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MANAGING PHYSICAL HEALTH ISSUES IN EVERYDAY LIFE

AN ETHNOGRAPHIC STUDY AMONG PEOPLE WITH SCHIZOPHRENIA

BY
BIRGITTE LERBÆK

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AALBORG UNIVERSITY
DENMARK

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by

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Curriculum vitae

Birgitte Lerbæk
RN, MSc in Health Sciences, PhD student at the Department of Psychiatry, Aalborg University Hospital and the Department of Clinical Medicine, Aalborg University, Aalborg.

Birgitte Lerbæk graduated from University College Lillebælt, School of Nursing in 2011, and finished the MSc in Health Sciences at the University of Southern Denmark in 2014. Since then, most of her work has been related to research and development projects within the Danish health care sector. Since the beginning of 2016, Birgitte has been working on her PhD at Clinic Psychiatry South, at Aalborg University Hospital and the Department of Clinical Medicine, Aalborg University in the North Denmark Region.

Birgitte has clinical work experience from different mental health care settings as a social- and health care worker and as a registered nurse.
General research interests are focused around exploring the current mental health care services from the perspectives of users and professionals, primarily using qualitative research methods. The objective of this research has been to gain insights, which can be used in improving care provision among those with severe mental illness. Previous research has focused on moral decision-making and identity work among case managers in assertive community treatment services.
Current research is focused on management of physical health in everyday life among people with schizophrenia.

English summary

Background: Excess mortality among people diagnosed with severe mental illness (SMI), and how this group is disproportionally affected by physical health, has been described as one of the greatest health disparities in contemporary society. Despite of several years of research reporting on this issue including possible causes and interventions to improve physical health among people with SMI, the issues remains. Schizophrenia is a severe and persistent mental illness that can cause serious disability in the mentally ill person's everyday life. Core symptoms of schizophrenia can lead to an altered experience of 'being', a lack of ability to interpret otherwise common-sense meanings in various everyday situations, and difficulties related to executive functions, such as planning and performing everyday activities.

Previous research has provided insight into the perspectives of people with SMI on physical health, healthy living, and on what they find meaningful when speaking of being healthy. Several of these studies have concluded that managing physical health issues in mental health care requires an increased focus and knowledge about the perspectives of those receiving the care, and about the factors that represent facilitators or barriers to dealing with physical health in everyday life. Recent research exploring physical health care provision report of a continued need to focus on existing unmet needs of the users, on the skills of the mental health care professionals (MHCPs) responsible for care delivery, and the motivation among MHCPs to address the issues as part of everyday care and treatment.

Aim: The aim of this research was to thoroughly investigate aspects of everyday life among a group of people with schizophrenia, to gain insight into how physical health issues were managed.

Methods: The research was designed as an ethnographic study and drew on social constructionism in a thorough investigation of the social worlds of a group of Danish people with schizophrenia. Nine participants with schizophrenia were recruited at two residential facilities (n=4) and at an outpatient clinic, providing treatment to younger people with newly diagnosed schizophrenia (n=5). The study was conducted in the North Denmark Region.

Qualitative methods were employed to explore the everyday life of the nine participants with schizophrenia, including; participant observation documented in field notes; individual, semi-structured interviews; audio-recorded conversations; and psychiatric interviews. Additionally, 27 mental health care professionals participated in three focus groups (n=22), as key informants in individual, semi-structured interviews (n=5).

Four analyses were conducted to explore the data material: 1) thematic analysis based on field notes, individual interviews and audio-recorded conversations, focused on exploring, describing and interpreting strategies used to manage physical health issues in everyday life among the participants with schizophrenia; 2) discourse analysis based on data materials from the focus groups, focused on examining situated accounts related to actions and responsibilities of MHCPs when dealing with physical

health issues in everyday practices; 3) thematic analysis based on individual interviews with five key informants, focused on key informants' experiences related to barriers to provision of physical health care in mental health care settings, and their suggestions about possible solutions to overcome existing barriers; and, 4) progressive focusing as an analytical process used to produce explanatory theory about management of physical health in everyday life by integrating key findings from the previous three analyses.

Findings:

The participants with schizophrenia experienced debilitating physical health issues in everyday life and two 'typical' strategies for managing these were identified. These were; *Modifying everyday life to manage discomfort* and *Retreating from everyday life to recover*. Both management strategies were inexpedient insofar as neither strategy resulted in transition towards better health. They were used repeatedly and constituted an ongoing process in which the individual sustained existing physical health issues and maintained the strategies used to manage them in everyday life.

The participants' management of physical health in everyday life was understood as social behaviour. The integrated findings present an explanatory theory to enhance understanding of the complex social processes that were enacted as part of the seemingly simple activities related to management of physical health in everyday life. The main impact of the interactional processes was related to sustaining physical health issues and the strategies used to manage these. Sustaining factors were identified as originating in three dimensions of social context. These were; 1) the *individual*; 2) the *immediate social context*; and 3) the *indirect social context*.

The findings describe some of the influential interactions that occurred between the sustaining factors within and across the dimensions of social context. Management of physical health issues with inexpedient strategies, was continuously sustained in the everyday life of participants with schizophrenia.

Conclusion:

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.

The sustaining factors were identified as interacting in complex, multi-dimensional processes in the social context of everyday life resulting in a deadlock in which management of debilitating physical health issues with inexpedient strategies, was continuously sustained among the participants with schizophrenia.

There is a need for future research that explores aspects of beneficial management of physical health issues among people with severe mental illness.

Dansk resume

Baggrund: Overdødelighed blandt mennesker diagnosticeret med svær psykisk sygdom, og uligheden i hvordan denne gruppe bliver ramt af fysiske sygdomme, er blevet beskrevet som en af de største uligheder i det moderne samfund. På trods af at mange års forskning har beskrevet disse omstændigheder, er overdødelighed fortsat et problem.

Skizofreni er en svær psykisk lidelse, som kan forårsage svær funktionsnedsættelse i hverdagslivet. Kernesymptomer ved skizofreni kan forårsage en ændret oplevelse af 'væren' i verden, manglende evne til at tolke og forstå ellers selvfølgelige betydninger i forskellige hverdagssituationer og vanskeligheder i forhold til at planlægge og udføre dagligdags handlinger. Forskning har givet indsigt i mennesker med svær psykisk sygdoms perspektiver på fysisk helbred, sund levevis og på hvad de synes, der giver mening for dem, når man taler om det at være sund. Flere af disse studier har konkluderet at håndtering af fysisk helbred i psykiatrisk pleje og behandling kræver et særligt fokus på og viden om hvad dem som modtager plejen og behandlingen mener, samt om hvilke faktorer, der faciliterer eller hæmmer håndtering af fysiske helbred i hverdagslivet. Nyere forskning, som har undersøgt behandling i forhold til fysisk helbred, rapporterer om et fortsat behov for at sætte fokus på brugernes uopfyldte behov for fysisk pleje og behandling, på de færdigheder som de sundhedsprofessionelle, der udøver denne pleje og behandling har, samt på deres motivation for at varetage pleje og behandling i forhold til fysisk helbred som en del af det daglige arbejde.

Formål: Formålet med dette forskningsprojekt var at foretage en dybdegående undersøgelse af hverdagslivets blandt en gruppe mennesker med skizofreni, for at opnå indsigt i hvordan problemer med fysisk helbred blev håndteret.

Metode: Studiet var designet som et etnografisk studie, der med udgangspunkt i socialkonstruktionismen udforskede en gruppe mennesker med skizofrenis sociale verdner med. Ni deltagere med skizofreni blev rekrutteret på to regionale psykiatriske bosteder (n=4) og i et ambulatorie, for mennesker med ny-diagnosticeret skizofreni (n=5). Studiet blev gennemført i Region Nordjylland.

Kvalitative metoder blev anvendt til at udforske hverdagslivet blandt deltagerne med skizofreni, inklusiv: deltagerobservation dokumenteret i feltnoter; individuelle, semi-strukturerede interviews; lydoptagelse af samtaler og psykiatriske interviews. Derudover, deltog 27 sundhedsprofessionelle i tre fokusgrupper (n=22), og som nøgleinformanter i individuelle, semi-strukturerede interviews (n=5).

Fire analyser blev udført i udforskningen af datamaterialet: 1) en tematisk analyse baseret på det etnografiske materiale, fokuseret på at udforske beskrive og analysere de strategier som deltagerne med skizofreni anvendte til at håndtere deres fysiske helbredsproblematikker i hverdagslivet; 2) en diskursanalyse, baseret på data fra de tre fokusgrupper, fokuseret på udforskning af deltagernes beskrivelser af deres handlinger og ansvar relateret til håndtering af fysiske helbredsproblematikker i deres daglige arbejde; 3) en tematisk analyse, baseret på interviews med 5 nøglepersoner.

Fokus i denne analyse var på nøglepersonernes erfaringer med den nuværende praksis i levering af fysisk pleje og behandling i psykiatriske kontekster og deres løsningsforslag til at overkomme de eksisterende barrierer; og 4) progressiv fokusering som analyseproces til udarbejdelse af en forklarende teori om håndtering af fysiske helbredsproblematikker i hverdagslivet, baseret på integration af nøgle fund fra de tre foregående analyser.

Fund:
Deltagerne med skizofreni oplevede forskellige helbredsproblematikker, der hæmmede deres hverdagsliv og studiet her fandt to typiske strategier som blev anvendt til at håndtere disse. De to strategier var; *Modificering af hverdagslivet for at håndtere ubehag* og *Tilbagetrækning fra hverdagslivet for at komme sig*. Begge strategier var uhensigtsmæssige, da ingen af dem førte til en forbedring af deltagernes helbred. De blev anvendt gentagende gange og udgjorde en vedvarende proces hvorved de fysiske helbredsproblematikker og brug af strategierne til at håndtere dem begge blev opretholdt.

Deltagernes håndtering af fysiske helbredsproblemer blev forstået som social adfærd. Fundene præsenterer en forklarende teori, som kan øge forståelsen af de komplekse sociale processer som fandt sted som en del af de tilsyneladende simple hverdagsaktiviteter, der knyttede sig til håndteringen af fysiske helbredsproblemer.

Interaktionelle processers primære indflydelse var relateret til opretholdelse af de fysiske helbredsproblematikker og strategierne som blev anvendt til at håndtere dem. Opretholdende faktorer blev identificeret som udspringende i tre dimensioner af social kontekst. Disse var; 1) *individet*; 2) *den nære sociale kontekst*; og 3) *den indirekte sociale kontekst*. Fundene beskriver nogle af de indflydelsesrige interaktioner, der fandt sted mellem de opretholdende faktorer i og på tværs af de tre dimensioner af social kontekst.

Konklusion:
Modificering af hverdagslivet for at håndtere ubehag var en strategi, som blev anvendt til håndtering af potential eller aktuelt ubehag i forbindelse med vedvarende fysiske helbredsproblemer, imens *Tilbagetrækning fra hverdagslivet for at komme sig* var en strategi som blev anvendt af deltagere, som oplevede gentagne, adskilte episoder med dårlig fysisk helbred karakteriseret af hurtig forværring. Begge strategier var uhensigtsmæssige, da de ikke førte til nogen forbedring i deltagernes helbredbredstilstand. Den social kontekst som var en del af deltagernes hverdagsliv var karakteriseret af manglende interaktioner med andre om deres eksisterende fysiske helbredsproblemer.

Fundene afspejlede en vedvarende kompleks interaktionel proces, som resulterede i en fastlåst situation, hvori fysiske helbredsproblematikker blev håndteret med uhensigtsmæssige strategier og forbedringer derfor udeblev. Karakteristisk var en mangel på interaktioner mellem deltagerne med skizofreni og centrale aktører i deres umiddelbare nærhed, omkring deres fysiske helbredsproblemer. Dette medførte manglende positive ændringer i deres helbredstilstand.

Gennem en integration af nøgle fund identificeredes nogle opretholdende faktorer som interagerede i komplekse, multi-dimensionelle processer i hverdagslivets sociale kontekst. Disse interaktioner resulterede i en fastlåst situation, hvor håndteringen af fysiske helbredsproblemer ved hjælp af uhensigtsmæssige strategier blev kontinuerligt opretholdt blandt deltagerne med skizofreni.

Der er behov for fremtidig forskning, som undersøger aspekter af gavnlig håndtering af fysiske problemstillinger blandt mennesker med svære psykiske lidelser.

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For the past four years, this research has been a very high priority in my life. The process has been a ‘game-changer’ for me, both personally and professionally. As some will know, my path towards this moment has been rather crooked and bumpy, but for some reason it all seems to be worth it in the end.

Even though it entails a lot of independent work, completing a PhD is not something you do by yourself. Many people have contributed to my PhD process in different ways, and I need to give thanks to some of them here.

First of all, I am truly grateful to the participants with schizophrenia, who agreed to take part in this research. I have been humbled by your hospitality and your willingness to share your private everyday life with me. I have done my very best to portray the realities of your lives, while also protecting your privacy. I hope you will find me worthy of your trust and engagement.

Also, I want to thank the mental health care professionals who have contributed through participation or by engagement in the research in other ways. This process has provided me with extended insights into the amazing work that is performed in everyday care and treatment. It has also raised questions about how current practices can be challenged, changed and hopefully become even better. I hope you will find the knowledge produced in this thesis relevant and useful to your future work.

I also extend a special thank you to Lotte, who I met several years ago in a completely different setting, and who became a pivotal collaboration and discussion partner during the time of this research. Thank you for all of the talks, reflections and discussions that we have shared related to mental health care and life itself.

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Jørgen Aagaard and Niels Buus were the inventors of this project, but it was turned over to me, and in collaboration with Rikke Jørgensen and Julie Nordgaard, we developed the initial research proposal. I thank you for trusting me with this research. I cannot imagine doing any other research as part of my PhD.

Andrea McCloughen and Marlene Briciet Lauritsen joined the project in 2018. I thank you both for your contributions and willingness to join in on this journey, even though it was already ‘halfway there’. Andrea, you have contributed with many valuable and knowledgeable comments and reflections since you joined the team. In addition, you have taken on an even larger role and responsibility as supervisor when I needed your support towards the end. It has been a great pleasure and I look forward to any future collaborations.

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I want to extend a special thank you to my PhD student-colleague at the Unit for Psychiatric Research, Helle Enggaard, for sharing the joys and frustrations of conducting research as a PhD student. I have enjoyed our talks, discussions, and sharing of this and that very much, and I hope to continue them far into the future.
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I also thank the Clinic for Internal and Emergency Medicine at Aalborg University Hospital, the Clinical Nursing Research Unit, my colleague Mette Geil Kollerup, and the group of post docs in clinical nursing, who have extended great support, time and patience, which made it possible for me to complete this process.

Finally, I want to express gratitude and thank you to my family and friends, who have endured the years of this research being a very high priority in my life. I am forever grateful for your never-ending support and understanding. I look forward to the many hours of catching up in the near future.
Thank you!

Birgitte Lerbæk,
March 2021

Thesis papers

Lerbæk, B., Jørgensen, R., Buus, N., Aagaard, J., Nordgaard, J., Lauritsen, M. B., McCloughen, A. Managing physical health issues by ‘modifying’ or ‘retreating’. An ethnographic study among a group of Danish people with schizophrenia. [*submitted*]

Lerbæk, B., Jørgensen, R., Aagaard, J., Nordgaard, J., and Buus, N. (2019). Mental health care professionals' accounts of actions and responsibilities related to managing physical health among people with severe mental illness. *Archives of Psychiatric Nursing*, 33, p. 174-181

Lerbæk, B., McCloughen, A., Lauritsen, M.B., Nordgaard, J., Aagaard, J., and Jørgensen, R. (2020) Barriers and possible solutions related to providing physical health care in mental health care settings. A qualitative study of key informants’ perspectives. *Issues in Mental Health Nursing* [e-pub ahead of print]

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Introduction

People diagnosed with severe mental illness (SMI) are reported to have poorer physical health, poorer access to health care services, and as being affected by unacceptable levels of excess mortality when compared to groups in the general population. Despite of several years of research into causes and interventions that might help improve the general health state among those with SMI, these serious physical health problems remain an issue of concern across clinical and political arenas.

The overall aim of the research conducted for this thesis, was to generate knowledge about everyday life among a group of people diagnosed with schizophrenia living in the North Denmark Region. The aim included a particular focus on how people with schizophrenia managed their physical health issues in an everyday life context. Different perspectives were sought to gain an in-depth understanding of what is at stake when dealing with physical health issues in the context of potential instability and unpredictability associated with a severe mental illness such as schizophrenia. Hence, the research presented in this thesis comprises of contributions from two important groups of stakeholders within the context of this research: a group of nine people with a diagnosis of schizophrenia, and a group of 27 mental health care professionals, who worked in mental health services and were engaged in the everyday lives of people with schizophrenia.

This thesis is to be understood as a representation of knowledge gained through the process of an outsider becoming immersed in and studying the everyday lives of others (Hammersley & Atkinson, 2019). This knowledge is considered relevant to health care professionals, organisations, and health authorities working in different mental health care-, general health care-, and/or policy settings, as it contributes with insights that can inform further development and implementation of health care services targeted people with schizophrenia.

An ambitious, long-term objective of this research has been to provide new perspectives and insights to the existing knowledge base related to people with a schizophrenia, their physical health condition, and the prevailing excess mortality levels, so that this population will have a chance of gaining longer and better lives. In continued attempt to reach this long-term goal, it is also the ambition to use the insights gained in further research within this area, when the PhD study is completed.

Thesis overview

The thesis describes the research conducted in the course of the PhD study (2016-2021). The Background section provides an overview of existing knowledge about schizophrenia, excess mortality among people with severe mental illness, structural issues related to mental health and physical health care services, the roles and attitudes of mental health care professionals in relation to dealing with the physical health of clients as part of their work, and the perspectives of people with SMI in relation to different aspects of health. This is part of the knowledge base that the thesis was built upon.

The next section introduces the epistemological position and theoretical perspective of the research. Then follows a presentation of methodology and methods. The Method and materials section include description of the field of research, participants and recruitment, and the data generation methods and analytical strategies employed in the study. As will be elaborated in the Methodology and Methods sections, the research conducted for this thesis was designed as an ethnographic study and qualitative research methods were used to generate data. The research is to be understood as one study comprising of four analyses using distinct analytical approaches.

Table 1: Overview of analyses and publications

Type	Title	Sample	Data material	Analysis
Scientific paper	*Managing physical health by 'modifying' or 'retreating'. An ethnographic study among a group of Danish people with schizophrenia*	n = 9 participants with schizophrenia	• Field notes • Individual, semi-structured interviews • Audio-recorded conversations • Psychiatric interviews	Thematic analysis, focused on latent and interpretative themes
Scientific paper	*Mental health care professionals' account of actions and responsibilities related to managing physical health among people with severe mental illness*	n = 22 mental health care professionals	• Transcripts from three focus groups	Discourse analysis, social psychological approach focused on 'accounts'
Scientific paper	*Barriers and possible solutions related to providing physical health care in mental health care settings. A qualitative study of Danish key informants' perspectives*	n = 5 key informants	• Audio-recordings of five individual, semi-structured interviews	Thematic analysis, focused on latent and interpretative themes
Thesis	*Managing physical health issues in everyday life. An ethnographic study of among people with schizophrenia*	n = 9 participants with schizophrenia n = 22 mental health care professionals n = 5 key informants	• Field notes • Individual, semi-structured interviews • Audio-recorded conversations • Psychiatric interviews • Transcripts from three focus groups	Progressive focusing and integration of findings across the three analyses

Table 1 provides an overview of how three analyses were conducted to explore the data materials, and a fourth analysis was conducted to integrate key findings of the previous three analyses. The three separate analysis conducted to explore the data materials have been described in scientific publications. Issues of the two published papers (Lerbæk, Jørgensen, Aagaard, Nordgaard, & Buus, 2019; Lerbæk et al., 2020) and a draft of the unpublished paper (Lerbæk et al., n.d.) are provided in Appendix A.

The subsequent section of the thesis is the Findings section, which provides summaries of key findings from the three separate analyses and presents the findings of the integrating analysis. Then follows the Discussion section, which includes discussions of the findings and of methods, including strengths and limitations of the research. The last parts of the thesis are the Conclusion, and Perspectives including implications for clinical practice and for future research.
Supplementary materials are provided in the appendices A-F from p. 127.

Chapter 1: Background

1.1. Schizophrenia: A severe mental illness

The research conducted for this thesis was informed by the significant public health issue of shortened life expectancy among people with a severe mental illness (SMI), and was specifically focused on the management of physical health issues in the everyday life of people diagnosed with schizophrenia (F20, ICD-10) (WHO, 1993). Schizophrenia is a severe mental illness, which can cause disturbances in a person's connection with the surrounding world (Parnas & Glenthøj, 2014). Even though the terms 'severe mental illness' or 'serious mental disorder' are commonly used in international research, they have not been clearly defined. Most commonly, they refer to psychiatric diagnoses such as schizophrenia, schizoaffective disorder, bipolar disorder, and moderate to severe depression. These conditions are persistent in severity and duration, and are associated with serious disabilities for the individual (NIMH, 2019; WHO, 2016, 2018). This research focused specifically on people diagnosed with schizophrenia.

Illness onset in schizophrenia typically occurs around 20-25 years of age among males, and late 20s to early 30s among women, and the prevalence is approximately 0.5 % (Parnas & Glenthøj, 2014; van Os & Kapur, 2009). Core symptoms of schizophrenia are characterised as 1) disturbances in the core structure of consciousness (autism), 2) expressive symptoms, which are related to behaviour, linguistic abilities and social interaction, 3) subjective symptoms, which are the inner experiences of the individual, e.g. ambivalence, self-disorders and emotional disturbance, and 4) psychotic symptoms, which are related to a disrupted sense of reality and include delusions and hallucinations (Parnas & Glenthøj, 2014). Anomalous self-experiences (or self-disorders) are central features of schizophrenia and can be characterised as a disrupted or altered experience of the 'self'. Subjectivity research within a phenomenological psychiatric tradition has focused on self-disorders as empirical phenomenon and how these are manifested in people's experiences (Parnas, Handest, Jansson, & Sæbye, 2005). Self-disorders can lead to an altered experience of 'being' (Henriksen & Parnas, 2014; Parnas, 2011; Parnas & Glenthøj, 2014), a disrupted sense of self-identity and a lack of ability to interpret and understand otherwise obvious or taken-for-granted meanings in various everyday situations (Parnas, Bovet, & Zahavi, 2002; Sass & Parnas, 2003; Zahavi & Parnas, 2014). People with schizophrenia can experience difficulties in sorting, interpreting and responding to internal as well as external stimuli. This can result in problems related to executive functions, such as planning and performing everyday activities, and in behaviour that might seem odd or maladjusted to people in the surrounding world (Parnas & Glenthøj, 2014).

Commonly occurring symptoms of schizophrenia such as lack of motivation, ambivalence and difficulties engaging in social interactions might prevent engagement with physical health services, and hence delay detection and treatment of physical illness among people experiencing these challenges. Altered or maladjusted behaviour related to physical health can be perceived by others as a lack of awareness of malaise or pain, as these aspects are considered obvious indications of physical health issues (Parks, Svendsen, Singer, & Foti, 2006; Torrey, 2013). These circumstances can manifest as illness behaviour that is considered different from the usual behaviour of people without mental illness, and can result in delayed help-seeking, poorer treatment options and poorer adherence to treatment (Crawford et al., 2014; De Hert, Cohen, et al., 2011; De Hert, Correll, et al., 2011; Knaak, Mantler, & Szeto, 2017). Thus, barriers associated with these issues are present at individual, intervention, and health systems levels (Melamed et al., 2019).

Different perspectives and implication related to the concepts of 'schizophrenia' and 'severe mental illness' will be addressed further in section *1.7. Theoretical concepts*.

1.2. Excess mortality among people with severe mental illness

International research has consistently reported serious excess mortality among people with SMI in addition to higher occurrence of physical health conditions and multi-morbidity (De Hert, Correll, et al., 2011; Kugathasan et al., 2019; Lawrence, Hancock, & Kisely, 2013). The life expectancy of those diagnosed with SMI is shortened by 13-30 years when compared to groups in the general population (De Hert, Correll, et al., 2011; Erlangsen et al., 2017; Jayatilleke et al., 2017; Wahlbeck, Westman, Nordentoft, Gissler, & Laursen, 2011). While unnatural deaths such as suicide and accidents are cited as pivotal contributors to this seriously shortened life expectancy, physical illness also constitutes a major contributor to this issue (De Hert, Correll, et al., 2011; Erlangsen et al., 2017; Wernlund & Aagaard, 2015). Physical illnesses are reported to account for almost three-quarters of all deaths among people with SMI, with cardiovascular disease representing the most common cause of death within this population (Holt & Peveler, 2010).

Several studies have focused on identifying the causes of excess mortality among people with SMI (Jayatilleke et al., 2017; Kugathasan et al., 2019; T. M. Laursen, Nordentoft, & Mortensen, 2014; Lawrence et al., 2013). An overrepresentation of risk factors related to lifestyle behaviour constitutes a major contributor to a higher prevalence of metabolic syndrome and onset of physical illness among people with SMI (Bartlem et al., 2015; McCloughen, Foster, Huws-Thomas, & Delgado, 2012; Parks et al., 2006; D. Scott & Happell, 2011; van Hasselt et al., 2013). This combination contributes to the excess mortality related to cardiovascular and respiratory diseases that is observed within this group (Erlangsen et al., 2017; Parks et al., 2006). Barriers to achieve lifestyle behavioural changes among people with SMI has been described as a combination of symptoms of schizophrenia, side effects from antipsychotic treatment and general life conditions such as social isolation (Hassan et al., 2020; Melamed et al., 2019; M. Nordentoft, Krogh, Lange, & Molkte, 2015).

Research has also focused on developing and evaluating various interventions aimed at improving physical health and changing risky lifestyle behaviours within this population. These interventions have targeted people with SMI in different settings including inpatient wards (Deenik et al., 2017; Deenik et al., 2019) and the home environment of the individual (Jakobsen et al., 2017; Speyer et al., 2016). Some of this research has been built on the assumption that the right intervention, if planned and introduced according to individual needs, would be successful in facilitating changes in lifestyle behaviour among people with SMI. Furthermore, that these changes would represent a turning point in relation to the gab of excess life-years lost that is seen between those with SMI and the general population. However, the studies have reported somewhat mixed results, and in particular, those studies focusing on specific and individualised interventions have failed to provide solid solutions (Doyle et al., 2019; Brenda Happell, Davies, & Scott, 2012; Jakobsen et al., 2017; Speyer et al., 2016). One example is that the mean effects of randomised controlled trials focusing on weight management among groups with SMI have been described as providing statistically significant, but clinically insignificant results (Speyer et al., 2019). Additionally, Danish research examining an individualised intervention for people with SMI concluded that life style interventions based on a narrow understanding of health and health promotion were not only ineffective (Jakobsen et al., 2017; Speyer et al., 2016), but that with such interventions there is also a great risk of creating adverse effects by inflicting feelings of shame, defeat and lack of acknowledgement on an already vulnerable group in society, if they do not succeed in achieving the proposed life style changes related to the goals of the intervention (Moltke, 2017).

1.3. Organisation of health care in Denmark

Many who are diagnosed with schizophrenia need intensive support to manage their everyday life, which, due to instability and frequent fluctuations in mental health state, caused by this severe and persistent mental illness, is characterised by uncertainties and unpredictability. Some people within this group are very likely to have continued contact with mental health care professionals throughout the course of their illness and their lives (Albus, 2012).

The general health care system in Denmark is a public system, which is financed through general taxes. The system is characterised by siloed organisational structure dividing general health care and specialist mental health care (Bento, Tagliabue, & Lorenzo, 2020). At the time of the study, the responsibility for managing mental health care services was divided between local municipal and regional health care authorities. A division which represents another aspect of the siloed organisational structure in the Danish health care system. The regional authorities were responsible for psychiatric hospital inpatient services and services specialized in outpatient care (various outpatient clinics). These services primarily focused on diagnosis and treatment in time-limited services (F. van Hoof et al., 2015). Responsibilities related to general residential care and social psychiatry were placed mainly with municipal authorities. The services provided were concerned with rehabilitation and maintaining everyday life (F. van Hoof et al., 2015). However, specialised mental health residential facilities were managed by the Special sector, which was part of the responsibilities of the regional health authorities. These residential facilities provided around the clock care for people with severe and persistent mental disabilities, who would typically also have several other disabling issues, such as severe and persistent physical disability or substance abuse. They provided intensive care to residents who could not be managed in the municipal social psychiatric service (Ministry of Social Affairs and the Interior2019).

The influence of body-mind dualism within current biomedical contexts promotes barriers to the treatment of physical health issues among users of mental health services (Switankowsky, 2000). This is illustrated in the organisation of health care in Denmark which, as mentioned above, includes an organisational separation of physical health care and mental health care, which facilitates fragmentation of these services. This separation inadvertently forces mental health care professionals (MHCPs) to prioritise mental health tasks in everyday care and treatment, resulting in a lack of attention to physical health in mental health care settings (B. M. Nielsen, 2018; Ministry of HealthSundhedsministeriet, 2017; Frank van Hoof et al., 2011). Diagnostic overshadowing is a known problematic phenomenon within health care systems internationally, which continues to contribute to delay in the detection of physical illness and in treatment of physical health conditions among those with SMI. Diagnostic overshadowing occurs when MHCPs overlook physical symptoms experienced by people with SMI by wrongfully interpreting them as related to symptoms of mental illness (Jones, Howard, & Thornicroft, 2008; Lawrence & Kisely, 2010; McNamee, Mead, MacGillivray, & Lawrie, 2013; Nash, 2013). Such practices are described as a characteristic of the stigma within the health care system, that is reinforced by negative attitudes among MHCPs (Jones et al., 2008; Nash, 2013).

The accumulating research reporting how those with SMI are disproportionally affected by physical health conditions, has for some years been the issue of political attention both globally and nationally in Denmark (Doyle et al., 2019; Gray, 2012; T. M. Laursen et al., 2014; M. Nordentoft, Krogh, et al., 2015; WHO, 2016, 2018). In the North Denmark Region, the regional health authorities responsible for mental health diagnostics and treatment services have described the physical health condition of those with SMI who engage with services, as a shared responsibility. Furthermore, they have proposed that aspects of physical health care provision should be an integrated aspect of overall care provision within the services. Despite the increased focus and these explicit expectations of care delivery, recent research has reported that people with SMI receive poorer treatment in relation to physical illnesses such as diabetes and heart failure, when compared to the general population in Denmark (Attar, Johansen, Valentin, Aagaard, & Jensen, 2017; Jørgensen, Mainz, Carinci, Thomsen, & Johnson, 2018; Jørgensen, Mainz, Egstrup, & Johnson, 2017).

1.4. Attitudes towards managing physical health issues in mental health care

The roles and attitudes of MHCPs in relation to management of physical health issues in mental health care, have been a focus of international research for several years. Some of the research has examined the contribution, responsibilities, and obligations of specific occupational groups such as psychiatrists (De Hert, van Winkel, Silic, Van Eyck, & Peuskens, 2010), general practitioners (Beecroft et al., 2001; De Hert et al., 2010; Oud et al., 2010; van Hasselt et al., 2013), and mental health nurses , see for example (Blythe & White, 2012; B. Happell, Scott, Platania-Phung, & Nankivell, 2012; Lundström, Jormfeldt, Ahlström, & Skärsäter, 2020). Mental health nurses have acknowledged the tasks related to management of physical health as part of their professional role in mental health care. However, the existing research reports ambiguity related to mental health nurses taking on these tasks, and uncertainty about whether they possess the skills and knowledge required to effectively address physical health issues (Blythe & White, 2012; Gray & Brown, 2017; B. Happell et al., 2012; Wynaden et al., 2016).

Some studies have focused on provision of physical health care in multi-professional groups such as MHCPs or case managers e.g. from assertive community treatment teams (Clancy et al., 2019; B. M. Nielsen, 2018). Examination of MHCPs' perceptions of physical health issues among people with mental illness showed an overall perception of poorer health conditions and higher occurrence of risky life style behaviour among those with SMI (Clancy et al., 2019). These physical health issues have also been reported in previous research, see for example (Bartlem et al., 2015; De Hert, Correll, et al., 2011; S. Leucht, Burkard, Henderson, Maj, & Sartorius, 2007). It was also reported, that regardless of these perceptions, the participating MHCPs tended to place the responsibilities related to management of physical health care within the primary care sector. MHCPs with occupational backgrounds in nursing and medicine presented with greater awareness of service policies related to management of physical health issues when compared to other occupational groups (Clancy et al., 2019). Some of the issues reported as suboptimal in contemporary general health care provision are inadequate assessments of physical health status, inadequate health promoting practices, insufficient provision of health-related advice to people with SMI, and inadequate referrals to external collaborators when needed (Bartlem et al., 2014; Bartlem et al., 2016; Crawford et al., 2014; Romain, Troitter, Karelis, & Abdel-Baki, 2020).

