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ORIGINAL ARTICLE

# Schizophrenia and type 2 diabetes: Perceptions and understandings of illness management in everyday life

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**Abstract**

People with schizophrenia and type 2 diabetes face complex challenges in daily life and the management of both illnesses is burdensome. This qualitative interview study aimed to explore perceptions and understandings of the day-to-day management of schizophrenia and type 2 diabetes. Fourteen semi-structured interviews were conducted between January 2020 and October 2021 in the participants' respective mental health clinics, in their homes or by phone. Thematic analysis led to four themes representing participants' self-management strategies and perceived challenges. The first theme showed that participants use self-learned strategies for managing schizophrenia. In contrast, they perceived type 2 diabetes self-management as governed by a set of rules and guidelines given by health professionals. The second theme showed that both psychotic and negative symptoms present challenges to diabetes management. Theme 3 illustrated that participants consider their type 2 diabetes to be a very serious illness. They worried about potential long-term consequences and expressed wishes and motivation to improve their lifestyle. The final theme showed that participants discuss challenges related to their schizophrenia with family and friends but not type 2 diabetes. In conclusion, this study highlights the importance of considering individual challenges and everyday routines when supporting this population. It underlines the need for future research to further explore the complexity of managing the illnesses and to understand the needs for treatment and support.

**KEYWORDS**
diabetes mellitus, type 2, interview, mental illness, qualitative research, self-management

## INTRODUCTION

People with severe mental illness, including schizophrenia, have two to three times higher mortality rates than the background population (Nielsen et al., 2013; Walker et al., 2015). Living with severe mental illness is associated with lifestyle behaviours that increase the risk of chronic physical illness such as type 2 diabetes (Stubbs et al., 2015; Vancampfort et al., 2017). Physical illnesses are main causes of most excess deaths among people with schizophrenia (Correll et al., 2022). Improving physical health and reducing physical illness among people with severe mental illness is of interest among researchers, healthcare professionals and policy makers globally (WHO, 2018).

## BACKGROUND

Schizophrenia is a mental illness that involves psychotic, negative and cognitive symptoms and affects how people think and behave (National Institute of Mental Health, 2021b). Psychotic symptoms include hallucinations and delusions, while negative symptoms include

loss of interest and pleasure in most daily activities (National Institute of Mental Health, 2021b). People with schizophrenia face considerable challenges in everyday functioning due to symptoms and adverse effects from medication (Møllerhøj et al., 2020), and self-management of the symptoms is crucial (Lean et al., 2019). Due to lifestyle choices, side effects from antipsychotic medication, and genetic factors, people with schizophrenia have a two- to three-fold increased risk of type 2 diabetes compared with the general population (Holt & Mitchell, 2014; Lindekilde et al., 2022).

People with schizophrenia and type 2 diabetes have shorter life expectancy and lower quality of life compared with people with diabetes only (Dickerson et al., 2008; Vinogradova et al., 2010). Treatment of type 2 diabetes requires several self-management tasks, including eating healthy, being physically active and taking medication (National Institute for Health and Care Excellence, 2015b). The evidence base suggests that people with coexisting schizophrenia and type 2 diabetes do not follow recommendations about healthy diet and exercise (Chen et al., 2014; Ogawa et al., 2011).

Research has highlighted the complex challenges in daily life, including navigation between many healthcare professionals and management of several symptoms and treatments among people with severe mental illness and diabetes (Balogun-Katung et al., 2021; Bellass et al., 2021; Rønne et al., 2020; Stenov et al., 2020). It has shown that severe mental illness governs the everyday life and overshadows diabetes, and managing diabetes along with severe mental illness is experienced as burdensome (Bellass et al., 2021; Stenov et al., 2020). Most studies have explored the challenges in people with severe mental illness and type 1 or type 2 diabetes. However, symptoms, treatments and self-management practices of the different severe mental illnesses vary greatly (National Institute of Mental Health, 2018, 2021a, 2021b), which also applies to type 1 and type 2 diabetes (National Institute for Health and Care Excellence, 2015a, 2015b). Moreover, research has mainly focused on the management of diabetes in people with severe mental illness rather than the management of both conditions (Rønne et al., 2020). To understand and support people in managing schizophrenia and type 2 diabetes, research focusing on the complex challenges of having those conditions is needed. The *aim* of our study was to explore perceptions and understandings of managing schizophrenia and type 2 diabetes in everyday life.

# METHODS

## Design

This qualitative interview study is reported following the consolidated criteria for reporting qualitative research, COREQ (Tong et al., 2007). The data collection and analysis were based on a hermeneutic approach, as it is useful for understanding and describing lived experiences (Dahlager & Fredslund, 2008). The hermeneutic approach was selected based on discussions between co-authors and because it enabled us to understand the experiences of the study population by interpreting data through our presuppositions. The analysis was conducted through an iterative hermeneutic process where we went back and forth between the specific parts and the whole dataset and had discussions between co-authors.

## Study context

The study was carried out in Region Zealand, Denmark. Five mental healthcare settings were used for recruitment: Four out of 13 psychiatric outpatient clinics in different towns in Region Zealand providing psychiatric care to the participants, and one clinic providing continuous and combined mental health and diabetes care.

## Research team

The team included a PhD student with a master's in public health STR, a PhD student with a nursing background VZ, a senior researcher with a PhD in Public Health LEJ, a senior researcher with a PhD degree and nursing background RJ, a psychiatrist and professor in psychotherapy SMA, and a PhD student with a master's in health psychology JVEB. All were female and experienced in qualitative research. RJ and SMA were experienced in research in people with schizophrenia, and STR who conducted the interviews had limited experience with people with schizophrenia.

