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"Modifying" or "Retreating"- Self-management of physical health among a group of people with schizophrenia. An ethnographic study from Denmark

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Abstract

The aim of this ethnographic study was to explore how a group of nine Danish people with schizophrenia managed physical health issues as they naturally occurred in everyday life. Qualitative methods were used in generation of data. Thematic analysis led to the description of two typical strategies used by participants to manage debilitating physical health issues in everyday life. *Modifying everyday life to manage discomfort* was a strategy employed to manage potential or actual discomfort associated with ongoing poor physical health, while *Retreating from everyday life to recover* was a strategy used by participants who experienced recurring discrete episodes of poor physical health characterised by fast deterioration. Both management strategies were inexpedient as they failed to produce any positive progress in terms of the participants regaining health. The social context of participants' everyday life was characterised by a lack of interactions with others about their prevailing and ongoing physical health issues. Repeated use of these inexpedient strategies to manage physical health caused potential worsening rather than improvements to physical health. There is a need for future research that explores aspects of beneficial management of physical health issues among people with severe mental illness. Relevant foci of such research include enhancing self-management of physical health, active help-seeking behaviours, and opportunities to engage in interactions with others about physical health issues.

Key words

Illness behaviour, qualitative research, schizophrenia, self-management, social interaction

Introduction

Deteriorating physical health among people with severe mental illness (SMI) has been a focus of government policy and a subject of international health research, for many years. Compared to the general population, people with SMI are reported to have higher occurrence of inexpedient life style behaviours, delayed help-seeking behaviour, poorer treatment options and adherence to treatment (Melamed et al., 2019, Lawrence and Kisely, 2010), which collectively increase their risk of developing physical illness (Bartlem et al., 2015, McCloughen et al., 2012). Furthermore, they present with higher occurrence of co-morbidity and multi-morbidity, and excess mortality (Kugathasan et al., 2019, Nielsen et al., 2013). Up to 60% of premature mortality among people with schizophrenia has been reported to be caused by physical illness (Lawrence et al., 2013). The objective of this study was to explore how a group of people diagnosed with schizophrenia managed physical health issues as part of their everyday life.

Background

In the literature 'severe mental illness' is a term used to refer to mental health problems causing impairments across everyday life functioning (van Duin et al., 2019). From a biomedical perspective, schizophrenia is a severe and persistent mental illness causing serious challenges in relation to a person's contact with the world. People with schizophrenia may require substantial support to maintain stability in everyday life, as they can experience difficulties related to executive functions, such as planning and performing everyday activities. The terms 'severe mental illness' and 'schizophrenia' are drawn from the dominant traditions of medicine and psychiatry. We appreciate that some people believe that neither term adequately reflects the uniqueness and complexities associated with the lived experience of mental health problems and each carries potential negative connotations in relation to recovery (Moncrieff and Middleton, 2015, Geekie and Read, 2009). The terms are used throughout this paper because they reflect the language of the sites where our study took place. We hold the terms lightly while also keeping the uniqueness of individual lived experiences in mind.

Despite well-documented understandings about the existence of physical health conditions among people with SMI, there are continued reports of insufficient physical health care in mental health care settings (Romain et al., 2020, Gray and Brown, 2017). Aspects of contemporary health care constitute additional barriers to adequate access to and provision of physical health care for people with SMI. The continued influence of body-mind dualism and reductionist perspectives within prevailing biomedical contexts, promote barriers to the promotion and treatment of physical health among people with mental health conditions (Switankowsky, 2000). This is illustrated in the siloed organisational structure of many contemporary health care settings (Bento et al., 2020), which promotes fragmentation of general health

care and mental health care. Evidence of this division is reported in studies describing how negative attitudes of mental health care professionals (MHCPs) towards providing physical health care constitute a barrier to provision of general health care within mental health services (Lerbæk et al., 2019, Bartlem et al., 2016). Within some outpatient services, attending to physical health has been described by MHCPs as disrupting relationships with patients and therefore de-prioritised to safeguard fragile relationships (Lerbæk et al., 2015). Consequently, management of physical health issues remains a marginalised area of care in some mental health contexts.