Attitudes of MHCPs towards providing physical health care have been reported as both positive and negative in mental health care settings (Bartlem et al., 2016; B. M. Nielsen, 2018; Wynaden et al., 2016) and remain a barrier to provision of adequate general health care within mental health services (Bartlem et al., 2016; Crawford et al., 2014). Negative attitudes held by MHCPs towards provision of physical health care to people with SMI are related to MHCPs experiencing lack of time and resources in everyday practice to perform physical health care tasks, and assumptions that those with SMI lack interest in achieving changes to lifestyle behaviours (Bartlem et al., 2016; B. M. Nielsen, 2018; Wynaden et al., 2016). Research has found that managing physical health issues was a marginalised area of care within mental health outpatient services. Taking on physical health issues in everyday care and treatment was found to disrupt stability in relation to fragile relationships with patients. Safeguarding relationships to patients was considered more valuable than complying to clinical guidelines regarding managing physical health in severe mentally ill persons. Therefore, such work tasks were de-prioritised or bended according to situational judgements of the MHCPs (Lerbæk, Aagaard, Andersen, & Buus, 2015; Møller, Møller, & Ledderer, 2020; B. M. Nielsen, 2018).

Research focused on the physical health care provided to people with SMI has also explored the perspectives of mental health service users. This research has identified high prevalence of physical health risk behaviour reported by people with mental illness, but also expressions of wanting to change this behaviour (Bartlem et al., 2015). Several studies have examined factors that service users experience as influential on healthy living (Abed, 2010; Graham et al., 2014), on what they find to be meaningful when speaking of being healthy, and what physical health actually means to them (Graham, Griffiths, Tillotson, & Rollings, 2013; Brenda Happell et al., 2016). Several of these studies have concluded that managing physical health issues in mental health care requires an increased focus and knowledge about the perspectives of those receiving the care, and about the factors that might facilitate or limit the possibilities for those with mental illness to deal with physical health in everyday life (Abed, 2010; Brenda Happell et al., 2016; Small et al., 2017). Additionally, some researchers have advocated for a holistic approach to care provision, that is based on broader understandings of physical health and the provision of more intensive support than current practices (Abed, 2010; Graham et al., 2013; Brenda Happell et al., 2016). Furthermore, some studies demonstrate that involving those with mental illness in development of care provision, can result in a process of empowering the participants in relation to managing their physical health (Graham et al., 2013; Small et al., 2017). Recent research exploring physical health care provision reports about a continued requirement to focus on existing unmet needs of service users, on skills of the MHCPs responsible for care delivery, and the motivation of MHCPs to address the issues as part of everyday care and treatment (Gray & Brown, 2017).

1.5. Summary

Excess mortality among people with SMI, and the existing inequality in health constitute a major public health problem in contemporary society (Chwastiak, 2015). Several factors related to structures in society and in health care systems have implications for the provision of physical health care to people with SMI. Inequalities related to allocation of resources in the healthcare sector, and the organisation of healthcare services are described as barriers contributing to people with SMI having poorer access to treatment of physical illness (De Hert, Correll, et al., 2011; T. Laursen, Munk-Olsen, Agerbo, Gasse, & Mortensen, 2009; Lawrence & Kisely, 2010; S. Leucht et al., 2007; Marmot, Friel, Bell, A J Houweling, & Taylor, 2008; M.

Nordentoft, Krogh, et al., 2015; Pedersen, 2009; Pedersen, Holst, Davidsen, & Juel, 2012; Sundhedsstyrelsen, 2013). Despite many years of research regarding causes and interventions for poor physical health, seriously shortened life expectancy among people with SMI remains an issue of global concern (Doyle et al., 2019; T. M. Laursen et al., 2014; NIMH, 2019; WHO, 2016, 2018).

The research conducted for this thesis took on an explorative and interpretative perspective that was based on encounters with the everyday life contexts of people with schizophrenia. These participants possess important opinions and knowledge about what constitutes physical health, and what is needed for this to become meaningful to them in everyday life. Even though the perspectives on different aspects of physical health of the mental health service users to some extent has been sought in previous research, there is a need to explore what goes on in everyday life at first hand. There is a need to gain an in-depth understanding of how physical health come into play in everyday life situations; How is physical health managed by people diagnosed with schizophrenia, and what factors influence on this in the context of everyday life. This exploration of everyday life provides insights that can be used in developing or adjusting the support that is provided to those with schizophrenia.

1.6. Aim and research questions

The overall aim of the research was to thoroughly investigate aspects of everyday life among a group of people with schizophrenia, to gain insight into how physical health issues were managed.

To reach this aim, the research needed to gain insight into the perspectives of a group of people diagnosed with schizophrenia, and of the MHCPs involved in everyday care and treatment in the home environment of the participants with schizophrenia.

The following research questions guided the investigation:

1. *What physical health issues are experienced by people with schizophrenia in their everyday life?*
2. *How do people with schizophrenia manage physical health issues in everyday life?*
3. *How do mental health care professionals account for everyday work related to managing physical health issues among people schizophrenia?*
4. *What are the factors that influence how physical health issues are managed in everyday life among people with schizophrenia?*

1.7. Theoretical concepts

This section introduces some of the main theoretical concepts used throughout the thesis. The purpose of presenting and briefly discussing these concepts is to provide the reader with insight into how these were understood and used throughout the research process. Drawing on a social constructionist perspective, this research built on the assumptions that we share some common ways of making sense of experiences and that different perspectives are equally important to the construction of experiences (Burr, 2003; Geekie & Read, 2009). The discussions below offer some reflections on how different perspectives came into play in relation to these selected concepts.

1.7.1. Schizophrenia and severe mental illness

Schizophrenia is a medical term originating from a traditional biomedical perspective, which describes schizophrenia as a severe and persistent mental illness, that can cause serious challenges in a person's contact with the surrounding world (Jablensky, 2010). People with schizophrenia may require a high level of contact with mental health services and substantial support to gain and maintain stability in everyday life. People diagnosed with schizophrenia can experience difficulties related to executive functions, such as planning and performing everyday activities, and might behave in ways that seem odd to others (Parnas & Glenthøj, 2014).

Severe mental illness is the collective name often used in the scientific literature when referring to mental health conditions such as schizophrenia, bipolar disorder, moderate to severe depression, and schizoaffective disorder. These mental health conditions are considered severe and persistent and can cause serious disability to the individual (van Duin et al., 2019).

As suggested in these brief introductions, the terms 'schizophrenia' and 'severe menta illness' are drawn from the dominant traditions of medicine and psychiatry. The terms does not adequately reflect the uniqueness and complexities associated with the lived experience of mental health problems and carries potential negative connotations in relation to recovery (Geekie & Read, 2009; Moncrieff & Middleton, 2015). A challenge related to the concept and diagnosis of schizophrenia includes that this clinical syndrome has come to represent 'everything psychotic' (Guloksuz & van Os, 2018). However, schizophrenia encompasses subjective experiences of symptoms and behavioural impairments (loss of functioning across various aspects of everyday life domains), and variable patterns in the course of illness (Guloksuz & van Os, 2018; Moncrieff & Middleton, 2015). Some suggest that in general terms, schizophrenia is characterised by unusual behaviour and unusual talk, and that equating schizophrenia or other mental health problems with illness or disease as any other condition originating in abnormal bodily function, becomes a way of exerting social control of unwanted behaviour (Moncrieff & Middleton, 2015).

It seems that despite the possible implications and a lack of clear evidence of such abnormal bodily functions in cases of this clinical syndrome, referring to schizophrenia in language of illness or disease is commonly accepted in clinical contexts and an object of academic consensus (Moncrieff & Middleton, 2015).

The terms are used throughout this thesis and the three papers because they reflects the language of the sites where the research took place, however I appreciate that these and other associated terms are contested (Guloksuz & van Os, 2018; Rosenberg, 2006) and subject to critical examination (Bister, 2018; Moncrieff & Middleton, 2015).

Throughout the thesis the term ‘severe mental illness’ will be used in cases where a broader perspective is addressed, for example if previous research has used this or similar concepts, is reported, or if participants have provided accounts that are not specifically targeted those with schizophrenia, but rather address those with severe mental illness in a broader sense.

Severe mental illness is abbreviated SMI in the thesis.

1.7.3. Health conceptualised as physical health

Health is a socially constructed concept that has been described as elusive and contested. Due to its abstract character, the concept of health is difficult to define in any precise way, as it holds different meanings to different people (Green, Cross, Woodall, & Tones, 2019). It is beyond the scope of this thesis to fully unfold the issues related to the concept of health and the different definitions, that has been suggested in the literature. However, selected aspects will be addressed.

In contemporary healthcare, the concept of health has been influenced by the medical model which entails a biomedical understanding of health as contingent on the absence of illness or disease (Farre & Rapley, 2017). As this research was conducted in settings which were influenced by contemporary mental healthcare practices, the polarise thinking about health and illness was not unfamiliar.

Some of the clearest distinctions between attempted definitions of health include whether focus should be on ‘well-being’ or on the beforementioned ‘absence of disease’ (Green et al., 2019). One working model of health includes the components of physical, social, and mental health. It is described to entail both positive and negative aspects and that these co-exist – meaning that well-being and disease co-exist, rather than exclude one another (Green et al., 2019). According to this model, being healthy is about balancing the three components of health – hence avoiding achieving high levels of social and mental health at the cost of ones’ physical health and vice versa. Health-related goals are dependent on individual preferences and influenced by societal values and norms. Achievement of good health is contingent on the individuals ability and empowerment to commit to a considerate way of life, that takes into account these three components of health (Green et al., 2019).

During its course, this research took on a somewhat polarised understanding of health, as the scope was limited to aspects of the participants’ everyday life that were associated with management of *physical health issues*. ***Physical health issues*** was held as an important concept throughout the process of conducting this research. The concept was gradually shaped through my interactions with the participants with schizophrenia and their knowledge and perspectives on what physical health and physical health issues comprised (Atkinson, 2015). During the study, *physical health issues* was condensed and contextualised as related to the presence of physical health symptoms and/or the presence of known physical health conditions, that caused limitations related to living everyday life. Consequently, it most of all became focused on physical *ill*-health. The use of the term *physical health* itself created a division between the biological/physical aspects of health and other psychosocial aspects that could be associated with being healthy or unhealthy (Blaxter, 1990; White, 2009).

As mentioned in the background, the influence of body-mind dualism and reductionist perspectives within prevailing biomedical contexts (Switankowsky, 2000) become apparent in the siloed organisation of healthcare services (Bento et al., 2020). My own education, training and work experience as a nurse was undoubtedly influenced by such mechanisms and the traditions of medicine and psychiatry. However, the choice to use the term *physical health* was related to the research objective of generating knowledge about how physical health issues, specifically, were managed. Exploration of health in a broader sense could generate equally important knowledge including aspects of social, psychological and spiritual health as well as physical health. However, exploration of these aspects of health were beyond the scope of this study.

The concept physical health as part of this research is further addressed in the discussion section (Chapter 6).

Chapter 2: Epistemological position and theoretical perspective

The epistemological position of the ethnography conducted for this thesis lies within constructionism. In constructionism, an important assumption is that the meaning we ascribe to the world that surrounds us, and the objects in it, is not something pre-existing waiting to be discovered. Rather, meaning is contingent on our social practices, and is constructed and shaped continuously as we interact with the world and the objects around us (Crotty, 1998).

From a constructionist perspective, knowledge represents versions of meaningful realities, and meaning-making is something that goes on in our interpretations of the world as our consciousness is engaged with it and with other people (Crotty, 1998).

To some extent, the research conducted for this thesis borders on the field of sociology as it is concerned with studying aspects of society in the form of social interactions, and patterns and culture of everyday life. Hence, a sociological theory of knowledge provided an appropriate framework for this research (Giddens & Sutton, 2012a, 2012b).

2.1. Social constructionism

Social constructionism is a sociological theory of knowledge which is concerned with development of social phenomena in social contexts. Within the social constructionist perspective, accounts in interactional language is understood as actively and continuously constructing versions of social reality. Three key aspects of social constructionism are that 1) Knowledge is socially constructed; 2) Language is essential to social construction; and 3) Knowledge construction is driven by historical, cultural and political notions. Knowledge being socially constructed also means that knowledge is sustained through social processes – that meaning is developed in coordination with other people (Burr, 2003). An overall understanding is that different versions of reality are continually constructed, negotiated, and reconstructed through the social interactions we engage in. In this way, our access to reality is through language (Gee, 2005; Potter, 1996). The processes of jointly-constructing versions of reality are influenced by central values and norms embedded in any particular social context, and hence, these are essential to the application of a social constructionist approach (Gergen, 1985, 2015). The role of language in social construction is related to the assumptions that rules of language-use shape our understandings of the world, and that language is never considered neutral, as language-use brings with it both resources and constraints in relation to our expressions and perception of the surrounding world. Understanding knowledge as driven by historical, cultural and political notions, is related how social constructs are depended on societal understandings. This aspect of social constructionism is concerned with understanding how people or groups of people develop and institutionalise social phenomenon, and how such phenomenon become accepted as natural or made into tradition (Burr, 2003).

Social constructionism seeks to understand the ways in which we are engaged in the construction of versions of reality, and how meaning associated with an object or certain behaviour is adopted by us in society. Another understanding within social constructionism is that social action and knowledge are inseparable. This means that our understandings of the world bring with it certain actions, and that our constructions of the world thereby sustain patterns of social actions. In the process of sustaining certain actions, other actions are excluded. The 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).

In this research, social constructionism provided a theoretical perspective for exploration and understanding of the meanings embedded in participant accounts, articulation and social behaviour related to managing physical health as part of everyday life.

Social constructionism is an interpretative theory focusing on the creation of meaning through language and social interaction, and on how meaning is ascribed to phenomena in social worlds (Crotty, 1998). In this ethnographic study, thematic analysis, discourse analysis, and integrative analysis were applied as tools to understand how the stakeholders interacting in the studied contexts constructed their experiences with managing physical health issues in their everyday reality (Galasiński, 2011).

Taking on a social constructionist perspective also implies that I, as researcher, took on an active role in the co-construction of the studied phenomenon (Hammersley & Atkinson, 2019). The meaning of this role and the influence that this has on the research is elaborated on in the sections further below.

Chapter 3: Methodology

A qualitative approach was used for this research as it provided frameworks to investigate behaviours and social interaction in specific contexts (Liamputtong, 2007; Pope & Mays, 2000). A qualitative approach represents a particular way of exploring the empirical world and focuses on the meaning that people ascribe to experiences or objects in their lives. It is an appropriate methodology when seeking knowledge about what people think and how they act in everyday surroundings (Taylor & Bogdan, 1998). The qualitative approach offered flexibility, which meant the research processes could be adapted according to the needs and challenges of everyday life for the participant group (Liamputtong, 2007).

3.1. Ethnography

The research was designed as an ethnographic study (Hammersley & Atkinson, 2019). The objective was to thoroughly investigate, describe and interpret patterns of social behaviour in everyday life of people with schizophrenia, with a specific focus on examining management of physical health issues in everyday life.

Ethnography is understood as a something to know as well as a way of knowing. The term 'ethnographic sensibility' refers to certain aspects of ethnography that makes it *ethnographic* – understood as distinct from being merely qualitative. These aspects are characteristic by being both embodied, empathetic and experiential in character (McGranahan, 2018). As McGranahan notes: "*An ethnographic sensibility requires depth and time; it is a theoretical commitment as well as a methodological practice. In that people's lives are a combination of the predictable and the uncertain, so too does ethnography, as a way of knowing about people's lives, tell us things that are also both predictable and not; it exceeds questions and answers, and its unique contribution is in that space of excess, of telling us more than we knew to ask*" (McGranahan, 2018, p. 7). This sensibility in ethnography refers to an attention to conditions of the way social lives are actually lived, and how it can become possible to gain access to it by attuning into shared worlds via participating in the social world of another (McGranahan, 2018). Ethnographic sensibility also refers to the understand that local or narrow views only can be understood via a broader one, and vice versa (Atkinson, 2015; McGranahan, 2018). An example from this research could be the way that an understanding of management of physical health was sought through exploration of everyday life in a broader sense. In this way, ethnography becomes a particular way of generating knowledge.

Previously, the ethnographic approach has been used to generate seminal knowledge through in-depth accounts of the lives of people experiencing severe mental disorders and the problems they face in inpatient settings (Goffman, 1961; van Dongen, 2004) and in the community (Estroff, 1985). Even though it did not focus particularly on managing physical health issues, the work of Estroff (1985) has been of particular interest to me in preparing for and conducting this research, as she provided insight into coping strategies used by people with severe mental illness to manage aspects of everyday life outside the mental health hospital (Estroff, 1985).

In contemporary research, the ethnographic approach is used in various contexts and by various disciplines such as educational research, health research, nursing research, and marketing research (Pelto, 2013). The term ‘ethnography’ tends to be used in different ways and therefore it is important to clarify how the term was understood and used in this thesis. In this study, ethnography was an approach used to describe and understand aspects of the social worlds of a group of people with schizophrenia (Emerson, Fretz, & Shaw, 2011). It is an appropriate approach when seeking to study what people do and the meaning of why they do as they do (Hammersley & Atkinson, 2019; Pelto, 2013). The use of the term ethnography has been described as closely related to the methods employed in the study (Hammersley & Atkinson, 2019) and the researcher is typically understood as the primary tool in generation of the data material (Hammersley & Atkinson, 2019; Lambert, Glacken, & McCarron, 2011). This understanding of the role of the researcher is in keeping with the assumptions of social constructionism and the co-production of data (Atkinson, 2015; Burr, 2003). The main activities in ethnographic research are related to the researcher’s participation in the daily routines of a social setting, and to writing, and otherwise documenting, what was observed, and learned about the setting, and the different actors interacting in it. Participating in the particular social context and documenting the work are interconnected activities (Atkinson, 2015; Emerson et al., 2011; Hammersley & Atkinson, 2019), and as will be described further in the following sections, they were practiced as such in the research process.

Taking an ethnographic approach is appropriate when studying the lives of other people using a first-hand perspective (Hammersley, 2006). Drawing on the theoretical perspective of social constructionism in the approach to do ethnography, I understood the social worlds of the participants as interpreted worlds, which are always undergoing social construction (Atkinson, 2015; Emerson et al., 2011; Hammersley & Atkinson, 2019). The study of these social worlds was undertaken while taking part in the everyday lives and activities of participants with schizophrenia, and by *getting close* to them, in the sense of being in close proximity both physically and socially to their daily activities (Atkinson, 2015; Emerson et al., 2011).

An ethnographic researcher seeks to become deeply immersed in the subject’s everyday life to gain a deeper understanding of this, from the inside. In other words, it is about getting to know how people live their lives, how they manage everyday activities, about getting insight into what they find meaningful, why, and how. With such ethnographic immersion, it becomes possible to achieve greater understanding of interactional and processual aspects of everyday life (Emerson et al., 2011). Immersion also provides access to experiences related to routines of everyday life, and the possible constraints or pressures that come into in play (Emerson et al., 2011). The process of getting immersed into the everyday lives of the participants with schizophrenia required particular attention to certain challenges and vulnerability caused by their mental health state. Dealing with the specific and individual circumstances, necessitated the use of a very flexible approach, as the participants mental health state required awareness of boundaries in relation to social interaction. Attempts to get close, both related to physical and social proximity, always involved careful consideration of the current state of mind of the individual participant, which could change within a moment and hence, potentially terminate an ongoing field work session. The ethnographic approach offered the flexibility to address such issues continuously (Hammersley & Atkinson, 2019; Liamputtong, 2007; H. M. Nordentoft & Kappel, 2011).

Another important aspect, when doing ethnographic research, is the inclusion of both participant (emic) and researcher (etic) perspectives. The latter represents an analytic perspective, which contains both descriptive and interpretative features, and often offers a different view on things being studies, than the ones held by participants themselves (Hammersley, 2006). The two perspectives underline the reflexive nature of an ethnographic approach. The knowledge gained from such research is based on the researcher's presence in the field, and that the data material is constructed in the processes of observing and interacting with participants. It is important to draw somewhat equally upon these two perspectives; however, the contribution and impact of the etic perspective cannot be denied. This is further emphasised by assumptions of meaning and social worlds being co-produced through interactions, held by the theoretical perspectives used this study (Hammersley & Atkinson, 2019; Lambert et al., 2011).

3.2. Reflexivity

Due to the reflexive nature of ethnography, the concept reflexivity needs to be addressed further. Reflexivity is a characteristic feature in all social research. It is concerned with how the social researcher always is part of the social world that is being studied, and that the social world and the people acting in it therefore are bound to be affected by the presence of the researcher (Hammersley & Atkinson, 2019; Schensul, Schensul, & LeCompte, 1999).

The ethnographic research process is understood as *active*, as versions of the social world is produced through the research activities performed. These activities are always in some way influenced or shaped by the values and interests that the researcher bring into the process. Hence, I - as researcher and primary tool of the investigation - am active in conducting selective observations and interpretation, through writing fieldnotes, asking questions and seeking an understanding of the social world of another (Hammersley & Atkinson, 2019).

By understanding the reflexive nature of ethnography and recognising how it is something that cannot be avoided, the ways in which you effect the social world and people being studied can become more clear (Hammersley & Atkinson, 2019).

As reflexivity is embedded in all aspects of ethnographic research, an ongoing self-reflexive practice is essential. An example of this is related to the process of entering the field of research. This involved a process of me transforming into the primary tool of data generation and finding my way in this role in shifting contexts. Entering the field of research requires that you become able to function in a culturally competent manner. Even though the impact I had on the context was unavoidable, I sought to minimize the influence of my presence in the settings, as people then would be more likely to behave as they usually would do in everyday life situations. The process of entering the field calls for careful and ongoing reflection about the meaning of experiences and on behavioural transformations that might be required to fit in (Schensul et al., 1999).

Throughout the thesis, I will address issues related to reflexivity in order to clarify aspects of my own ongoing self-reflexive practice. As a first step, I will provide some insight into aspects of my personal and professional background which has played a role in my encounter with and immersion into everyday life of the participants with schizophrenia.

3.2.1. My personal and professional background

For several years, I have had personal and professional interest in the experiences of people with mental health issues and the services provided to people with severe mental illness – including the provision of general health care to people affected by severe mental illness.

Taking on this research, I brought with me a professional background as a social and healthcare worker and as a registered nurse. I have worked in different Danish mental health care settings, including a residential facility settings similar to the one included in this study and various inpatient wards treating people experiencing acute worsening in their mental health state.

Previous research has also been focused on mental health care services provided to people with persistent and severe mental illness who were enrolled in assertive community treatment programs.

Based on these previous experiences, I had gained a general understanding of mental illness experiences, of care services and potential stakeholders. To some extent, I was also able to draw on previous experiences in relation to how I would be able to establish relationships with participants and other actors in these particular social contexts.

My knowledge about mental health issues and mental health care settings, necessitated an ongoing process of becoming aware of and challenging my assumptions about what might be at stake in the management of physical health issues in everyday life of the participants with schizophrenia. By being aware of preconceptions and being able to challenge them allowed an openness towards unanticipated aspects of the social world of the participants.

In some of the sections following further along in the thesis, I will elaborate on how my knowledge base about this field of research has influenced my role as researcher doing ethnography.

Chapter 4: Methods and materials

The following sections provide introduction to methods and materials and include description of the field of research, study context, participants and recruitment, ethical considerations and the qualitative data generation methods used in the study.

4.1. Field of research

This section will introduce the two mental health care settings, that were the starting points of the field work I conducted as part of this research. In this study, the field of research was understood as the natural setting where I would be able explore everyday life of a group of people diagnosed with schizophrenia. In other words, it was the locations where everyday life of these participants played out (Schensul et al., 1999). Hence, the field of research covered various physical places and varied according to the life of each participant. At the time of the study, these participants were in contact with the Danish mental health care services, either through enrolment in treatment services or as residents at mental health care residential facilities. To gain access to these settings of everyday life, it was decided to recruit participants with schizophrenia from the following two mental health care settings: 1) from two mental health residential facilities, and 2) from one outpatient clinic specialised in early intervention services for young people with schizophrenia. These settings were chosen because their target populations represented residents and patients who were currently living in what was considered to be their ‘home environment’. Hence providing a potential gateway to the everyday life of people with schizophrenia. For some participants, ‘home’ was comprised by a private room at a residential facility. For others, ‘home’ was represented by a room in a friend’s or relatives’ apartment, their own apartment, or a room at a student dormitory.

4.1.1. Study context

To provide the reader with an understanding of the contexts of everyday life and of the support provided to the participants with schizophrenia by the mental health care services in these contexts, the two mental health care settings will be described in the following.

The two mental health care settings described here, represented the starting point of the field of research in the study, as they were the places selected for recruitment of participants with schizophrenia. The services that was provided in these settings played a pivotal role in achieving and maintaining stability in everyday life among the participants with schizophrenia. They are described in some detail, as the settings and the MHCPs working within them became the gateway and gatekeepers through which participants with schizophrenia were reached.

An overview of the two settings is provided in Table 2:

Table 2: Overview of mental health care settings selected for recruitment

	Residential facility	**Outpatient clinic**
Description	Specialised in providing care to people with severe and persistent mental health disabilities. MHCPs worked in three shifts, that covered day, evening and night. Verbal and non-verbal handover between shifts was normal practice. The facility was part of the regional mental health services under the Special Sector. The facility did not practice in accordance with one specific approach to care delivery, but incorporated recovery and rehabilitation as recurring key approaches. User involvement in care planning was an important aspect of practice, to ensure that each resident's perception of 'a good life' was considered in the planning process.	Specialised in providing early and individualised interventions to prevent or minimise the potential negative impacts that symptoms of schizophrenia might induce on everyday life. The service was available on weekdays from 7.30am to 4.00pm. It comprised of a high intensity care programme (frequent contacts, group-based activities), and used a persistent and assertive approach. The service offered frequent contact with a primary case manager, an overall effort based on individual needs, medical treatment, group-based activities, psychoeducation, and support related lifestyle behaviour. The outpatient clinic was part of the diagnostic and treatment related mental health services.
Mental health users	Users were referred to as residents. Age range of residents: 18-75 years Residents experienced great difficulties in managing everyday life and hence, needed individualised care to maintain stability. They were referred to the facility by municipal authorities, and a municipal social worker would evaluate the residents service needs once a year based on a report from the facility.	Users were referred to as patients. Age range of patients: 18-35 years. Patients had been diagnosed with schizophrenia recently and had been treated with antipsychotic medication for no more than three months prior to enrolment in the service. Patients were referred through other mental health care services or the general practitioner[2].
Staff	An interdisciplinary group of MHCPs[1], which comprised of social- and healthcare workers, support workers, nursing assistants and nurses, with social- and healthcare workers and support workers being the dominant professions.	An interdisciplinary group of MHCPs, which comprised of nurses, psychologists, social workers, and occupational therapists. A chief physician was in charge of the medical treatment.
Primary professional resources	Social rehabilitation and pedagogical approaches	Health care
Interactional contact	Team-based approach with one MCHP as primary contact person. One MHCP was appointed the task as 'daily contact person' in each shift. In theory, MCHPs and residents could meet several times a day, however, frequency of encounters depended on whether the resident was present in the common areas. In some cases, weekly appointments were scheduled e.g. in relation to cleaning or doing laundry.	Team-based approach with one MHCP as primary case manager. The primary case manager was responsible for contacts with the patient. The team functioned as 'partners for discussion' on specific issues. In this way, the different occupational backgrounds of the team came into play when needed. Patient and the primary case manager would meet once a week. Flexibility in the approach made it possible to increase the frequency of visits when needed.

		Telephone consultations were commonly used.
Engagement with the service	Unlimited, when the resident was considered eligible to the service by the municipal authority	Time-limited, two-year service

[1] MHCPs: Mental Health Care Professionals [2] The uptake area of the outpatient clinic covered the North Denmark Region (population: 589.936 in 2020, area: 7.887 square kilometres)

4.1.1. Residential facilities

Two mental health residential facilities in the North Denmark Region were selected as places to recruit participants with severe and persistent schizophrenia (ICD-10, F20) (WHO, 1993). These facilities were specialised in provision of long-term and around-the-clock care to people, who due to severe and persistently reduced physical or psychiatric capability needed comprehensive care and support to manage everyday life. Residents were referred to these facilities by their home municipality, when the municipality was not able to provide the needed support (Ministry, 2019). At the time of the study, there were six facilities aimed at providing these mental health services in the North Denmark Region. The selection of the two included facilities was based on research into the differences and similarities of the existing facilities, combined with a pragmatic aspect related to the geographical accessibility of the facilities. Information on each of the six facilities was gathered from the facilities' official webpages and through telephone conversations with the local managers.

At the time, the two included facilities provided housing for 73 residents (46 and 27 residents, respectively), and their age range was from early twenties to late seventies. The residents at both the chosen facilities were mainly people diagnosed with a severe mental illness. Several residents in these facilities had serious competing problems such as drug and/or alcohol abuse or severe physical disabilities. According to the local managers, the main reason for referral of more than half of the residents were disabilities linked to schizophrenia. They also described residents as presenting with very complex conditions.

MHCPs employed at the two facilities were social and health care workers, support workers, occupational therapists and nurses, with social and health care workers being largest group in both facilities.

Both facilities were placed in rural areas of the region. They were organised as housing facilities with staff employed specially to deal with main tasks related to cleaning and cooking. The facilities were designed with common areas which represented eating areas, a kitchen and sitting rooms. Also, every resident had a private room and bathroom. Much of the everyday life and activities of the participants with schizophrenia were played out in these surroundings.

From these two residential facilities, four participants with schizophrenia were recruited. Two from each facility.

4.1.2. Outpatient clinic

Recruitment also took place at an outpatient clinic aimed at providing early intervention and treatment to young people with newly diagnosed schizophrenia. This type of outpatient service was introduced in several places across Denmark from the 1990s (M. Nordentoft, Melau, et al., 2015). The target population in this particular clinic was young people between 18-35 years of age, recently diagnosed with schizophrenia, and who had been prescribed psychopharmacological treatment for no more than three months. The outpatient clinic offered an intensive, time-limited two-year service, which entailed close collaboration with one primary case manager and a multidisciplinary team of health care professionals. The team consisted of nurses, clinical psychologists, occupational therapists and social workers. At the time of the study, nurses were the largest professional group. The team also included a psychiatrist who was responsible for the medical treatment for schizophrenia. In addition to treatment and support for management of everyday life in general, the service also offered psychoeducation programs on schizophrenia, and counselling related to illness prevention and healthy living in everyday life.

Patients were referred to the clinic by any other psychiatric service (e.g. other outpatient services or inpatient wards) or by the general practitioner (through a central psychiatric referral and assessment service). The geographical uptake area for this clinic was the entire North Denmark Region. The main offices of the service were placed at the psychiatric hospital in the capital city of the North Denmark Region. Patients lived in their own home in the community, and contacts with the service took place in various places directly related to the outpatient service, in the patient’s home or other places related to the services provided to the individual (offices of the municipality, place of work, general health care wards, general practitioner consultation, the local grocery store, pharmacy etc.). Five participants with schizophrenia were recruited from this mental health care setting. Even though the participants were recruited through the outpatient service, the social context of their everyday life will be referred to as a community setting, as the outpatient clinic in itself, only was considered to be a part of the whole that constituted the social setting of everyday life of these participants.

4.2. Participants and recruitment

The research comprised in this thesis included different groups of participants that each contributed with different perspectives on how physical health issues are managed in the everyday life of people with schizophrenia. A pivotal source of knowledge about this issue was the participants with schizophrenia. However, during the time spent with these participants, two other groups were identified as potentially able to provide valuable contributions to the research. These were MHCPs, who in their everyday work had contact with people with severe mental illness, and a small group of key informants (Pelto, 2013) who had special interests and experience related to the area of managing physical health in mental health care. In the following section, these three groups of participants are described as well as how they were recruited and contributed to the research.

4.2.1. Participants with schizophrenia

Purposeful sampling (Palinkas et al., 2015) was used to recruit nine participants with schizophrenia (ICD-10, F20)(WHO, 1993) into the study. Ethnographic research is considered small-sample research, and the relatively small sample is appropriate to facilitate the in-depth investigation of the studied social behaviour (Hammersley & Atkinson, 2019). The choice of eligible participants was based on their potential to provide thorough insights into their everyday life. MHCPs in both recruitment settings were important gatekeepers and collaboration partners in the process of including participants with schizophrenia.

The purpose of sampling in this study was not to achieve a group that could be considered representative of the population of people with schizophrenia. Rather it was to include a selection of information-rich participants, who were considered especially knowledgeable about the topic being researched (Palinkas et al., 2015). Based on these considerations, four participants were residents from two mental health residential facilities in the North Denmark Region, and five participants were patients of the early intervention outpatient clinic in the same region. The group included seven males and two females. These participants were considered the primary source of knowledge related to management of physical health in everyday life.

Additional characteristics on the participants is provided in Table 3.

At the time of the study, all but one of the nine participants were single. None were married or had children. 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. Four of the nine participants went through one or more admissions to a psychiatric inpatient ward during the time of the study due to acute worsening in their mental health state.