## Data collection

### Recruitment of participants

A convenience sample of participants with type 2 diabetes (ICD-10: E110-E119 in medical record) and schizophrenia (ICD-10: F200-F209 in medical record) was recruited concurrently with data collection. They were recruited with assistance from mental health nurses at the clinics. The nurses introduced the study to eligible participants who attended routine consultations, and those who were interested were referred to STR. Potential participants were only asked if the nurses assessed them to be able to talk about everyday life and provide informed consent. STR contacted participants by phone and provided them with information about the study and arranged interviews. After receiving information, one refused to participate because of personal issues. We stopped the recruitment when 15 individuals had been approached, of whom 14 accepted to take

part in the study. Participant characteristics are shown in Table 1.

We used the concept of *information power* as guidance for attaining sufficient sample size (Malterud et al., 2016). Initial coding concurrent with data collection and memo writing after the interviews were used to consider the adequate number of interviews.

## Interviews

Explorative interviews were conducted using a semi-structured approach. The interview guide included questions covering five areas: *Everyday life and routines, health and illness in everyday life, coexisting schizophrenia and type 2 diabetes, social relations and illness support, and wishes for their future*. It was based on existing knowledge about self-management of severe mental illness and type 2 diabetes and identified research gaps (Rønne et al., 2020). A simplified and shortened version of the guide was prepared and used in three interviews with people with severe cognitive deficits. This version was more applicable for the participants with decreased concentration and impaired memory.

The interview guide was used very flexible and continuously adjusted to the participants' descriptions and our gained understandings though the whole data collection. Also, probes were used frequently during interviews to further explore the participants' expressions and stories.

Participants were given the opportunity to participate in phone interviews, if they had difficulties attending the clinics. Nine people were interviewed on the phone, four in their respective mental health clinics, and one at home. The interviews were conducted between January 2020 and October 2021, and they lasted between 11 and 72 min with a mean of 47.5 min. We asked participants to take part in follow-up phone interviews 2 weeks after the first interview, which nine accepted. The period of 2 weeks was a pragmatic choice. The purpose of the follow-up interviews was to get impressions of how fluctuating symptoms might have affected the participants' understandings, and to gain deeper insights into their perceptions. The follow-up interviews lasted between 7 and 26 min with a mean length of 17 min. During the interviews, we collected participant characteristics (Table 1). All interviews were conducted in Danish, and audio recorded, which all participants gave consent for.

**TABLE 1** Participant characteristics, $N = 14$.

| | |
|---|---|
| Men (*n*) | 11 |
| Age in years, mean (range) | 47.1 (28–70) |
| Duration of schizophrenia diagnosis in years, mean (range) | 19.2 (0.5–50) (missing: 3) |
| Duration of type 2 diabetes diagnosis in years, mean (range) | 4.4 (0.5–10) (missing = 1) |
| Educational level (*n*) | |
| Primary school | 7 |
| Vocational, high school or university | 3 |
| Missing | 4 |
| Job (*n*) | |
| Early retirement | 7 |
| Job seeking | 2 |
| Retirement | 2 |
| Sheltered employment | 1 |
| Missing | 2 |
| Cohabitation status (*n*) | |
| Living alone | 8 |
| Living with a partner | 3 |
| Living in a residential institution | 3 |
| Diabetes treatment (*n*) | |
| Tablet | 13 |
| Insulin | 1 |
| Other physical illness (*n*) | |
| Other physical illness or conditions (e.g., back pain, alcohol abuse, osteoarthritis, high cholesterol) | 8 |
| None | 3 |
| Missing | 3 |

*Note*: Participant characteristics were collected from participants during the interviews.

## Analysis

We conducted a reflexive thematic analysis based on the six-phase framework proposed by Braun and Clarke (2006, 2021):

1. Familiarizing with data: STR and a student assistant transcribed the interviews. STR read transcripts and wrote memos including ideas about immediate patterns and thoughts on each participant's stories.
2. Initial code generation: STR developed initial codes at a semantic level related to areas within the interview guide. Transcribed sections which were not within the scope of the guide were not coded. The memo writing included descriptions and immediate interpretations of each participant's experiences. Two random transcripts were discussed with four other qualitative researchers to bring in new perspectives and verify the initial coding. Phase one and two of the thematic analysis were performed concurrent with data collection. The software programme NVivo 12 was used for coding and memo writing (QSR International, 2022).
3. Searching for themes: STR sorted codes into code-groups and afterwards the code-groups were combined into initial themes. The development of themes was data-driven and not predefined from the interview guide. Themes were created at the interpretive level. NVivo 12 and tables were used as visual representations

to organize this phase, and the process was discussed with co-authors.
4. Revision of themes: STR re-read data extracts within each main theme and subthemes as well as memos and the entire data set as a whole to review the meaningfulness and coherence of the themes. To consider relevance and validity of the created themes in clinical practice, the themes and code-groups were discussed with three health care professionals working with the target group.
5. Defining themes and creating names: We defined and named four themes by considering the *story* within each theme, its relation to the other three themes, and how each theme contributed to the overall narrative.
6. Producing the manuscript: We wrote up the themes by providing data extracts representing expressions of the participants. These exemplars were embedded within our interpretations and understandings, providing the readers with insight into illness management of schizophrenia and type 2 diabetes in everyday life.

## RESULTS

The thematic analysis led to four themes showing participants' perceptions and understanding of self-managing schizophrenia and type 2 diabetes. Supporting example quotations for each theme and subtheme are shown in Table 2.