Knowledge about factors that facilitate or limit the possibilities of managing physical health in everyday life by people with mental illness, is necessary for providing adequate support for physical health issues in mental health care services (Happell et al., 2016, Small et al., 2017). Studies have examined factors that mental health service users experience as influential on healthy living (Graham et al., 2014, Abed, 2010), what they find meaningful when speaking of being healthy and what 'physical health' means to *them* (Happell et al., 2016, Graham et al., 2013), and how they experience physical health services (Gedik et al., 2020). This research has demonstrated how active involvement in the development of care provision can result in empowering people with SMI to manage their physical health (Small et al., 2017, Graham et al., 2013).

While the perspectives of mental health service users on different aspects of physical health, have been investigated, there is a need to further explore this topic through the lens of 'everyday life'. This study used an explorative and interpretative approach to investigate everyday life among a group of Danish people diagnosed with schizophrenia. The aim was to explore how this group managed physical health issues as they naturally occurred in everyday life. The knowledge gained from this inquiry can inform the types of support that might be helpful for people with schizophrenia who experience physical health issues.

Methods

Design

This study was based on an ethnographic approach as this is appropriate for studying the lives of people with schizophrenia at first hand (Hammersley and Atkinson, 2019). This approach informed the methods, and research activities mainly consisted of the primary researcher's (first author) participation in the daily social setting of participants and activities related to writing up observations (Hammersley and Atkinson, 2019). The study builds on social constructionism. According to this perspective, our understandings and constructions of the world sustain some patterns of social actions while excluding others. Implications of

this are related to what we perceive as expected behaviour in everyday life situations, and how we engage with the people around us (Burr, 2003). Ethnographic research is understood as *active*, as versions of the social world are continuously produced through research activities that are shaped by the socio-historical values and interests, as well as previous experiences, of the researcher (Hammersley and Atkinson, 2019).

Study context

The study was conducted in the North Denmark Region. The Danish health care system is a public service system characterised by a siloed organisational structure dividing general health and specialised mental health care (Bento et al., 2020). In this study, the participants' 'home' environments constituted the field of research. The field of research contained different physical locations and was shaped by the participants' activities of daily living (Hammersley and Atkinson, 2019). Two mental health care settings were selected for recruitment: 1) two mental health residential facilities, and 2) one outpatient clinic specialising in early intervention services to younger people with schizophrenia. In both mental health care settings, care was provided by multi-disciplinary staff, referred to in this paper as 'mental health care professionals' (MHCPs). At the residential facilities the main focus of care was social and long-term rehabilitation. This was reflected in the selection of employed staff which was mainly social- and healthcare assistants and social support workers with very few occupational therapists and nurses. At the outpatient clinic the focus of care was intensive treatment and support related to mental health issues, and staff mainly consisted of nurses, social workers, and occupational therapists.

Data collection

Participants

Purposeful sampling (Palinkas et al., 2015) of participants with a diagnosis of schizophrenia as per ICD-10, F20 (WHO, 1993) was used. Eligible participants were identified in collaboration with MHCPs (primarily social and healthcare worker, social support workers and nurses) involved in care delivery in the recruitment settings and were individuals who could be approached in their home environment and were able to share insights about their daily lives. Regional managers within the specialised mental health services and local managers at the recruitment locations authorised the study and recruitment of participants. Eligible participants received written and oral information about the study from the first author, individually or in a small group, before giving informed consent for participation. Nine participants were recruited. Eight participants provided written consent, while one preferred to provide oral consent.

Participants had been diagnosed with schizophrenia between 2 months to 27 years. Total scores from the Positive and Negative Syndrome Scale (PANSS) interviews (Kay et al., 1987) ranged from 51-109, (median: 82 (IQR: 67 – 101)). Four participants lived at residential facilities, and five participants lived in the community. All but two participants were male. Ages ranged from 21 to 70 years (median: 30; IQR: 25-55). At the time of the study, none were married or had children. All but one, were single. The four participants who lived at the residential facilities had lived there between 11 and 16 years. They had moved there from other similar facilities or directly from mental health inpatient wards. The five participants who were included through the outpatient clinic lived in private homes in the community. Two lived by themselves, while three lived in apartments shared with relatives or friends.