Table 3: Characteristics of participants (P) with schizophrenia

	Setting	**Age**	**Source of income**	**Substance use**	**Mental health diagnosis**	**Time since onset of schizophrenia**[1]
P1	Residential facility	57	Early retirement benefit	No	Paranoid schizophrenia	27 years
P2	Residential facility	70	Retirement pension	No	Schizophrenia	51 years
P3	Residential facility	37	Early retirement benefit	No	Schizophrenia (unknown specificity)	16 years
P4	Residential facility	55	Early retirement benefit	No	Paranoid schizophrenia	Unknown
P5	Outpatient clinic	25	State educational grant	No	Paranoid schizophrenia	2 months
P6	Outpatient clinic	27	Unknown	Yes	Paranoid schizophrenia	2 months
P7	Outpatient clinic	30	Unknown	Yes	Simple schizophrenia	2 years
P8	Outpatient clinic	25	Social security	Yes	Paranoid schizophrenia	Unknown
P9	Outpatient clinic	21	Social security	Yes	Paranoid schizophrenia	2 years

[1] Self-reported by participants,

People with a severe mental illness, such as schizophrenia, are considered part of a vulnerable group in contemporary society, and researching aspects of their everyday life at first hand, proved to be challenging (Liamputtong, 2007). As the objective of sampling was to avoid excluding potential participants because of this vulnerability (Kristensen & Ravn, 2015), only a few exclusion criteria were defined prior to the recruitment process. These criteria were based on aspects concerned with safety for both the participants and me, as the researcher. More specifically, the exclusion criteria were defined as persons with schizophrenia experiencing acute psychotic episodes involving unpredictable or potentially dangerous behaviour. Furthermore, a person would not be eligible for participation if he or she were under guardianship or were unable to provide informed consent. The complexities related to conducting research and attempting to get involved in everyday life of people experiencing ongoing instability due to mental illness, will be addressed further in the sections below describing the data generation methods, ethical considerations and in the discussion.

4.2.2. Mental health care professionals

In close collaboration with local managers at the recruitment settings, MHCPs who were engaged in everyday care and treatment of people with SMI were invited to participate in focus groups. The objective with the focus groups was to gain insight into the MHCPs perspectives on managing physical health issues among residents and patients as part of their everyday work.

In total, 22 MHCPs agreed to participate and three focus groups were conducted from December 2016 to January 2018. This purposive, non-probability sample consisted of MHCPs with different occupational backgrounds. Their employment in the clinical settings ranged from 5 months to 38 years. The majority of participants were women (n=17).

Further information on the three focus groups and the participants is provided in Table 4 (Lerbæk et al., 2019).

Table 4: Focus groups and participants

Focus group	**Setting**	**Duration** (h:min)	**Partici-pants** (n)	**Occupational groups** (n)	**Age** Median [IQR][1]
1	Residential facility	1:27	9	Registered nurse (1), Nursing assistant (1), Social education worker (1), Residential support worker (1), Social and health care worker (4), Student (1)	55.5 [55-59][2]
2	Residential facility	1:38	7	Registered nurse (1), Residential support worker (2), Social and health care worker (3), Student (1)	38 [32.5-47.5][3]
3	Outpatient clinic	1:44	6	Registered nurse (3), Psychologist (1), Occupational therapist (2)	48.5 [35-51]
Total		4:50	22		51 [36.5-55]

[1] IQR = Interquartile range, [2]Information on age of three participants was not available, [3]Information on age of 2 participants was not available

(Lerbæk et al., 2019)

The focus groups were conducted so that participants joined a group with everyday colleagues, and the location of each focus group was the workplace of the participants. Conducting these focus groups was planned so that participants could take part in the research during their normal working hours.

4.2.3. Key informants

This group of participants were MHCPs who either presented themselves as having a special interest and experience in relation to the area being studied, or who were suggested by others as having specific knowledge about physical health issues or health and illness behaviour among people with SMI. This group of participants were referred to as ‘key informants’ (Pelto, 2013; Schensul et al., 1999). A key informant was defined as someone presenting with special interest in the topic being studied, and possessing information, that is not considered general knowledge in the social setting. The ability and willingness to reflect critically on current provision of health care were essential characteristics of the key informants, as their role was to assist me, as researcher, in achieving insider information about behaviours and beliefs embedded in the settings, cf. (Pelto, 2013; Schensul et al., 1999).

The objective of conducting these interviews was to explore the MHCPs' perspectives on how physical health was managed in the context of mental health care. They all possessed insider knowledge about the included mental health contexts. These participants were of particular interest to this research, because they could provide knowledge about the health and illness related behaviours of people with SMI of how the mental health contexts would attempt to manage physical health issues of people with SMI in everyday work.

When working with key informants in a qualitative study, it is difficult to specify in advance how many participants are needed. This depends on the particular study, the opportunities that present in the settings, and the knowledge gained in the interviews. An important aspect of identification of key informants, was to aim for breadth. Not in attempt to achieve a representative group, but rather to achieve breadth of knowledge in relation to the topic being studied (Pelto, 2013; Schensul et al., 1999). Five MHCPs were identified as potential key informants, during the field work sessions. They were approached, informed about the study, and invited to participate in individual, semi-structured interviews. All five agreed to participate. The group of key informants comprised of two nurses, two social support workers and one physiotherapist, and all were experienced in working with care and treatment of people with schizophrenia. At the time of recruitment, they were all employed in the two mental health care settings. Their previous professional experiences were related to general health and mental health care, such as at a general practitioner's practice, in psychiatric inpatient wards, in care facilities for physically disabled, providing care and treatment across a larger mental health organisation, as volunteer worker in the community, and at residential facilities. Two participants had completed additional courses on educational psychology, managing issues related to dual diagnosis, and advanced mental health nursing. The group consisted of four women and one man, and the age range was 34 to 55 years. The group represented extended knowledge about a broad segment of health care provision and organisation of health care across different settings and sectors.

Further information on key informants and the individual interviews is provided in Table 5 (Lerbæk et al., 2020).

Table 5: Overview of key informants (KI) and individual interviews

KI	**Employment setting**	**Special interest**	**Duration** (h:min)
1	Residential facility	Initiating and conducting smaller projects focused on diet and exercise in everyday life at the facility	0:47
2	Regional health service	Management of complex issues among people with SMI, e.g. severe mental illness and physical co-morbidity, substance abuse, and managing medical treatment	0:51
3	Residential facility	Actively engaged in planning of various activities focused on health and well-being among people with SMI, e.g. exercise, runs, group activities related to preparation of food, and nature experiences	1:26
4	Residential facility	Previously involved in projects focused on diet and exercise in everyday life among people with SMI	1:11
5	Regional health services	Working with physical health and bodily experiences of people with SMI.	0:57
		Total	5:12

(Lerbæk et al., 2020)

4.3. Ethical considerations

The study was presented to the regional Ethical committee, who responded that according to Danish regulations their approval was not necessary for the study. Reply from the regional ethics committee is provided in Appendix B.

The Danish Data Protection Agency was notified about the study (journal no. 2008-58-0028, id. 2016-50) and regulations and guidelines regarding the handling of data were followed throughout the research period. Replies from the Danish Data Protection Agency is provided in Appendix B.

In the two recruitment settings, the local managers authorised the study to take place. All participants received written and oral information about the study and gave informed consent before participating (WHO, 2001). An example of the information letter, recruitment materials and the written consent forms are provided in Appendix C and D. Written consent was obtained at the time of inclusion in the study. Furthermore, specific consent was obtained from participants with schizophrenia at times of using video-recordings as research documentation.

One participant with schizophrenia did not want to provide a signature on the written consent form. The participant was very explicit when providing oral consent to participate, which was given in the presence of both myself and the primary case manager from the mental health care service. This was accepted as sufficient provision of consent.

The MHCPs who were included as participants in focus groups or as key informants received separate written and oral information related to these specific research activities.

As some of the field work was conducted in areas that could be characterised as being semi-public, people who were regularly present in these settings were informed about the study on posters that were visible throughout the duration of the study. This especially applied at the residential facilities and at the office location of the outpatient clinic. MHCPs employed in the included settings were informed about the study taking place, about the overall aim, methods, and expected duration in written and in oral presentations. Additionally, anyone with concern or comments that related to the study were encouraged to use contact information provided in the information materials.

4.3.1. Conducting research among people with severe mental illness

As the primary group of participants in the study comprised of people diagnosed with schizophrenia, certain ethical considerations needed to be addressed continuously throughout the research process. These concerned aspects such as recruitment through gatekeepers, how to assess current state of mind of participants with schizophrenia, changes in mental health, and how to provide this group of participants with circumstances within the research activities that respected individual limitations and resources.

Identifying possible participants and recruitment was conducted through gatekeepers, who were MHCPs employed in the mental health care settings (Allbutt & Masters, 2010; Schensul et al., 1999). This was based on considerations about these gatekeepers' knowledge about the possible participants and on the grounds of local managers expressing that this was the necessary process. Recruiting through gatekeepers from the local settings was both helpful and limiting for the research. It was helpful because gatekeepers' possessed insider knowledge about potential participants and could assess their mental health conditions. They were also willing to leverage the trust they shared with the person with schizophrenia, to introduce me to possible participants. In some cases, this developed into a fruitful collaboration, where the MHCPs became very engaged in the study, and at the same time expressed that their involvement also provided them with new insights for their everyday work. The collaboration became limiting for the research in situations where gatekeepers only took it upon themselves to decide who among the potential participants I was allowed to approach or not. This resulted in some persons with schizophrenia being excluded from participation without actually having the chance to decide for themselves whether it was something they could manage or not (Allbutt & Masters, 2010).

During the course of the research, the design and methods provided the flexibility needed to adapt the study according to the everyday circumstances of the individual participants. The research approach facilitated participation in the study despite some residents or patients experiencing unstable mental health conditions and sometimes very unpredictable everyday lives. Throughout the process, the participants' mental state was continuously assessed in close collaboration with both the participants

themselves and the MHCPs. Vulnerability was considered an inherent aspect of the existing conditions and everyday life of the participants, which the researcher was obligated to take into account when conducting the research (Oeye, Bjelland, & Skorpen, 2007). Specific examples of how this was undertaken during the course of the research is provided in section 4.4. Data collection.
Further ethical considerations related to conducting this research is addressed in the discussion section (Chapter 6).

4.4. Data collection

The process of generating data in ethnographic research was understood as innovative and flexible, and in this study, a combination of multiple qualitative data generation methods was employed. In line with literature on ethnographic research, this study incorporated some of the most commonly used methods: field work with participant observation and writing of field notes and different types of interviews (Hammersley & Atkinson, 2019). In addition to this, focus groups (Bloor, 2001; Halkier, 2010) and individual, semi-structured interviews (Brinkmann & Kvale, 2015; Holstein & Gubrium, 1995) were conducted with MHCPs as participants.
The following sections provide an overview of the different data generating methods and the data materials generated in the research process.

4.5. Field work

Field work can be described as the actual research activities taking place in the field. Doing field work offers possibilities to combine different data generation methods, however as in this study, field work often incorporates participant observation, writing field notes, and various types of interviewing as the main activities. Doing field work is a complex process that has the researcher as the primary tool in the generation of data. Taking on this role, the researcher has to deal with the constant uncertainties that come with using an adaptable and flexible research approach (Hammersley & Atkinson, 2019; Schensul et al., 1999). In this study, field work included the following key components: to listen, to record and understand local meaning and language, to observe and interpret behaviour, to document, organise and understand information, and to reflect on everything relevant in the local setting (behaviour, values, language) including my own behaviour (Hammersley & Atkinson, 2019; Schensul et al., 1999). As will be described further in the following sections, these components were approached with both structure and flexibility in order to manage the continued generation of data.

The field work took place from July 2016 till late January 2018. In total, 505 hours were spent conducting field work in the everyday lives of the participants with schizophrenia (Hammersley & Atkinson, 2019; Pelto, 2013). Due to practical reasons related to available time for conducting the study, and the geographical distances between the different locations of the research, the field work was divided into two phases. The first phase was focused on participants from the two residential facilities, which were situated in rural areas of the region. The second phase focused on participants recruited from the outpatient clinic, who all lived in community setting of the region capital. In addition, it made good sense to separate the field work in the two different mental health care settings, as it provided opportunity to focus on the particular social contexts and immersion into the everyday lives that played out within each of them.

Due to continued instability in several of the participants' mental health conditions, the process of conducting field work took on an assertive and flexible approach. This involved consideration of each individual participant's mental state on a day-to-day basis, and in relation to all aspects of the data generation process (Liamputtong, 2007). Five of the nine participants with schizophrenia experienced episodes of severe deterioration in their mental health during the time they were engaged in the study. During these episodes, their participation in the study was put on hold until they were ready to continue.

One approach that was used to increase flexibility and assertiveness in relation to making and maintaining appointments with the participants, was to contact them prior to the appointment to check if they were still okay with the time and place that we had agreed on previously. These contacts were made on the day before or even hours before the session was scheduled to take place. Some participants could not manage this form of contact, and therefore appointments were made each time we met. At any next appointment an assessment was made in collaboration with the participant and/or the involved MHCPs about whether or not it would be possible to spend time with the participant on that particular day. If not, I would meet with the participant to agree on when we should try to meet up the next time. In addition, it was made clear to all participants at the point of recruitment and consent, that their participation in the study was to be on their terms, and that cancellations or rescheduling of appointments was not a problem.

An important part of conducting field work was related to me entering the field of research and negotiations in the social context about my role. Entering the field was a process of gaining access to the locations where the everyday life of people with schizophrenia naturally took place (Hammersley & Atkinson, 2019; Schensul et al., 1999). As described previously, the field of research was not considered a fixed and clearly demarcated place, rather it was viewed as a phenomenon created through collaboration with the different actors involved in the research, and through the process of the research itself (Atkinson, 2015). This was also the case in this study, as everyday life of the participants played out in very different contexts.

Entering the field of research was also about entering a different social world than your own. To do this required self-conscious reflection and background knowledge about the settings that were entered (Schensul et al., 1999).

Entering the everyday life of the participants with schizophrenia involved an ongoing negotiation of my role in the field and of my access to the field (Hammersley & Atkinson, 2019). As part of the planning of this research, different possible roles or positions that I could take on or be ascribed during the research was considered. Entering the field, it proved difficult to control how I was presented and perceived. My professional background as a nurse and social and healthcare assistant was known to many of the people I interacted with. However, it became clear to me that I needed to engage in ongoing negotiations of my position.

The most marked roles I was ascribed were ‘the nurse’ and ‘the researcher’. Both positive and negative associations were related to these roles. From my perspective, both of them carried some problematic associations, but at the same time constituted true elements of me as a person and as a researcher. This positioning work was characterised by dualities. Entering mental healthcare settings that were known to me through previous work experience, it was important for me to position myself as someone who was not there to perform nursing as part of my research. At the same time, my experience was, that being a nurse facilitated trust and accept of my presence among the participants with schizophrenia as well as the MHCPs. Hence negotiations around this part of my role was a balancing act between being a nurse, but without engaging in the tasks that could be expected of a nurse in these settings.

The role as ‘the researcher’ was difficult in these negotiations, and initially I tried to avoid using the term in my introductions. However, doing a PhD made it somewhat dishonest to disclaim this position as part of me presence. However, it was difficult to act in a culturally competent manner as ‘ the researcher’, as it caused some disturbance and resistance in parts of the research setting. Resistance towards this position was especially evident in my attempts to interact with some MHCPs – and especially at the residential facilities - as the role of ‘the researcher’ seemed strange, uncommon, and even intimidating to some who performed their work in these settings. It seemed to induce insecurity about what my presence entailed and hence also what they were to expect. Negotiations that softened the reactions towards me (as the researcher) entailed sharing stories about my own professional background, hence representing myself among the MHCPs as ‘someone like them’ while also being someone conducting research. Negotiations about my role and access was ongoing, as the social context of everyday life of the participants with schizophrenia included many different actors.

The following data generation methods were used as part of the field work: participant observation sessions and writing field notes, conducting individual semi-structured interviews, audio-recording of conversations, and collection of written documentation materials. The combination of these qualitative methods resulted in rich data material including perspectives from those with schizophrenia, and the MHCPs in their immediate everyday surroundings.

4.5.1. Participant observation

The field work sessions were based on participant observations that focused on exploration of activities of daily living among the participants with schizophrenia. As managing physical health was understood as part of everyday life, it was not defined in advance which activities were to be in categorised as relevant or important. Rather, the actual exploration of the everyday lives of the participants guided which activities were observed. As a result, participant observations included sessions of drinking coffee and small-talk, watching movies, watching the participant play computer games, going for walks, going grocery shopping, participating in sport activities, cleaning up the home, participating in group activities (primarily in the setting of the outpatient clinic), and following the participant to examinations with their general practitioner, or at the general hospital. Due to the unpredictable conditions surrounding the everyday life setting, field work sessions were difficult to plan ahead. However, several attempts were made e.g. in order to be able to go with the participant to the general practitioner.

The length of field work sessions with the participants varied greatly. Some participants were able to endure the social contact for several hours, while others drew back from the sessions after only a few minutes. With those participants who seemed comfortable with longer sessions, it was necessary to assess their condition continuously, as they risked pushing themselves too far in an attempt to please me and help the study. For some, this effort could trigger worsening in their mental health state. Some of the mental health care professionals involved in the everyday care and treatment were valuable collaboration partners in this process. They engaged by being attentive to both the participants with schizophrenia, and their mental state, but also by taking their time to elaborate on everyday life in the two mental health care settings. The physical surroundings related to the two mental health contexts meant that the field work sessions would play out differently depending on the setting. When conducting field work at the two residential facilities, it was possible to incorporate breaks between sessions or conversations. These breaks provided opportunity to observe interactions in the common areas. The breaks also made the social interaction more manageable for those participants who could only endure very short sessions. Sessions with participants from the outpatient clinic most often took place in the home of the participants, or somewhere near their home. In this type of social setting it was difficult to leave, give both parties a break, and then return and resume the session. It was important to meet the preferences of the individual participant, and this was the objective of applying both a structured and flexible research design. The level of participation also varied from session to session, and from participant to participant (Atkinson, 2015; Pelto, 2013). In situations where there was no one else present but the participant, my participation/engagement would typically increase. In some situations, this happened because the participant expressed discomfort if they were not doing an activity together with me. Some expressed a need to provide ‘entertainment’ and had difficulties enduring episodes of silence in our sessions. However, with other participants, the level of interaction remained limited, and it was possible to decrease participation and primarily observe what was going on (Pelto, 2013).

Conducting field work and writing about the experiences gained in the field are interconnected activities (Emerson et al., 2011; Hammersley & Atkinson, 2019). Therefore, it is appropriate to present these activities successively.

4.5.2. Field notes

The process of writing field notes is a regular and systematic way of producing written record of observations and experiences related to the settings and objects being studied. This process involves many of the previously-mentioned key components of field work (Hammersley & Atkinson, 2019; Schensul et al., 1999). Typically, individual preferences of the researcher will influence the way of representing the experiences gained from the field work in the notes (Emerson et al., 2011). Writing field notes is a time-consuming and completely essential activity when conducting ethnographic research (Hammersley & Atkinson, 2019). In this study, field notes were produced after each session of field work. The process of writing the notes developed and changed several times during the course of the research and took on slightly different approaches depending on the setting. At times, it made sense to record jottings on the spot, which were then later developed into notes in a more narrative style (Emerson et al., 2011). Sometimes, it was possible to move back to the staff offices and write down essential and longer passages of text while having a break from the social engagement in the settings. This particularly applied in the residential facility setting. However, most of the time, the field notes were recorded in a word document after the session had ended.

I used a narrative writing style, with the objective to capture key situations that had occurred during the particular field work session, relevant observations about interactions in the context, and any reflections and thoughts these had facilitated. In the very beginning of conducting field work, the notes contained a lot of descriptions of places and the people that interacted in them. At this point, the field notes included drawings of rooms and buildings, and descriptions of the participants' physical and social appearances, aa well as any first-hand impressions that made an impression (smells, colours, noises) (Schensul et al., 1999). My professional background within nursing in menta health care settings was in some ways reflected in my fieldnotes, as a tended to use clinical terms as well as terms drawn from the participants word-use. Some sections of the field notes were used to recap conversations that had taken place as verbatim as possible to ensure my access to examples of the specific language-use of the participants further on in the process of the study.

During the course of the study, the notes became more focused around the aspects of everyday life that seemed to contain elements related to management of physical health. Physical health was not defined prior to conducting the study, as it seemed important to let the research process guide what was of importance, and what might play a role in these particular everyday lives. Consequently, the field notes also contained a lot of descriptions related to everyday life in a broad sense.

When doing ethnographic research, the researcher engages with the data material both during data generation and during the analysis. In this study, the field notes were further developed each time I read through them. More details or elaborations were added and things that would be interesting to follow-up on were noted. At certain times important conversations that had played out were reproduced as close to verbatim as possible. During the research process, the field notes served to inform the field work from session to session. In this way they worked as a field work journal, and became a tool for reflection and preparation for the up-coming sessions in the field (Hammersley & Atkinson, 2019). At the end of the study, the field notes comprised a large amount of data, but as the notes had been kept rather systematically during the course of the research, they were manageable to work with in the process of constructing rich participant descriptions. This work is described in more detail in the section on analytical strategies.

The participant observations and related field notes were complemented by data material from the individual, semi-structured interviews and the audio-recorded conversation, which are described in the following.

4.5.3. Individual, semi structured interviews with participants with schizophrenia

The nine participants with schizophrenia were invited to participate in individual, semi-structured interviews during the study period. Individual, semi-structured interviews is a qualitative method used to gain insight into a participant’s point of view. In ethnographic research, individual interviews provide an opportunity for in-depth exploration of particular aspects related to social life (Hammersley & Atkinson, 2019; Pelto, 2013). Additionally, they facilitate the researcher’s understanding of the meaning participants ascribe particular experiences (Brinkmann & Kvale, 2015). In this study, the interview approach was used to provide insight into the participants’ subjective experiences of managing physical health issues in everyday life. Interviewing was understood as an interactional process in which both researcher and participant were active in the generation of knowledge (Brinkmann & Kvale, 2015; Holstein & Gubrium, 1995). As a research method, individual, semi-structured interviews can be characterised as conversations with a particular structure and purpose. In this study, interview guides were used to facilitate structure, and to guide the interaction with each participant towards specific topics (Brinkmann & Kvale, 2015). The interview guides slightly differed for each of the interviews with participants diagnosed with schizophrenia, as they were based on knowledge gained through the field work which occurred prior to the interviews. 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?*

Early in the process of the research, it proved difficult to engage the participants in interviews that were focused toward physical health aspects of life. While the objective was to gain insights into how physical health naturally occurred in the everyday life of the participants; asking specific questions about it, seemed to facilitate an inexpedient and unnatural focus on the topic in the mind of some participants. It proved more fruitful to observe everyday life, identify which actions might relate to the management of physical health, and then following the field work sessions, to explore the participants' own perspectives on particular actions related to specific situations. The audio-recorded conversations which are described next, proved to be an appropriate and less formal way of generating data about the participants' first-hand perspectives.

Four of the nine participants participated in individual, semi-structured interviews. Two participants were unable to participate in an individual interview due to worsening of their mental state. The remaining three were not conducted as the methods proved difficult to employ. Three interviews were conducted in the private homes of the participants during field work sessions. The fourth one was conducted in a meeting room at the psychiatric hospital. The locations were decided by the participants. The interviews lasted between 19 and 34 minutes. Each interview was transcribed verbatim with basic interactional features such as pauses and overlapping talk indicated (Jefferson, 2004), and these were combined with other data sources in the construction of participant descriptions (described in section 4.9.1. Thematic analysis I: Ethnographic data material).

4.5.4. Audio-recorded conversations

As part of the field work, it proved both insightful and helpful to audio-record some of the everyday conversations that played out when I visited the participants. These conversations were used as a type of informal and unstructured interview (Hammersley & Atkinson, 2019). Most often these interactions took on features normally associated with a friendly conversation and were about whatever was on the participant's mind (Hammersley & Atkinson, 2019; Pelto, 2013). Typically, the conversations were initiated by asking questions about how the day or week was going so far. In this way, it was up to the individual participant to choose the focus of the conversation. Using this informal type of interaction, it became possible to have multiple, explorative sessions with some of the participants; some of which had difficulties engaging in more informal interview sessions. These participants became familiar with the recorder and the conversations became an important tool in the field work process. Some conversations focused more specifically on events or experiences related to an episode with physical health symptoms. Such very specific experiences were sometimes useful when seeking insight into the participant's perspective on the experience. However, the participants often did not remember the specific episode, or had not taken much notice of it when it occurred.

The recordings of informal conversations varied in length, lasting between 6 and 52 minutes. Each time a conversation was recorded, the participant gave their consent. The recordings were not transcribed but were listened through multiple times during the process of analysis (Lerbæk et al., n.d.).

Table 6 provides an overview of the duration and number of audio-recorded conversations, individual, semi-structured interviews, and psychiatric interviews conducted with each participant diagnosed with schizophrenia.

Table 6: Individual interviews, audio-recorded conversations, and psychiatric interviews

Participant	**Interview**	**Duration** (h:m:s)	**Audio-recorded conversations** (n)	**Duration** (h:m:s)	**PANSS**[2]	**Duration** (h:m:s)	**EASE**[3]	**Duration** (h:m:s)
Resident	+	0:34:45	10	0:44:26 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	+	1:02:48	+[4]	0:48:44
Resident	+	0:26:14	5	0:26:06 0:27:44 0:23:53 0:30:33 0:06:32	+	0:33:37	+[4]	0:28:46
Resident	+	0:30:42	-		+	1:04:01	+[4]	0:42:30
Resident	-		1	0:08:52	+	0:54:03	+[4]	0:54:31
Patient			2	0:33:11 0:07:31	+	0:46:40	+	0:49:21
Patient	+	0:19:02	-		+	0:34:53	+	0:48:44
Patient	-		2	0:11:09 0:06:34	+	0:43:44	+	1:07:10
Patient[1]	-		-		-		-	
Patient			7	0:52:46 0:29:54 0:09:01 0:19:19 0:28:29 0:14:27 0:09:37	+	0:57:02	+	0:39:57

[1] Participant did not consent to interviews, audio-recorded conversations or psychiatric interviews, [2] Positive and Negative Syndrome Scale (PANSS) (Kay et al., 1987), [3] Examination of Anomalous Self-Experience (EASE) (Parnas et al., 2005), [4] EASE not fully assessable

4.6. Psychiatric interviews with participants with schizophrenia

Psychometric data related to the participants with schizophrenia was generated using the Positive and Negative Syndrome Scale (PANSS) (S. R. Kay, Fiszbein, & Opler, 1987), and Examination of Anomalous Self-Experience (EASE) (Parnas, Møller, et al., 2005). These measures could provide insight into the participants' mental health state (PANSS) at the time of the study, and their inner experiences of their sense of 'self', and how they related to the surrounding world (EASE). The PANSS interview focused on the current state of mental health state (based on experiences from the past week), whereas the EASE interview provided insight related to a broader time frame by referring to the participants' prior life experiences before the onset of schizophrenia, as well as current aspects. This research did not include interventions in any form hence these data were generated with the sole purpose of describing the mental health condition of the participants with schizophrenia. The interviews were conducted using individual, semi-structured interview approaches with standardised interview guides (S. R. Kay et al., 1987; Stanley R Kay, Opler, & Fiszbein, 2001; Parnas, Møller, et al., 2005). I received training in conducting and rating the PANSS interview and conducted these interviews. The EASE interviews required specific and extended training in relation to psychopathology and were conducted by supervisor Julie Nordgaard, as this was within her field of expertise. The interviews were audio and video recorded when permitted by participants. In this study, the video recordings were used for rating purposes only.

The EASE interview was originally developed as a differential diagnostic tool, with a primary target population of people experiencing first episode psychosis (Parnas, Møller, et al., 2005). The interview proved very difficult to use with five of the nine included participants with schizophrenia. One participant was not able to participate in the EASE interview, due to poor mental health state. With the group of residents (n = 4), the onset of schizophrenia had occurred many years back, and the features of self-disorders were difficult to separate from the experienced psychotic symptoms, hence difficult to assess and describe adequately. Therefore, the specific features of self-disorders are not reported in this research. However, during the course of the research process, it became clear that both PANSS and EASE interviews generated valuable insights into the participants' perspectives on how they managed everyday life and on aspects related to their experiences of physical health. Therefore, the interviews were transcribed and used in relation to their qualitative features. In this way, they provided valuable knowledge to the ethnographic analysis (Lerbæk et al., n.d.).

The psychiatric interviews were transcribed verbatim and with indication of basic interactional features (Jefferson, 2004). Eight of the participants were able to participate in these interviews (see Table 6 for further information on the psychiatric interviews).

The PANSS interviews were rated using standardised rating criteria (Stanley R Kay et al., 2001). Four of the interviews were rated together with a group of research assistants, who all were trained and experienced in rating using the PANSS criteria. I rated the additional four interviews without the group. When rating the PANSS interview, 30 items are assessed on a seven-point scale: 1) absent, 2) minimal, 3) mild, 4) moderate, 5) moderate severe, 6) severe, 7) extreme. Hence, a high score indicated severe symptoms. The 30 items cover positive symptoms (7 items), negative symptoms (7 items), and general psychopathology (16 items). The total score range is 30-210 points. Score range for the three sub-scales are 7-49 points in the positive and negative scales, and 16-112 in the general psychopathology scale. A copy of the rating sheet is provided in Appendix E. In this study, ratings were based on video-recordings of the interviews and background knowledge about the participants gained through the field work. In this study, a total PANSS score >57 was considered indication of ‘mild mental illness’, scores from 58-75 indicated ‘moderate mental illness’, score from 76-95 indicated ‘marked mental illness’, and total scores <95 indicated ‘severe mental illness’ (Stefan Leucht et al., 2005). All scores, including sub-scale scores, are also available in Appendix E to provide insight into the main mental health issues that individual participants experienced at the time of the study.

In addition to the data sources that were directly related to the participants with schizophrenia, data materials which could reflect the perspectives of MHCPs were also generated. These MHCPs comprised a group of professionals who most commonly engaged in everyday life interactions with the participants with schizophrenia.

4.7. Focus groups with mental health care professionals

Focus groups were conducted with 22 mental health care professionals from the two mental health settings (Lerbæk et al., 2019). Focus group interview is a qualitative research method, which can be used to generate knowledge about meanings, uncertainties and ambiguities related to group assessments, as well as knowledge about normative understandings of groups (Bloor, 2001). Focus groups are suitable to use in combination with other research methods (Bloor, 2001). In this research, focus groups were an appropriate method to employ as they facilitated data generation which focused on insights into meanings, processes and norms among a particular group of MHCPs. When conducting focus groups, the data is constructed in the discussions that play out among participants, and this interactional data material provide unique possibilities to explore how a social concept such responsibility is negotiated (Bloor, 2001; Halkier, 2010). This study focused particularly on MHCPs’ perspectives on managing physical health issues as part of their everyday work in the two mental health care settings.
The focus groups consisted of participants of pre-existing groups (Bloor, 2001), as they were day-to-day colleagues in each of the three locations. I facilitated these sessions and took on the role as moderator of the discussions (Bloor, 2001). Each focus group session began with an introduction round, in which the participants

provided information about their occupational background and previous as well as current experiences with employment in mental health settings. As interactions between participants is an essential feature of focus groups (Bloor, 2001), each session was facilitated by the introduction of six themes related to management of physical health issues in everyday work situations. The themes were constructed based on the knowledge gained about the local contexts and daily activities, while conducting field work among the participants with schizophrenia. Further, they were informed by knowledge gained from a selection of the existing literature on the matter, see (Blanner Kristiansen et al., 2015; B. Happell et al., 2012) for previous focus group studies focusing on the perspectives of MHCPs and mental health care users on matters related to managing physical health.
The themes used to facilitate the focus groups are listed in Table 7.

Table 7: Themes used in focus group discussions

Themes
1) How are you involved in managing health and illness among the patients? *Please provide concrete examples*
2) Which dilemmas do you experience in relation to managing health and illness among your patients? *How are they manifested?* *How are they handled?*
3) Do you have influence on the choices, which the patients make related to health and illness in everyday life? *How is this manifested?*
4) How do you assess health among the patients you meet in your everyday work? *How does this manifest?*
5) In your experience, how are people with severe mental illness able to feel and understand symptoms of physical illness?
6) Sometimes it seems difficult to work focused on physical and mental health at the same time. When is it necessary to prioritise? *How do you prioritise one or the other?*

As shown in Table 7, the themes included questions and statements related to the MHCPs involvement and experiences with how people with SMI were able to manage their physical health. The themes were introduced to the participants at the beginning of each session, where they were asked to prioritise the themes according to how they wanted to discuss them. This functioned as the primary focusing exercise of each session (Bloor, 2001). Three focus groups were conducted between December 2016 and January 2018; one in each of the three mental health locations of the study. At each session, an observer was present and took on the task of writing notes on non-verbal interactions in the group. Further information on the focus groups was provided in Table 4 . Focus groups can be used as a stand-alone data generation method or in combination with other methods (Bloor, 2001). The data material generated in these three focus groups provided the basis for a discourse analysis, which focused on MHCPs' accounts of actions and responsibilities related to managing physical health issues among those with severe mental illness. The analysis and full extent of the findings was described in a separate paper (Lerbæk et al., 2019). Details on this analysis is presented in the section 4.9. Analytical strategies.