### Self-management as learning by doing and following rules

The first theme showed that participants' approaches to manage schizophrenia in everyday life differed from their approaches to manage type 2 diabetes.

#### Managing schizophrenia is learning by doing

Participants experienced they had to find their own ways to cope with their psychiatric symptoms. Many found out that distraction from the psychotic symptoms was effective for being able to manage the basics of daily life. Some listened to music to drown out their voices, some stayed away from other people to avoid anxious symptoms, and some inflicted self-harm.

> I have had many problems with shopping, until I found out I could just put some music in my ears and just keep a focus on what I must do. Now it has become a lot easier, and now I can go shopping by myself […] I feel very autodidact in managing this schizophrenia
>
> (Man, 32 years)

Another participant expressed:

> When the voices come, I turn up the music, which drowns the voices. Or I can sit down and write, or something like that. […] I have some strategies, that I know work for me
>
> (Woman, 45 years)

The participants were competent in modifying their daily living continuously to manage psychiatric symptoms the best way they could. The use of self-learned strategies to manage schizophrenia seemed to be in contrast with their approaches for type 2 diabetes management, where participants focused on following rules.

#### Following type 2 diabetes rules described by healthcare professionals

Participants expressed that they tended to follow advice received from health professionals to manage type 2 diabetes.

> I eat a lot of rye bread, but that is because I have been told it is good when you have diabetes
>
> (Man, 55 years)

Participants described they had been given recommendations about following a healthy diet, being physically active and taking diabetes medication by health professionals, with the aim of improving their blood glucose levels. In addition, they drew on common knowledge about healthy living.

> I went to a dietitian a couple of times, but then I felt like, now I have heard enough. I know how to eat. Deep inside I know. I have to follow that food pyramid
>
> (Man, 55 years)

Participants were familiar with the guidelines, and they experienced the management of type 2 diabetes as a set of rules, which they were supposed to follow to lower their blood glucose levels, lose weight and reduce diabetes medication.

### Schizophrenia challenges diabetes management

This theme illustrates that the burden of living with psychiatric symptoms can be a barrier to diabetes self-management. Psychiatric symptoms affected self-management in a range of different ways. Participants with psychotic symptoms often felt controlled and forced to behave in specific ways, for example, making unhealthy choices in everyday life, and anxiety was the

**TABLE 2** Themes, subthemes and supporting data.

| Themes | Subthemes | Supporting data |
|---|---|---|
| Self-management as learning by doing and following rules | Managing schizophrenia is learning by doing | 'I wrote down my history. I think that was the most important thing I did in this healing process. It improved my understanding of my own illness' (Woman, 26 years)<br>'Sometimes I get nada. It is ear acupuncture. I was offered it once, and I still do it sometimes when I feel bad […] it helps me relax' (Man, 68 years) |
| | Following type 2 diabetes rules described by healthcare professionals | 'I just want to do what the doctor tells me to. You can die from diabetes' (Man, 28 years)<br>'Sometimes I cheat. I go to the harbour and have an ice cream, or I buy some candy. But it shows on my blood glucose […] I can't follow the strict diet' (Man, 68 years)<br>'Some years ago, I used drink a couple of beers or three once a day. But I do not drink that much anymore, because the doctor told me it was bad to me' (Man, 55 years) |
| Schizophrenia challenges diabetes management | Voices interfere diabetes self-management | 'If I did not have schizophrenia, I would probably have a membership in a gym. Sometimes I think that would be fine. But the idea about 25 sweaty people and pumping music ends that dream' (Woman, 45 years)<br>'When talking about walks, well, if the voices are there I rather stay at home. That is the biggest problem' (Man, 45 years)<br>'When I am in a bad period, she [the voice] can be a kind of support, because it is like having a friend next to you. She [the voice] says that everything will become fine. "Just remember to take your medicine, remember that and that, or just try to come a little further with that"' (Woman, 33 years) |
| | Negative symptoms affect diabetes self-management | 'I can't go for walks. That's hard. I am so tired. And that is the worst. Maybe it does not sound much, but it really is' (Man, 36 years)<br>'I have absolutely no energy for simple things like shopping and preparing meals. That's a problem, I admit that' (Woman, 45 years) |
| Perceiving diabetes as a serious illness | Worries about diabetes complications | 'I had some problems with blurry vision, and I thought it was because of my diabetes. But the doctor examined me, and it was fine. […] But I do get worried. I worry about getting food ulcers' (Woman, 33 years) |
| | Motivation for lifestyle changes | 'I would like to take less diabetes medication at some point. I don't like taking medication. I would nice if I did not have to take any medication for diabetes' (Woman, 26 years)<br>'I hope, and maybe it is unrealistic, but it is alright to set goals. It is my goal that I, at some point, will need a lower dose of metformin and do not need to take the injections' (Woman, 45 years) |
| | Pulling oneself together | 'It is my goal to lose 25 kilos. If I could put on weight, I should also be able to lose it again' (Man, 50 years)<br>'I lost weight without any kind of help. It's all just about pulling yourself together. […] When you do not get any help, you must take matters into your own hands' (Man, 32 years)<br>'When I come home from the bakery and eat what I have just bought, I feel very bad with myself. I know it is wrong' (Man, 57 years) |
| Sharing mental problems but not diabetes concerns | Sharing mental problems with relatives and peers | 'We are a couple of people who meet [in the drop-in centre] some mornings. We speak with each other and drink coffee. They know a lot about the anxious symptoms from themselves. […] It makes me relax' (Man, 57 years)<br>'We [other people with mental illness in the drop-in centres] understand each other. All that about having bad days. Sometimes I just sit there for 10 minutes and then I start feel a little bit better. But sometimes my symptoms get more worse from being there' (Man, 45 years) |
| | Not sharing diabetes concerns with relatives and peers | Interviewer: 'Can you talk to your friends at the center about diabetes?'<br>Participant: 'Well, a lot of them have diabetes actually"<br>Interviewer: 'Really? Do you then talk about it sometimes?'<br>Participant: 'No, not really' (Man, 57 years) |

reason for avoidance of or withdrawal from healthy activities. On the other hand, people with negative symptoms lacked interest and motivation for many aspects in their everyday life, including diabetes management.