Data generation
Qualitative data generation methods were applied (Hammersley and Atkinson, 2019): participant observation documented in field notes; individual, semi-structured interviews; and informal conversations. For the individual, semi-structured interviews, interview guides were used to facilitate a structured conversation (Brinkmann and Kvale, 2015). The interview guides slightly differed for each interview as they were based on knowledge of each participant gained through the field work. The guides comprised of a brief introduction to the interview and a combination of various question types. These questions included: 1) Open-ended questions to initiate and facilitate conversation, e.g. *Can you tell me about what it means to you to be in good health?* 2) Probing questions to facilitate elaborations, e.g. *How does that typically play out?* or *Can you tell me a bit more about that?* and 3) Participant-specific questions about relevant topics or shared experiences related to situations in which physical health had appeared to be an issue, e.g. *Earlier, you told me that you sometimes worry about your physical health. Can you tell about what is on your mind when these worries occur?* This guided the interaction with each participant towards specific topics of interest while also leaving room for exploring topics brought up by participants during the interview (Brinkmann and Kvale, 2015).

Psychiatric interviews were conducted to provide an objective view of the mental state of the participants at the time of the study. PANSS (Kay et al., 1987) and Examination of Anomalous Self-experience (EASE) (Parnas et al., 2005) were used. These interviews included a range of descriptions and perspectives that were relevant to the focus of the study, and so the qualitative component of these interviews was included in the analysis along with the individual, semi-structured interviews and audio-recorded conversations. Table 1 provides an overview of the data material, which was generated from July 2016 to January 2018. Table 2 provides detailed information on duration of the interviews and conversations. All interviews were

transcribed verbatim and with indication of basic interactional features (Jefferson, 2004). Selected sections of the audio-recorded conversations were also transcribed verbatim. These sections were the ones where management of physical health as part of everyday life came into play.

[Insert Table 1]
[Insert Table 2]

Analysis

Analysis focused on description and interpretation of typical situations in everyday life involving management of physical health issues (Hammersley and Atkinson, 2019, Burr, 2003). Thematic analysis was conducted at a latent, interpretive level and consisted of six phases (Braun and Clarke, 2006):

Phase 1: *Getting familiar with the data material*.

This initial phase involved reading through transcripts and field notes and listening to audio-recorded conversations while writing memos.

Phase 2: *Generating initial codes, writing and developing memos*.

This phase entailed using a broad perspective to gain understanding of different components of everyday life and how physical health issues played a role. Codes were developed related to the different aspects of everyday life and initial thoughts on strategies employed by participants when managing physical health issues. Memo writing in this analytical phase included developing tabular overviews and rich participant descriptions based on the different data sources.

Phase 3: *Searching for initial themes by examining the written memos and coding of the material*.

Initial themes were developed across participants. The analysis became more narrowly focused on aspects of everyday life containing physical health issues. These included displays of symptoms causing severe impairment in everyday life, and aspects related to lifestyle and behaviour.

Phase 4: *Revision and further development of the initial themes*.

In this phase the scope of initial themes was further condensed with a narrower focus on key aspects related to participants' management of debilitating physical health issues. In this phase, the analysis moved from a broad descriptive form towards more detailed accounts of key aspects.

Phase 5: *Defining and naming the themes that dominated the data*.

Two dominating themes were defined, which entailed ways of managing debilitating physical health issues. Based on the extended contextual knowledge gained through the field work, the strategies employed to manage the physical health issues were interpreted as '*modifying'* and '*retreating'*

Phase 6: *Producing the report and writing up the themes*.

Creation of 'personas' was used as a method to write up the themes and illustrate patterned behaviour to manage physical health issues in the particular social contexts of the participants (Nielsen, 2019). The anonymised personas are presented as deidentified narrative exemplars that represent the experiences of participants (Foster et al., 2019) constructed using a collection of words and illustrative quotes from participants and extracts from the fieldnotes. This approach can provide rich contextual insights and strengthen the readers' engagement with the researchers' interpretations.

Ethics

The regional Research Ethics Committee concluded that the study did not need approval according to Danish regulations. The study was registered at the Danish Data Protection Agency.

The study is reported using the SRQR guideline for qualitative studies (O'Brien et al., 2014).

Findings

Two common patterns of managing physical health issues were identified. These patterns illustrate how some participants experienced various, ongoing symptoms of physical ill health and modified their way of life according to the symptoms to manage discomfort. Other participants experienced repeated discrete episodes of severe physical symptoms and tended to retreat from everyday life to recover (see Table 3). The management strategies used by participants are presented in the themes '*Modifying everyday life to manage discomfort*' and '*Retreating from everyday life to recover*'. The strategies to modify or retreat were adopted where participants experienced debilitating physical health issues which were characterised as limiting activities of daily living and participation in the world.