4.8. Individual, semi-structured interviews with key informants

Individual, semi-structured interviews as a data generation method was described previously (in section 4.5.3.). The five key informants (Pelto, 2013; Schensul et al., 1999) were interviewed using a similar individual, semi-structured approach. The interviews were semi-structured to allow flexibility during the interaction to pursue various issues that came up, if these were of relevance to the study (Brinkmann & Kvale, 2015; Holstein & Gubrium, 1995).

The interviews were conducted at the workplace of the informants and within working hours. They took place from December 2016 to January 2018. As described in Table 5, these participants had special interest, knowledge and experience related to different aspects of management of physical health in everyday life among those with SMI and associated organisational practices. The interview guides were constructed to explore each individual's particular interest point and critical reflections on current mental health care practices. Each interview was structured using an interview guide with a brief introduction to the interview and a combination of question types. These were: 1) Open-ended questions, e.g. *In your experience, how do you as mental health care professional have influence on the choices that people with SMI make related to their physical health?* 2) Probing questions, e.g. *Can you give an example of this related to your everyday work?* and 3) Informant-specific questions that would facilitate the individual key informant's perspective on the studied issue, e.g. *Based on your experiences, do you think a disrupted experience of the body can affect how this group manages their physical health?* The interview guides differed for each interview, as the informant-specific questions were based on the informants' individual interest and knowledge points related to managing physical health among people with SMI (Pelto, 2013). The interview guides were also influenced by field work conducted in the two mental health care settings prior to the individual interviews taking place.

This data material provided the basis for a thematic analysis focused on the latent and interpretative patterns of themes (Braun & Clarke, 2006). The material contributed knowledge about the key informants' perspective on barriers to health and illness behaviour with roots in the everyday context of people with severe mental illness and insights into management of physical health issues in mental health care settings based on the critical reflections of the key informants. These insights were valuable to the study and strengthened the understanding of the social contexts (Lerbæk et al., 2020). The analysis is described in section 4.9. Analytical strategies.

This concludes the presentation of data generation methods. In the following sections, the four analyses are described in detail, leading to the presentation of the findings.

4.9. Analytical strategies

When undertaking ethnographic research, the process of analysis is often based on working with somewhat unstructured data. The analysis does not follow a distinct guide but is considered an ongoing process throughout the course of the research. The analysis is very time-consuming work due to the extent and unstructured nature of the data (Hammersley & Atkinson, 2019). Data is not taken at face value but rather 'contested' by seeking out different perspectives on the social phenomenon being studied. As described in the section related to the theoretical perspective, the data material generated for this study were not understood as fixed entities, but rather as phenomenon, which continued to change and develop as I engaged with it (Järvinen & Mik-Meyer, 2005). In this study, the process of analysis incorporated an abductive and iterative approach, which enabled me to be attentive to any unfamiliar aspects of the studied settings that might emerge from the data (Hammersley & Atkinson, 2019; Tavory & Timmermans, 2014). Abductive analysis is an approach that is focused on empirical observations of social worlds and interpretation based on theoretical assumptions (Tavory & Timmermans, 2014). As abductive analysis is based on the philosophical assumptions found in pragmatism, the approach was appropriate to ethnographic research (Hammersley & Atkinson, 2019). The process of abductive analysis involved leaving preconceived ideas behind and engaging in creation of new narratives about the observed phenomenon. This process was based on an openness towards the empirical observations that might not fit the existing theory about the studied phenomenon, and a willingness to engage in attempts to understand such unexpected observations through theoretical generalisations (Tavory & Timmermans, 2014).

In this study, the iterative aspect referred to the cyclic nature of the process of analysis, where exploration of data led to investigation of specific data materials in separate analyses, which then led back to the initial exploration of data (Miles, Huberman, & Saldaña, 2014). The abductive and iterative aspects of the analysis were particularly noticeable in the way that the initial phases of the analytical work led to the three analyses which are presented below as thematic analysis of ways of managing physical health (Lerbæk et al., n.d.) and key informants' perspectives (Lerbæk et al., 2020), respectively, and the discourse analysis of focus group discussions (Lerbæk et al., 2019). A fourth analysis focused on integrating the finding of these three analyses and the presentation of explanatory ideas (Hammersley & Atkinson, 2019) about the process of managing physical health as part of everyday life. This is described further below.

In this research, one of the initial steps of analysis included the construction of rich participant descriptions based on the available data materials. This work functioned as a way of getting familiar with the large amount of data, and develop some preliminary ideas about the contribution of different data sources in relation to the studied phenomenon (Hammersley & Atkinson, 2019). This initial phase of analysis facilitated awareness of relevant perspectives and contributions embedded in different data materials which informed in the decision to conduct three analyses; one focused on exploring the perspectives of the participants with schizophrenia; one focused on accounts of MHCPs in the focus group data material; and one focused on the perspectives of MHCP key informants.

The complete findings from the analyses are reported in three scientific papers (see Appendix A) (Lerbæk et al., n.d.; Lerbæk et al., 2019; Lerbæk et al., 2020).

Summaries of the main findings from the three analyses, and a presentation of complementary findings across the three analyses derived from an integrative analysis are presented in Chapter 5.

In the following sections, the thematic, discursive, and integrative analytical approaches are described.

4.9.1. Thematic analysis I: Ethnographic data material

This analysis was related to the first and the second research question;

1) *What physical health issues are experienced by people with schizophrenia in their everyday life?*

2) *How do people with schizophrenia manage physical health issues in everyday life*?

The aim was to thoroughly investigate, interpret and describe patterns of social behaviour in the everyday life of participants with schizophrenia with focus on management of physical health issues.

This thematic analysis was action-focused or, as described by Hammersley and Atkinson (2019) it was focused on what people do, and why. In line with this, the analysis was concerned with description of reoccurring situations, actions, trajectories and their consequences. An important aspects of this analysis was related to making sense of participants' actions in the social context of their everyday lives, therefore the analysis also focused on the interactions, that participants engaged in (Burr, 2003; Hammersley & Atkinson, 2019).

In this study, rich participant descriptions were constructed based on insights gained from the different data sources, which included: field notes; individual, semi-structured interviews; audio-recorded conversations; EASE interviews; and PANSS interviews. The participant descriptions included demographic characteristics, past and current mental health issues, on management of everyday life, and notes related to physical health issues. The participant descriptions became the basis for identifying patterns of behaviour and interactions. An overview of the template used to develop these descriptions is provided in Table 8.

Table 8: Template for participant description

Data sources

Demography and background
Age
Living arrangements
Income
Family and social life
Educational level
Work
Hobbies

Mental health issues
Diagnosis
Past and current mental health issues

Description of everyday life
Home
Physical appearance
Structure in everyday life
Managing everyday life
Social life
Relationship with the family
Typical activities during field work sessions

Notes related to managing physical health or well being
Diagnosis
Issues related to physical health

Thematic analysis was used to explore the data material (Braun & Clarke, 2006) and to structure a cultural interpretation of patterns (Wolcott, 1990). Thematic analysis is appropriate for analysing patterns and themes within qualitative data (Braun & Clarke, 2006). The analysis was conducted at a latent, interpretative level. This approach takes the analysis beyond an explicit level and draws on broader assumptions about latent meanings embedded in the data material (Braun & Clarke, 2006). The process of analysis and interpretation went beyond the descriptive level by incorporating knowledge about the social contexts, the participants' perspectives and the researcher's understanding of the identified patterns (Lambert et al., 2011; Wolcott, 1990). Including material from the different data sources resulted in a triangulated analysis drawing on both emic and etic perspectives (Hammersley, 2006; Hammersley & Atkinson, 2019).

This level of analysis builds on the general assumptions of constructionism as it involves the researcher´s active engagement with and interpretation of the data material in the development of the themes (Braun & Clarke, 2006).

The thematic analysis consisted of six phases (Braun & Clarke, 2006):
Phase 1: *Getting familiar with the data material*.
This initial phase involved reading through transcripts and field notes and listening to audio-recordings while writing memos.
Phase 2: *Generating initial codes, writing and developing memos*.
This phase entailed analysis using a broad perspective to gain an understanding of different components of everyday life and how physical health issues played a role within this.
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 potential risk behaviour. These physical health issues are referred to as debilitating physical health issues.
Phase 4: *Revision and further development of the initial themes*.
This revision let to further condensing the scope of the analysis, and a narrower focus on key aspects related to how participants managed 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. They 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'*, respectively. Hence, the final themes were named '*Modifying everyday life to manage discomfort*' and '*Retreating from everyday life to recover*'.
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 (L. Nielsen, 2019). The anonymised personas are presented as deidentified narrative exemplars that represent the experiences of participants (Foster, Mitchell, Van, Young, & McCloughen, 2019) constructed using a collection of words and illustrative quotes from participants with schizophrenia and extracts from the fieldnotes. This approach can provide rich contextual insights and strengthen the readers engagement with the researchers' interpretations. Findings from this analysis are reported in a scientific paper (Lerbæk et al., n.d.). A draft of the paper is available in Appendix A.

4.9.2. Discourse analysis: Focus group discussions among MHCPs

The analysis was related to the third research question; *How do mental health care professionals account for everyday work related to managing physical health issues among people with schizophrenia?*
The aim of the analysis was to explore MHCPs' accounts about their actions and responsibilities related to management of physical health issues as part of their everyday work practices.

There are several different approaches to the conduct of discourse analysis. At a general level, discourse analysis is about gaining insight into performance in social interaction, and about our relation to culture, groups, and institutions in the social worlds that we engage in. These are connected functions of human language, and discourse analysis represent tools to use when seeking to understand how language is used in context and to what it means (Gee, 2005).

The discourse analysis was based on data material produced in the three focus groups (Bloor, 2001; Halkier, 2010) with MHCPs from the two mental health care settings. The particular approach used was developed within the field of social psychology and entailed a detailed investigation of language-in-use (Edwards & Potter, 2001; Potter & Wetherell, 2007). It drew on central assumptions of social constructionism, as described in Chapter 2 on epistemological position and theoretical perspectives (see pp. 33-35), and language-in-use was understood as activities in social interaction. The approach provided an opportunity to study verbal communication as it occurred in social settings, such as institutional settings. The focus of this analytical approach was on action-orientation of talk, and on discursive recourses, which were drawn upon by participants in the particular contexts (Edwards & Potter, 2001). Three features of discourse were of importance when conducting this analysis. These are related to an understanding of discourse as being 1) action-orientated, 2) situated, and 3) constructed/constructing (Edwards & Potter, 2001; Potter & Wetherell, 2007). Discourse is *action-oriented* in the sense that it is always serving a purpose related to actions embedded in language-use, e.g. by requesting, commanding or accusing. Discourse is understood as *situated* in three ways, as it is situated in a certain sequence of talk, it is situated rhetorically, and it is situated in an institutional context. These three ways of being situated are all essential when seeking understanding of what is going on through analysing language-in-use. Lastly, discourse is both *constructed* and *constructing*. It is constructed in the sense that it is constructed by speakers and their linguistic resources. It is constructing in the sense that it is simultaneously constructing versions of the social world using different versions of accounts (Edwards & Potter, 2001). The analysis examined participants' situated accounts and was based on the understanding of accounts as discursive strategies that were used when explaining unusual, untoward or unanticipated behaviour. Accounts usually serve to neutralise the potential consequences that can be related to such behaviour (Potter & Wetherell, 2007; M. Scott & Lyman, 1968).

The process of analysis included thematic content as well as discursive strategies represented in the data material. In this analysis, a detailed examination of the participants' situated accounts was used to gain insight into their understanding of their work practices related to accepting responsibility of actions, or attempts to disclaim or shift responsibility elsewhere (M. Scott & Lyman, 1968).

After transcription, the process of analysis can be described in three phases:
Phase 1: Reading through the data material several times and producing memos with the objective to identify initial themes and discursive strategies used in the participants accounts. I continuously discussed the preliminary themes and patterns of discursive strategies with two of the supervisors (Niels Buus and Rikke Jørgensen).
Phase 2: Final development of the themes, and as part of this work, sections of the data material were chosen as illustrative examples of the findings. Further details related to interactional and pronunciational features were added to the transcriptions of these sections (Jefferson, 2004; Potter & Wetherell, 2007). In this phase, the analytic process continued with building of analytic claim about what was going on in the focus group discussions through in-depth analysis of discursive components such as speech delivery (Hutchby & Wooffitt, 1998).
Phase 3: Writing up the final themes with the illustrative, contextual examples. The presentation of detailed analysis of three extracts was provided as illustrative examples of the discursive strategies that were found to be dominant throughout the data material. Findings from this analysis have been published in a scientific paper (Lerbæk et al., 2019), which is available in Appendix A.

4.9.3. Thematic analysis II: Individual interviews with key informants

This analysis was also related to the third research question; *How do mental health care professionals account for everyday work related to managing physical health issues among people schizophrenia?*
The aim was to explore MHCPs key informants' perspectives on provision of physical health care in mental health care settings.

The thematic analysis was based on audio-recorded individual, semi-structured interviews conducted with the five key informants. The analysis was relevant to include, as it provided insights into the experiences and perceptions of a group of people with specific interest in this particular area of practice, and therefore possessed extended knowledge on the matter (Lerbæk et al., 2020; Pelto, 2013; Schensul et al., 1999). Thematic analysis is a flexible approach that has been widely used in analysis of qualitative data materials. As in the thematic analysis described in section 4.9.1., this analysis focused on the latent and interpretative level, seeking interpretation of the material that goes beyond the sematic meaning (Braun & Clarke, 2006). Working with thematic analysis is appropriate when aiming for somewhat thick descriptions of the data and provides opportunity for the researcher to generate insights about unforeseen topics embedded in the materials. The objective of doing a thematic analysis was to present interpreted knowledge, rather than rephrased and described findings (Braun & Clarke, 2006).

In this analysis, interpretation was achieved by drawing on extended contextual knowledge gained through field work in the social contexts referred to in the data material, and through this to develop some deeper insight about the underlying assumptions or meanings of the actual accounts. This type of analysis is described as essentially independent of theory and epistemological position. However, analysing at the latent and interpretative level is appropriate when taking on the theoretical perspective of social constructionism (Braun & Clarke, 2006; Lerbæk et al., 2020).

The analysis was conducted in six phases, as described by Braun and Clarke (2006):

Phase 1: *Getting familiar with the data material*. The audio-recorded interviews were not transcribed but were listened through several times.

Phase 2: *Generating initial codes and writing memos related to the content*. As the material was not fully transcribed, coding was a process of noting particular sections of the audio-recordings with the generated codes. The codes were guided by the content of the material.

Phase 3: *Searching for initial themes by examining memos and coding of the material*. This resulted in five initial themes.

Phase 4: *Revision and further development of the initial themes*. This process involved interpretation of the data based on contextual knowledge. In this phase the initial themes were revised, and the content merged across themes.

Phase 5: *Defining and naming the themes that dominated the data*. These focused on 1) barriers for provision of physical health in mental health care, and 2) suggested solutions that could help overcome existing barriers.

Phase 6: *Producing the report and writing up the themes*. This included providing contextualised, illustrative extracts that would strengthen the presentation of the interpretations made. The findings from this analysis are published in a scientific paper (Lerbæk et al., 2020), which is available in Appendix A.

4.9.4. Progressive focusing: An integration of key findings

This analysis was related to the fourth research question; *What are the factors that influence how physical health issues are managed in everyday life among people with schizophrenia?*

The aim was to provide in-depth description of the social processes that contribute to the ongoing experience of physical health issues among people with schizophrenia and how they are managed.

In their description of the process of analysis, Hammersley and Atkinson (2019) write about producing theory, understood as developing potential explanatory ideas, that can help us understand ‘why things are as they are’ (p. 168). The process is explained as progressive focusing, in which the process shifts from describing somewhat specific social events and processes towards producing theory (Hammersley & Atkinson, 2019). Ethnographic analysis does not follow any particular formula, however Hammersley and Atkinson (2019) encourage the use of a flexible and iterative approach while keeping in mind the research question, the available data and the phenomenon being studied . In this research, the development of theory was based on an analysis in which findings from the three previously described analyses was integrated. Central to this analysis were the findings describing the strategies used by participants with schizophrenia when managing debilitating physical health issues in everyday life. Main findings from the discursive analysis of focus group discussions and the thematic analysis of key informants' accounts served to provide further depth and nuances to understanding how social context played a role in sustaining the physical health issues and management strategies of the participants. By using this approach, it was possible to produce a new, coherent whole. Integrating key findings across the separate analyses and subsequently developing new, more nuanced conclusions.

The analysis was conducted in four steps:
Step one included the process of revisiting the findings produced in the three separate analyses. This led to the identification of specific key points across each analysis.
Step two focused on developing preliminary explanatory ideas and involved initial identification of factors that contributed to debilitating physical health issues and the strategies associated with participants managing these issues in everyday life being sustained. These factors were identified through a process of condensing of the key points. They are referred to as '*sustaining factors*'.
Step three involved developing theory to provide insight into the relationship between the identified sustaining factors. Three interacting dimensions of social context were identified; 1) the *individual*; 2) the *immediate social context*; and 3) the *indirect social context*. Developing theory included description of the association between the sustaining factors within and across these dimensions of social context.
Step four of the analysis included writing up and presenting a new and more nuanced understanding of the studied phenomenon. This step focused on articulating in-depth description of the sustaining factors, their associations and interactions. These descriptions illustrate the complexities embedded in the social processes that sustain physical health issues and management strategies in everyday life.
This process resulted in the drafting of Figure 1 which is presented in Chapter 5.
Appendix F includes a tabular overview to illustrate the process of developing the theory explaining how factors influenced on the process of managing physical health.

Chapter 5: Findings

This chapter provides brief summaries of the main findings from the three analyses and the result of an integration of these findings.

5.1. Summary thematic analysis I: Strategies for managing physical health

The analysis led to the description and interpretation of two ‘typical’ strategies used by participants with schizophrenia to manage debilitating physical health issues in everyday life. These were 1) *Modifying everyday life to manage discomfort* which was employed to manage discomfort associated with ongoing poor physical health, and 2) *Retreating from everyday life to recover* which was employed by participants to manage recurring, discrete episodes of poor physical health characterised by fast deterioration. The strategies were adopted in situations where participants experienced physical health issues that caused different levels of limitations, which in the analysis were interpreted as impacting on everyday life. Impact was characterised by limiting activities of daily living or increasing behaviours with potential for poor outcomes (e.g. social isolation or significantly decreased self-care). The strategies employed by participants to managing physical health were inexpedient, and potentially caused worsening rather than improvements to their physical health.

The social constructionist perspective and the ethnographic approach applied illuminated how the management strategies were sustained in the social contexts of the participants.

The analysis contributed to answering the first and second research question by providing insight into the physical health issues experienced by participants with schizophrenia, and by enhancing understanding of how self-management of physical health issues takes place in everyday life.

The analysis 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 aspects that need to be considered in the future. The findings underline the necessity to enhance empowerment and capacity for self-care in relation to other aspects of health, in addition to mental health, among people with schizophrenia (Lerbæk et al., n.d.).

5.2. Summary discourse analysis: Accounts of actions and responsibilities

The analysis led to the identification of three typical ways for MHCPs to account for actions and responsibilities related to managing physical health issues among patients in everyday work situations. The discursive psychological approach focused on analysing both thematic content and discursive strategies, hence providing in-depth insight into the MHCPs’ understanding of their roles, actions and responsibilities in relation to this specific aspect of care. The MHCPs accounted for these practices by: 1) *positioning people with SMI as difficult to motivate and actively resisting life style* *interventions*, 2) *positioning people with SMI as so severely impaired that interventions were futile*, and 3) *arguing that people with SMI are undertreated for physical conditions and might be suffering from undetected physical illnesses that staff are not aware of due to prominent mental illness*. These findings were illustrated with contextualised extracts from the focus group discussions. Accounting for current practices in these three ways were used by participants to legitimise the descriptions of not acting on potential physical health issues, or life-style behaviour that could potentially cause physical conditions among patients, if they remained unchanged. Participants also downplayed the potential trouble related to accounts of not succeeding in motivating patients to lifestyle changes or in promoting better compliance with medical treatment of physical illnesses. This analysis contributed to answering the first and third research questions by providing insight into the physical health condition of people with schizophrenia, and into MHCPs accounts of actions and responsibilities related to dealing with physical health issues as part of their work. These may constitute barriers to physical health care provision in mental health care settings. The findings point to a need for continued awareness of negative attitudes and potential discrimination within mental health care settings. MHCPs need to engage actively in a process of changing such attitudes in order to achieve changes (Lerbæk et al., 2019).

5.3. Summary thematic analysis II: Perspectives on barriers and solutions

The analysis led to description and interpretation of two themes, which were: 1) *barriers to the provision of physical health care in mental health settings*, and 2) *possible solutions to overcome existing barriers*.

The barriers included aspects related to the presence of persistent and severe mental illness among the mental health service users, unintentional resistance to physical health initiatives (from mental health services users and from MHCPs), and limited education and training of the employed MHCPs.

The possible solutions addressed by the participants revolved around suggestions of providing integrated care, of adjusting attitudes among MHCPs, and of physical health being a shared responsibility.

This analysis contributed to answering the third research question by providing insight into aspects of everyday work situations that constitute barriers for provision of physical health care within mental health care settings, and how these could be addressed in the future.

Negative attitudes and limited specialist health care knowledge among mental health care professionals constituted serious barriers. To effectively address these barriers, mental health services need to be reoriented toward the prioritisation of physical health alongside mental health. This will require equipping mental health professionals with relevant knowledge and skills and organisational resources, to effectively work with people experiencing or at risk of physical comorbidities (Lerbæk et al., 2020).

5.4. Integrated findings: Factors sustaining physical health issues and management strategies

The analytical process of progressive focusing led to the development of an explanatory theory focused on providing insight into some of the complexities embedded in the ongoing social processes that influenced on management of debilitating physical health issues in everyday life of participants with schizophrenia. The main influence found was that existing physical health issues experienced by the participants and the strategies used to manage these, were sustained over time. To provide insight into these complex, multi-dimensional interactional processes, the following sections will introduce: *The process of managing physical health issues in everyday life* and *Sustaining factors and their interactions*.

The different factors that was identified as sustaining physical health issues as well as the strategies used to manage them, interactional processes between the factors, and three dimensions of social context are illustrated in Figure 1 (p. 82) and will be addressed in the sections below. The factors and interactions depicted in Figure 1 and described here do not represent a finite sample; it is recognised that many other factors and possible interactions can exist, however, a selection based on the data generated for this research have been addressed here

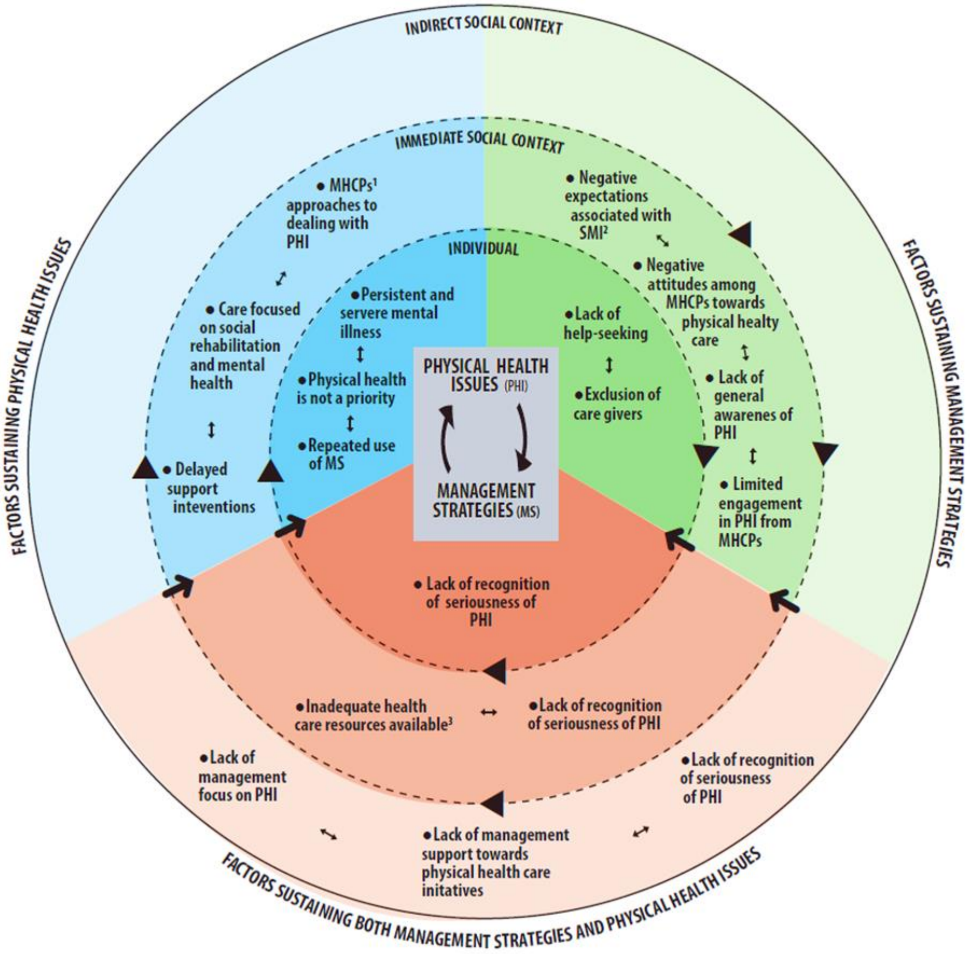
5.4.1 The process of managing physical health issues in everyday life

The process of participants experiencing debilitating physical health issues and the strategies they employed to manage them in everyday life, is central to these findings. Therefore, an illustration to signify this ongoing process is placed in the square at the centre of Figure 1.

Most of the participants with schizophrenia recruited for this research experienced debilitating physical health issues as part of everyday life. The strategies used by these participants to manage physical health issues (*Modifying everyday life to manage discomfort* or *Retreating from everyday life to recover*, respectively) were inexpedient insofar as neither strategy resulted in transition towards better health. For these participants, better health could mean that despite the presence of physical health issues, they would not experience significant limitations in everyday life. Rather, the management strategies used by the participants were oriented towards the likelihood of poorer health outcomes. For example, *modifying* everyday life to manage any worsening of ongoing physical health issues, which was the strategy used by participants living at residential facilities, could result in slow and continued deterioration in physical health; and *retreating* when experiencing discrete and repeated episodes of physical health symptoms, which was the strategy used by participants living in the community, was characterised by fast deterioration with a high risk of participants experiencing irreversible damage to health.

The strategies to *modify* or *retreat* to manage physical health issues, were used repeatedly by the participants without any noticeable positive change. The rounded arrows at the centre of Figure 1 illustrate these repetitions and how they constituted an ongoing process in which the individual sustained existing physical health issues and maintained the strategies used to manage them in everyday life.

Figure 1: Factors sustaining physical health issues and management strategies



[1] Mental health care professionals is abbreviated MHCPs [2] Severe mental illness is abbreviated SMI [3] This factor mostly applied at the residential facilities

The participants’ management of debilitating physical health in everyday life was understood as social behaviour, that was continuously shaped through interactional processes between the participants and other people in the social context related to their everyday life. Participants living at residential facilities and participants living in the community lived socially isolated lives. This social isolation was evident during the conduct of the research, where there were very few situations where participants were observed to interact with others about their physical health issues. However, accounts from MHCPs who was engaged in the everyday social contexts of the participants, provided valuable insight into factors that contributed to physical health issues and the management strategies being sustained. Integration and interpretation of these different perspectives on the management of physical health in everyday life resulted in an explanatory theory that can enhance understanding of the complex social processes that are enacted in the seemingly simply activities daily living related to management of physical health.

Through the process of analysis and integration, three dimensions of social context became evident. These were; 1) the *individual*, and included factors that originated within and around the individual experiencing physical health issues; 2) the *immediate social context*, which included factors related to direct interactional processes in the immediate surroundings of everyday life of the individual, e.g. attitudes, accounts and actions of the MHCPs; and 3) the *indirect social context*, which included factors that impacted indirectly on aspects related to the individual by working through interactional processes with factors in the immediate social context. Factors in the indirect social context included attitudes and priorities describes as related to the management/organisation level of mental health services. These factors primarily originated from the accounts by MHCPs.

The three dimensions of social context are illustrated as three circles in Figure 1. They illustrate how factors with different proximity or distance to the individual impacted on everyday life behaviours embedded in the process of managing physical health. These three dimensions of social context are not wholly separate, hence in Figure 1 they are distinguished by dotted lines. The factors identified as impacting on management of physical health appeared to be intertwined in complex and multi-dimensional interactional processes, taking place within and across these three dimensions of social context.

5.4.2. Sustaining factors and their interactions

The main impact of the interactional processes found in this research was related to sustaining physical health issues and the strategies used to manage these. Therefore, the factors identified as influential in these processes were named *sustaining factors*. As illustrated in Figure 1, the sustaining factors (depicted as descriptive terms) represented different domains, as some primarily contributed to sustaining management strategies (green area) and some primarily contributed to sustaining physical health issues (blue area). With a third group of sustaining factors, it was difficult to ascertain where the primary influence occurred. These are depicted as contributed to sustaining both physical health issues and management strategies (red area).

Relationships occurring between the sustaining factors were characterised as *interactions* and occurred both within and across the different dimensions of social context. The term interaction refers to how some factors were prerequisite of other factors, while some factors were co-existing.

5.4.2.1 Interactions between factors within each dimension

A general assumption about the interactions between sustaining factors within each of the three social context dimensions was, that all factors which sustained management strategies also indirectly contributed to sustaining the physical health issues experienced by participants. This assumption was based the findings related to the inexpedient nature of the strategies used by participants to manage physical health issues. Using the identified strategies did not result in improvement of physical health. This interaction is illustrated with arrows on the dotted lines, indicating a direction from factors sustaining management strategies towards the factors sustaining physical health issues. As an example, *Negative expectations associated with SMI*, *Negative attitudes among MHCPs towards physical health care*, *Lack of general awareness of physical health issues*, and *Limited engagement in physical health issues from MHCPs* were all factors in the immediate social context which sustained management strategies used by participants. However, these factors were also understood to be associated with the *MHCPs approaches to dealing with physical health issues*, *Care focused on social rehabilitation and mental health*, and *Delayed support interventions*, which were factors primarily contributing to sustaining physical health issues. The consequences related to these factors and their interactions were that both the physical health issues experienced by participants with schizophrenia and the inexpedient management strategies used to deal with them was sustained over time.

Interactions between sustaining factors within each domain in each of the three dimensions of social context took on different forms. In Figure 1, these interactions are illustrated with double-sided arrows placed between the factors. In the dimension related to the individual, the factor *Exclusion of care givers* was understood as part of (co-existing with) a *Lack of help-seeking*. A lack of help-seeking occurred when participants excluded potential caregivers while experiencing physical health issues. Both of these factors contributed to sustaining management strategies.

Among the factors related to the individual identified as sustaining physical health issues, the presence of *Persistent and severe mental illness* and *Physical health is not a priority* were understood to be prerequisites of the third factor; *Repeated use of management strategies*. Assumptions about this interaction and the proposed sequential order were based on knowledge gained through field work conducted in the homes of the participants with schizophrenia. In many cases, dealing with issues related to symptoms of mental illness became the overarching task in everyday life, leaving little excess energy to manage issues that were related to anything else, including physical health. Limited resources to manage everyday life contributed to repeated use of known strategies, even though these were unhelpful. In addition, some participants explicitly articulated how dealing with mental health issues such as severe anxiety or paranoid delusions was their main concern.

Within the immediate social context, reciprocal interactions occurred among the factors which sustained the strategies used by participants to manage physical health;

Negative expectations associated with SMI and *Negative attitudes among MHCPs towards physical health care* were both considered to be prerequisites for and a consequence of a *Lack of general awareness of physical health issues* and *Limited engagement in physical health issues from MHCP*. It was difficult to ascertain which of these factors were primary in sustaining the management strategies for dealing with physical health issues among the participants. Rather, these factors reflected an ongoing spiral of negative attitudes which contributed to unhelpful actions in the everyday work practices of the MHCPs related to dealing with physical health issues among the participants with schizophrenia; e.g. not engaging in physical health issues, resistance towards tasks related to physical health care, or dismissal of the potential risks associated with not taking actions. Analyses of focus group discussions and of accounts from key informants provided insight into how these four sustaining factors within the immediate social context were associated with *Inadequate health care resources available* among the employed MHCPs at the residential facilities. In these facilities, the majority of MHCPs were educated and trained in dealing with social aspects of long term rehabilitation, rather than in dealing with physical health issues. This lack of health care resources caused negative attitudes and resistance against physical health related work tasks among MHCPs. In the community setting, the four factors sustaining management strategies in the immediate social context were explained by MHCPs as the result of organisational structures, which forced MHCPs to prioritise mental health issues over other issues, in everyday work situations. Even though the factors and interactions involved in sustaining management strategies in the immediate social context originated from different circumstances (such as a lack of health care resources and organisational structures), the impact was similar, as they resulted in limited engagement between participants with schizophrenia and MHCPs related to management of physical health issues and a lack of positive changes to managing physical health in everyday life.