### Voices interfere with diabetes self-management

Some participants heard voices telling them not to take medication or persuading them that eating healthy was unimportant. One man stated:

> Sometimes the voices tell me that I should not take my pills. (…) They talk about all kinds of medicine – the pills I take to stop the voices, the blood pressure medicine, and the diabetes medicine. (…) and I try to stay healthy and have some healthy meals, you know. But the voices are there, and they have the power to make me buy the wrong food. (…) They control a lot
>
> (Man, 45 years)

Some participants described how psychotic symptoms, including voices, controlled their everyday lives, by ordering them to act in specific ways, and some participants experienced the psychotic symptoms to impede doing what was best for them and hindered them in taking care of diabetes. Participants who heard voices directing them specifically about healthy choices and diabetes self-management described that it took additional effort to eat healthily and take medication, because they constantly had to overcome the voices.

Many participants had anxiety, which they experienced as a barrier to getting out of the house and meeting other people.

> When I sit at home and it is time for me to exercise, and then I feel the anxiety coming. That makes it very difficult to get out and exercise. Then I really just want to stay at home
>
> (Man, 57 years)

The anxiety was perceived as a significant barrier to being physically active. It made many participants avoid fitness centres and walks as they got uncomfortable when meeting with other people or being away from home.

### Negative symptoms affect self-management

Negative symptoms of schizophrenia were described as tiredness and lack of pleasure and motivation, which made participants struggle with the basics of daily life such as cooking or shopping for groceries. When talking about diabetes management, some participants described their lack of energy as a barrier to eating healthy:

> All that about healthy eating, I have absolutely no energy for that right now. I have no energy to cook. I am in a period where I have fast food every day. It is very difficult
>
> (Woman, 33 years)

Feelings of depression and lack of pleasure were experienced as very hard to struggle with, and such negative symptoms were perceived as a serious burden. Participants lacked motivation and interest for many aspects in life, and especially making healthy choices and taking care of diabetes were perceived as less important and less achievable.

Some participants had depressive symptoms and ate more when they felt sad:

> I have a tendency to "eat my feelings" […]. If a get bad news or if something bad happens to my mom, I have a tendency to do it. Few days ago, I had two Snickers and a whole box of toffee pops. Afterwards I felt not well. I go high on sugar, which is not good. It means that my blood sugar fluctuates. Afterwards I crash on the couch. I feel sad and ask myself, why I did that. […] Then I feel sad, and I just want to eat more […]. It feels like a vicious cycle. […]. Currently, it happens to me every day
>
> (Woman, 33 years)

Participants who described 'to eat their feelings' used it as a short-term strategy to manage their depressive symptoms. They felt guilt and shame about overeating, and they expressed frustrations about not having the control to stop. The increasing blood sugar levels and body weight made participants perceive the compulsive overeating as very inappropriate for their diabetes, and they felt shame because the eating strategy led to harmful effects on their diabetes.

## Perceiving diabetes as a serious illness

Participants perceived diabetes as a serious and life-threatening illness, but they also felt that diabetes had no or very limited impact on how they lived their daily life. Some participants worried about serious consequences of diabetes, they expressed motivation for taking better care of it, and they felt shame about having it.

### Worries about diabetes complications

Participants' perceptions of diabetes being a serious illness was followed by worries. A participant described:

> I worry about what can happen to me if I continue behaving stupidly, you know, eating the wrong food. I worry about what will happen to me in the end
>
> (Man, 45 years)

The diabetes-related worries mainly concerned their risk of developing diabetes complications. Participants described that their capability and energy to follow the diabetes recommendations often were low. The lack of capability to follow the given recommendations seemed to some participants to result in more worries, frustrations, or feelings of hopelessness. Some shared that coexistence of psychiatric symptoms made them worry more about diabetes:

> When you also have schizophrenia there are so many things you speculate about. A normal person would probably never speculate that much about it. I don't think so. But I have many speculations, and it frustrates me a lot. I believe it is abnormal. […] There is not a day, where I don't think of illness or diabetes or blood sugar or high cholesterol
>
> (Man, 55 years)

Participants who described that schizophrenia made them worry a lot about many aspects of their life, including diabetes, experienced such worries as frustrating. Some expressed concerns about their risk of diabetes complications and not succeeding in losing weight. The worries were perceived as burdensome and limiting daily life.

### Motivation for lifestyle changes

Many participants had desires and goals about living healthier. They were aware of their physical health challenges, and they had ambitions about making improvements. They were motivated to lose weight. One woman stated:

> In the future I will work on losing weight. I want to feel better physically. I really want to lose weight, because that would make the other problems disappear, and it would take away some of all my worries […] It is something I really want, but at the same time, it is just very hard to get started. I really need some kind of support
>
> (Woman, 33 years)

Some participants described how they tried by themselves to eat healthily and be more physically active, while other expressed their need for support for getting started. In addition to weight loss, participants had ambitions about reducing their diabetes medication and improving blood glucose levels.