[Insert Table 3]

Modifying everyday life to manage discomfort

This theme illustrates how participants managed the symptoms associated with physical health issues by modifying their everyday life to minimise discomfort. This strategy was used by participants living at residential facilities, where the focus of care was social rehabilitation and interactions mainly occurred with other residents and MHCPs. The symptoms experienced by these participants were ongoing and related to existing conditions such as chronic obstructive pulmonary disorder (COPD), arthritis or severe constipation, or occurred in the absence of a diagnosed illness, for example, shortness of breath, numbness in the

extremities or difficulties when eating or drinking. These participants described themselves as generally healthy and were reluctant to speak about physical health issues or illness with the researcher. When physical health issues were noticeably experienced during field work sessions, they were passed off as 'nothing important'. The primary strategy was avoidance of situations with potential for discomfort caused by the physical symptoms. This meant avoiding certain situations, physical activities, places and foods. Consequently, activities of daily living were limited, however, these strategies to avoid discomfort induced control and maintained predictability in everyday life.

Jacob

Jacob was in his fifties and had lived at a residential facility for over 10 years. He was diagnosed with paranoid schizophrenia about 15 years ago and experienced frequent and severe episodes of psychosis and anxiety. He had been a smoker for most of his life. Some years back he broke his leg and due to limited rehabilitation, he was "*in pain almost all the time*". Generally, his mobility was limited, and most of Jacob's time was spent in his private room.

Jacob experienced various health issues. His "*lungs were worn*" and he struggled with "*a heavy cough*" and having to "*blow the nose*" again and again, particularly in the morning. On these mornings he described himself as "*not doing well at all*". Jacob also experienced frequent episodes of "*tightness in the chest*", "*shortness of breath*", and "*a rapid heartbeat*". In the main, these experiences contributed to a feeling of general discomfort, but sometimes he felt his entire chest "*locking, so that it is difficult to breathe*". Some of the symptoms Jacob experienced were triggered by walking short distances or lying down. Other symptoms, like "*a tingling sensation*" in his legs and feet, occurred in response to limited mobility and a lack of physical activity. Due to his experiences of discomfort and pain, he was very aware of the activities in his life, where they took place, and whether he thought it possible for him to participate. This applied to social activities as well as activities of daily living (e.g. attending meals in the common areas of the facility). He worried about walking distances and the potential presence of stairs or slippery sidewalks. Often, he declined to take part in activities that might exacerbate his discomfort and preferred to confine himself to the safe and predictable environment that his private room constituted. Even inside his private room, Jacob continued to make modifications to manage ongoing physical health issues. Due to the discomfort he experienced in relation to his breathing and limited mobility, he slept sitting up on the couch every night, instead of lying in bed.

Most MHCPs employed in the residential facility lacked general awareness about physical health care, as this was not the primary focus of their education and training. This potentially contributed to a lack of support for Jacob to manage physical health issues and a lack of recognition of the strategies he used to compensate for the impacts. The field notes illustrated this lack of awareness about physical health:

> "There are several conversations about the physical health of the residents among the staff today. Jacob's health is also addressed, as his condition has changed during the past weeks. His mental health has also changed, but particularly one MHCP, Betty, who is a nurse, points out that this has not caused the symptoms of poor peripheral perfusion that has been observed (Betty mentions great variation in oedema and fatigue). In Betty's opinion, there should be an appointment made with the general practitioner, and they need to discuss this with Jacob this morning […] Betty makes an effort to explain to the students in the room, that the symptoms mentioned have no direct connection to Jacob's mental state, when thinking of the pathology of poor peripheral perfusion, but that the general health condition just also seems to be changing. The tone towards the co-workers is quite hard (maybe even blaming). Betty seems frustrated that the observations made around the physical health condition of the resident, are dismissed as something that is just 'old news'. My experience is that they (the co-workers) believe that Betty is overreacting, while Betty believes that they are completely overlooking the risks related to Jacob's physical health condition" (Field notes, 23rd August).

Jacob did not generally complain about his physical health. Part of modifying his life to manage physical health, was to dismiss the health issues as "*nothing of importance*" and reject conversations about how the issues affected his life. Dismissal of health concerns was verified by the MHCPs who had limited interactions with Jacob about his physical health. Occasionally Jacob expressed worries about having "*something in the lungs or heart*". He wondered whether it could be "*some undetected and untreated illness*". When he shared these worries with MHCPs they were dismissed as unwarranted and the issues remained unchanged. As Jacob described it, "*some think I'm some kind of hypochondriac*".