These explanations from MHCPs pointed towards aspects of care that was related to organisational priorities and suggested the existence of interactions taking place between sustaining factors across the three levels of social context.

5.4.2.2. Interactions between factors across dimensions

Identifying factors that contributed to sustaining physical health issues and management strategies related to the individual, the immediate social context, and the indirect social context, respectively, did not adequately explain the social processes that were influential on management of physical health. It was apparent that complex interactional processes also occurred between sustaining factors across the dimensions of social context. These interactions across dimensions are illustrated by the arrows placed on the dotted lines directed towards the centre of Figure 1.

Taking this multi-dimensional understanding of management of physical health issues in everyday life into account, provides further depth to the findings. As an example, it is possible to add nuances to the finding that factors sustaining physical health issues in the individual dimension; *Persistent and severe mental illness* and *Physical health is not a priority* would lead to a *Repeated use of management strategies*. These factors in the individual dimension were influenced by interactional processes with different sustaining factors in the immediate social context such as *Lack of general awareness* *of physical health issues* and *Limited engagement in physical health issues from MHCPs*. These interactions were understood as displays of the ongoing co-constructions taking place in the social context of this research related to attitudes and actions associated with management of physical health issues. The MHCPs were important actors in the limited social network of the participants with schizophrenia. Hence, the lack of MHCPs' awareness of and limited engagement in physical health issues experienced by the participants with schizophrenia, had negative consequences, as no change towards developing more beneficial manage strategies was facilitated, and hence the physical health issues remained. Another interaction and representation of a shared understanding about the management of physical health issues in everyday life, was related to attitudes towards severe mental illness. In the context of the individual, the presence of Persistent and severe mental illness was understood as contributing to sustaining physical health issues, ad various issues and concerns expressed by participants related to the experience of severe mental illness made it difficult for them to manage different aspects of everyday life, including physical health issues. This was also reflected in accounts from MHCPs, who described how the presence of severe mental illness greatly impacted on the physical health of people with SMI and on their ability to deal with other problematic issues occurring as part of everyday life. This was captured in the factor *Negative expectations associated with SMI* which was identified as sustaining management strategies in the immediate social context.

As described above, interactions between factors within the immediate social context facilitated *Limited engagement in physical health issues from MHCPs* in everyday work situations. In practice, this meant that few of the interactions occurring between MHCPs and people with schizophrenia concerned physical health issues. By not engaging with each other, the existing beliefs about physical health held by both parties remained unchallenged. In this way, the enacted interactional processes also sustained the practices held by both the participants with schizophrenia (*Physical health is not a priority*) and the MHCPs (M*HCPs approaches to dealing with physical health issues, Care focused on social rehabilitation and mental health, Delayed support interventions*). Consequently, prevailing debilitating physical health issues were sustained.

Factors in the immediate social context that contributed to sustaining physical health issues among participants with schizophrenia were understood as associated, as *MHCPs' approaches to dealing with physical health issues* and *Care focused on social rehabilitation and mental health* were identified as factors that would lead to *Delayed support interventions* for people with schizophrenia. The MHCPs' approaches to dealing with physical health issues in everyday work situations identified in MHCPs' accounts, were unsystematic and occasional in nature and characterised by MHCPs not providing support until the physical health state of the participants had already worsened. In combination with accounts from MHCPs describing how physical health was a deprioritised area of care (compared to social rehabilitation at the residential facilities and management of mental health issues in the community setting), this added to a potential explanation of why interventions of supporting participants with schizophrenia in managing their physical health issues was delayed and sometimes omitted. Addressing this issue including factors from across the three dimensions of social context, it was apparent that a *Lack of management focus on physical health issues* in the indirect social context resulted in *Inadequate health care resources available, Lack of general awareness of physical health issues,* and *Limited engagement in physical health issues from MHCPs* in the immediate social context. In addition, (and as described above) these factors in the immediate social context were likely to influence the individual's *Repeated use of management strategies*. In this way, it was understood that although some factors originated in social context dimensions more distant from the individual, they still impacted on to the individual through interactions inwards through the dimensions. However, the influence of identified factors was not necessarily bi-directional, as factors originating in the individual or immediate social contexts did not facilitate influence in an outwards direction towards the indirect social context (illustrated by the arrows only directed towards the centre of Figure 1). This one-directional process was illustrated in accounts from participants with schizophrenia, who experienced having their physical health issues dismissed by MHCPs as nothing to worry about (having no impact on immediate social context), and by accounts from key informants who experienced a continued lack of responsiveness in the indirect social context when they attempted to address issues of inadequate physical health care provision with their local managers (having no impact on the indirect social context). As a consequence, sustaining factors identified closest to the participants experiencing debilitating physical health issues, were without any real influence on how practices in the other two dimensions of the social context played out. In addition, the participants with schizophrenia seemed to be unable to recognize their need of support related to managing physical health issues, and they made no effort to receive such support.

As illustrated in Figure 1, the factor *Lack of recognition of seriousness of physical health issues* was present in all three dimensions of social context. This finding points to the presence of a general attitude in the context of this research, where debilitating physical health issues in everyday life were not acknowledged as important enough to require attention. This attitude was enacted in the actions and accounts of participants with schizophrenia, and the accounts of MHCPs engaged in the immediate social context. Furthermore it was found in accounts from key informants who described how the presence of poor physical health among people with SMI had become *normalised* within these contexts of mental health care, to the extent that MHCPs did not necessarily take action on physical health issues despite the risk of deterioration when physical health issues remained unchanged.

This *Lack of recognition of seriousness of physical health issues* across the three dimensions of social context was understood as the product of ongoing interactional processes, in which poor physical health among people with SMI was co-constructed as 'normal'. Indications of these interactional processes appeared in accounts from participants with schizophrenia in which they described their own debilitating physical health issues as something that was 'not of importance', in MHCPs dismissing the issues as caused by mental health issues, and in MHCPs describing poor physical health as something that was 'expected' among people with SMI, and how physical health was not considered a priority among their colleagues or local managers. The overall presence of this attitude towards management of physical health issues constituted a major sustaining factor, which only consolidated the shared understanding of the current practices related to managing physical health issues as unproblematic.

Overall, these findings reflect ongoing, complex interactional processes resulting in a deadlock in which management of physical health issues with inexpedient strategies, was continuously sustained in the everyday life of participants with schizophrenia. Characteristic of these findings was a lack of beneficial interactions between the participants with schizophrenia and the main actors in their immediate social surroundings, about their physical health issues and limited positive change in their physical health conditions.

Chapter 6: Discussion

This chapter includes a discussion of selected key findings of the research conducted for this thesis, followed by a discussion of the methodology and methods focused on strengths and limitations.

This ethnographic study explored how a group of people diagnosed with schizophrenia managed debilitating physical health issues in everyday life. The study was informed by the experiences and knowledge gained while I engaged in the social worlds of these participants. The study has brought forth the perspectives of those diagnosed with schizophrenia, and of a group of the MHCPs who were involved with everyday care and treatment of the participants. The intention of this research was to build on what is currently known about deteriorating physical health among people with SMI and about what people with SMI find meaningful and influential about healthy living, (Graham et al., 2013; Brenda Happell et al., 2016), and their experiences of health care services (Abed, 2010; Gedik, Günüsen, & Ince, 2020; Stenov, Joensen, Knudsen, Hansen, & Tapager, 2020). An objective of this research was to explore at first-hand what happens when a group of people with schizophrenia experience physical health issues as part of their everyday life. Discovering, interpreting and providing potential explanations related to how these participants managed their physical health can potentially improve our understanding about how to provide support that fits the needs of others in similar situations.

The findings of this research build on the existing knowledge by providing access to insights about how self-management of physical health issues takes place in everyday life, and how potentially ineffective self-management strategies and physical health issues are sustained because of interactional processes in the social context of the participants.

6.1. Discussion of findings

A key finding from this research was the identification, description, and interpretation of two typical strategies for managing debilitating physical health issues used by the participants with schizophrenia. These strategies were *Modifying everyday life to manage discomfort* and *Retreating from everyday life to recover*, which were illustrated in the form of two personas (Lerbæk et al., n.d.). The participants management of physical health issues in everyday life was characterised by a lack of beneficial social interactions with others about the physical health issues they were experiencing. In general, the participants were unable to successfully manage their physical health issues in the absence of meaningful support and their conditions or symptoms did not improve.

This research also provided insight into how managing physical health issues as part of everyday life is a complex and multi-dimensional process, in which various factors interacted in ongoing social processes which shaped everyday life actions. These processes resulted in a deadlock where physical health issues experienced by the participants with schizophrenia, and the strategies they used to manage them, were continuously sustained, rather than interrupted or discontinued. An important finding was the description of an ongoing co-construction of poor physical health among people with schizophrenia as '*normal'*, '*accepted'*, and '*nothing of importance*' in the social context of this research. Resulting in an overall lack of recognition of the potential seriousness of the physical health issues experienced as part of everyday life.

There is a general sociological understanding that life is organised around routines and that the 'ordinariness' of everyday life is socially produced in the interactions that we engage in (Chambliss, 1996; Giddens & Sutton, 2012a). The work of Daniel F. Chambliss (1996) which has illustrated how the spectacular or abnormal can become part of the routines of everyday life, can provide insight into the process of normalization and how routine is maintained. Normalization or routinisation of abnormal conditions is a way of creating a manageable state for ordinary life (Chambliss, 1996). When considering the social context of this research, which was illustrated by an everyday life environment in which people with schizophrenia experienced various ongoing physical health issues and daily challenges related to mental and physical health, both the participants with schizophrenia and the MHCPs may have become habituated to these issues as a usual and expected aspect of life. While there may be some community and professional outrage about how people with SMI face slowly deteriorating physical health and an early death (Chwastiak, 2015; R. E. Nielsen, Straszek, Kovacs, & Licht, 2020; Thornicroft, 2011), there is high potential for ill-health to be perceived as a normal part of everyday life. Witnessing or experiencing these troubles over and over again becomes routine and remains unchallenged, which in turn minimises or blurs any moral imperative to facilitate change (Chambliss, 1996). However, as Chambliss points out, normalization is not just about getting used to certain circumstances and requires more than merely time and repetition. Normalization is also about becoming accustomed to the particular space, language and people involved with the social context, and developing acceptance of the situation as normal. This requires transformation of one's thinking and the introduction of a new way of relating to people and situations. In terms of managing physical health issues in everyday life, this would entail – as suggested by the findings of this research – a shared understanding of poor physical health as 'normal' by the involved parties (Chambliss, 1996). In this case, the moral ambiguity of responding to poor physical health among people who also have persistent and severe mental health issues, may become lost in the recurrence and enduring nature of issues and events and the social construction of 'ordinary' everyday life (Chambliss, 1996).

'Normalization of deviance' is another concept drawn from sociology, that can provide insight into some of the practices that were enacted in the social contexts of this research, see for example (Banja, 2010; Price & Williams, 2018; Wright, Polivka, Odom-Forren, & Christian, 2021). Normalization of deviance occurs when people within a specific context or organisation becomes insensitive to deviant practices (Wright et al., 2021, p. 4). Such insensitivity is described as imperceptible and developing over time, e.g. as people working in certain contexts continues to bend rules or reduce standards of their work to the point where ‘a new normal’ is reached over time. An important factor in normalization of deviance is that the deviant practices continue, because no negative outcome appears to follow immediately after these actions (Price & Williams, 2018; Wright et al., 2021). The trouble begins, as other critical factors line up and disasters occur (Wright et al., 2021). Even though this concept was coined based on work related to understanding the Challenger space shuttle disaster[1], it is highly applicable to health care settings, where normalization of deviance is described to have a strong, pervasive presence (Banja, 2010; Wright et al., 2021). In relation to this research, speaking of deviant practices would relate to the practices of the MHCPs who were engaged in providing care and treatment to people with schizophrenia. However, the potential existence of deviant practices in the context of this research can – through the complex, multi-dimensional social interactional processes described in the findings of this research as part of managing physical health issues – become influential on everyday practices of others involved (the participants with schizophrenia). Understanding the findings of this study based on the notions of normalization of deviance, the presence of deviant practices among MHCPs related to dealing with physical health-related work tasks could reinforce the ‘invisibility’ of the prevailing issues. Consequently, sustaining social processes that reinforce what could be characterised as a slowly developing disaster of poor physical health and excess mortality among people with SMI, though the acceptance of the presence of these issues in the context of their everyday work. Banja (2010) explains how disaster is not triggered by a single mistake or a single case of bending the rules. Rather, serious harm occurs as a group of people commits multiple seemingly innocent mistakes, that causes reduction of practice standards (Banja, 2010). In this case, MHCPs not being aware of physical health issues and not engaging with the participants with schizophrenia about the physical health issues they experienced, might seem innocent in a single situation. However, understood as repeated patterns of deviant practices, that result in the creation of ‘a new normal’, not engaging can cause serious damage over time. What starts as deviations from standard practice - for example, not applying systematic approaches to manage physical health issues among a group of people who are at risk of developing ill-health, can become normalised patterns of behaviour through repetitions (Banja, 2010; Chambliss, 1996). Previous research has described how management of physical health issues in the context of some mental health services entails dilemmas, which might lead to MHCPs resorting to deviant practices, such as bending clinical guidelines and omitting certain tasks in order to safeguard fragile relationships with mental health users (Lerbæk et al., 2015; Møller et al., 2020). Different factors can lead to such deviant practices. They have been described as originating in productivity pressure, generalised complacency, social pressure or negative acculturation, or peer pressure to comply to deviant practices (Wright et al., 2021). All of these seem possible in the case of this research, where MHCPs described various factors related to the organisation of care and

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[1] Normalization of deviance was described by sociologist Dr. Diane Vaughan based on her work related to the Challenger space shuttle disaster, which occurred in 1986; see Vaughan, D (1996), *The Challenger launch decision: Risky technology, culture and deviance at NASA*. Chicago; University of Chicago Press

potential conflicts within the group of MHCPs that posed barriers for the provision of physical health care as part of their everyday work. By not triggering an immediate negative outcome, normalization of deviance reinforces practices that are related to cutting corners (Wright et al., 2021) – e.g. as MHCPs in the community setting of this study experienced pressure to comply to organisational demands of delivering mental health care as their primary task, 'forcing' them to deprioritise management of potential physical health issues (Lerbæk et al., 2019). Highlighting these potential deviant practices, I do not intend to suggest that the MHCPs who worked in the settings of this research were not doing their very best. In my understanding, they were doing what they believed to in the best interest of the participants with schizophrenia. Rather, these points of discussion represent attempts to provide further explanatory ideas about what goes on in the process of managing physical health issues as part of everyday life practices.

In this study, *Modifying everyday life* was a strategy used by participants with schizophrenia to manage potential or actual discomfort associated with ongoing poor physical health, while *Retreating from everyday life* was a strategy used by participants who experienced recurring discrete episodes of poor physical health characterised by fast deterioration. Viewed from a psychological perspective, both of these strategies employed to manage physical health issues, could be characterised as forms of adaptive behaviour. Adaptive behaviour is a constellation of conceptual, social and practical skills that essentially enable people to function and deal with different demands in everyday life (Oakland & Harrison, 2008; Tasse, 2013). Some adaptive behaviours may be effective in dealing with the natural and social demands of the environment, for example people continuously adapt to social circumstances when engaging in different everyday life situations, hence we might act differently at work, then we do in the privacy our home. However, in this study, adapting behaviour was associated with potential negative consequences, as participants with schizophrenia were at great risk of their physical health issues going undetected by others and subsequent deterioration in their health. As an enduring strategy, *modifying everyday life* often resulted in shifts in behaviour to manage discomfort, avoid worsening of symptoms or changes in physical health, which occurred without effective interpersonal communication and in the absence of help-seeking behaviour. This meant that opportunities for relevant intervention were unnoticed and treatment was absent or delayed. Managing by *Retreating* entailed fast deterioration in the physical health state of the participants, and exclusion of care givers in the social network meant that potential negative consequences could be irreversible.

People diagnosed with schizophrenia may experience changes in their adaptive competencies (e.g. personal care, language and communication, interpersonal skills) as part of their illness experience (Adelsky, Bowie, Goldberg, & Serper, 2011; Harvey et al., 1998). Adaptive skills related to health and safety are described as part of the conceptual adaptive behaviour domain (Oakland & Harrison, 2008). However, accounts of how reduced adaptive competence may impact on managing physical health issues in everyday life by people with SMI, have not previously been described.

Competence in adaptive skills is highly associated with expectations of the individual held by the surrounding society. Possessing good adaptive skills will make aspects of an individual's behaviour 'invisible' to others, as they will not 'stand out' in relation to what is expected of them (Tasse, 2013). In the context of this research, and as addressed previously in this discussion, poor physical health among people with schizophrenia had become normalised (Lerbæk et al., 2020), and there were no expectations that people with schizophrenia would be able to independently manage their physical health issues because of the severity and persistence of their mental illness (Lerbæk et al., 2019; Lerbæk et al., 2020). The behaviours associated with adapting to avoid discomfort without seeking help (Lerbæk et al., n.d.), may have become inevitable and therefore undetected because the behaviours did not stand out as 'different' in the social context. In light of the concept of adaptive skills, it seems that people with schizophrenia and debilitating physical health issues became 'invisible', as did the physical conditions they experienced, because in the mental health care settings that constituted their everyday life, their behaviours were expected by the actors in their immediate surroundings and community (Tasse, 2013).

In terms of the suggested normalisation of poor physical health among people with schizophrenia, an important task would be to try to change the expectations embedded in the social context of everyday life, so that deteriorating health is not accepted or untreated. An important consideration is that when provided with relevant interventions and support a person's adaptive skills can increase and result in improved ability to meet the expectations of society (Tasse, 2013). Therefore, identifying beneficial management strategies and engaging actively in sustaining these could potentially lead to positive outcomes related to physical health among people with schizophrenia. However, for such interventions towards modification of adaptive skills to become beneficial to the physical health state of people with schizophrenia, the incorrect beliefs and attitudes embedded in the social contexts of everyday life – and in society - needs to change as poor physical health among people with schizophrenia cannot be accepted as the 'normal'.

Previous research has described the responsibilities of different occupational groups such as case managers, psychiatrists (De Hert et al., 2010), general practitioners (Oud et al., 2010; van Hasselt et al., 2013), and mental health nurses (Blythe & White, 2012; Brenda Happell, Platania-Phung, & Scott, 2014; B. Happell et al., 2012; Møller et al., 2020), and of people with SMI (Butler et al., 2020) related to management of physical health issues. Managing these issues has been described as a shared responsibility in research (van Hasselt, Oud, & Loonen, 2014) and in clinical guidelines. Perhaps in attempt to invoke a sense of obligation among the many different actors who play a role in the varied social contexts and support mechanisms of people with SMI – and in people with SMI themselves. The findings of the research conducted for this thesis point towards issues within the specific social contexts related to a shared lack of recognition of the seriousness that the existing physical health condition entails. The findings also illustrate some of the many different factors that needs to be taken into account if current state of issues is to change.

Based on the understanding of management of physical health issues is a shared responsibility, this research furthermore points towards a shared responsibility related to breaking out of the deadlock and challenge the ‘normality’ of deteriorating physical health issues among people with schizophrenia and other severe mental health issues.

Some of the findings presented in this thesis, are similar to those reported by others. Examples include descriptions of higher occurrence of physical health issues among people with SMI, when compared to the general population (Bartlem et al., 2015; McCloughen et al., 2012), and MHCPs’ lacking time and resources to manage such issues sufficiently in their everyday work practice (Brenda Happell et al., 2014). However, the research reported in this thesis extends the existing knowledge base by providing in-depth descriptions and interpretations of patterns of behaviour and social interactions that come into play in the everyday lives of people with schizophrenia who are also experiencing physical health issues. Furthermore, it presents unique, insider perspectives based on both emic and etic perspectives related to how physical health is managed and how the strategies used potentially influenced the outcome of such actions. These finding were combined with interpretations of how some wider contextual aspects might have influence on ways of managing physical health in these mental health care settings. Additionally, the different analytical strategies provided detail and depth to the description and interpretations presented (Hammersley & Atkinson, 2019; Schensul et al., 1999).

6.2. Strengths and limitations

The following sections addresses some of the considerations and choices made throughout the research process. The sections include discussion of methodology, the methods used for generating data and for conducting analyses, and of the use of the concept physical.

6.2.1. Methodology

Planning and conducting research require considerations and decisions related to epistemology, theoretical perspective, methodology and methods. These elements set the frame for the research process and the knowledge produced, as different epistemologies, theoretical perspectives, methodologies and methods will bring forth different types of data, as well as be appropriate for answering different types of research questions (Crotty, 1998).

In the case of this research, applying an ethnographic approach offered positive possibilities for exploring aspects of somewhat unpredictable everyday life contexts of the participants with schizophrenia. However, this approach required me to deal with the continuous uncertainties, that came with applying a very flexible and adaptable approach. Managing this approach required capability to make and change decisions, and preparedness to adapt to the changing circumstances of the field (Hammersley & Atkinson, 2019). These aspects of the ethnographic approach were of great importance due to the instability of the everyday life of the participants diagnosed with schizophrenia. Here, instability of everyday life refers to the unpredictability embedded in everyday life of participants experiencing ongoing changes in their mental health state. The unpredictable nature of their everyday life made it difficult to make any certain plans, as neither they or I was able to predict how they would feel on the specific day – and sometimes even how the next hour would turn out. The adaptability and flexibility embedded in the ethnographic approach (Hammersley & Atkinson, 2019)was challenging for me as a novice researcher still in the process of learning how to conduct research independently. However, the process strengthened my skills into dealing with such issues related to conducting clinical research enormously.

As described in the methodology section of the thesis, conducting ethnographic research is about immersion into the social world of others (Emerson et al., 2011). Even though this research was conducted in mental health settings that were similar to the ones known to me from previous work experiences as a social and health care assistant and as a nurse, it was obvious that as a researcher entering the field, you are always marginalised, you are an outsider, in the setting where a study is conducted (Schensul et al., 1999). In some of the locations of this research, gatekeepers did not willingly accept me, as the 'the researcher', to trespass into their domain. In these situations, I was immediately marked as the outsider, and needed to negotiate my way in (Hammersley & Atkinson, 2019). Sharing my personal history as a social and health care assistant and as a nurse having previously worked in similar mental health settings, became a way for me to become accepted in these settings. Being understood as 'one of their own kind' made way for a common understanding of their reality, and my presence was accepted.

Ethnographic research is small-sample research. This is often advised to ensure possibility for deep immersion into the social worlds of the ones being studied (Hammersley & Atkinson, 2019). The study included nine participants, and immersion into the different settings that constituted everyday life of these participants was challenging and time-consuming. The task was managed by conducting field work in two phases; one phase which focused on participants living at residential facilities; and one focused on participants living in the community setting. Here, the pragmatic approach embedded in ethnography also represented a positive feature which made it possible for me to conduct the research according to the possibilities and limitations of the field of research.

Conducting ethnographic research generates a large amount of data that is typically unstructured in nature. In the study, this was seen in the way that different participants contributed to different combinations of data materials. As the field notes provided the overall basis of the research material, the unstructured feature of the remaining data was not an issue of specific concern. Rather this way of adapting the methods to the individual participants, seemed to strengthen the general generation of data material (Hammersley & Atkinson, 2019).

6.2.2. Participants and methods used for data generation

This study included three types of participants; 1) participants with schizophrenia; 2) mental health care professionals (focus group participants); and 3) mental health care professionals (key informants). The primary group was the participants with schizophrenia, as they were the primary sources of information about management of physical health issues in their everyday life. Purposeful sampling was used to recruit the nine participants with schizophrenia (Palinkas et al., 2015). The criteria for including participants were very broad and did not display a lot of specific demands related to traits of these participants. The resulted in a small, but also broad sample. Reaching a representative sample was never an objective of this sampling process, and hence the purpose strategy was appropriate (Palinkas et al., 2015).

Various criteria could have been applied in order to reach a more specific sample. These criteria could have included aspects related to the physical health state of the potential participants e.g. participants with co-existing schizophrenia and diabetes. Research based on a more specific sample of participants could provide equally relevant knowledge, however focused on the management of the co-existing illness.

From the initial phase of the research, individual, semi-structured interviews with participants with schizophrenia were considered to be an appropriate method for exploring subjective perspectives and experiences on issues in everyday life that were associated with physical health (Hammersley & Atkinson, 2019; Holstein & Gubrium, 1995). However, in practice this approach did not work out well, and an alternative approach to gaining access to these perspectives and experiences was found in the audio-recorded conversations. The flexible and pragmatic approach embedded in the design made it possible to change strategy and try out different methods for gaining insight into these perspectives of the participants (Hammersley & Atkinson, 2019; Liamputtong, 2007).

The group of people with schizophrenia were not the only group of participants. The mental health care professionals were an equally important source of knowledge related to the issue, for example as key informants. Although these informants represented a small sample, the thematic analysis conducted on the basis of the individual, semi-structured interviews with these informants, illustrated how small-scale studies have the possibility to contribute valuable knowledge that will enrich the interpretations and understandings of specific social settings (Pelto, 2013; Schensul et al., 1999). Selecting people with SMI as a group of key informants would have provided different yet equally relevant perspectives on the issue of managing physical health in mental health care. However, key informants representing that group did not come forward during the study. Furthermore, the MHCPs as key informants provided valuable knowledge of some organisational aspects of care provision that contributed to deeper understanding of the current practices of the MHCPs as a group.

Although being identified as key informant, this group of participants were not expected to know everything about everything there was to know about managing physical health in mental health care settings. The knowledge they contributed with was understood as provided by them as a group. This was also a reason why it was important to seek breadth in knowledge and in experiences the inclusion of key informants (Schensul et al., 1999). When working with key informants in ethnographic research critical reflections about the validity of their accounts must be made. The insight provided by key informants can be cross-checked by examining other perspectives on the issue of interest. In this research, the use of different data generation methods and analytical strategies allowed for such validation of accounts to take place via triangulation of data and findings across analyses (Pelto, 2013; Schensul et al., 1999).

Mental health care professionals also contributed with knowledge through participation in the three focus groups. When conducting focus groups, a key feature of the method: reaching some kind of group consensus, can be of general concern, as this ‘hidden aim’ can make it difficult for participants to voice deviant or contrasting perspectives (Bloor, 2001). However, in the current study, conducting the focus groups within the local settings, and within groups of participants that were day-to-day colleagues, might have facilitated a comfortable and safe space for expressing differences of opinion. This can be one advantage of conducting focus groups within already established groups (Bloor, 2001). Recognising this, it is also noted that conducting focus groups based on groups of strangers might have facilitated different discussions among participants (Bloor, 2001). The explicit and critical perspectives of the MHCPs were sought through individual, semi-structured interviews with key informants, who were included exactly on the basis of their potential to reflect critically on the current practices, based on their specific insider knowledge (Pelto, 2013; Schensul et al., 1999). Therefore, these two data generation methods and groups of participants complemented each other well in relation to providing insight into the perspectives of the MHCPs of the two mental health care settings.

The ethnographic design and use of several qualitative data generation methods, resulted in a large amount of data. However, using a structured and consistent approach to organising the materials throughout the course of the research, including the use of a field work journal, memo-writing, writing notes on specific events, and producing tabular overviews of the materials, made it manageable (Hammersley & Atkinson, 2019; Schensul et al., 1999). This work continued through the process of analysis

6.2.3. Ethical considerations

It is of pivotal importance for researchers to protect the privacy and identity of participants when conducting studies that involve the participation of other people

(WHO, 2001). When conducting small-sample research and research among vulnerable groups it is equally important to address particular ethical considerations related to such issues. To this end, certain data have not been made available in the thesis out of consideration for the protection of the participant's identities or examples have been provided in ways that were considered safe. This applies to materials such as interview guides used in individual, semi-structured interviews with participants with schizophrenia and key informants, and the participant descriptions developed and used in the analysis.

The patterns presented in the findings are based on behaviours and interactions that were observed across participants, so that no single person was singled out. While the participants with schizophrenia or the MHCPs close to them might recognise these patterns or even see them as related to specific persons, this is expected due to their extended knowledge and engagement in the research.

Qualitative research that include participant who are considered part of vulnerable groups, such as people with SMI, has been criticised for lacking transparency in relation to ethical considerations in description of methodology and inclusion of participants. As a consequence, this type of research risk losing trustworthiness even if other aspects of the research has been described in detail (Carlsson, Blomqvist, & Jormfeldt, 2017). Such critique was taken into consideration and some of the ethical considerations that were dominant throughout the course of the research have been explicitly described.

A pivotal ethical consideration was related to the collaboration with gatekeepers (Allbutt & Masters, 2010; Schensul et al., 1999). This was experienced as a balancing act due to recruitment of participants being dependent on the gatekeepers' trust in the project and the intentions of me as researcher, and their critical views on and assessment of which possible participants would be given the opportunity to participate. Their selection was based on intentions to protect the people with SMI, who were in their care, combined with professional assessment of their mental health state. Collaborating with gatekeepers also meant accepting their opinion about who was approachable and who was not. Nonetheless, some potential participants were not given the chance to decide for themselves, as the gatekeepers chose not to inform them about the study taking place. Reflecting on this, and how this gatekeeper selection of participants can potentially silence some of those who have valuable insights to contribute with (Kristensen & Ravn, 2015), it must be encouraged that MHCPs who take on the role of the gatekeeper, need to be willing to trust the researcher to comply with common ethical guidelines regarding research, that involves human subjects, such as principles of autonomy, confidentiality, protecting the subjects, and doing no harm. Furthermore, that all participants are given the opportunity to give their informed consent, based on voluntariness (Kristensen & Ravn, 2015; Oeye et al., 2007; WHO, 2001). In line with this, qualitative researchers need to be clear and transparent when communicating information about a study, so that any uncertainties that might exist among gatekeepers are potentially addressed.

In relation to the chosen methodology, the overall flexibility and adaptability embedded in the approach, and a willingness to deal with unpredictability throughout the course of the research, created a space where participants could voice their experiences, despite of some extraordinary life conditions that made them vulnerable (Hammersley & Atkinson, 2019; Liamputtong, 2007).

6.2.4. Analytical approaches

Different analytical approaches were applied in this study and the findings from three separate were integrated in attempt to facilitate a structured management of the large amount of data. In addition, the objective of managing the various data materials in this way, was to provide in-depth descriptions and interpretations of the studied phenomenon on the basis of different perspectives (Hammersley & Atkinson, 2019).

The analyses conducted as part of this research were thematic analyses, discourse analysis, and a process of progressive focusing to reach integration of key findings.

The discursive analytical strategy applied, contributed with an important perspective to the ethnographic research by combining microanalysis of individuals accounts (spoken or written) view the overall ethnographic view (Galasiński, 2011). In this research, the discourse analysis focused on description and interpretation of situated accounts from focus group discussions among groups of MHCPs (Edwards & Potter, 2001; M. Scott & Lyman, 1968). The data materials were based on the interactional process and negotiation of social phenomenon, such as actions and responsibilities. It provided insight into group norms and descriptions, and in this study, some typical ways for MHCPs to account for situations that were challenging, hence was constituted justifications for potentially problematic decisions made.

The thematic analysis conducted as part of this research, was based on characteristics that are similar to those of discourse analysis. The approach to explore latent and interpretative patterns focused on meanings and assumption embedded in the accounts of participants, as well as on the semantics (Braun & Clarke, 2006). The thematic analytical approach was used in two separate analyses; 1) based on the ethnographic data materials; and 2) based on interviews with key informants.

These three analyses were both complementary to and combinable with the overall ethnographic design, as their objective was to address a shared overall aim, but from different perspectives and providing different levels of detail in analysis and interpretation. Once again, the flexible and adaptable ethnographic approach provided the appropriate frame for combining the findings of such analytical strategies to reach in-depth understanding of the patterns of social behaviour being studied (Hammersley & Atkinson, 2019).

The fourth analysis was used to integrate the findings from the three separate analyses. This led to the development of more nuanced descriptions of some of the social interactional processes that were influential on management of physical health as part of everyday life. As pointed out by Hammersley and Atkinson (2019), the process of conducting ethnographic analysis is not based on a specific procedure. In this case, the process, which they have named progressive focusing (Hammersley & Atkinson, 2019), was oriented towards precisely that – a focusing of key findings in a process that entailed movement from more specific findings toward more general explanatory ideas about the interactional processes that occurred in the social context of this research. An important objective in this analytical process was to develop new understanding based on the integration of the findings from the three separate analysis, and not merely to re-produce summaries.