### Pulling oneself together

Participants explained their diagnosis of diabetes by the adverse effects of antipsychotic medication and their struggling with basics of daily life because of psychiatric symptoms. However, some participants felt guilty for having developed diabetes.

> After I got the diagnosis of diabetes, I felt very guilty. I felt I had been eating myself to death
>
> (Woman, 33 years)

Participants also perceived that changing lifestyle was something they had to do by themselves:

> I have to lose weight, so I just need to pull myself together
>
> (Man, 50 years)

They perceived it as their responsibility to make lifestyle changes, lose weight and manage diabetes, and they considered themselves as being in the principal role of managing lifestyle and diabetes. They were aware that their lifestyles were not in accordance with the guidelines given by their health professionals, and they expressed feelings of guilt about not being able to manage diabetes sufficiently.

## Sharing mental health problems but not diabetes concerns

The fourth theme illustrates that speaking with family and friends about their psychiatric symptoms and challenges was important for managing schizophrenia. In contrast, participants rarely shared thoughts and experiences about diabetes-related challenges.

### Sharing mental health problems with relatives and peers

Participants perceived speaking with others about psychiatric symptoms as supportive, and especially talking to people with similar mental health problems was perceived as helpful for managing schizophrenia:

> She [the spouse] hears voices like me. She has anxiety. She is also paranoid. Just like me. When I feel bad, she really understands how

> I feel. You do not need all these explanations. […] We can help each other because of that
> (Man, 59 years)

Participants expressed that providing other people with descriptions and explanations of psychiatric symptoms could be draining, but that feelings of being understood by people living with similar mental health problems were less demanding in daily life and more helpful for schizophrenia management.

Likewise, giving support to others with mental health problems was perceived as meaningful:

> It makes me feel less of a burden when I am able to support someone the other way around. […] It enhances my own sense of self-worth
> (Woman, 45 years)

Participants experienced that being able to support others improved their mental health. It generated energy and improved their quality of life to experience that they 'could actually be used for something' (Man, 59 years).

### Not sharing diabetes concerns with relatives and peers

During interviews the participants did not talk about sharing diabetes-related challenges with other people. Some expressed that making appointments for walks and exercise with friends were helpful, and some perceived it as supportive to be with a partner or a close friend who helped maintain daily routines. However, sharing thoughts or experiences about self-management approaches, related worries, medication, or diabetes-specific needs with family, friends, or other people with diabetes, were not described by participants. In settings where diabetes was the 'shared' illness, participants expressed to speak more about psychiatric challenges than diabetes. One woman stated:

> One of my closest friends has also type 2 diabetes, and sometimes we speak a bit about the diabetes medication and so. But it is not much. We speak more about what happens in my head
> (Woman, 45 years)

Schizophrenia took up a lot of space in their daily life, which it also did in social contexts. As diabetes had limited impact on their everyday life, it also took up less space when being with other people.

## DISCUSSION

The results of this study enhance our understanding of the complex challenges people with schizophrenia and type 2 diabetes face in everyday life. They highlight the importance of considering individual challenges and everyday routines when giving support.

The first theme illustrated that self-learned strategies for managing schizophrenia were different from following diabetes rules. This has not been described previously, but studies in people with only diabetes have shown that type 2 diabetes management is not just perceived as simple rules but embedded in social contexts of life (Hinder & Greenhalgh, 2012; Rogvi et al., 2021). A German qualitative study indicated that people with low education perceived type 2 diabetes recommendations from healthcare professionals as rules which they strictly had to follow, while more highly educated people developed their own individual strategies to manage type 2 diabetes in daily life. The authors explained this by arguing that people with low education are used to live with more restrictions in their everyday life compared to people with high education, who have resources to develop individual strategies (Fink et al., 2019). Our study might be an illustration of this because people with schizophrenia are used to living with more restrictions and fever resources. They perceive diabetes guidelines given by their healthcare professionals as rules to be followed strictly rather than developing their own personal diabetes self-management strategies, and they describe feelings of guilt when not following the rules. Considering this, very specific diabetes-related rules adapted to the participants' everyday life and agreed by the participant and the healthcare professionals might be useful for participants.

Another finding that has not been addressed in previous research is the manner the variety of symptoms seen in schizophrenia challenges illness management in distinctive ways. Presumably, this has not been addresses because most studies have examined populations of people with a mixture of severe mental illnesses (Bellass et al., 2021; Rønne et al., 2020; Stenov et al., 2020). Studying multiple illnesses together limits the possibilities of gaining deep understandings of how the different psychiatric symptoms challenges diabetes management. This finding highlights the needs for considering individual symptoms, everyday challenges, and daily routines, when providing diabetes-specific support for people with schizophrenia.

Participants in this study expressed motivation and wishes for changing their lifestyle, and they perceived themselves as being the responsible persons for making these. Other studies have shown that people with severe mental illness and diabetes have high levels of diabetes distress, worries related to the long-term consequences of diabetes, but they lack motivation for maintaining healthy lifestyles (Knudsen et al., 2022; Stenov et al., 2020). However, motivational factors and beliefs about responsibilities for managing and treating diabetes have not been investigated among people with schizophrenia and type 2 diabetes. Such insights are important

when designing lifestyle interventions targeting this population and need further attention.