Retreating from everyday life to recover

This theme illustrates how some participants who experienced re-occurring, discrete episodes of quite severe physical symptoms retreated from everyday life to recover. These symptoms comprised of stomach-ache, diarrhoea, severe nausea, vomiting, and dizziness, and were typically experienced as somewhat lengthy episodes that significantly impaired everyday functioning. Typical consequences were increased social isolation and pronounced decrease in ability to perform self-care and fulfil basic human needs. Participants described these episodes as also impacting negatively on their mental state.

Participants who retreated to recover lived in the community setting and had limited social network. Even though they were engaged in intensive outreach programs, their social setting enabled them to retreat from everyday life when they felt ill. The episodes were characterised by fast deterioration in health followed by the retreating behaviour. While participants recognised having somewhat poor physical health, they did not seek out help when episodes occurred. Consequently, any realisation about the person's deteriorating state of physical health occurred after the episode had started, at which time offers of support were largely rejected. The exception was MHCPs who were sometimes permitted to intervene in limited ways. The strategy of retreating to recover with minimal external intervention, was often repeated and resulted in lack of change to or worsening of the participants' state of physical health, with the potential for life-threatening or irreversible damage to their physical health.

David

David was in his late twenties, living in a shared apartment in an urban city area. He had been diagnosed with schizophrenia for one year and experienced difficulty with showing initiative, ability to plan and executing activities of daily life, and repeated episodes of anxiety. David was enrolled in the psychiatric outpatient clinic and had a primary case manager. David had a small social network who he had limited contact with, and generally lived a socially isolated life. David experienced repeated episodes of severe physical symptoms, which he called '*turns*'. He explained a turn as *"Simply one or two weeks where I just lie in my bed and throw up. And it is not particularly funny*". He explained how he "*endured a lot with the stomach.*" and described having "*a troubled stomach, stomach cramps and often going to the toilet and stuff like that*". In his experience, "*the worst thing about it is the nausea, really*". He would get "*really bad nausea and there's not really anything that I can keep down for about maybe a week or two*". These two weeks were: *"ten days where it is at its worst and then just about four days at the end, where I still feel nauseous and can't eat, but feel somewhat okay*".

When the symptoms occurred David would retreat and "*really just lie in bed all the time*". Almost no one was allowed into his home. He cancelled appointments and became less accessible to people, who found it difficult to get in touch with him. He explained that he was "*not able to do anything with the nausea*" and he would "*get a bit absent, if you can say it like that*", because he could not *"always manage to answer the phone. So, it can take a while for me to answer to texts and stuff like that*". Due to the severity of the symptoms, retreating became a way of managing the immediate situation as well as a strategy to recover over the longer term. A lack of control over the symptoms impacted on many activities of daily living and

for David this meant "*having trouble going out and getting groceries*" because he did not "*really feel up to It*". Consequently, he would eat "*whatever was in the home*". Tending to personal hygiene constituted an immense task that was too difficult to tackle, resulting in days or weeks without David having a shower or brushing his teeth.

David's 'turns' generally came to the attention of the case manager when David cancelled their appointments. Typically, these cancellations occurred when he had already become unwell and retreated to bed. When David's symptoms were at their worst, the case manager would provide intensive support to ensure that David's basic human needs were met. David explained that the case manager, "*well, practically feeds me (he laughs). You know, stuff-feeds me or forces me to eat anyway (he laughs). And brings my medication in here and makes sure that I get it […] she has been here three times a day when I'm at my very-worst*". He experienced this as "*a good help*", but also that it could be "*a bit difficult"* when the case manager *"comes here that much*". At these times, the case manager was the only person allowed into David's home and permitted to provide support. Anyone else in his social network was denied access. Their offers of help provoked anger and frustration as David could not manage others' attempts to support him when he was feeling unwell.

