they felt embarrassed or did not want to cause any trouble. Sharing thoughts about diabetes with peers was in all cases perceived as a benefit.

3.2. Different Disclosure Strategies

The informants seemed to use a primarily open or a primarily closed disclosure strategy. The open strategy was characterised by the informants telling most of their social network about the condition immediately or shortly after diagnosis. Those who were open about their condition experienced that management was easier when social relations knew about their diagnosis:

"Well, to me, this just makes it 10 times easier, because no one asks questions." (IP12)

Even those who were generally open about their diabetes thought carefully about to whom they disclosed their condition. They mostly kept the information about T2DM to their immediate network of close friends and family but would be open to disclosing diabetes among friends and colleagues after careful consideration and under certain circumstances.

"Well, it is my immediate friends and family. But if you are going to meet some friends' friends, I'm not the one who tells it. Then I don't say anything. Just like I don't know if I should tell it at my new workplace." (IP15)

Informants who were primarily closed about their diabetes diagnosis would typically let very few people into their life and struggles with T2DM. They felt that they had to build a close and trusting relationship with people before disclosure and they worried about the consequences of telling about the condition in wider social contexts. Those who were overall closed about the condition generally had small networks and characterised themselves as private persons. Furthermore, they had strong feelings of self-blame and felt that others also would blame themselves for their T2DM diagnosis:

" I think it is awkward to have diabetes. It's related to being very fat, and that you have eaten very unhealthy foodand it is not nice that others have to know that you have diabetes, because you think they look down on you. Many times, I avoid saying it." (IP5)

In summary, the two different disclosure strategies revealed different thoughts and feelings about telling or not telling others about the condition. Open informants experienced that telling about the condition made it easier for them to adjust to everyday life and management, whereas closed informants feared disclosure would lead to negative labelling and judgement based on prejudice.

3.3. Disclosure and Adjustment to Living with T2DM

Most informants found that it was easier to talk about the condition with spouses, close relatives and friends; in time, they disclosed the diagnosis to more distant social relations. Informants described how disclosure of T2DM became easier over time:

"But now I think it's easier, but maybe it's because you have grown accustomed to it (T2DM) and it's now a part of you. But it really was not in the beginning. So, I think it has become easier to tell it." (IP15)

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Furthermore, some informants considered T2DM to be a private thing, and felt they had to reconcile with their situation and cope with living with a chronic condition before they were ready to disclose the condition:

"to me it is somehow private... I was not ready to tell it to other people in the beginning, but my husband was. It was not until I accepted it myself". (IP15)

Thereby, informants experienced a process from being closed about their diabetes in the beginning to being more open over time. This duration of this process varied from days to months. One informant told how he had moved from only telling a few people about his T2DM to being completely open about it:

"In the beginning and in the first six months, I only told it to a few friends, family and colleagues ...And I also thought a lot about how to tell it to more distant friends; after six months, I chose to write an update on Facebook." (IP2)

This process of becoming more open was related to perceptions of gaining control over diabetes management and acceptance of the condition. On the other hand, informants tended to be less open about the condition when they felt their diabetes self-management was not successful, for example, during periods where they did not exercise enough or gained weight.

Being open about the condition was often used either as a deliberate or less conscious strategy to obtain emotional or practical support for self-management. Getting positive feedback from social relations gave the informants the courage to be even more open. One informant described how he received positive feedback and how this helped him:

"I only got good and positive feedback from others. There was no condemnation or anything like that. On the contrary, all the reactions I got were about how impressive it was that I had done something to fight it. And of course, I could use that." (IP2)

Despite the positive experiences of disclosing the T2DM diagnosis, some informants afterwards felt uncomfortable about their relations having personal knowledge about them. Furthermore, most of the informants felt different after getting the condition. One informant expressed how this affected disclosure and the difficulties related to disclosing it to people in her more distant social network.

"So I don't think telling it (having T2DM) is easy. Maybe it's because I want to be normal like everybody else ...I just want it to be like before." (IP15)

This feeling of being different changed along with adjustment of the condition to informants' everyday life. They felt more normal when they talked to others about the condition, and when they talked to other people with T2DM.