Participants talked about their psychiatric symptoms to relatives and that being with other people with similar mental challenges was perceived as supportive. However, they rarely talked to other people about their diabetes-related worries and challenges. Effects of social support and peer-support have been studied widely among people with either diabetes or severe mental illness and studies have shown that support from social networks and peers can improve self-management of the illnesses respectively (Beentjes et al., 2020; Carpenter et al., 2019; Degnan et al., 2018; Lloyd-Evans et al., 2014; Schram et al., 2021). However, literature on social support and peer-support among people with severe mental illness and type 2 diabetes is sparse. An American qualitative study has explored experiences of being enrolled in a peer educator training programme among people with severe mental illness and diabetes (Blixen et al., 2015). The authors concluded that using strengths and skills from peers might be an effective way of supporting people in managing both illnesses (Blixen et al., 2015). In addition, a systematic review about peer-support for hardly reached people, for example, people with diabetes, mental illness, other chronical illness and/or low social support, has indicated that peer-support is effective (Sokol & Fisher, 2016). Taken together, this indicates potentials for integrating peer-support in future support to people with schizophrenia and type 2 diabetes.

To uncover perceptions and understandings of living with schizophrenia and type 2 diabetes further, the overall findings of this study can be understood in relation to the concept *burden of treatment*. The burden of treatment covers the daily work that people need to do to undertake their treatment, including changing lifestyles, managing medications, and visiting multiple healthcare professionals (Sav et al., 2017). The burden of treating either schizophrenia or type 2 diabetes in everyday life can be large (Møllerhøj et al., 2020; Rogvi et al., 2021), and findings of this study indicate that living with both illnesses further adds to the burden. As burden of treatment accumulates and people become overwhelmed, the consequence can be difficulties in managing the illnesses and negative health consequences (Shippee et al., 2012). In terms of reducing the *burden of treatment*, May et al. (2009) has described *minimally disruptive medicine* as a patient-centred framework that aims to prioritize individual goals for life and health but with a focus on reducing the *burden of treatment*. May et al. (2009) suggest that by assessing treatment burden and adjusting the treatment to this, for example, prioritizing and simplifying treatments, the *treatment burden* can be reduced and result in improved self-management and health. Based on findings of this study, we argue that healthcare professionals' understandings of the individual treatment burden, including illness management strategies, daily routines, and life constrains among people with schizophrenia is essential when supporting lifestyle change or diabetes management.

## Strengths and limitations

Strengths of this study include the concurrent data collection and analysis because it enabled us to use our new understandings from the analysis in the data collection by continuously adjusting the interview guide. Likewise, our conduction of follow-up interviews enabled us to 'check' our understanding of the participants' responses, ask additional questions and gain deeper insights. A limitation of this study is our use of convenience sampling, because this method often causes nonrepresentative samples (Neuman, 2013). We have not systematically gathered information about the number and characteristics of those who were not asked for participation by the mental health nurses and those who were asked but declined. However, participants with severe psychoses and negative symptoms took part in this study. This indicates that our findings not only represent perspectives from people with mild symptoms and high cognitive functional levels. The heterogeneity in participants' symptom severity improves the strengthen information power. Based on previous research and the empirical data, our thematic findings are likely to be transferable to other adults with schizophrenia and type 2 diabetes in Denmark and in similar countries. Potential subgroup differences including cultural differences need to be further explored. Also, the interviews were conducted during the COVID-19 pandemic and some participant experiences might be influenced by lockdowns and restrictions. Lastly, the interviews were conducted in Danish, and quotes were translated into English for this paper. Some meanings and nuances of participants' stories might have got lost in the translation process (McKenna, 2022).

# CONCLUSION

People living with schizophrenia and type 2 diabetes have serious hardships in managing both illnesses in everyday life. It adds to existing literature by highlighting that managing schizophrenia was perceived as learning by doing and managing diabetes was perceived as following a set of rules. It improves our understanding of how psychotic and negative symptoms challenge diabetes management, and it points out that people with schizophrenia consider their type 2 diabetes as a serious illness. They worry about consequences and express motivation for taking better care of it. However, participants rarely talk about their diabetes-related challenges or worries with family or friends. This study highlights the need for future research to further explore and understand challenges and needs this population.

## RELEVANCE FOR CLINICAL PRACTICE

According to the present findings, people with schizophrenia should be offered diabetes treatment and support corresponding to their individual routines and needs, and we suggest that insights into their individual daily routines, psychiatric symptoms and management strategies are extremely important for planning and adjusting this. Diabetes-related demands seem to further add to the burden of treating schizophrenia and result in difficulties in managing diabetes, and therefore, we argue that assessment and reduction of the individual burden of treatment is imperative. For example, healthcare professionals and people with both illnesses could in the manner of shared decision making develop simple diabetes-specific rules based on the individual resources and needs. Lastly, previous research and present findings suggest potential benefits from involving peers in the managing of severe mental illness and diabetes, and the potential of integrating peer-support in clinical practice should be further studied.

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## CONFLICT OF INTEREST STATEMENT

There are no conflicts of interest.

## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

## ETHICAL APPROVAL

The study was approved by the Danish Data Protection Agency (REG-043-2019) and followed the principles of ethics in the Helsinki II Declaration. According to the Danish legislation, approval from an ethics committee is not required in interview studies. All participants received oral and written information about the study and gave informed written consent.

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## REFERENCES

Balogun-Katung, A., Carswell, C., Brown, J.V.E., Coventry, P., Ajjan, R., Alderson, S. et al. (2021) Exploring the facilitators, barriers, and strategies for self-management in adults living with severe mental illness, with and without long-term conditions: a qualitative evidence synthesis. *PLoS ONE*, 16, 1–28.