6.2.5. The concept of physical health

An important concept throughout the course of this research was *physical health*. This concept was not specifically defined ahead of conducting the field work, but rather it was understood as a concept that was to be gradually defined through knowledge about the particular participants, and their perspectives on what physical health and physical health issues comprised (Atkinson, 2015). During the study, the field work was focused on aspects that appeared to be related to managing physical health as part of an everyday life among the participants with schizophrenia. Through this process of interacting with the social contexts of the participants, physical health was rather narrowly contextualised as related to the presence of physical symptoms and the presence of a physical health diagnosis. Towards the end of the research process and during analysis, the focus of this research was further condensed and finally demarcated as concerned with experiences of *debilitating physical health issues*.

Several circumstances may have influenced the development and narrowing of the concept. One aspect is related to the use of the concept of *physical* health from the beginning of the process, which in itself creates a division between the biological and physical aspects of health and any other psychosocial aspects that might be associated with being healthy or unhealthy. However, the choice to use *physical health* as a key concept was guided by the research objective of generating knowledge about how physical health issues, specifically, were managed. This knowledge could be useful in relation to developing and planning health care provision, so that those with SMI have the possibility to gain longer and better lives. Therefore, the scope of this research was limited to what aspects of the participants' everyday life that were associated with this concept. Exploration of health in a broader sense could generate equally important knowledge including aspects of social, psychological, spiritual as well as physical health. This could be the aim of future research.

Another aspect associated with the narrowing of the physical health perspective, is related to the methodological concept *reflexivity*, which was understood as the influence that I, as researcher, had on the research process. With a professional background of working as a MHCP in similar settings as the ones included in this study, the perspectives that I brought to the planning of the research, the generation of data and analysis cannot be denied. Getting involved by engaging in the social worlds of others is a key feature of ethnographic research, however, it is a feature that should be handled carefully and consciously in order to minimise distortion of the findings that could be related to any personal interests, whether these are political or practical in nature (Hammersley & Atkinson, 2019). Throughout the study, managing this issue was an ongoing process that among other things involved engaging in discussions with researchers and supervisors about the experiences and knowledge gained in the field work and analytical processes. These discussions and reflections made it possible for me to become aware of situations where my personal background might limit the perspectives. The way of moving forward from such situations was to consistently reflect on and challenge my views and perspectives in order to open up and be attentive to unexpected observations and experiences (Hammersley & Atkinson, 2019). Nevertheless, focusing on the concept of *physical health,* limited the current investigation to primarily that.

During this study, two participants did not experience physical health symptoms with negative impacts in everyday life. However, in line with other participants their everyday lives included behaviours that could be characterised as risky in terms of potentially developing future physical health issues. Examples included poor eating habits, high levels of social isolation, inactivity, and stress. These participants were living in the community and had been diagnosed with schizophrenia within one year of this study. Fieldwork provided insight into how learning to manage symptoms associated with schizophrenia in everyday life represented a significant challenge, leaving them limited resources to deal with anything else.

Most participants were challenged by lifestyle behaviours that could potentially negatively impact their future physical health. Even though these issues were beyond the scope of this thesis, they are important to mention as part of this discussion, as dealing with physical health or health more broadly, should not only be a priority when issues become evident. Working with health as an integrated part of everyday life, might offer some opportunities to prevent physical illnesses developing in people with mental health issues, while also promoting effective health behaviours and strengthening health literacy (Rodgers et al., 2018; Watkins, Stein-Parbury, Denney-Wilson, Ward, & Rosenbaum, 2020).

Previous research has suggested that integrated care models could offer some solutions to the issues of managing poor physical health among people with SMI (Small et al., 2017). The findings of this research support this suggestion and highlight the need for individualised care so essential needs are not overlooked (Rodgers et al., 2018). Furthermore, engaging service users in development and planning of care services, has the potential to empower people in relation to managing their physical health issues (Small et al., 2017).

Despite the limitations of this research, it 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 and interactions in everyday life, that makes it possible for the reader to assess how the patterns related to managing physical health presented in the findings are relevant and transferable to similar contexts of care.

Chapter 7: Conclusion

The aim of this research was to thoroughly investigate aspects of everyday life among a group of people with schizophrenia, to gain insight into how issues related to physical health were managed. The group of people with schizophrenia who contributed to this research have provided access to valuable knowledge about aspects of their everyday life that are not easily or typically accessible. The study contributes insights that can inform future development and implementation of health care services targeted at people with schizophrenia.

Four research questions guided the research: 1) *What physical health issues are experienced by people with schizophrenia in their everyday life?* 2) *How do people with schizophrenia manage physical health issues in everyday life?* 3) *How do mental health care professionals account for everyday work related to managing physical health issues among people schizophrenia?* And 4) *What are the factors that influence how physical health issues are managed in everyday life among people with schizophrenia?*

Research questions 1 and 2 were answered by conducting a thematic analysis based on a large amount of ethnographic data material which included fieldnotes, individual interviews and audio-recorded conversations with nine participants with schizophrenia. The participants experienced debilitating physical health issues in everyday life and managed these by *Modifying everyday life to manage discomfort* or *Retreating from everyday life to recover*. Repeated use of inexpedient strategies to manage the physical health issues they experienced meant that no improvement in health occurred – both the physical health issues and the management strategies were sustained.

Research question 3 was answered by conducting a discourse analysis of data material generated in focus groups with MHCPs, and a thematic analysis of individual interviews with key informants, who were also MHCPs. These analyses provided insight into accounts of MHCPs about their actions and responsibilities in relation to dealing physical health issues as part of everyday work practices, and into perspectives on barriers within the context of mental health care and some solutions to overcome them.

Research question 4 was answered by conducting an analysis which resulted in integration of key findings across the three separate analyses. An explanatory theory was developed to provide insight into the complexities embedded in the process of managing physical health issues in everyday life. The findings suggest that the identified factors and their interactional processes was sustaining both physical health issues experienced by the participants with schizophrenia, and the management strategies they used to deal with them. Latent attitudes in the social context of this research entailed a lack of recognition of the seriousness that the prevailing physical health issues could entail. Furthermore, the findings pointed to the worrying fact that poor physical health among people with schizophrenia had become normalised to the extent, that neither the participants who experienced these debilitating issues or the MHCPs engaged in everyday care, acknowledged these as something to worry or deal with. Consequently, the complex, multi-dimensional process of managing physical health issues in everyday life resulted in a deadlock, characterised by a lack of beneficial interactions and a lack of transition towards improvement in physical health.

Chapter 8: Perspectives

This final section of the thesis is dedicated to perspectives related to the implications for everyday life practice of people with schizophrenia, for mental health practice and for future research.

As mentioned in the very beginning of the thesis, a long-term objective of this research was to contribute perspectives and insights related to those diagnosed with a severe mental illness, so that they have a chance of gaining longer and better lives. The perspectives presented in the following provides some suggestions to how this thesis can contribute to future work in practice and in research.

8.1. Implications for mental health practice and future research

The findings presented in this thesis represents knowledge that is of importance to people diagnosed with schizophrenia who experience physical health issues as part of their everyday lives. The findings suggest that some people in this group have difficulties managing their physical health in a way that actually promotes their health. The findings are also of importance and relevance to professional groups working with people with schizophrenia in different contexts of care and point to continued risk of insufficient provision of health care to people with schizophrenia in specific contexts of mental health care services.

This findings points to specific areas of health care in the social context of this research that needs attention, and these include; 1) management of co-existing schizophrenia and ongoing physical symptoms for example, shortness of breath, numbness in the extremities or difficulties when eating or drinking and existing conditions such as chronic obstructive pulmonary disorder (COPD), arthritis or severe constipation, or occurred in the absence of a diagnosed illness; and 2) management of co-existing schizophrenia and re-occurring, discrete episodes of quite severe physical symptoms such as nausea, stomach ache, vomiting, diarrhoea, and fever. Aspects of the findings of this research described how poor physical health among people with schizophrenia had become normalised and that a lack of interactions between the participants who experienced physical health issues and primary actors within the immediate social context of their everyday life related to physical health issues played a role in sustaining this 'new normal'. There is a need for physical health issues to become recognised as important. Even though a single, specific situation of not dealing with physical health issues might not trigger an immediate negative outcome, there is a great risk that continued dismissal of the importance of these issues will result in a the slowly developing disaster of ongoing deterioration of physical health and poor long-term outcomes.

This research was based on a broad investigation into the everyday life of people with schizophrenia. Possibilities within future research could be related to conducting focused ethnography in general health and mental health care settings, e.g. related to those who are diagnosed with SMI and physical comorbidity (Knoblauch, 2005). This type of research has the potential to provide valuable knowledge about current practices, which can be used in development and adjustments of more specific clinical practice, hence increasing the possibilities of fitting the needs of vulnerable patient groups.

Overall organisational structures have implications for everyday practices related to management of physical health issues among people with severe mental illness. Continued findings related to issues of excess mortality and multi-morbidity among people with SMI underline an urgency for developing interventions, which can help address the problems at hand. Aspects of this continued issue seem to be systemic in nature and changes in clinical practices requires interventions across organisational levels and sectional barriers (Bartlem et al., 2016; Henderson et al., 2014; Knaak et al., 2017). Hence, one suggestion would be that a possible next step could call for research based in the Complex Interventions methodology (Craig et al., 2008).

An interesting point to consider, when developing care services and initiating physical health care initiatives in the time ahead, is that these services and interventions need to be morally justifiable (Vallgårda, 2019). This means, that we need to stick to implementing services that we have found to be beneficial to the users of that particular service. Very recent research examining the potential effect of existing interventions, has reported that if three areas of modifiable risk factors are targeted then the estimated gain in life expectancy for adults with schizophrenia would be 5-7 years. These modifiable risk factors included 1) *lifestyle factors* such as smoking, diet, obesity, and metabolic syndrome; 2) *healthcare factors* such as treatment with clozapine, access, and treatment disparity, and 3) *social factors* such as social deprivation, social isolation, and stigma. As the research team also note, targeting these three areas of modifiable risk factors would only be achievable through a cross-sectional approach (Dregan et al., 2020). Even though this potential gain in life expectancy was 5-7 years, it seems that actual and specific suggestions to how such comprehensive intervention regimens are to be realised are needed. Based on some of the findings of this ethnography, it seems that trying to make everyday life in general more manageable for those with schizophrenia would be a first step on the way.

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Appendices

Appendix A: Thesis papers
  Paper 1: Draft, submitted
  Paper 2: Published paper, reproduced with permission from the journal
  Paper 3: Published paper, reproduced with permission from the journal

Appendix B: Permissions
  Response from the Danish Data Protection Agency
  Response from the regional ethics board
  Response from the Danish Data Protection Agency, extension of study period I
  Response from the Danish Data Protection Agency, extension of study period II

Appendix C: Declaration of consent
  General consent obtained at inclusion, participant with schizophrenia
  Consent to video-recording of psychiatric interview
  Consent to participate in focus group, mental health care professional
  Consent to individual, semi-structured interview, key informant

Appendix D: Information materials
  Information letter to participants
  Example of notice placed in semi-public areas

Appendix E: PANSS: supplement materials
  PANSS rating sheet (Danish version)
  PANSS scores, total scores and sub-scale scores

Appendix F: Analysis integrating findings
  Display of progressive focusing

Appendix A

Managing physical health issues by ‘modifying or ‘retreating’. An ethnographic study among a group of Danish people with schizophrenia

Lerbæk, B; Jørgensen, R. Buus, N; Aagaard, J; Nordgaard, J; Lauritsen, Marlene B.; McCloughen, A.

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.

Data collection

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. Nine participants were recruited. They had been diagnosed with schizophrenia between 2 months to 27 years. 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).

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. Additionally, psychiatric interviews were conducted to provide an objective view of the mental state of the participants at the time of the study. The Positive and Negative Syndrome Scale (PANSS) (Kay et al., 1987) and Examination of Anomalous Self-experience (EASE) (Parnas et al., 2005) were used. The qualitative component of these interviews was included in the analysis 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.

[Insert Table 1]

Analysis

Analysis focused on description and interpretation of typical situations in everyday day involving management of physical health issues (Hammersley and Atkinson, 2019, Burr, 2003). Thematic analysis was conducted at a latent, interpretive level in six phases (Braun and Clarke, 2006). Creation of 'personas' was used as a method to write up the themes as summarised 'typical' strategies used by participants to manage physical health issues (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 and extracts from the fieldnotes.

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. Participants received written and oral information about the study before giving informed consent for participation.

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 2). 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 2]

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 .

William

William was in his fifties who 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 William's time was spent in his private room.

William 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*". William 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 William 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, William 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 William 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. William'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 William this morning […] Betty makes an effort to explain to the students in the room, that the symptoms mentioned have no direct connection to William'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 William's physical health condition* " (Field notes, 23rd August).

William 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 William about his physical health. Occasionally William 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 William 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.

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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
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: 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 • 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])	• Stomach ache • 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

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Mental health care professionals' accounts of actions and responsibilities related to managing physical health among people with severe mental illness

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ABSTRACT

Background: Life expectancy of people with severe mental illness (SMI) is greatly shortened compared to the general population, and despite extensive research, this issue is unsolved. Although it is widely recognised that people with SMI need support from health care services to manage health related issues, profound health inequalities exist within provision of health care. The aim of this study was to examine how mental health care professionals accounted for their actions and responsibilities related to managing physical health issues among people with SMI.

Methods: Three focus groups were conducted with 22 mental health care professionals, employed at three mental health care locations. Participants' situated accounts were subjected to discourse analysis.

Results: Participants accounted for actions and responsibilities in three typical ways; 1) by positioning people with SMI as difficult to motivate and actively resisting intervention, 2) by positioning people with SMI as so impaired that intervention was futile, and 3) by arguing they are undertreated for physical conditions and might have physical illnesses that staff are not aware of because of prominent mental illness. These discursive strategies seemed to legitimise situations where participants described not responding to physical health issues, and to downplay potential trouble in situations where participants described not succeeding in facilitating lifestyle changes or promoting compliance to treatment of physical conditions.

Discussion and conclusion: Mental health care professionals need to increase their awareness of latent discriminating attitudes towards people with SMI. Such attitudes are suggested to reinforce barriers for people with SMI receiving physical health care.

Introduction

Research from recent decades have shown unacceptable levels of excess mortality among people with severe mental illness (SMI) when compared to groups in the general population as their life expectancy is shortened by 13–30 years (De Hert et al., 2011; Laursen & Nordentoft, 2011; Nielsen, Uggerby, Jensen, & McGrath, 2013; Saha, Chant, & McGrath, 2007; Wahlbeck, Westman, Nordentoft, Gissler, & Laursen, 2011). This excess mortality is explained by unnatural deaths like suicide and accidents, but also by physical illness (De Hert et al., 2011; Laursen, Nordentoft, & Mortensen, 2014; Wernlund & Aagaard, 2015). Studies have shown high prevalence of physical illness among people with SMI and an overrepresentation of risk factors related to life style, which constitute a major contributor to onset of physical illness (McCloughen, Foster, Huws-Thomas, & Delgado, 2012; Parks, Svendsen, Singer, & Foti, 2006; Scott & Happell, 2011; van Hasselt

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et al., 2013). Further, the presence of poor physical health among young people with SMI underline the urgency for interventions targeted prevention of physical illness and promotion of health within this group (McCloughen et al., 2012).

People with SMI are among the most vulnerable and disabled groups in society. Many struggle with instability in everyday life due to relapse and worsening of mental illness. Symptoms such as lack of motivation, ambivalence and difficulties engaging in social interactions might delay detection and treatment of physical illness among people experiencing these challenges. Cognitive deficits may have negative impact on executive functioning and organisational skills and contribute to difficulties in managing everyday life. Furthermore, inequalities related to allocation of resources in the health care sector, and deficiencies within the organisation of health care provision are described as factors contributing to poorer access to treatment of physical illness among people with SMI (De Hert et al., 2011; Lawrence & Kisely, 2010; Leucht, Burkard, Henderson, Maj, & Sartorius, 2007; Marmot, Friel, Bell, A J Houweling, & Taylor, 2008; Mesidor, Gidugu, Rogers, Kash-MacDonald, & Broadman, 2011; Nash, 2013). People with SMI need intensive support from the health care system to manage health related issues. However, there are profound health inequalities within health care services which seem to contribute to poor physical health outcomes among people with SMI (Lawrence & Kisely, 2010; McNamee, Mead, MacGillivray, & Lawrie, 2013). In addition, the process of health care professionals wrongfully attributing symptoms of physical illness to mental illness (known as 'diagnostic overshadowing') has been suggested as a contributing factor in diagnosis and treatment delays (Jones, Howard, & Thornicroft, 2008; Nash, 2013). Potential causes of this includes stigma and negative attitudes towards people with mental illness among health care professionals (Nash, 2013).

Several studies have examined the roles of professional and their presumed responsibilities related to the provision of physical health care in different mental health care settings. Some with specific focus on professional groups such as case managers, psychiatrists (De Hert, van Winkel, Silic, Van Eyck, & Peuskens, 2010), general practitioners (Beecroft et al., 2001; De Hert et al., 2010; Oud et al., 2010; van Hasselt et al., 2013), and mental health nurses, see for example (Blythe & White, 2012; Happell, Platania-Phung, & Scott, 2014; Happell, Scott, Platania-Phung, & Nankivell, 2012). Especially mental health nurses are reported to acknowledge the management of physical health issues as part of their professional role. However, studies also report expressed ambiguity related to whether mental health nurses should take on these tasks or not, and uncertainty related to whether mental health nurses possess the needed skills and knowledge to take action (Blythe & White, 2012; Happell et al., 2012; Wynaden et al., 2016).

Recent studies have suggested that mental health care professionals' (MHCP) delivery of preventive services has increased, but that the level of care provision remain suboptimal as MHCPs provide inadequate assessment of physical health status, give insufficient health related advice to people with SMI, and do not refer to external collaborators if needed (Bartlem et al., 2014; Bartlem et al., 2016; Crawford et al., 2014). Recent research has suggested that preventive interventions solely focused on changing lifestyle behaviour to promote health might not be effective (Jakobsen et al., 2017; Speyer et al., 2016). Further, persistent efforts to make targeted groups comply with health norms of contemporary society might lead to unintended consequences inflicting feelings of shame, defeat and powerlessness on people who does not succeed in making lifestyle changes (Moltke, 2017). Attitudes among MHCPs towards providing services related to physical health care are reported as generally positive; however, MHCPs' perception of people with SMIs lack of interest in changing risky health related behaviour and the lack of time resources in daily practice to perform these tasks remain barriers in this area of care provision (Bartlem et al., 2016).

Despite many years of research and intervention within this area, the challenges with severe mental illness and comorbid physical illness seem overwhelming. The excess mortality among people with SMI remains an unsolved problem and the gap of lost years between this group and the general population continues to increase (Laursen et al., 2014; Saha et al., 2007). In this paper, we will approach these issues through a social constructivist approach, which can provide alternative insight into MHCPs understandings of their everyday practices and their verbalised motives and intentions related to dealing with physical health issues among people with SMI.

Theoretical perspective

This study builds on a social constructionist approach to discourse analysis developed in social psychology (Edwards & Potter, 2001; Potter & Wetherell, 2007). This approach investigates details of language-in-use as activities in social interaction and is appropriate for studying verbal communication between people embedded in institutional settings. The focus is on action-orientation of talk and on the discursive resources used in these practices (Edwards & Potter, 2001; Potter & Wetherell, 2007). Within this perspective, discourse is understood as all written texts and talk. It is treated as a domain of action in its own right as it does not simply mirror or describe a pre-fixed representation of the world, but rather is used to produce different versions of the social world to construct the lived reality of the speaker (Potter & Wetherell, 2007). When analysing social talk and texts, three features needs to be taken into account; discourse is (1) *action-oriented* as it is always serving an action-related purpose (e.g. requesting, accusing or persuading), (2) *situated* in three ways, a) in a sequence of talk, b) in an institutional context, and c) rhetorically, which all are of importance to the analysist, when trying to understand, what is going on, and (3) *constructed/constructing*, as it is *constructed* by the speakers use of linguistic resources and at the same time *constructing* different versions of the social world through use of different versions of accounts (Edwards & Potter, 2001).

The aim of this study was to examine how mental health care professionals account for actions and responsibilities in their everyday work related to managing physical health issues among people with severe mental illness. Accounts are discursive strategies used when explaining unusual, or untoward actions or unanticipated behaviour, and serve to neutralise potential consequences. By examining situated accounts, we can gain insight into the MHCPs' understanding of their practices of accepting responsibility of actions or attempts to disclaim or shift responsibility elsewhere (Edwards & Potter, 2001; Potter & Wetherell, 2007; Scott & Lyman, 1968).

Materials and methods

The study was designed as a qualitative focus group study.

Focus groups and participants

Data were generated through three focus groups (Bloor, 2001) conducted at three mental health care locations in the North Denmark Region. Participants were recruited from two mental health care settings; two mental health residential facilities and one outpatient clinic; all run by regional authorities. In both settings, multi-professional teams provide comprehensive care to people with SMI; the main part of the target population being people with schizophrenia. All health care staff members at the two settings were invited to participate in a focus group and planning of the focus groups were done in close collaboration with local managers. The purposive, non-probability sample included 22 MHCPs participants. All but five were women. Participants' employment at the included locations ranged from 5 months to 38 years. Table 1 provides information on the focus groups and the participants.

In focus groups, the interactions between participants give access to situated accounts reflecting group norms and descriptions (Bloor, 2001; Halkier, 2010). To facilitate the discussions, participants were asked to

Table 1
Focus groups and participants.

Focus group	Setting	Duration (h:min)	Participants (n)	Occupational groups (n)	Age Median [IQR][a]
1	Residential facility A	1:27	9	Registered nurse (1), Nursing assistant (1), Social education worker (1), Residential support worker (1), Social and health care worker (4), student (residential support worker) (1)	55.5 [55–59][b]
2	Residential facility B	1:38	7	Registered nurse (1), Residential support worker (2), Social and health care worker (3), student (social and health care worker) (1)	38 [32.5–47.5][c]
3	Outpatient clinic	1:44	6	Registered nurse (3), Psychologist (1), Occupational therapist (2)	48.5 [35–51]
Total		4:50	22		51 [36.5–55]

[a] IQR = Interquartile range.
[b] Information on age of 3 participants was not available.
[c] Information on age of 2 participants was not available.

prioritize and discuss six themes related to the management of physical health issues among people with severe mental illness. The themes were developed based on previous focus group studies focusing on mental health care professionals' and patients' perspectives on managing physical health issues in a mental health care setting (Happell et al., 2012; Kristiansen et al., 2015). Additionally, they were based on experiences gained during participant observation conducted by the first author at all three mental health care locations prior to the focus groups. Themes covered in the current study included areas such as MHCPs involvement in everyday management of physical health issues, their experiences of assessing physical health status among people with SMI, their views on how people with SMI are able to perceive, understand and act on symptoms of physical illness, and on their ability to manage physical health issues in general.

The focus groups were conducted from late 2016 to early 2018. All focus groups were moderated by the first author. At every occasion an observer was also present and took notes on the interaction of the groups.

Ethics

The Danish Data Protection Agency and the regional Research Ethics Committee were notified about the study and rules and regulation regarding data storage were followed. Local managers authorised the study to take place and participants received written and oral information about the study and gave written informed consent before participating. Extracts from the data material that are presented below have been modified to protect the identity of individual participants.

Analysis

Typically, the analysis within the tradition of discursive psychology does not follow a pre-fixed pattern. Rather, it follows certain areas of interest put forth by the researcher about what is accomplished through talk (Potter & Hepburn, 2005). The current analysis focus on the thematic content as well as on discursive strategies used by MHCPs to account for actions and responsibilities related to their engagement in management of physical health issues among people with SMI (Scott & Lyman, 1968). This included basic analysis of participants' tacit reasoning procedures, that is participants' procedures of producing and making sense of talk (Hutchby & Wooffitt, 1998).

The focus groups were audio recorded and transcribed verbatim with indication of basic interaction. The analysis was done in three phases. Phase one, entailed repeated reading of the data material and memo writing related to developing initial themes and gaining insight into the patterns of discursive strategies used in MHCPs' accounts. During this phase memos and themes were continually discussed among the first, second and last author. In the second phase, final themes were developed and illustrative sections of the data material were selected for detailed transcription and thorough analysis of discursive components such as speech delivery and building analytic claim about what is going on in participants' discussions (Hutchby & Wooffitt, 1998). Detailed transcriptions included indication of several interactional and pronunciational features (Jefferson, 2004; Potter & Wetherell, 2007). The last phase entailed the process of writing up the findings and providing contextual examples. The final themes are presented below as three typical ways for MHCPs to account for actions and responsibilities related to management of physical health issues in their everyday work. They are illustrated in detailed analysis of three data extracts. These extracts were selected to represent the discursive strategies, which were dominant throughout the whole data set. In this phase, the extracts used in the presentation of results were translated from Danish to English by the first and last author.

Findings

The focus group discussions reflected an on-going negotiation among the participating MHCPs about their responsibilities and obligations in relation to management of physical health issues among people with SMI. They accounted for professional actions and responsibilities in three typical ways: 1. By positioning people with SMI as difficult to motivate and actively resisting intervention, 2. By positioning people with SMI as so impaired that intervention was futile, and 3. By arguing that people with SMI are undertreated for physical conditions and might be suffering from undetected physical illnesses that staff are not aware of because of prominent mental illness. Such accountings were used to legitimise descriptions of not taking action on physical health issues. Likewise, it seemed to downplay the potential trouble related to situations where they described not succeeding in facilitating lifestyle changes or promoting optimal compliance to treatment of physical conditions.

People with severe mental illness are difficult to motivate and resist interventions for lifestyle changes

According to the MHCPs, motivational work was a primary aspect of their work related to management of physical health issues among people with SMI. This involved providing information about potential risks and consequences of having what MHCPs described as unhealthy lifestyle and about necessary precautions related to living with comorbid physical illness. Unhealthy lifestyle was described as poor eating habits, lack of physical exercise, social isolation, smoking and drug abuse. It was depicted as a time-consuming task, which in many cases ended up being unfruitful due to what MHCPs depicted as active resistance towards making such changes. MHCPs described different dilemmas and frustrations related to this work. One concern was that they would have to be careful not to become too paternalistic or intrusive when trying to push or nudge people with SMI towards lifestyle changes. Some MHCPs were very aware not to portray themselves as "holy" on these matters and repeatedly raised concern about the risk of them "preaching morality" in their efforts to motivate lifestyle changes. They were concerned that by using such efforts they would risk ruining already fragile interpersonal relationships. To MHCPs in the outpatient clinic, broken relationships would mean people with SMI disengaging from their services and them losing all leverage in relation to providing both mental and physical health care.

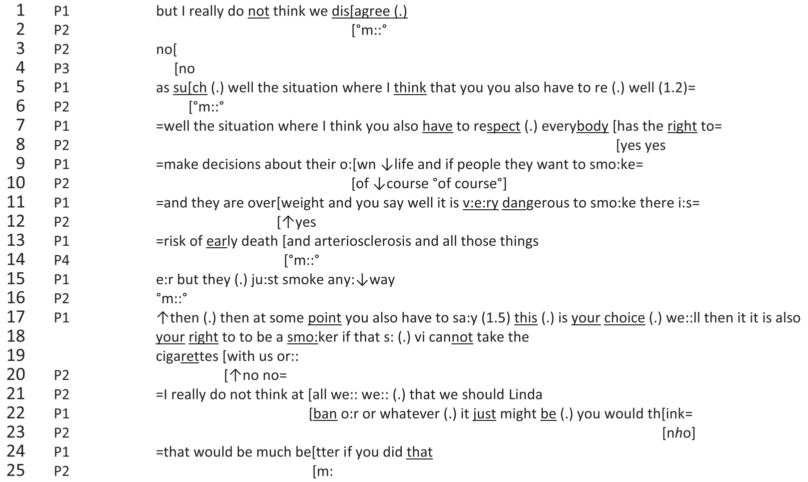
In relation to their actions and responsibilities, MHCPs across the focus groups described that if the individual with SMI was not prepared to make the suggested lifestyle changes or did not acknowledge their importance despite motivational efforts, then the MHCPs could not do anything and they would "give up" and step back. This was typically justified by claims of accepting the personal choice of the person in question e.g. if a lifestyle-related goal (weight loss, smoking cessation, increasing exercise) had been targeted for some time without achieving any results. By using such justifications, MHCPs in effect declined taking responsibility for dealing with the physical health issues, even though not taking action might result in a worsening of the individual's physical health status. A negotiation between participants around this issue is illustrated in Extract 1 (Fig. 1). The speakers P1–P4 are participating MHCPs. Prior to the extract, P1 has been pushing the others towards presenting concrete solutions to these very complex issues by posing questions about what they can actually do beyond providing information to clients. The others have suggested keeping up their efforts despite clients' resistance and trying different approaches to boost motivation, but without providing arguments that satisfied P1.

P1 begins by stating how they do not disagree on the matter [about their obligations] (line 1), then hesitates before completing the statement with "as such" (line 5). Using the "as such" construction might suggest some reservation and seem to contradict the claim of being in agreement. P2 and P3 acknowledges with "no" (line 3–4), most probably agreeing not to disagree. P1 explains how they "have to respect" the individual "right to make decisions about their own life" (lines 5, 7 and 9). A false start (repeating line 5 in line 7) and pause (line 5) might indicate P1s awareness of the potential disagreement embedded in using this point to justify not taking action on physical health matters. By emphasising keywords "have", "respect", "everybody" and "right" including stretching of "o:wn", P1 seem to underline the moral aspect embedded in not respecting individual choice. P2 responds with "of course of course" (line 10) indicating a mutual understanding about their obligation to respect the right to autonomy, however not necessarily to agree on this as justification for stepping back.

P1 exemplifies a frustration by explaining how "if people want to smo:ke" or are overweight and "you" have told them about the dangers of doing so (line 13), but then "they just smoke any:↓way" (line 15). This statement, mildly caricaturises the frustration related to their motivating efforts being unfruitful by emphasising and stretching of "v:e:ry" and "dangerous". This is further emphasised by the rhetoric construction in line 15, which might imply people with SMIs continued smoking as an act of defiance.

P1 continues to explain how they at some point "have to" leave the choice with the individual, underlining this using direct speech and emphasis on keywords ("this (.) is your choice", "also your right") (line 17–18). At the end, P1 brings matters to a head stating an argument that no one can disagree with: that they cannot coercively "take the cigarettes" away (line 18–19) or "ban or whatever" (line 22). Speaking simultaneously, P2 responds in agreement, but also strongly rejects the thought of using such intrusive measures (line 20–21).

MHCPs across the focus groups depicted this motivational work as a balancing act between accepting an individual's right to autonomy and at the same time risking to fail helping people with SMI by providing insufficient support. Some expressed a very strong obligation to keep trying to motivate changes in the lifestyle in situations where continued



1	P1	but I really do not think we dis[agree (.)
2	P2	[°m::°
3	P2	no[
4	P3	[no
5	P1	as su[ch (.) well the situation where I think that you you also have to re (.) well (1.2)=
6	P2	[°m::°
7	P1	=well the situation where I think you also have to respect (.) everybody [has the right to=
8	P2	[yes yes
9	P1	=make decisions about their o:[wn ↓life and if people they want to smo:ke=
10	P2	[of ↓course °of course°]
11	P1	=and they are over[weight and you say well it is v:e:ry dangerous to smo:ke there i:s=
12	P2	[↑yes
13	P1	=risk of early death [and arteriosclerosis and all those things
14	P4	[°m::°
15	P1	e:r but they (.) ju:st smoke any:↓way
16	P2	°m::°
17	P1	↑then (.) then at some point you also have to sa:y (1.5) this (.) is your choice (.) we::ll then it it is also
18		your right to to be a smo:ker if that s: (.) vi cannot take the
19		cigarettes [with us or::
20	P2	[↑no no=
21	P2	=I really do not think at [all we:: we:: (.) that we should Linda
22	P1	[ban o:r or whatever (.) it just might be (.) you would th[ink=
23	P2	[n*h*o]
24	P1	=that would be much be[tter if you did that
25	P2	[m:

[from focus group 3, time: 0:43:59-0:44:33]

Conventions used in transcripts: (.) indicates pause < 1 second, (x.0) indicates pause in x seconds, = indicates latching between utterances, [indicates interruption and simultaneous speech, ::: indicates stretching of sound, sti*h*ll indicates breathiness, sti(h)ll indicates the word is said while laughing, emphasis, °spoken quieter°, ↑ indicates rising or ↓ falling intonational shift. Linda is a fictional name of P1.

Fig. 1. Extract 1.

risk behaviour would potentially worsen the physical health state. These MHCPs would also reject the claim, that their job was sufficiently done, by making sure that people with SMI were made aware of the consequences of their lifestyle behaviour. In some of these accounts, the illustrations of the difficulties related to living with SMI also became the justification for keeping up persistent efforts focused on physical health issues. However, several participants described difficulties in succeeding with their motivational efforts.