Even when each episode had resolved David's subsequent exhaustion had further impacts. Following an episode, it was "*really hard to get back into things. Really, really hard, you know, to get out the door and stuff like that. Because for those two weeks I just lie in bed. That is what I do. Maybe, if I'm feeling okay, I can watch some tv-series or something. But otherwise I just lie in bed. I just doze in and out of sleep*". David did not possess the energy to clean up during an episode and getting back on track when the episode resolved was very challenging. Field notes illustrate this:

"*The room bears a mark of another episode of David being sick and vomiting. On the bedside table there is a mountain of curled up toilet paper and paper towels. It looks like paper that has been used for blowing his nose. Additionally, there are popsicle sticks and ice cream wrappings on the bedside table. Next to the bed is the bucket that he vomits in when he feels sick. It has been emptied, but like at the last visit, there are dashes of vomit up the sides inside the bucket. On the table with the computer lies four emptied packs of chocolates, a pile of popsicle sticks, wrappings and some other trash (it looks like emptied food wrappings of different kind). The smell in the room is pungent. It smells like sweat and is very stuffy.*" (Field notes, 14th November)

Aside from retreating, David could not think of anything to make him feel better during the episodes; in his experience "*it just takes time*". He explained how "*it's just something I get, those turns. Once in a while. And then I just have to go through that time and get better".* David retreated "*because it was the easiest*" thing to do, but "*It's not really as if it has helped*". These recurring episodes "*hampered a lot of things*" in David's life and resulted in him "*not being able to do a lot of things*" that he would have liked to. Seeking out help as an alternative to retreating was challenging to consider. David recognized that he "*probably hadn't been that good at it*", and those times where he would seek advice from his general practitioner were usually when he "*was probably most of all pressed to do it (he laughs)*" by the case manager. However, he recognised that it was "*probably good that someone pushed*" him when he could "*not manage to do it*" himself.

Discussion

Key findings of this study highlighted two 'typical' strategies for managing debilitating physical health issues, characterised by *modifying* or *retreating*. Previous studies have described perspectives of people with SMI in relation to what they find meaningful and influential about healthy living, (Happell et al., 2016, Graham et al., 2013), and their experiences of health care services (Gedik et al., 2020, Stenov et al., 2020, Abed, 2010). Our study contributes to the existing body of literature by enhancing understanding of how self-management of physical health issues occurs in everyday life for a group of people with schizophrenia.

Modifying was employed to manage potential or actual discomfort associated with ongoing poor physical health, while *Retreating* was used by participants who experienced recurring discrete episodes of poor physical health characterised by fast deterioration. Both management strategies can be viewed as adaptive behaviour (Tasse, 2013) which is understood as a constellation of conceptual, social and practical skills that enable people to deal with different demands in everyday life. Adaptive behaviour essentially renders people invisible because the more skilled people become at adapting, the less they stand out to others (Tasse, 2013). While some adaptive behaviours may be effective in dealing with the natural and social demands of the environment, in this study, adapting behaviour was associated with potential negative consequences. Participants were at great risk of their physical health issues going undetected and subsequent slow deterioration in their health. As an enduring strategy, *Modifying to manage* physical health, in the absence of effective interpersonal communication, meant that relevant intervention and treatment was absent or delayed due to a lack of help-seeking. Managing by *Retreating* entailed fast deterioration and exclusion of care givers in the social network meant that potential negative consequences could be irreversible.

People with schizophrenia may experience changes in their adaptive competencies (e.g. personal care, language and communication, interpersonal skills) (Adelsky et al., 2011, Harvey et al., 1998). However, accounts of how reduced adaptive competence may impact on managing physical health issues in everyday life by people with SMI, has to our knowledge not previously been described. Further exploration of the types of adaptive behaviours that are helpful to people with mental illness to manage different aspects of everyday life, particularly physical health concerns, is needed.

Both of the strategies used by participants to manage physical health issues could be characterised as poorly-judged illness behaviour (Young, 2004, Mechanic, 1995). Understood as illness behaviour these management strategies provide insight into how participants experienced and defined symptoms of poor health, and how they (inter)acted to cope with them (Mechanic, 1995). Illness behaviour shapes our recognition of illness and has implications for patterns of health practices (Mechanic, 1995). To go through an illness experience refers to movement through critical transition stages and decision-making points in which the lack of help-seeking has consequences for prognosis and progress towards regaining health (Mechanic, 1995, Suchman, 1965). Our findings illustrate how *modifying* or *retreating* to manage debilitating physical health issues failed to produce any positive progress in terms of regaining health. Future research needs to explore aspects of beneficial illness behaviour among people with SMI. Relevant focus areas could include enhancing engagement in dealing with physical health and active help-seeking behaviours.