Beentjes, T.A.A., van Gaal, B.G.I., van Achterberg, T. & Goossens, P.J.J. (2020) Self-management support needs from the perspectives of persons with severe mental illness: a systematic review and thematic synthesis of qualitative research. *Journal of the American Psychiatric Nurses Association*, 26(5), 464–482.

Bellass, S., Lister, J., Kitchen, C.E.W., Kramer, L., Alderson, S.L., Doran, T. et al. (2021) Living with diabetes alongside a severe mental illness: a qualitative exploration with people with severe mental illness, family members and healthcare staff. *Diabetic Medicine*, 38(7), e14562.

Blixen, C., Perzynski, A., Kanuch, S., Dawson, N., Kaiser, D., Lawless, M.E. et al. (2015) Training peer educators to promote self-management skills in people with serious mental illness (SMI) and diabetes (DM) in a primary health care setting. *Primary Health Care Research & Development*, 16(2), 127–137.

Braun, V. & Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101.

Braun, V. & Clarke, V. (2021) One size fits all? What counts as quality practice in (reflexive) thematic analysis? *Qualitative Research in Psychology*, 18(3), 328–352.

Carpenter, R., DiChiacchio, T. & Barker, K. (2019) Interventions for self-management of type 2 diabetes: an integrative review. *International Journal of Nursing Sciences*, 6(1), 70–91.

Chen, S.R., Chien, Y.P., Kang, C.M., Jeng, C. & Chang, W.Y. (2014) Comparing self-efficacy and self-care behaviours between outpatients with comorbid schizophrenia and type 2 diabetes and outpatients with only type 2 diabetes. *Journal of Psychiatric and Mental Health Nursing*, 21(5), 414–422.

Correll, C.U., Solmi, M., Croatto, G., Schneider, L.K., Rohani-Montez, S.C., Fairley, L. et al. (2022) Mortality in people with schizophrenia: a systematic review and meta-analysis of relative risk and aggravating or attenuating factors. *World Psychiatry*, 21(2), 248–271.

Dahlager, L. & Fredslund, H. (2008) Hermeneutic analysis - understanding and pre-understanding. In: Vallgårda, S. & Koch, L. (Eds.) *Research methods in public health*, 4th edition. Copenhagen: Munksgaard Danmark, pp. 157–181.

Degnan, A., Berry, K., Sweet, D., Abel, K., Crossley, N. & Edge, D. (2018) Social networks and symptomatic and functional outcomes in schizophrenia: a systematic review and meta-analysis. *Social Psychiatry and Psychiatric Epidemiology*, 53(9), 873–888.

Dickerson, F., Brown, C.H., Fang, L., Goldberg, R.W., Kreyenbuhl, J., Wohlheiter, K. et al. (2008) Quality of life in individuals with serious mental illness and type 2 diabetes. *Psychosomatics*, 49(2), 109–114.

Fink, A., Fach, E.M. & Schröder, S.L. (2019) "Learning to shape life" – a qualitative study on the challenges posed by a diagnosis of diabetes mellitus type 2. *International Journal for Equity in Health*, 18(1), 19.

Hinder, S. & Greenhalgh, T. (2012) "this does my head in". Ethnographic study of self-management by people with diabetes. *BMC Health Services Research*, 12, 83.

Holt, R.I.G. & Mitchell, A.J. (2014) Diabetes mellitus and severe mental illness: mechanisms and clinical implications. *Nature Reviews Endocrinology*, 11, 79.

Knudsen, L., Hansen, D.L., Joensen, L.E., Wibaek, R., Benros, M.E., Jørgensen, M.E. et al. (2022) Need for improved diabetes support among people with psychiatric disorders and diabetes treated in psychiatric outpatient clinics: results from a Danish cross-sectional study. *BMJ Open Diabetes Research and Care*, 10(1), e002366.

Lean, M., Fornells-Ambrojo, M., Milton, A., Lloyd-Evans, B., Harrison-Stewart, B., Yesufu-Udechuku, A. et al. (2019) Self-management interventions for people with severe mental illness: systematic review and meta-analysis. *British Journal of Psychiatry*, 214(5), 260–268.

Lindekilde, N., Scheuer, S.H., Rutters, F., Knudsen, L., Lasgaard, M., Rubin, K.H. et al. (2022) Prevalence of type 2 diabetes in psychiatric disorders: an umbrella review with meta-analysis of 245 observational studies from 32 systematic reviews. *Diabetologia*, 65(3), 440–456.

Lloyd-Evans, B., Mayo-Wilson, E., Harrison, B., Istead, H., Brown, E., Pilling, S. et al. (2014) A systematic review and meta-analysis of randomised controlled trials of peer support for people with severe mental illness. *BMC Psychiatry*, 14, 39.

Malterud, K., Siersma, V.D. & Guassora, A.D. (2016) Sample size in qualitative interview studies: guided by information power. *Qualitative Health Research*, 26(13), 1753–1760. Available from: https://doi.org/10.1177/1049732315617444.

May, C., Montori, V.M. & Mair, F.S. (2009) We need minimally disruptive medicine. *Medical Journal*, 339(7719), 485–487.

McKenna, L. (2022) Translation of research interviews: do we have a problem with qualitative rigor? *Nurse Author & Editor*, 32(1), 1–3.

Møllerhøj, J., Os Stølan, L., Erdner, A., Hedberg, B., Stahl, K., Riise, J. et al. (2020) "I live, I don't work, but I live a very normal life"—a qualitative interview study of Scandinavian user experiences of schizophrenia, antipsychotic medication, and personal recovery processes. *Perspectives in Psychiatric Care*, 56(2), 371–378.