People with severe mental illness are so severely impaired that interventions are futile

Across the focus groups, severity and persistence of mental health problems were depicted as major barriers for achieving lifestyle changes among people with SMI and as having profound negative impact on illness behaviour among those with comorbid physical illness. Symptoms of behavioural character, e.g. lack of ability to apply to normal conduct, and social norms were depicted as influential on behaviour in everyday situations. An example used by MHCPs in the institutional setting was related to behaviour of people with SMI when participating in communal meals. In these situations, some people with SMI were depicted as “savage” or “greedy” and as eating in an “unnatural” and “out of control” manner if they were not restricted. The strong words used in these explanations seemed to justify MHCPs' use of somewhat intrusive measures when trying to prevent the otherwise excessive intake of food.

Besides behavioural symptoms MHCPs described bizarre delusions, hallucinations, disrupted bodily experiences, and cognitive deficits as very impairing. MHCPs explained how they would sometimes choose not to take action on physical health issues, because it seemed in vain to try to reason with a person in such a poor mental state. These accounts also entailed examples of pronounced psychosis, which served to legitimise MHCPs choice not to take actions on physical health matters. In other cases, MHCPs used examples of severity of mental illness to depict how symptoms of physical illness could be misinterpreted by people with SMI as being caused by other factors than physical illness. Extract 2 (Fig. 2) illustrates this scenario. In this part of the focus group, MHCPs have been explaining how some people with SMI with disrupted bodily experiences might interpret their experience of pain differently than people without mental illness and how this in combination with delusions might affect their way of perceiving physical symptoms in general. In Extract 2 (Fig. 2), P5–P8 are the participating MHCPs and M is the moderator.

P5 begins by stating how “it is just difficult” if people with SMI are not able to feel symptoms, because then the symptoms “are ignored” (line 1 and 3). Hesitation halfway through this statement (line 1) might indicate awareness of the seriousness embedded in this fact. In line 6–7, P5 provides another observation; that symptoms “are interpreted” and references an example given by a colleague earlier (line 7). The interposed sentence “I think we all experience as well” (line 6) suggest the intention to depict this as a common understanding. P5 elaborates by depicting what might be going on: that it is “probably true that they [teeth] do not really work” and that “they may hurt” and how the person with SMI will not be worried about it, because new teeth will grow out. After pausing (line 12) P5 describes the bizarre, paranoid delusions that some people with SMI experience by explaining how physical symptoms are misinterpreted as being caused by external agents, such as receiving radio signals through the teeth or having microphones implanted in the teeth and this being the cause of pain. The repeated use of “right” (line 10, 12, 13) might indicate further attempts to establish this as an agreed matter. The absurdness of such delusional beliefs is used to depict the impossible scenario they are facing. This is further emphasised by P5 slightly laughing while speaking (line 13). P5 concludes that this is “difficult to compete with” (line 18) because “you cannot convince” a person who is paranoid that the delusions are not true (line 20). Emphases and shifts in intonation in key words underlines this impossible scenario and provides justification for not trying to achieve changes or improved illness behaviour with people who are in such a mental state. After pausing (line 20) P5 repeats the first comment, but this time, with stronger emphasis by adding the word “damn”. Accounts such as these and the severity of psychosis that was depicted, served as a common discursive strategy for MHCPs to legitimise not taking action even though they observed risky lifestyle or illness behaviour that posed potential risk of worsening the physical health of the individual.

People with severe mental illness are undertreated for physical conditions and present conditions are difficult to detect

Some participants voiced the opinion that people with SMI were generally undertreated for physical health conditions. They believed this to be a consequence of on-going stigmatisation within the health care system and depicted how people with SMI faced hardship because physical complaints were dismissed as being part of their psychosis.

1 P5: bu:t it is just difficult if they are not able to fee:l them (.)
2 M: m::
3 P5: then they are ignored
4 M: °yes°
5 P6: °.hh° ((clears throat))
6 P5: and then they can also (.) e: that I think we all experience that they are interpreted (1.3) so that
7 exactly just like Ben is saying there some ne:w teeth will grow out
8 M: yes[
9 P7: [m:::
10 P5: right (.) because it is probably tr[ue that they do not really work] and they may hurt=
11 P8: [((clears throat))]
12 P5: =but new ones will grow out ↑right (1.6) and it can just might be:: (.) I have also experienced people
13 who receive ra(h)dio mos(h)kow in their ↑teeth because there is a toothache ↑right
14 M: m:
15 P7: °yhes°
16 P5: then there are micro↑phones and ↓all that (.) so
17 P7: °yhes°
18 P5: and that is just difficult to compete with
19 M: yes
20 P5: because (.) you cannot ↑convince someone who has paranoia that this does not exist (1.3) that is just
21 ↑damn difficult

[from focus group 1, time: 0:47:09-0:47:46]
Ben in a fictional name of P7.

Fig. 2. Extract 2.

Further, they provided examples of how some were denied proper care and treatment for physical conditions because their mental health problems could not be handled within the somatic health care services. MHCPs described these situations as unfair and potentially harmful to the physical health of people with SMI and explained how they would sometimes intervene to make sure that patients were taken seriously and received proper treatment. In both settings, MHCPs reflected on how they sometimes unintentionally contributed to the stigmatisation of people with SMI. They explained that being employed in mental health care made them focus on psychiatric issues and not physical health issues. These accounts reflected MHCPs' insecurities about putting enough effort into dealing with health risk behaviour and inappropriate illness behaviour.

To further emphasise the challenges they faced when dealing with issues of poor physical health in their work, MHCPs described how some people with SMI were unable to articulate the symptoms of physical illness. This particularly became an issue among those with severely disrupted bodily experiences. MHCPs employed in the outpatient setting explained how they used screening tools in assessing symptoms and monitoring physical health among their clients. They explained how the thorough questioning about experienced physical symptoms helped them detect physical conditions, which they would otherwise have overlooked. The MHCPs employed at the psychiatric institutions explained how they in these cases typically based their assessment of physical health on personal knowledge about the individual and primarily took action if the behaviour was "different than normal" or if something was visibly wrong. Extract 3 (Fig. 3) provides a typical example of MHCPs accounts on these practices. Prior to the extract, the MHCPs have been discussing how people with SMI react in different ways when experiencing ill physical health.

At the beginning, P10 states that it is "a problem" when people with SMI "are not able to verbalise" their physical conditions (line 1). Hereby, acknowledging the difficulties they [MHCPs] face in these situations. The quietly spoken interposed sentence "you could say" might indicate an attempt to downplay the potential trouble embedded in this. P12 joins in providing another view on the matter; that "they are able to feel it" [physical symptoms] (line 5). The turn is taken over by P10 (line 6), who explains how "sometimes you can also see" referring to their practice of assessing physical health. P10 interrupts herself and agrees with P12 with an emphasised "yes", then continues to explain how they "interpret" certain behaviours as related to physical health issues (line 7, 10–11). Hesitation and rephrasing of the sentence (line 7) might indicate some insecurity about how to present this practice. Emphasising keywords "punches", "ache", and "clenched" in the example (line 10, 11) might serve to underline the point about the obvious connection between behaviour and potential symptom, hence justifying this approach. Then P10 explains how "it is very often of the basis of su:ch" "things" they "interpret" (line 14, 17). Stretching of "su:ch" and hesitation before continuing with "things" suggest awareness of the trouble embedded in this somewhat vague description of practice. Providing another reason for their interpretative practice, P10 explains how "it is not out spoken" (line 17) because the person does not do that. P10 concludes that the resident is a "huge challenge (1.0) in being heard", although leaving it unclear whether the challenge is on the resident or them.

Even though these situations were recognised as challenging, the approach illustrated in Extract 3 (Fig. 3) seemed to be accepted as typical in this setting. A dilemma related to this was embedded in a mismatch MHCPs experienced between the intensions and values of in care provision, the available resources and the support needs of people with SMI. MHCPs described how their field of work during recent years had become more goal-oriented and controlled by rate-based systems. From their point of view, this meant fewer resources for dealing with non-psychiatric issues. It was depicted how, in the extreme, the limited time resources caused by the goal-oriented regulation of their work would only allow them to focus on the issues that they were "paid to deal with" – that being mental health issues.

Discussion

This study examined MHCPs' situated accounts about their actions and responsibilities in relation to managing physical health issues among people with SMI. The study builds on previous focus group studies conducted with professionals and patients dealing with physical health issues in mental health care settings (Happell et al., 2012; Kristiansen et al., 2015). These studies reported findings in keeping with the ones found in the current study: awareness of the presence of severe physical health issues among people with SMI; awareness of patients' needs of support from staff trained within mental health in making healthy lifestyle choices in everyday life; lack of resources to deal with physical health issues which seem to reinforce fragmentation of health care provision; and staff experiences of people with SMI de-prioritising physical health issues and resisting lifestyle changes. Furthermore, the studies uncovered role ambiguity and uncertainties about responsibilities among MHCPs and identified needs for continued improvement within physical health care provision (Happell et al., 2012;

```
1   P10:   bu but it ↑is a (.) a °problem you could [say]° that they are not e:r (.) able to verbalise it o:r (.)
2   P11:                                            [m::]
3   P12:   °m:: °
4   P10:   °yhes°
5   P12:   because I [believe  they  are  able  to feel it ]
6   P10:             [well sometimes you can also see] (.) yes but but someone like Henry also sometimes we
7          can (.) ↓yes in (.) well we interpret (.) when he is exasperated a:nd
8   P12:   m::
9   P13:   m::
10  P10:   punches himself in the stomach that it is because he has a stomach ache or (0.6) when he had trouble
11         with his teeth [you could also see how clenched his teeth were and
12  P14:                  [m:::
13  P12:   m::
14  P10:   but it is very often of the basis of su:ch (.)
15  P15:   yes
16  M:     m::
17  P10:   things that we interpret (.) well you see it is not °out spoken° (.) it is because (.) he [does not do=
18  P12:                                                                                             [m::
19  P10:   =that °but° (1.6) °yes° (.) so in that way he is a huge challenge (1.0) in being heard
```

[from focus group 2, time: 0:31:33-0:32:03]
Henry is a fictional name of a resident

Fig. 3. Extract 3.

Kristiansen et al., 2015). These previous studies focused on analysing thematic content of the focus group discussions. In the current study, the discursive psychological approach to analysing both thematic content and discursive strategies, contributed with deeper insight into MHCPs' understanding of their roles, actions and responsibilities related to the provision of physical health care. This approach has provided insights into continued presence of well-known issues within the included mental health care settings, but also into how attitudes among MHCPs are verbally enacted in discussions among colleagues. The analysis showed how examples of severe and persistent mental illness was used by MHCPs as part of discursive strategies to depict the comprehensive support needs of people with SMI in relation to managing everyday life. Moreover, these strategies underlined the almost impossible scenarios MHCPs described related to trying to achieve changes towards healthier lifestyle and more optimal illness behaviours.

The accounts of how MHCPs would sometimes choose not to take action on physical health issues due to the severity and persistence of the mental problems among residents and clients might reflect a latent discriminating attitude towards people with SMI embedded in the local cultures. Participants to some extent confirmed this in their sporadic reflections about their contribution to continued stigma against people with SMI, even though this was depicted as unintentional. Recent research has reported that negative and discriminating attitudes among MHCPs pose a barrier for treatment and recovery for people with mental illness (Horsfall, Cleary, & Hunt, 2010; Knaak, Mantler, & Szeto, 2017). Such untoward attitudes among staff is a well-known issue in mental health care and general health care, and it has been described how MHCPs tend to be less optimistic about the outcomes of people with SMI (Henderson et al., 2014; Horsfall et al., 2010; Thornicroft, Rose, & Kassam, 2007). Negative attitudes among staff and staff being unaware of their presence contributes to stigma and may have severe consequences as they influence the help-seeking behaviour of people with SMI, leads to poorer quality of care, poorer compliance to suggested treatment and poorer outcomes (Knaak et al., 2017). Another implication related to such negative attitudes embedded in clinical practice could be that people who are diagnosed with severe and persistent mental illness, who needs the support related to physical health issues the most, might not receive optimal care. Measures to increase staff awareness and acceptance of the presence of such negative attitudes, including a focus on promoting positive attitudes, seem to be essential in order achieve changes, as positive attitudes among staff members towards their role in providing preventive care and the possible outcomes, have been reported to increase the likelihood of clinicians providing such care (Bartlem et al., 2016).

Insights gained from this study also points to aspects of current mental health care that needs continued focus. As suggested in previous research, MHCPs need to be actively involved in a process of increasing awareness of potential discrimination or stigma against people with mental illness, and of challenging such beliefs in order to change attitudes (Horsfall et al., 2010). Continued education of MHCPs is fundamental to increase awareness of discrimination, stigma and the potentially damaging effects such attitudes can have on outcome of people experiencing mental health problems (Happell et al., 2014; Horsfall et al., 2010; Knaak et al., 2017). The application of a humanist, person-centred approach has been suggested as a way to minimise potential discrimination and stigma. This approach would include working with people with SMI as equal partners in different aspects of health care (Horsfall et al., 2010). Advocates of this approach to health care provision also voiced their opinion in our focus group discussions. However, the accounts related to not taking action predominately entailed descriptions of non-partnership relationships with residents or clients, as MHCPs most commonly described making decisions based on what they believed to be in the best interest of the person with SMI.

Resent research have suggested that interventions based on narrow understandings of what health promotion entails are not only ineffective (Jakobsen et al., 2017; Speyer et al., 2016), but might also increase the risk of a boomerang effect leaving already vulnerable groups of society with feelings of shame, lack of acknowledgement and defeat if they do not succeed in achieving the proposed lifestyle related goals (Moltke, 2017). To improve effectiveness of health promoting interventions, it has been suggested that attention need to change from the traditional focus on inequality in health and illness towards a broader perspective focused on structural issues related to improving equality in life possibilities and increasing social investment (Barr, Higgerson, & Whitehead, 2017; Link & Phelan, 1995; Moltke, 2017). In this context, the narrow lifestyle perspective that was reluctantly promoted by the study participants can be seen as limiting rather than meaningful and effective. A way forward for the MHCPs might be to collaborate with health care authorities to develop and implement structural interventions that reach beyond the individual level (Link & Phelan, 1995).

Continued reports of the presence of stigma and negative attitudes among staff employed in health care services, indicates that these issues might be systemic in nature and related to organisational culture (Henderson et al., 2014; Knaak et al., 2017). To achieve systemic change, there is a need to work with comprehensive organisational interventions including the aspects of overall priorities related to health care provision, general perceptions of people with mental illness and continued staff education (Bartlem et al., 2016; Henderson et al., 2014; Knaak et al., 2017).

Several limitations need to be mentioned related to the current study. Due to practical reasons (e.g. limited access to MHCPs during their workdays), participants were recruited through principles of convenience sampling. A purposive sampling strategy would have been preferred, as it could have resulted in participants who were specifically interested in the area of managing physical health among people with SMI. Furthermore, the participants were grouped with day-to-day-colleagues. If participants had been mixed across settings this might have facilitated different negotiations and descriptions of their everyday practice. Conversely, the participants' familiarity with each other seemed to create a trusting environment, which made it safe for them to share, disclose, and discus their work experiences and viewpoints. Finally, the findings were based on analysis of situated accounts and these cannot be understood as being equal to the MHCPs' actual clinical practices.

In conclusion, this study reports three typical ways that MHCPs accounted for their practices related to managing physical health issued among people with SMI. Furthermore, the study provides insight into latent discriminating attitudes that might reinforce some well-known barriers for people with SMI receiving physical health care. Based on these insights and knowledge on access mortality among people with SMI being a continued and unresolved issue, we suggest that change in the current conditions might not only rely on a change of attitudes, but also include taking a step further back to work on increasing awareness of potentially discriminating attitudes and stigma within mental health care settings. Highlighting these results, we have no intentions of claiming that MHCPs' accounts represent a clear image of their actual actions and professional practices, however we urge MHCPs to increase awareness of the presence of discriminating attitudes and to engage actively in a process towards changing them. Such attitudes reflect issues related to staff motivation to take on managing physical health issues despite any previous, unsuccessful attempts.

Declaration of interest

The authors report no conflicts of interest.

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Barriers and Possible Solutions to Providing Physical Health Care in Mental Health Care: A Qualitative Study of Danish Key Informants' Perspectives

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ABSTRACT

Provision of physical health care to people diagnosed with severe mental illness is widely reported as inadequate. This interview study explored perspectives of a group of key informants on current practices of providing physical health care within two mental health care settings in Denmark. Thematic analysis of their accounts provided insights into 1) barriers to the provision of physical health care in mental health settings, and 2) possible solutions to overcome existing barriers. Negative attitudes and limited specialist health care knowledge among mental health care professionals constituted serious barriers. To effectively address these barriers, mental health services need to be reoriented towards the prioritisation of physical health alongside mental health. This will require equipping mental health professionals with relevant knowledge and skills and organisational resources, to effectively work with people experiencing or at risk of physical comorbidities.

Background

The excess mortality among people diagnosed with severe mental illness, and how this group is disproportionally affected by physical health issues, has been described as one of the greatest health disparities in contemporary society (Chwastiak, 2015). Severe mental illness (SMI), also referred to as serious mental illness, is a collective term often used in the scientific literature to describe mental illnesses associated with a high burden reflected in impairments across social, economic and daily life functioning (van Duin et al., 2019). Examples of particular SMI include bipolar disorder, severe depression, schizophrenia and other disorders associated with psychosis (WHO, 2018). High levels of excess mortality among people with SMI is a well-established problem, and physical health issues within this population are characterised by an overrepresentation of lifestyle risk factors (Bartlem et al., 2014; McCloughen et al., 2016; van Hasselt et al., 2013), comorbidity, and multi-morbidity, when compared to the general population (Kugathasan et al., 2019). While preventive health care for people with mental illness has increased in some settings (Bartlem et al., 2014), research has described how people with SMI are provided insufficient physical health care in the general health care system. Related to preventive health care, health care professionals perform inadequate assessments of physical health status, limited health promoting practice, insufficient provision of health-related advice to people with SMI, and limited referrals to external agencies when needed (Bartlem et al., 2014; Crawford et al., 2014; Romain et al., 2020). Related to specific physical illnesses such as diabetes and heart failure, people with schizophrenia do not receive the same interventional treatment as the general population (Attar et al., 2017; Jørgensen et al., 2017, 2018).

People diagnosed with a SMI are considered to be part of a vulnerable group (Liamputtong, 2007) often needing substantial support to manage their everyday life, which can be characterised by instability due to recurring episodes of their mental health condition. Therefore, many people within this group continue to have contact with mental health care professionals (MHCPs) throughout the course of their illness. The roles and attitudes of MHCPs in relation to management of physical health issues among people with SMI have previously been explored and reported as both positive and negative (Bartlem et al., 2016; Lerbæk et al., 2019; Lundström et al., 2020). Several studies have examined the contribution, responsibilities and attitudes of specific occupational groups in relation to managing physical health within this population, e.g. general practitioners (De Hert et al., 2010; Oud et al., 2010; van Hasselt et al., 2013) and mental health nurses (Blythe & White, 2012; Lundström

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et al., 2020, Happell et al., 2012). Mental health nurses acknowledge the tasks related to management of physical health as part of their professional role, but also express ambiguity related to taking on management of physical health issues, and about whether they possess the qualifications needed to address such issues (Blythe & White, 2012; Happell et al., 2012; Wynaden et al., 2016). In multi-professional groups of MHCPs such as 'case managers', those with occupational backgrounds in nursing and medicine portray greater awareness of service policies related to management of physical health issues than other occupational groups. However, despite the reported awareness of these issues, MHCPs in general tend to place the responsibilities related to management of physical health care within the primary care sector (Clancy et al., 2019).

Several factors related to structures in health care systems have implications for the provision of physical health care to people with SMI. Inequalities related to allocation of resources in the healthcare sector, and the organisation of healthcare services are described as barriers contributing to people with SMI having poorer access to treatment of physical illness (De Hert et al., 2010; Laursen et al., 2009; Nordentoft et al., 2015). Diagnostic overshadowing is a problematic phenomenon within health care systems internationally, which contributes to delay in the detection of physical illness and in treatment of physical health conditions among those with SMI. Diagnostic overshadowing occurs when MHCPs overlook physical symptoms experienced by people with SMI by wrongfully interpreting them as related to symptoms of mental illness (Jones et al., 2008; McNamee et al., 2013; Nash, 2013). Such practices are described as a characteristic of the stigma within the health care system, that is reinforced by negative attitudes among MHCPs (Jones et al., 2008; Nash, 2013).

Across settings it seems that MHCPs' negative perceptions of people with SMI as lacking an interest in changing their own risky lifestyle behaviour remain a barrier to provision of adequate general health care within mental health services (Bartlem et al., 2014; 2016; Crawford et al., 2014; Lerbæk et al., 2019). In addition, a recent study of physical health care practices at different organisational levels within a mental health care context described managers' attitudes as influential on the practices of those delivering everyday care and treatment. Unambitious managerial visions about physical health care provision was reflected in a lack of physical health care practices by MHCPs in clinical mental health settings (Nielsen, 2018). Recent research has described mental health nurses' perceptions of factors facilitating promotion of physical health and healthy lifestyle among people with SMI (Lundström et al., 2020). These factors included care provision focused on health promotion in every encounter, providing individualised support, and health promotion as a responsibility across all organisational levels (Lundström et al., 2020). However, for knowledge about such facilitating factors to become transferrable to similar care and treatment contexts, there is a need to understand the barriers embedded in the social contexts. The aim of the study was to explore a group of key informants' perspectives on current provision of physical health care as part of everyday care delivered to people with severe mental illness in Danish mental health care settings.

Theoretical perspective

The study was based on a social constructionist understanding of how to conduct and analyse qualitative interviews. Within a social constructionist perspective, accounts in verbal interactions are understood as actively constructing versions of social reality. A core assumption is that our knowledge about the surrounding world is constantly negotiated in social interactions. The world becomes assessable through social processes of constructing, reproducing and presenting reality in language (Burr, 2003). In this study, construction of data was achieved through interactions between interviewer and interviewees. Engaging with data and producing interpretations was also understood as a way of interacting with the data to gain understanding about the realities presented in the participants' accounts. This theoretical perspective provided possibilities for engaging with the participants accounts and combining these with some broader assumptions about the underlying meanings embedded within the actual talk and text (Braun & Clarke, 2006).

Materials and methods

Design

This was a qualitative interview study conducted as part of a larger ethnographic study exploring management of physical health issues among a group of people with schizophrenia.

Study context

The mental health care settings represented in this study included two residential facilities and one outpatient clinic that were managed by public health authorities. Both settings were located in the North Denmark Region. In Denmark, mental health care services are part of a public health system, which is financed by general taxes. The two residential facilities provided rehabilitating, long-term care to those who experience serious and persistent disabilities due to severe mental illness such as schizophrenia. The outpatient clinic offered a time-limited assertive service that was based on principles for early intervention teams targeting younger people diagnosed with schizophrenia. In both settings, care and treatment was provided by interdisciplinary groups of MHCPs. At the residential facilities the group comprised of social- and healthcare workers, support workers, nursing assistants and nurses, with social- and healthcare workers and support workers being the largest professional group. In the outpatient clinic the group comprised of nurses, psychologists, social workers, occupational therapists, and a chief physician, with nurses representing the largest professional group.

Participants and data collection

Interviews with key informants were included as part of the data generation in the larger ethnographic study (Pelto, 2013; Schensul et al., 1999). In ethnographic research, a key

Table 1. Characteristics of key informants (KI) and interviews.

KI	Employment setting	Special interest	Duration (h:min)
KI 1	Residential facility	Initiating and conducting smaller projects focussed on diet and exercise in everyday life at the facility	0:47
KI 2	Residential facility	Previously involved in projects focussed on diet and exercise in everyday life among people with SMI	1:11
KI 3	Residential facility	Actively engaged in planning of various activities focussed on health and well-being among people with SMI, e.g. exercise, runs, group activities related to preparation of food, and nature experiences	1:26
KI 4	Regional health service	Management of complex issues among people with SMI, e.g. severe mental illness and physical co-morbidity, substance abuse, and managing medical treatment	0:51
KI 5	Regional health services	Working with physical health and bodily experiences of people with SMI.	0:57
Total			5:12

informant is defined as someone presenting with special interest in and knowledge of the topic being studied and possessing information that is not considered general knowledge in the social setting (Pelto, 2013; Schensul et al., 1999). In this study, the ability and willingness to reflect critically on current provision of health care were essential characteristics of the key informants, as their role was to assist the researcher in achieving insider information about behaviours and beliefs embedded in the settings (Pelto, 2013; Schensul et al., 1999). When working with key informants, it is difficult to foresee how many participants are needed. This depends on the study and there is a pragmatic element embedded in recruitment that is closely related to the particular study context and the opportunities that present in the settings. An important aspect of identification of key informants, is to aim for breadth and depth of knowledge of the topic being studied, and not to achieve a representative group (Pelto, 2013; Schensul et al., 1999). Ideally, key informants can present with either broad knowledge about a social setting or deep knowledge about a certain aspect of the topic being studied. This knowledge is typically gained through their position in the setting and by their previous experiences. This enables them to provide important, exploratory information and useful perspectives to the research (Schensul et al., 1999).

During field work sessions conducted as part of the ethnographic study (Hammersley & Atkinson, 2019), five individuals were identified as potential key informants across the two mental health care settings. The key informants were identified by the first author among the employed MHCPs. They were experienced individuals possessing valuable knowledge about the local behaviours and beliefs related to physical health care provision. These five MHCPs qualified as key informants, due to their level of engagement in physical health care as part of their everyday practices and their previous experiences with specific projects and initiatives to increase awareness among mental health service users and MHCPs about the potential benefits of improving physical health. Some of them spontaneously presented with critical views and concern related to the current state of physical health care provision. Such engagement and reflected opinions were otherwise rare in these settings. The reason for choosing this particular group of informants, was to gain insight into their critical insider perspectives on physical health care provision and into the organisational aspects related to such care (Pelto, 2013; Schensul et al., 1999).

The five key informants were recruited through purposeful sampling (Palinkas et al., 2015). They were approached by the primary researcher of the ethnographic study (first author), informed about the interview study, and invited to participate in individual interviews. All agreed to participate and were interviewed using an individual, semi-structured interview approach (Holstein & Gubrium, 1995).

The group of key informants comprised of two nurses, two social support workers and one physiotherapist, and all were experienced in working with care and treatment of people with SMI. The age range was 34–55 years. Their previous work experiences were related to general health care and various mental health care settings, such as at a practice of general practitioners, at psychiatric inpatient wards, care facilities for people with physical disability, providing care and treatment across a larger mental health organisation, as volunteer worker in the community, and at residential facilities. Hence, as a group they possessed knowledge about a broad segment of health care provision and organisation of health care across different settings and sectors. In addition, they possessed in-depth knowledge about the current state of provision of physical health care in the included mental health care settings. There were four women and one man. Additional information on the informants and the interviews is provided in Table 1.

Interviews were conducted between late 2016 and early 2018 at the workplace of the informants. Each face-to-face interview was audio-recorded and structured using an interview guide in which open-ended questions, probing questions and interviewee-specific questions were combined to facilitate the individual's perspectives on the issue of interest. The interview guide differed for each interview as the interviewee-specific questions were based on the informants' individual interest and knowledge related to managing physical health among people with SMI (Pelto, 2013). The interview guides were also influenced by the field work conducted in the mental health care settings prior to these individual interviews taking place.

Ethics

The Danish Data Protection Agency were notified about the study and Danish regulations regarding storage and management of data materials were followed. The informants received written and oral information about the study and provided informed, written consent when agreeing to participate. According to Danish legislation, the study did not need ethics approval. This was confirmed by a regional research ethics board.

Analysis

A thematic analysis of the data was conducted. This approach is widely used for analysing patterns and themes within qualitative data (Braun & Clarke, 2006). The analysis explored the data at a latent and interpretative level and drew on some broader assumptions about meanings embedded in what was articulated by the informants. This type of analysis involves the researcher's interpretation of the material in the development of the themes. This level of thematic analysis is appropriate when drawing on the general assumptions of social constructionism (Braun & Clarke, 2006).

The analysis was conducted in six phases, as described by Braun and Clarke (2006):

Phase 1: Getting familiar with the data material. The audio-recorded interviews were not transcribed but were listened through several times. This was combined with memo-writing.

Phase 2: Generating initial codes, writing and developing memos. As the material was not fully transcribed, coding was a process of noting sections of the audio-recordings with the generated codes. Even though the interviews were semi-structured and focussed on informants' reflections on barriers and possible solutions, the codes applied in this phase were guided by the content of the data material.

Phase 3: Searching for initial themes by examining the written memos and coding of the material. During this phase, five initial themes were identified across the participants' accounts and the written memos. These themes were: 1) specific initiatives, 2) barriers in current practices, 3) responsibilities and decision-making, 4) suggestions to overcome barriers, and 5) content related to specific context.

Phase 4: Revision and further development of the initial themes. In this phase, the themes were revised, and the content merged across themes. This process involved interpretation of the data based on contextual knowledge.

Phase 5: Defining and naming the themes that dominated the data. The final themes were named 1) barriers for provision of physical health in mental health care, and 2) possible solutions to overcome existing barriers. Their content is presented below.

Phase 6: Producing the report and writing up the themes. This included providing contextualised, illustrative quotes that could strengthen the presentation of the two themes and the interpretations made. The findings represent themes that were found across the entire data materials. The selected quotes were transcribed and translated into English.

Themes have been presented using a narrative style. This approach aims to provide the reader with rich contextual insights as well as direct quotes from the data. This approach is relevant to an analysis conducted at the latent and interpretative level. Providing contextual knowledge is a way to strengthen how the reader can engage with the researchers' interpretations.

Findings

The participating informants shared some similar experiences and perspectives related to provision of physical health care, and suggestions about how things could be done differently to overcome particular barriers, even though they were employed in different mental health contexts. These aspects represented the two dominant themes throughout the data material. When speaking about provision of physical health-related care, the informants referred to a broad range of aspects related to management of known physical illness, management of physical symptoms that might indicate the presence of illness, management of bodily experiences, prevention of illness, and health promotion initiatives. The informants reflected critically on the current provision of physical health care. In these reflections, they each presented work experiences and views related to the difficulties they experienced when working to provide sufficient levels of physical health care as part of everyday care and treatment to people with SMI. A recurring motif in their accounts was that current practice was characterised by MHCPs who lacked adequate qualifications in health care, that physical health was often managed based on personal experiences rather than professional knowledge, and a general lack of focus on physical health as part of everyday practices. They shared the opinion, that these were modifiable factors, hence represented issues that could be changed.

Theme 1: Barriers to provision of physical health care in mental health care

This theme includes descriptions of barriers to provision of physical health care that were prominent across the interviews. These included aspects related to the presence of persistent and severe mental illness among the mental health service users, unintentional resistance to physical health initiatives (from mental health services users and from MHCPs), and limited education and training of the employed MHCPs.

The informants identified persistent and severe mental illness as a barrier that in and of itself contributed to insufficient provision of physical health care in the two mental health settings. In their experience, poor mental health could affect the person's understanding of any physical symptoms or ability to recognise physical health issues. Aspects of poor mental health that were described as particularly influential were disrupted bodily experiences, delusional misinterpretations of physical symptoms, lack of motivation and initiative, limited ability to communicate verbally, and anxiety. As a result, persistent and severe mental illness could negatively impact help-seeking behaviour, or ability to adhere to treatment for existing physical illness or lifestyle intervention regimens as part of everyday life.

Informants described how poor mental health could become justification for decision-making when MHCPs decided not to intervene if 'risky' lifestyle behaviour or potentially damaging physical health conditions were observed among those with SMI. They described how dealing with mental health was the first priority in care provision in these settings. Poor general health among those diagnosed with persistent and severe mental illness was described as a condition that had become normalised to MHCPs to the extent that higher levels of poor physical health were accepted as part of their conditions. KI 4, who was an experienced registered nurse, was an informant who had experienced this at one of the residential facilities:

> The staff have gotten used to this miserable health status actually, and well they have these four rotten pegs in the mouth for example and (.) we don't really get anything done about it (.) and well, then also they actually don't get to the general practitioner regularly enough (.) So now that you do have COPD then you do have to have an annual check in September or October, right, for example (.) or a regular diabetes control or whatever it might be.
>
> (Interview with KI 4, (0:26:49))

KI 4 had several examples of how general physical health issues among the residents seemed to be accepted by the co-workers. As a consequence, the care and treatment that was delivered became inadequate. In the view of some of the informants, accepting of poor physical health among those with SMI occurred because the majority of the MHCPs employed at the residential facilities did not have the education and training into health care that was needed to observe or assess physical health related issues, or to understand the potential consequences of not dealing with existing physical health conditions.