The social constructionist perspective and the ethnographic approach illuminated how the management strategies were sustained in the social contexts of the participants. Participants who *modified* to manage discomfort lived at residential facilities, where a lack of awareness and response to residents' physical health problems by MHCPs, was commonplace. Hence, the social context potentially promoted and reinforced their behaviour. Previous research in managing physical health issues among people with SMI has reported a need for MHCPs to prioritise physical health care (Lerbæk et al., 2020, Lerbæk et al., 2019, Berry et al., 2020, Butler et al., 2020). Consequently, MHCPs need to receive relevant education and training that will equip them to effectively work with mental health service users to manage the complexities associated with co-existing physical health issues (Lerbæk et al., 2020). The residential facilities in this study, focused care on social and pedagogical aspects of rehabilitation (Lerbæk et al., 2020). While this focus may be illustrative of Danish residential mental health settings, it also points to a need to explore how care that is contextualised to residential and rehabilitative settings is arranged, classified and understood in mental health practice more broadly. Drawing on Bister's (2018) work, there is a need to

consider how and why particular forms of care, for example, attention to physical health experiences, are in some way isolated from other care practices within the daily arrangements of residential mental health settings.

Participants who *retreated* to recover from recurring episodes of debilitating physical health issues were younger people living in the community. This setting constituted a social context in which opportunities to withdraw were easily sustained, particularly as support offered by family and friends was rejected. Support from MHCPs was generally only tolerated as a result of their persistence and intensive efforts. Social isolation is a well-known issue among people with SMI and constitutes a morbidity and mortality risk factor (Cacioppo and Hawkley, 2003). Social isolation also plays an influential role in mental health, psychological wellbeing and in the prognosis of recovery from psychotic symptoms (Wang et al., 2017). In our study, *retreating* constituted behaviour that entailed negative consequences related to physical health, but also resulted in increased social isolation and experiences of deterioration in mental health. Our findings illustrate how participants' decision-making in relation to illness behaviour (Suchman, 1965) remained unchallenged due to the lack of social interactions with others. This resulted in repeated patterns of behaviour. Future research needs to focus on exploration of beneficial interactional practices employed as part of everyday life.

Strengths and limitations

Ethnography is often small-sample research to promote the possibility for deep immersion into the social worlds of the people being studied (Hammersley and Atkinson, 2019). Therefore, triangulation of research methods, data sources and researcher perspectives was important for establishing trustworthiness of data and validation of the interpretations and conclusions made in our study (Hammersley and Atkinson, 2019). This study represents an example of small-sample research in which extended contextual knowledge contributed to the construction of in-depth descriptions and interpretations of patterns of social behaviour in everyday life. This enables the reader to assess how the identified management strategies are potentially relevant to similar contexts.

Conclusion

This study presented in-depth insight into two patterns of social behaviour related to the management of physical health in everyday life by a small group of people with schizophrenia. The study was exploratory and interpretative and therefore no specific interventions or solutions can be drawn from the findings. However, the descriptions, interpretations and discussion of the identified ways of managing physical

health have highlighted issues for future consideration. The strategies of modifying and retreating were inexpedient, and potentially caused worsening rather than improvements to physical health. People experiencing severe mental health issues should be offered services according to their individualised needs, supported to develop their health literacy, and educated in helpful adaptive competence behaviours to manage varied aspects of their illness experience. Physical health needs to be systematically addressed as an integrated part of everyday care and treatment, and this requires healthcare staff and organisations to be appropriately equipped.

Relevance for clinical practice

Participants with schizophrenia continuously used inexpedient strategies to manage debilitating physical health issues in everyday life. The social context of everyday life was characterised by a lack of interactions with others about their ongoing physical health issues. There is a need to ensure, that the adapting skills of people with SMI in relation to managing physical health does not result in 'invisibility' and delayed support and treatment. There is a shared responsibility embedded in the task of enhancing everyday life interactions between people with schizophrenia and people in their immediate social context, about physical health issues. Based on the findings of this study we recommend that MHCPs across different mental health care settings take an active role and responsibility in relation to addressing this task. We suggest working toward increasing general awareness about the presence and implications of physical health issues and integrating this into everyday work practices in a systematic, yet individualised manner. At an organisational level, there also needs to be enhanced understanding about the potential and actual needs of people experiencing coexisting physical and mental health issues, and strategies to build capacity among MHCPs and service users to address prevailing issues related to physical healthcare.