Support from healthcare professionals also played an important role in the adjustment process. Informants experienced a willingness from the healthcare professionals to talk with them about the condition, including the fears and feelings connected to the condition. This could contribute positively to incorporating the condition in the informants' everyday life and lead to encouragement and supportive attitudes towards self-management.

In summary, adapting T2DM into everyday life was a complex process where the change from a closed to more open disclosure behaviour positively affected the emotional and practical adjustment to living with T2DM. When the informants decided to be open about the condition, they mostly experienced positive feedback. Talking with others and healthcare professionals about the condition seemed to result in better coping with T2DM.

3.4. Disclosure and Self-Management

Informants experienced the various diabetes-related tasks as burdensome in a busy everyday life with work, leisure time activities, children and household chores. They felt that sharing thoughts and information about their daily life with diabetes with social relations was necessary to obtain social support for diabetes management. For example, informants experienced, support and motivation for healthy behaviour, such as going for a walk or prepare healthy food.

One informant explained how it was an advantage to his self-management that his colleagues knew about the T2DM diagnosis:

"I really think it is an advantage because now you don't have to avoid the issue if there is cake or something like that. Because in the end, it can also mean you talk less about it because when other people know it, they will not time after time keep asking me why I'm not having any cake." (IP2)

Informants experienced how self-management became easier when they became more open about their diabetes status in the adjustment process.

They did not always wish to talk with others about their condition, particularly when they felt unsuccessful in their diabetes self-management. This could be when they had gained weight or exercised too little. This resulted in a negative loop, where they did not seek help to cope with negative feelings or self-management support.

In summary, to be open about diabetes helped informants to gain responsibility and motivation to maintain diabetes selfmanagement activities. To keep the condition a secret had a negative impact on self-management, because the informants would then be left alone with the responsibility for selfmanagement.

4. DISCUSSION

Early-onset T2DM is a challenging condition, both physically and psychologically. The informants explained how they perceived difficulties in being open about their condition, often due to fear of condemnation and social exclusion. However, all of them described a development from being quite closed about their diabetes diagnosis to becoming gradually more open; this process was related to their own emotional adaption to the condition. Despite the fear of condemnation, most informants had positive disclosure experiences, which often lead to emotional and practical support concerning diabetes management.

The first theme of the current study, 'Aspects of disclosure', covers four aspects showing that disclosure is more than just telling about the condition for the first time. A review by Ridder et al. [28] found that patients with a chronic condition who acknowledged and expressed their emotions about their condition to others had the best possibility of successfully adjusting to the challenges of living with a chronic condition. This was also reflected in our study, as disclosure to friends and colleagues seemed to help to further adjust to life with T2DM. The model of cognitive adaption points out the importance of illness acceptance and perceptions of control over the condition [29]. Our findings indicate that disclosure is a central strategy to obtain both acceptance and perception of control in line with individual stress and coping model strategies to manage the condition [30]. Further, our findings indicate that disclosure is essential to cope with the feelings caused by the condition and the interactions in social contexts in relation to food and exercise. In our study, informants found it difficult to integrate self-management into daily life. In another study [31], self-management integration was considered an ongoing process. Informants were continuously confronted with situations that challenged their coping strategies, and they had to find new ways of coping to adjust to new situations in daily life.

Browne et al. showed a higher prevalence of diabetesrelated distress among adults with early-onset T2DM compared to older adults [32] and research has shown associations between distress and suboptimal self-management [12, 33, 34]. The early-onset target group in our study experienced pressures unique to their age group [32] as it is a time in life, where most people undergo important life transitions [8]. In our study, informants experienced distress like worries, guilt and anxiety and many had difficulties accepting their condition and adjusting their lives to the new circumstances. However, in our study disclosure seemed to be related to informants' adjustment, and the overall positive feedback and support experienced by informants was a buffer for distress related to their diabetes. This function of disclosure has been outlined in theory about disclosure of hidden stigmatised conditions [18], and it underlines the importance of integrating disclosure guidance and support in diabetes care for the target group.