National Institute for Health and Care Excellence. (2015a) *Type 1 diabetes in adults: diagnosis and management*. Available from: https://www.nice.org.uk/guidance/ng17/resources/type-1-diabetes-in-adults-diagnosis-and-management-1837276469701 [Accessed 20th February 2020].

National Institute for Health and Care Excellence. (2015b) *Type 2 diabetes in adults: management*. Available from: https://www.nice.org.uk/guidance/ng28/resources/type-2-diabetes-in-adults-management-1837338615493 [Accessed 20th February 2020].

National Institute of Mental Health. (2018) *Bripolar Disorder*. Available from: https://www.nimh.nih.gov/health/topics/bipolar-disorder [Accessed 15th February 2022].

National Institute of Mental Health. (2021a) *Depression*. Available from: www.nimh.nih.gov/SAD [Accessed 15th February 2022].

National Institute of Mental Health. (2021b) *Schizophrenia*. Available from: https://www.nimh.nih.gov/health/topics/schizophrenia [Accessed 15th February 2022].

Neuman, W.L. (Ed.) (2013) Qualitative and quantitative sampling. In: *Social research methods: Pearson new international edition*. Harlow: Pearson Education Limited, pp. 245–280.

Nielsen, R.E., Uggerby, A.S., Olrik, S., Jensen, W. & Mcgrath, J.J. (2013) Increasing mortality gap for patients diagnosed with schizophrenia over the last three decades-a Danish nationwide study from 1980 to 2010. *Schizophrenia Research*, 146(1–3), 22–27.

Ogawa, M., Miyamoto, Y. & Kawakami, N. (2011) Factors associated with glycemic control and diabetes self-care among outpatients with schizophrenia and type 2 diabetes. *Archives of Psychiatric Nursing*, 25(1), 63–73.

QSR International. (2022) *NVIVO*. Available from: https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home [Accessed 18th May 2022].

Rogvi, S., Guassora, A.D., Tvistholm, N., Wind, G. & Christensen, U. (2021) "It is a full-time job to Be ill": patient work involved in attending formal diabetes care among socially vulnerable Danish type 2 diabetes patients. *Qualitative Health Research*, 31(14), 2629–2640.

Rønne, S.T., Zabell, V., Joensen, L.E., Jørgensen, R., Gaede, P.H. & Hemmingsen Arnfred, S.M. (2020) Perceptions and experiences of living with coexisting type 2 diabetes and severe mental illness: a scoping review. *Diabetic Medicine*, 37(10), 1627–1639.

Sav, A., Salehi, A., Mair, F.S. & McMillan, S.S. (2017) Measuring the burden of treatment for chronic disease: implications of a scoping review of the literature. *BMC Medical Research Methodology*, 17(1), 140. Available from: https://doi.org/10.1186/s12874-017-0411-8

Schram, M.T., Assendelft, W.J.J., Van Tilburg, T.G. & Dukers-Muijrers, N.H.T.M. (2021) Social networks and type 2 diabetes: a narrative review. *Diabetologia*, 64(9), 1905–1916.

Shippee, N.D., Shah, N.D., May, C.R., Mair, F.S. & Montori, V.M. (2012) Cumulative complexity: a functional, patient-centered model of patient complexity can improve research and practice. *Journal of Clinical Epidemiology*, 65(10), 1041–1051.

Sokol, R. & Fisher, E. (2016) Peer support for the hardly reached: a systematic review. *American Journal of Public Health*, 106(7), e1–e8.

Stenov, V., Joensen, L.E., Knudsen, L., Lindqvist Hansen, D. & Willaing Tapager, I. (2020) "Mental health professionals have never mentioned my diabetes, they Don't get into that": a qualitative study of support needs in adults with type 1 and type 2 diabetes and severe mental illness. *Canadian Journal of Diabetes*, 44(6), 494–500.

Stubbs, B., Vancampfort, D., De Hert, M. & Mitchell, A.J. (2015) The prevalence and predictors of type two diabetes mellitus in people with schizophrenia: a systematic review and comparative meta-analysis. *Acta Psychiatrica Scandinavica*, 132(2), 144–157.

Tong, A., Sainsbury, P. & Craig, J. (2007) Consolidated Criteria for Reporting Qualitative Research (COREQ): a 32-item checklist for interviews and focus groups. *Acta International Journal for Quality in Health Care*, 19, 349–357. Available from: https://doi.org/10.1093/intqhc/mzm042

Vancampfort, D., Firth, J., Schuch, F.B., Rosenbaum, S., Mugisha, J., Hallgren, M. et al. (2017) Sedentary behavior and physical activity levels in people with schizophrenia, bipolar disorder and major depressive disorder: a global systematic review and meta-analysis. *World Psychiatry*, 16(3), 308–315.

Vinogradova, Y., Coupland, C., Hippisley-Cox, J., Whyte, S. & Penny, C. (2010) Effects of severe mental illness on survival of people with diabetes. *The British Journal of Psychiatry*, 197(4), 272–277.

Walker, E.R., McGee, R.E. & Druss, B.G. (2015) Mortality in mental disorders and global disease burden implications: a systematic review and meta-analysis. *JAMA Psychiatry*, 72(4), 334–341.

WHO. (2018) *Management of physical health conditions in adults with severe mental disorders WHO GUIDELINES*. Available from: https://apps.who.int/iris/bitstream/handle/10665/275718/9789241550383-eng.pdf

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