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Table 1: Overview of data material

Method	Participants (n)	Entities	Description of research activity	Data material
Participant observation	9	505 hours	Researcher's participation in everyday life activities	Field notes
Individual, semi-structured interviews	4	4 interviews	Semi-structured interviews informed by an interview guide, which was adjusted to fit the individual participant, based on knowledge gained through field work	Transcripts of interviews
Audio-recorded conversations	6	27 conversations	Informal, unstructured conversations with participants, exploring everyday life topics	Audio-recordings Transcripts of selected sections
PANSS[1] interview	8	8 interviews	Semi-structured interview based on standard interview guide	Transcript of interviews
EASE[2] interview	8	8 interviews	Semi-structured interview based on standard interview guide[3]	Transcript of interviews

[1] Positive and Negative Syndrome Scale (PANSS), see (Kay et al., 1987, Kay et al., 2001) [2] Examination of Anomalous Self-Experience (EASE), see (Parnas et al. 2005) [3] Conducted by JN

Table 2: Individual interviews, audio-recorded conversations, and psychiatric interviews

	Individual interview	Audio-recorded conversations	PANSS[1]	EASE[2]
Everyday life setting	Duration (h:m:s)	Duration (h:m:s)	Duration (h:m:s)	Duration (h:m:s)
Residential facility	N/A	0:08:52	0:54:03	0:54:31
Residential facility	0:30:42	N/A	1:04:01	0:42:30
Residential facility	0:26:14	0:26:06 0:27:44	0:33:37	0:28:46

		0:23:53		
		0:30:33		
		0:06:32		
Residential facility	0:34:45	0:44:26	1:02:48	0:48:44
		0:39:28		
		0:38:38		
		0:45:27		
		0:33:05		
		0:22:58		
		0:50:53		
		0:23:35		
		0:12:14		
		0:15:50		
Community		0:52:46	0:57:02	0:39:57
		0:29:54		
		0:09:01		
		0:19:19		
		0:28:29		
		0:14:27		
		0:09:37		
Community	N/A	N/A	N/A	N/A
Community		0:11:09	0:43:44	1:07:10
		0:06:34		
Community	0:19:02	N/A	0:34:53	0:48:44
Community		0:33:11	0:46:40	0:49:21
		0:07:31		

[1] Positive and Negative Syndrome Scale (PANSS) (Kay et al., 1987) [2] Examination of Anomalous Self-Experience (EASE) (Parnas et al., 2005)

Table 3: Overview of theme characteristics

Theme	Modifying everyday life to manage discomfort	Retreating from everyday life to recover
Overall symptom characteristics	Various, ongoing physical health issues	Repeated, discrete episodes of severe physical symptoms
Symptoms	• General poor physical health condition	• Stomach ache

	• Limited mobility • Pain (e.g. arthritis) • Severe constipation • Incontinence • Tightness in the chest • Shortness of breath • Rapid heartbeat • Discomfort or difficulties when eating or drinking • Heavy cough (COPD[1]-related) • Numbness and pain in lower extremities (PPP[2])	• Diarrhoea • Severe nausea • Vomiting • Dizziness
Strategy (participants)	• Modify behaviour to manage situations that trigger discomfort (avoidance) • Pass physical health issues off as nothing of importance • Worry about undetected physical illness	• Retreat to bed • Wait and see
Development	No improvement in health condition, slow deterioration of physical health Social isolation	Unchanged or worsening of physical health state (potentially life threatening) Increased social isolation Worsening of mental health Decreased ability to self-care (neglected personal hygiene, poor diet etc.)
Response (MHCPs[3])	• Limited response • No interventions to support improvement in physical health condition • Modifying behaviour is promoted • Rejection of service user's worries • Disagreements among MHCPs about the seriousness of the physical symptoms	• Intervention • Intensify services (frequency and form) • Support basic human needs (food, drink, sleep, keeping clean, essential medication etc.)
Pattern	Slow deterioration of physical health, ongoing modification to potential worsening of symptoms, limited response	Fast deterioration, repeated episodes, and repeated strategy and response
Potential consequences	Great risk of exacerbation of symptoms and potential deterioration	Potentially irreversible damage to physical health

[1] COPD: Chronic Obstructive Pulmonary Disorder [2] PPP: Poor peripheral perfusion [3] MHCPs: Mental health care professionals