T2DM has been associated with prejudice and stigma [8, 21, 35, 36]. In our study, perceived stigma was one of the most important reasons for non-disclosure, and informants described feelings of shame and guilt. Other studies found that the experience of stigma in diabetes had behavioural and psychological consequences [21, 37, 38]. Chronic conditions such as T2DM are normally associated with older age [2, 39], and the informants in our study experienced to feel old. Coping with stigma involves several strategies including the decision about disclosing or concealing the condition [40]. In our study, fear of shame and condemnation was reported as the main reason for non-disclosure. A wish to be normal or fear of negative judgement from others could be reasons for concealing diabetes status. Fear of disclosure because of perceived or experienced stigma are repeated themes in other studies of adolescents and early-onset individuals with T2DM [3, 41]. These results in combination with our findings emphasise that people with T2DM need support to overcome

the psychological consequences of their diabetes. Future healthcare services should provide guidance for people with T2DM on the benefits of being open about their condition and on handling feelings of shame in social contexts.

The informants in this study expressed a need to discuss T2DM and self-management with peers. Miglany *et al.* showed that young people with diabetes are not always prepared to discuss their condition with others [42], despite the potential benefits of disclosure of the condition. Peer support is known to have a positive impact on diabetes self-management including improvements in factors such as BMI/weight, physical activity, self-efficacy and depression [43, 44]. Talking with healthcare professionals about the condition and related feelings was very important to our informants. Evidence has shown that communication skills, courtesy and openness of healthcare professionals play an important role in individuals' inclination and the possibility to disclose feelings and fears about T2DM, and thus affect the support and quality of care [19, 45].

In contrast to previous studies of stigma and disclosure [46, 47], our study did not identify a clear pattern of gender differences. This might have appeared if we had a higher representation of males among informants.

Our study has some important methodological strengths and limitations. The study sample was heterogeneous and varied according to sex, age, educational level, and duration of time living with T2DM. The broad variation in places of recruitment increased the population variation and thus the transferability of study findings [25]. The use of ecomaps to guide the interviews strengthened the study, because it promoted a relational process between interviewer and informant and made it easier for the informants to tell about their experiences [27].

Several of the informants had lived with T2DM for less than a year, and thus, they had only initial experiences of the disclosure, however, they had a better recall of the experiences of first disclosures. Regardless of diabetes duration, all informants had several experiences with the disclosure of diabetes, and how the challenges of disclosure changes over time. We believe that we achieved data saturation in the understanding of disclosure and self-management with the 15 individual interviewed, which is a criterion for the chosen sample size in qualitative studies [24]. Only a few informants received intense medical treatment (insulin), so we were not able to make any conclusion about differences between individuals with different treatment regimens. Neither did we have the opportunity to explore negative disclosure experiences in-depth, as they were hardly reported. However, due to the potential harm of negative disclosure experiences, it will be important for future studies to examine how often people in the target group experience negative reactions to T2DM disclosure, and how such experiences affect their management and wellbeing.

CONCLUSION

This study provides insight into how the growing but still often overlooked group of individuals with early-onset T2DM experience disclosure of their diabetes in the first years after diagnosis. Disclosure allowed informants to gain social, emotional and practical support for diabetes management, but disclosure also represented an ongoing emotional challenge for the informants, because of their fear of negative judgements and social exclusion.

Healthcare professionals' ability to support individuals to overcome feelings of shame and fear of disclosure may improve diabetes management among adults with early-onset T2DM.

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

The study was approved by the Danish Data Protection Agency (J.no. 2015-57-0002) Denmark.

HUMAN AND ANIMAL RIGHTS

Not applicable.

CONSENT FOR PUBLICATION

At the start of each interview, aim and conditions were clarified and written informed consent was obtained.

AVAILABILITY OF DATA AND MATERIALS

All data were anonymised with an 'IP' number used to match audio files.

FUNDING

Declared none.

CONFLICTS OF INTERESTS

The authors declare no conflicts of interest, financial or otherwise.

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MN, AB, HTM and ASJ conceived the study idea. MN conducted and transcribed the interviews, and performed the primary coding and analysis of the interviews. ALJ supervised the qualitative analysis. All authors interpreted the results and drafted the manuscript. All authors read and approved the final version of the manuscript.

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