All the informants expressed the opinion that physical health care was not sufficiently prioritised within mental health care. Some described how initiatives related to lifestyle behaviour and management of existing physical illness would be met with active resistance from both people with SMI and from co-workers. An example of resistance from people with SMI was related to changing the menu at a residential facility to healthier food choices. Several residents, unsatisfied with the new menu, would then eat fast food. This was described as particularly problematic if the same residents had also expressed wishes to change their diet to achieve weight loss. Informants perceived these conflicting wishes and actions performed by residents as an example of how they had difficulties controlling impulses, hence struggling with making the 'right choice' when standing at the buffet.

The informants also described how their co-workers could work against physical health initiatives, and that this resistance made working with health promotion and illness prevention as part of everyday care and treatment, difficult. Some of the informants had experienced lack of support from co-workers and described the promotion of physical health and preventive care, as an 'uphill' task. In worst-case scenarios, the informants had experienced co-workers undermining their efforts, if they did not agree on initiatives, or if they talked across purposes. KI 1, who worked at one of the residential facilities, described one of these experiences:

> When we first started on the diet-project, I actually experienced that I had a lot of colleagues who thought it was bloody annoying that they (.) firstly they had to help prepare those vegetables. Then I said "well, just take them with you and ask some of the residents if they would help do them", right. Yes well, then they wouldn't have cake. And then I have colleagues who simply collects money among themselves and go and buy cake, right. You know, instead of having the fruit.
>
> (Interview with KI 1 (0:14:28))

Such resistance was experienced as extremely frustrating. The informants believed that the current care provided needed an increased focus on physical health issues, and as part of this, a focus on healthier food choices. This was especially relevant in the residential facilities, where the facility kitchen was responsible for planning, preparing and serving all meals. The resistance from co-workers was described by informants as unintentional actions that illustrated a lack of understanding of the seriousness behind the initiatives, and a lack of knowledge about the importance of serving healthier food options for residents.

Suggestions made to improve the quality of usual care or to increase focus on promoting physical health or preventing illness, was something that could cause trouble in the workplace. Some informants experienced that repeated attempts to address complex health care issues related to managing known physical illness among people with SMI (e.g. medication administration or preventive care delivery) were met with negative attitudes from their co-workers. They described the experience of co-workers reacting as if they were intimidated by anyone who would question their usual work routines, and that some would take constructive feedback as a personal critique. This attitude among the MHCPs was perceived as a prominent barrier to working with physical health initiatives or focus areas as an integrated part of everyday care and treatment. Repeated experiences that involved resistance from co-workers were described as demotivating to those who were dedicated to try to address some of the problematic areas of current care provision. Reflecting on the experiences of dealing with the negative attitudes of co-workers some of the informants expressed how previously failed attempts to support those with SMI in achieving lifestyle changes or improving adherence with treatment of physical illness could contribute to resistance among their co-workers. However, these informants believed that one of their most essential efforts related to provision of physical health care was to support people with SMI to manage their health and to keep trying to motivate them if they struggled.

The third aspect of the current practices that constituted a barrier to provision of physical health care was related to limited education and training among the employed MHCPs. This aspect was mostly related to the residential facility setting, where health care qualifications were scarce. Informants described how the main group of MHCPs employed at these facilities were social support workers or social and health care workers. These groups of staff had no or only limited education and training in specific areas of disease, illness and injury, mental health and mental illness, illness prevention and health promotion. The main focus and contribution from these MHCPs in everyday care was related to social and pedagogical aspects of rehabilitation.

Informants described how these MHCPs often had many years of work experience and did tremendously well in their field of work, but that they did not possess the specialist knowledge to assess and effectively respond to the complex health conditions that residents at these facilities often presented with. KI 4 provided an example from the work performed to increase awareness on the complexities of the physical health conditions of some of the residents at one of the facilities. This example involved a male resident, who was overweight and who would spend his days sitting in a chair, smoking cigarettes. He struggled with poorly regulated diabetes, and had several toes amputated due to late complications. He had a chronic wound associated with one of the amputations that would not heal and needed changing and compression bandaging. Health care qualified MHCPs were extremely sparse at the time, and managing the complicated wound became an issue. KI 4, explained:

> …but the social support workers believe that they should be taught how to change the wound. It also needs compression. And this task of applying compression bandages and changing a diabetic foot wound, I simply don't believe it is a task for the social support workers. Then you might as well get the neighbour to do it, or the farmer, or the black smith, or whatever. Something. They have no basis for doing it. And there is no reason why he should be put in a worse position. It would never happen in other private homes. If he didn't have a mental health diagnosis and didn't live in a residential facility, you would never think of sending a social support worker to redress a wound.
>
> (Interview with KI 4, (0:11:18))

Teaching different groups of MHCPs tasks that were beyond their qualifications and scope of practice was a strategy used at the facilities to compensate for the lack of sufficiently qualified MHCPs. However, the informants described it as a worrying strategy that could potentially leave the people with SMI with even poorer health care provision. Some of the informants believed that a lack of nurses especially contributed to an insufficient focus on the overall health care complexities related to physical health and comorbidities among the residents at such facilities. Not having adequate knowledge and qualifications meant that the current group of MHCPs did not know what to observe, or how and when to act in complicated cases involving physical conditions. The informants strongly believed that the availability of MHCPs with relevant physical health care qualifications needed to change if the general attitude among the MHCPs and their practices were to improve.

Theme 2: Possible solutions to overcome current barriers

This theme includes description of the informants' reflections about possible solutions to the existing barriers to physical health care provision in mental health care settings. These revolved around suggestions of providing integrated care, of adjusting attitudes among MHCPs, and of physical health as a shared responsibility. The key informants all voiced the opinion that physical health, promotion of health, preventive care, and assisting those with SMI in understanding and interpreting bodily experiences needed to become a priority within mental health care. Some suggested that this included allocation of resources specifically to coordination of initiatives to improve physical health as part of everyday care and treatment. These informants typically also expressed the view that health was not something you could choose to address occasionally, but rather something that should be understood as an integrated part of the individual's way of living. Across the two mental health settings, the informants advocated for provision of integrated care that was based on more assertive, persistent and systematic aspects, than the current practice. To some, an ideal approach should be based on needs and wishes of those with SMI as well as their available resources. Initiatives should be meaningful to the individual, hence enhancing the probability of achieving the personalised goals.

Some of the informants implied that MHCPs needed to adjust their attitude towards the physical health aspects of care. They suggested that one way of addressing physical health differently involved acknowledging that making change in lifestyle behaviour was based on long-term processes that should be divided into several smaller and more manageable steps. Taking a step back while in this process of changes, should not be perceived as a failure, but rather, as a reason for MHCPs to keep encouraging the individual to try again. Therefore, they believed that MHCPs needed to accept the responsibility for providing continued motivating support to the people who struggled with aspects of physical health. Additionally, health should be understood as including both physical and mental aspects. The separation of the two was embedded in the organisational culture, and informants thought this to be problematic.

KI 5 had years of experience working with bodily expressions and experiences among people with SMI and used this as an approach to work with the issues that these people presented with. KI 5 used a thorough physical examination and interview process to decode what seemed to be the most important aspects of health to the individual and therefore required specific attention. If needed, the following work could be focussed on very specific aspects of lifestyle behaviour e.g. weight management and physical activities. KI 5 described how the people who had been physically examined and interviewed usually learned something very valuable about how to manage their physical health:

> What they usually take with them is a deeper understanding of their body, and they have a deeper understanding of how their mental health condition actually can be reflected in their body. Many of them get better at listening to their body, they are less afraid of the things they feel (.) and their self-care is improved.
>
> (Interview with K5 (0:19:45))

In KI 5's experience, the positive insights gained by people with SMI were something that could be useful when managing everyday life in general. KI 5 was very passionate about this work and the insights experienced by people. KI 5 believed that these insights often were achieved by the people who were supported to deal with their bodily experiences in a different way than would usually occur.

The informants described that, in their experience, many people with SMI with whom they worked had very limited social networks, and that important influences on managing everyday life, and thus on health behaviour, would come from the MHCPs. Physical health among those with SMI was portrayed as a shared responsibility that required engagement from both the individual and those involved in care delivery. Across settings, the informants described themselves and their co-workers as responsible for motivational support, particularly in the absence of family and other key informal networks, and for maintaining a meaningful appreciation of the difficult aspects of everyday life for many people diagnosed with mental illness. In addition, physical health issues, whether they presented as known conditions or suspicions about undetected illness, were also part of their responsibilities as professionals. As one of the barriers that was described as prominent was related to the limited healthcare education and training among the employed MHCPs, the informants were convinced that more health care qualified MHCPs, such as nurses or physiotherapists would have a positive effect on the general provision of physical health care across the settings. However, the inclusion of nurses or physiotherapists was expected to have most impact at the residential facilities, were MHCPs with these qualifications were almost non-existent at the time. KI 1 was one of the informants who commented on this issue.

KI 1 had been involved in several initiatives, mainly related to health promotion, at one of the facilities. KI 1 was of the opinion that the lack of qualified MHCPs in the setting was holding them back in relation to succeeding with the initiatives that were started. Based on work experiences, KI 1 believed that physical health was not a priority among the local managers, and hence no resources were allocated to address such matters. KI 1 was determined to achieve changes and investigated the experiences of others in similar settings:

> There is another residential facility somewhere. They do this a lot there. They have physios employed. Really, and have designed some physical exercise projects. And it works super well (.) So I pleaded a lot the last time we were employing people and said 'hire a physio' [laughs] 'let's get some in here now.'
>
> (Interview with KI 1 (0:12:47))

KI 1 described that despite the very direct effort to get MHCPs with relevant qualifications employed in the workplace, nothing had changed. The lack of sufficient MHCPs with specialist health care education and training needed to be addressed. According to the informants, dealing with complex physical conditions, which were often present among people with SMI, should be the responsibility of MHCPs with specific health-related qualifications. Several of the informants called for more explicit managerial responsibility and engagement in relation to providing such resources. Additionally, some advocated that management in their organisation should take responsibility for explicitly expressing expectations related to the contribution of the different professional groups within the staff. One participant worked in a setting where this was already part of practice, and it was described as essential that efforts targeted mental health as well as physical health needs. Management needed to be clear on what qualifications were required to deliver everyday care and treatment of the target population of their services. They were responsible for having an overview of the varied qualifications held by their staff, and how to best make use of the associated specialist knowledge and skills. Expecting different professional groups to perform the same tasks, was believed by informants to be a waste of resources, demotivating for MHCPs, and not at all profitable for those receiving the care. Hence, management was also responsible for acknowledging the need for more health care professional resources and making these a priority when employing new MHCPs.

The current barriers to provision of physical health care within mental health care settings and possible solutions as described by the informants, revolved around some modifiable aspects of care and treatment in everyday work practice (e.g. collaboration between MHCPs and people with SMI; attitudes of MHCPs; motivation of people with SMI; general resources among people with SMI), and the overall organisation of care (e.g. allocation of resources to focus on physical health aspects; relevant health-related qualifications among MHCPs; managerial engagement and responsibility). Even though the term 'modifiable' would suggest that the aspects of concern could be readily amended, most of the informants believed that a lot of things would need to be changed in order to achieve optimal provision of physical health care to people with SMI.

Discussion

This study examined a group of key informants' perspectives on the provision of physical health care across two Danish mental health care settings. The perspectives presented were based on their experiences gained in everyday work situations. The thematic analysis provided insight into their experiences of current barriers and possible solutions related to this area of practice. In the current study, the key informants were valuable due to their contextual insights, their continued engagement with initiating interventions in everyday care that focussed on physical health aspects within mental health care settings, and due to their ability to reflect critically on these matters (Pelto, 2013, Schensul et al., 1999). Their insights and contribution of knowledge were critical and constructively reflected their viewpoints about current barriers and relevant solutions to these issues. Being a small-sample study, triangulation of data was important to checking the accuracy of the information that was provided (Pelto, 2013). Several of the points made during the interviews were triangulated with accounts of other informants and with contextual knowledge gained by the first author while conducting fieldwork in the two mental health care settings. Applying the individual, semi-structured interview approach in the current study, and an individualised interview guide containing questions that specifically addressed some of the personal interest point of the informants, provided a context that made informants feel safe to reflect openly and rather critically on current practices in the mental health care settings, they were familiar with. In this way, the findings could provide an in-depth and critical understanding of current practices across the included mental health care settings.

The content of the informants' accounts illustrated negative attitudes embedded in existing mental health care practices, as everyday work situations were marked by co-workers' lack of support towards and engagement with health promoting initiatives in general, and a lack of managerial interest and willingness to prioritise the matter. This was experienced as resistance, albeit not necessarily intentional, as relevant knowledge and skills limitations potentially influenced the attitudinal stance of staff. The findings related to attitudes and how this can affect the actual practices of MHCPs in different settings, are somewhat related to those previously described in the literature, where lack of managerial ambitions towards the issue seemed to be influential on practices throughout the organisational levels (Nielsen, 2018). Previous research has suggested that such negative attitudes among MHCPs towards the health outcomes of people diagnosed with mental illness, continues to be a major barrier for improvement of their physical health conditions in Danish as well as international settings (Bartlem et al., 2016; Crawford et al., 2014; Lerbæk et al., 2019). These attitudes among MHCPs seem to be unintentionally reinforcing stigma towards people with SMI within their own mental health services (Lerbæk et al., 2019).

The barriers related to the presence of persistent and severe mental illness and resistance to physical health initiatives are potentially somewhat entangled in the third barrier, as limited specialist education and training about physical health among employed MHCPs might well form the origin of the two others. As has been described in previous research (Lerbæk et al., 2015; 2019; Nielsen, 2018), the key informants who participated in the current study, experienced how poor mental health became justification for MHCPs not focussing on physical health issues in mental health care settings. Additionally, some informants reflected on the worrying fact, that MHCPs might have become used to poor physical health conditions among people with SMI, to a point where this became normalised and an acceptable standard for health. This underlines the urgency of taking responsibility to change current practices.

At the residential facilities a main issue was related to a lack of health care qualifications among the employed MHCPs which impacted on capability to manage the complex health conditions of the residents. This mismatch between health support needs among the residents and the qualifications of MHCPs needs to be addressed if the provision of care is to improve (Abed, 2010; Gray & Brown, 2017; Small et al., 2017). The professional contribution of the current groups of MHCPs was related to social and pedagogical aspects of rehabilitation, which is an important part of long-term care. However, these aspects of care cannot stand alone when the target population consists of people with persistent and severe mental health disabilities in combination with physical comorbidities and/or substance abuse. Research into this particular area of mental health care at residential facilities is sparse, however recent international research into the association between staff education levels in general hospital wards, has reported that higher education and qualification of nursing staff is associated with positive patient outcomes, such as lower odds for hospitalisation, shorter stay in hospital if admitted, and decreased mortality (Audet et al., 2018; Haegdorens et al., 2019). Even though these studies report from different health care settings, there is reason to believe that adequately qualified MHCPs at these residential facilities could potentially contribute to improving the physical health condition of the residents. The strategy to teach unqualified MHCPs to perform complex health care tasks, as described in the current study, entails a great risk of potentially worsening the physical conditions of the people they are responsible for, hence, contributing to poorer physical health among people with SMI. The informants in our study suggested that relevant health care practices could be more readily available through employing more nurses and physiotherapists in the residential facility settings. Through their training and education, nurses would be sufficiently equipped to deal with the complex health conditions present in this setting. Previous international research has described how mental health nurses typically accept provision of physical health care as part of their professional responsibility. However, some are hesitant to deal with these issues due to a lack of confidence in their knowledge and skills, and therefore require suitable additional education, and supportive organisational structures (Wynaden et al., 2016; Happell et al., 2012).

The informants in the current study expressed the necessity to break down barriers related to fragmentation of health care and mental health care services as part of the way to achieve sufficient provision of physical health care to people diagnosed with SMI. Previous research within this area has emphasised the need for an integrated care approach and explicit expectations about the responsibilities of MHCPs in relation to provision of physical as well as mental health care (Kristiansen et al., 2015; Small et al., 2017). It has been suggested that change needs to happen across organisational levels (Lerbæk et al., 2019; Lundström et al., 2020), and that physical health care needs to be considered part of mental health care, and to become a priority at all levels involved in this area of shared responsibility. The findings from the current study suggests that such conclusions have yet to be translated into practice. Dealing with such extensive changes in a health care system would require dedicated engagement throughout the levels of care provision and across sectors (Dregan et al., 2020). This type of change would call for future research and development projects designed to deal with such changes across organisation levels and to address intersectoral barriers, such as that described in complex interventions framework (Craig et al., 2008).

Strengths and limitations

The framework for conducting the thematic analysis provided a flexible approach to analyse and interpret patterns of themes in the data material. Combined with contextual knowledge about the settings that were reference points for the informants accounts, this provided opportunity for presentation of broader assumptions about meanings embedded in the accounts of the informants (Braun & Clarke, 2006) and facilitated an in-depth understanding of the interview data. This study was a small-sample interview study including five key informants. While this might be perceived as a relatively small sample, justification is based on the key informants' specific knowledge and critical reflections about the particular area of physical health care provision in mental health care settings. Additionally, the interviews provided valuable knowledge related to insider perspectives on barriers and solutions to provision of adequate physical health care in particular contexts and their critical reflections of these aspects of the current and future practices (Pelto, 2013; Schensul et al., 1999). Choosing MHCPs as key informants was an informed decision, made with the intention to gain insight into their experiences from previous and current work situations, and their insider knowledge about the organisational context. This contributed to deeper understanding of the current practices of the MHCPs as a group within the included Danish mental health care contexts. Recruiting people with SMI as key informants would also elicit very relevant and valuable knowledge about this area. While this was outside the scope and aim of this particular interview study, it is considered a highly relevant perspective to pursue in future research.

Conclusion

Negative attitudes impacted by a lack of specific health care-related qualifications among mental health care professionals constitute serious barriers to the provision of physical health care within some mental health settings. MHCPs with specific interest in working within this area of practice could provide valuable and critical knowledge to inform practice change. Mental health care organisations need to work collaboratively with staff and service users, and other sectors to actively implement solutions that address barriers to the promotion of physical health and provision of tailored physical health care. According to the key informants participating in this study, sharing responsibility about physical health care meant considering the wishes, limitations and resources of individuals diagnosed with SMI. Alongside this important issue, we advocate that a key first step is to ensure that mental health professionals have the relevant knowledge, skills and qualifications to provide essential physical health promotion and physical illness prevention and intervention strategies.

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Appendix B

Birgitte Lerbæk / Region Nordjylland

Fra: Forskningsanmeldelse
Sendt: 14. marts 2016 10:07
Til: Birgitte Lerbæk / Region Nordjylland
Emne: SV: Anmeldelse af projekt
Vedhæftede filer: Tjekliste.doc

Kære Birgitte

Det projekt, du har anmeldt: " Barrierer for somatisk behandling blandt personer med skizofreni", er omfattet af Region Nordjyllands paraplyanmeldelse ved Datatilsynet – Sundhedsvidenskabelig forskning i Region Nordjylland (2008-58-0028).

Projektet har internt id-nummer 2016-50, som du bedes oplyse ved eventuelle fremtidige henvendelser vedrørende projektet.

Projektet starter den 1. maj 2016 og slutter d. 30. april 2019.

Husk at være opmærksom på at gemme eventuel identifikationsnøgle med cpr-nr. forsvarligt adskilt fra forskningsdata på id-nummerniveau.
Bemærk at hvis der skal laves opslag i elektroniske patientjournaler uden en aktuel patient-behandler-relation eller et informeret patientsamtykke, gælder retningslinjen Adgang til helbredsoplysninger i elektroniske systemer for særlige personalegrupper.

Hvis du har spørgsmål eller andet, er du meget velkommen til at ringe eller maile til mig.

Med venlig hilsen / Kind Regards

AALBORG UNIVERSITET

Christina Øllegaard Elmer
Ph.D. coordinator | Department of Clinical Medicine
The Faculty of Medicine, Aalborg University

T: (+45) 2434 8495 | Email: coel@dcm.aau.dk / c.elmer@rn.dk | Web: www.klinisk.aau.dk
Klinisk Institut | Forskningens Hus | Sdr. Skovvej 15 | 9000 Aalborg

Fra:	Forskningsanmeldelse
Sendt:	14. oktober 2016 08:30
Til:	Birgitte Lerbæk / Region Nordjylland
Emne:	SV: Anmeldelse af projekt

Kære Birgitte

Jeg har modtaget og registreret dine oplysninger om ændringer i datamaterialet vedr. projektet "Barrierer for somatisk behandling blandt personer med skizofreni" med id nummer 2016-50.

Med venlig hilsen / Kind Regards

Christina Øllegaard Elmer
Ph.D. coordinator | Department of Clinical Medicine
The Faculty of Medicine, Aalborg University
T: 9940 7179 / 2434 8495

Birgitte Lerbæk / Region Nordjylland

Fra: Videnskabsetisk Komité
Sendt: 2. marts 2016 15:32
Til: Birgitte Lerbæk / Region Nordjylland
Emne: Forespørgsel vedr. anmeldelsespligt

Kære Birgitte Lerbæk

Du har ved mail af 23. februar 2016 forespurgt om anmeldelsespligt at dit planlagte projekt.

På baggrund af nedenstående fremsendte oplysninger, herunder at der er tale om en interview- og observationsundersøgelse samt indsamling af relevant journalmateriale, er projektet e *ikke* omfattet af komitélovens (lov nr. 593 af 14/6/2011) definition på et sundhedsvidenskabeligt forskningsprojekt og skal ikke anmeldes til og godkendes af komitéen, jf. komitélovens § 14, stk. 2.

Projektet kan iværksættes uden yderligere tilbagemelding fra Den Videnskabsetiske Komité for Region Nordjylland.

Du skal dog i stedet være opmærksom på bestemmelsen i sundhedslovens § 46, stk. 2, hvoraf følger at Styrelsen for Patientsikkerhed i visse situationer skal godkende indhentelse af oplysninger fra patientjournaler, jf. hjemmeside.

Klagevejledning: afgørelsen kan, jf. komitélovens § 26, stk. 1, indbringes for Den Nationale Videnskabsetiske Komité senest 30 dage efter, afgørelsen er modtaget. Den Nationale Videnskabsetiske Komité kan, af hensyn til sikring af forsøgspersoners rettigheder, behandle elementer af projektet, som ikke er omfattet af selve klagen. Klagen samt alle sagens dokumenter sendes til: Den Nationale Videnskabsetiske Komité – DKetik@DKetik.dk

Med venlig hilsen

SEKRETARIATET for DEN VIDENSKABSETISKE KOMITÉ for REGION NORDJYLLAND
Niels Bohrs Vej 30
9220 Aalborg Ø
Tlf. 97 64 84 40
vek@rn.dk
www.vek.rn.dk

Birgitte Lerbæk

Fra: Forskningsanmeldelse
Sendt: 1. november 2019 13:10
Til: Birgitte Lerbæk
Emne: SV: Vedrørende forlængelse af projekt

Kære Birgitte

Tak for din henvendelse vedrørende forlængelse af projektet med ID-nummer 2016-50.

Jeg har registreret en ny slutdato for projektet 31. december 2020.

Med venlig hilsen

Lone Frøkjær Christensen
Datamanager
Fastnet: 97 66 62 76
Mail: lonni@rn.dk

AALBORG UNIVERSITETSHOSPITAL
Forskning, Uddannelse og Innovation
Enhed for Klinisk Biostatistik
Forskningens hus
Sdr. Skovvej 15
9000 Aalborg
aalborguh.rn.dk

Birgitte Lerbæk

Fra:	Forskningsanmeldelse
Sendt:	27. november 2020 11:32
Til:	Birgitte Lerbæk
Cc:	Forskningsanmeldelse
Emne:	SV: Ansøgning om forlængelse af projektperiode
Vedhæftede filer:	2016-50 Bilag 2.pdf
AppServerName:	esdh.rn.dk
DocumentIsArchived:	0
FileUpdateStatus:	1

Kære Birgitte,

Hermed fremsendes registrerede ændringer for projektet ”Barrierer for somatisk behandling blandt personer med skizofreni” med det interne ID-nummer 2016-50.

Med venlig hilsen,
Anne-Kathrine Sørensen
Forskningsdatakonsulent
97666276
ars@rn.dk

Region Nordjylland
Forskning, Uddannelse og Innovation
Forskningsdata og Statistik
Sdr. Skovvej 15
9000 Aalborg

Her kan du læse om dine rettigheder, når regionen behandler oplysninger om dig.

AALBORG UNIVERSITETSHOSPITAL
– i gode hænder

Forskning, Uddannelse
og Innovation
Forskningsdatakonsulenterne
Direkte 97 66 62 76
forskningsanmeldelse@rn.dk

27. november 2020

NOTAT

Bilag 2

Registrerede ændringer af projektet "Barrierer for somatisk behandling blandt personer med skizofreni" med id-nummer 2016-50.

Dato	**Ændring**
27-11-2020	Projekt forlænges fra 31-12-2020 til 31-12-2021

Appendix C

Samtykkeerklæring

Informeret samtykke til deltagelse i et sundhedsvidenskabeligt forskningsprojekt

Projektets titel: *Barrierer for somatisk behandling blandt personer med skizofreni*

Erklæring fra den der giver information

Jeg erklærer, at nedenstående projektdeltager har modtaget mundtlig og skriftlig information om forskningsprojektet.

Efter min overbevisning er der givet tilstrækkelig information om projektet til at træffe et informeret valg om deltagelse.

Navn på den, der har informeret projektdeltageren: ____________________________

Dato:________________ Underskrift: ____________________________

Erklæring fra projektdeltageren

Jeg har læst den skriftlige information om forskningsprojektet og har fået mundtlig information om projektet i et sprog, som jeg forstår.

Jeg ved tilstrækkeligt om projektets formål, metoder samt fordele og ulemper til at kunne sige ”Ja” til at deltage.

Jeg er informeret om, at det er frivilligt at deltage og om, at jeg til enhver tid kan trække mit samtykke tilbage og træde ud af projektet, uden at give en grund og uden at dette får betydning for min behandling eller mine rettigheder i øvrigt.

Jeg er informeret om, at jeg får udleveret en kopi af dette samtykke til eget brug samt om at jeg kan få viden om projektets resultater, når disse foreligger.

Samtykket vedrører dataindsamling ved interview, feltobservationer, adgang til relevant journalmateriale samt interview om psykiatrisk lidelse. Med min underskrift giver jeg samtykke til at deltage i projektet.

Navn på projektdeltager: ____

Dato:________________ Underskrift: ____________________________

Jeg ønsker at modtage en kort rapport med projektets resultater Ja ☐ Nej ☐

Samtykkeerklæring vedrørende videooptagelser

I forbindelse med at du deltager i et interview, der handler om din psykiatriske lidelse, beder vi om tilladelse til at optage samtalen på video.

Formålet med videooptagelsen er forskningsdokumentation og undervisning af fagpersoner. Medvirken ved videooptagelsen er frivillig. Ønsker du ikke at medvirke, har det ingen betydning for dit behandlingsforløb.

Erklæring fra projektdeltageren:
I forbindelse med videooptagelsen er jeg blevet mundtligt informeret om optagelserne, og jeg er informeret om, at jeg til enhver tid kan trække min tilladelse tilbage og få optagelserne slettet.

Jeg giver hermed tilladelse til videooptagelsen som sker i forbindelse med forskningsprojektet "Barrierer for somatisk behandling blandt mennesker med skizofreni", ansvarlig for forskningsprojektet er Birgitte Lerbæk.

Navn:____

Sted og dato for
optagelsen:____

Jeg giver hermed samtykke efter ovenstående retningslinjer:

____
(Dato) (underskrift)

Særlige forhold vedrørende brug af videooptagelsen, som jeg ønsker respekteret:

Erklæring fra den projektansvarlige:
Undertegnede projektansvarlig bekræfter herved, at der er givet information om videooptagelserne i forbindelse med indhentning af samtykket, og at optagelserne efterfølgende til enhver tid vil blive slettet på forlangende:

____
(Dato) (underskrift)

Samtykkeerklæring

Informeret samtykke til deltagelse i et sundhedsvidenskabeligt forskningsprojekt

Projektets titel: *Barrierer for somatisk behandling blandt personer med skizofreni*

Erklæring fra den der giver information

Jeg erklærer, at nedenstående projektdeltager har modtaget mundtlig og skriftlig information om forskningsprojektet.

Efter min overbevisning er der givet tilstrækkelig information om projektet til at træffe et informeret valg om deltagelse.

Navn på den, der har informeret projektdeltageren: ____________________________

Dato:________________ Underskrift: ____________________________

Erklæring fra projektdeltageren

Jeg har læst den skriftlige information om forskningsprojektet og har fået mundtlig information om projektet i et sprog, som jeg forstår.

Jeg ved tilstrækkeligt om projektets formål, metoder samt fordele og ulemper til at kunne sige ”Ja” til at deltage.

Jeg er informeret om, at det er frivilligt at deltage og om, at jeg til enhver tid kan trække mit samtykke tilbage og træde ud af projektet, uden at give en grund.

Jeg er informeret om, at jeg får udleveret en kopi af dette samtykke til eget brug samt om, at jeg kan få viden om projektets resultater, når disse foreligger.

Samtykket vedrører deltagelse i fokusgruppe.

Med min underskrift giver jeg samtykke til at deltage i projektet.

Navn på projektdeltager: ____

Dato:________________ Underskrift: ____________________________

Jeg ønsker at modtage en kort rapport med projektets resultater Ja ☐ Nej ☐

Samtykkeerklæring

Informeret samtykke til deltagelse i et sundhedsvidenskabeligt forskningsprojekt

Projektets titel: *Barrierer for somatisk behandling blandt personer med skizofreni*

Erklæring fra den der giver information

Jeg erklærer, at nedenstående projektdeltager har modtaget mundtlig og skriftlig information om forskningsprojektet.
Efter min overbevisning er der givet tilstrækkelig information om projektet til at træffe et informeret valg om deltagelse.

Navn på den, der har informeret projektdeltageren: ____________________________

Dato:________________ Underskrift: ____________________________

Erklæring fra projektdeltageren

Jeg har læst den skriftlige information om forskningsprojektet og har fået mundtlig information om projektet i et sprog, som jeg forstår.
Jeg ved tilstrækkeligt om projektets formål, metoder samt fordele og ulemper til at kunne sige ”Ja” til at deltage.

Jeg er informeret om, at det er frivilligt at deltage og om, at jeg til enhver tid kan trække mit samtykke tilbage og træde ud af projektet, uden at give en grund.
Jeg er informeret om, at jeg får udleveret en kopi af dette samtykke til eget brug samt om, at jeg kan få viden om projektets resultater, når disse foreligger.

Samtykket vedrører deltagelse i individuelt interview.
Med min underskrift giver jeg samtykke til at deltage i projektet.

Navn på projektdeltager: ____

Dato:________________ Underskrift: ____________________________

Jeg ønsker at modtage en kort rapport med projektets resultater Ja ☐ Nej ☐

Appendix D

Deltagerinformation

Projektets titel: Barrierer for somatisk behandling blandt personer med skizofreni

Mit navn er Birgitte Lerbæk. Jeg er ph.d. studerende ved Psykiatrien på Aalborg Universitetshospital. I forbindelse med min forskeruddannelse laver jeg et forskningsprojekt, der handler om sundheds- og sygdomsadfærd hos mennesker med skizofreni.

Deltagere til studiet findes bl.a. gennem OPUS. Da du er tilknyttet der, vil jeg gerne invitere dig til at deltage i projektet. Dette brev indeholder information om projektets baggrund, formål, forløb, fordele og ulemper ved deltagelse samt om dine rettigheder som deltager.

Om projektet
Det er et alvorligt problem, at mange personer med alvorlige psykiske lidelser har dårligt fysik helbred. Jeg vil gerne studere, hvad personer med skizofreni tænker om sundhed og sygdom samt hvad de gør, for at holde sig sunde i hverdagen.
Projektet undersøger, om faktorer forbundet med skizofreni kan føre til, at man har en ændret adfærd i forhold til sundhed og sygdom og om det kan være en barriere, der medvirker til, at man modtager et dårligere behandlingstilbud. Vi undersøger også, hvordan kontakten vi har med andre i vores hverdagsliv kan have indflydelse på, hvordan vi reagerer i forhold til sundhed og sygdom.
Det undersøger vi ved at få indblik i deltagernes hverdagsliv. Gennem dette indblik i hverdagslivet vil vi se på hvordan personer med skizofreni opfatter sygdom og anvender sundhedsydelser. Det vil give viden om mulige barrierer for adgangen til undersøgelse og behandling i sundhedsvæsenet.

Formålet med projektet
Formålet er at undersøge sygdomsforståelse samt sundheds- og sygdomsadfærd blandt personer med skizofreni samt hvilken betydning samspil med omverdenen kan have herpå.

Projektets forløb
Projektet varer 3 år (2016-2019) og i den tid følges 4-6 personer med tilknytning til OPUS og 4-6 personer, der bor på regionale psykiatriske boformer.
Jeg er ansvarlig for projektet og det er primært mig, du har kontakt med i forbindelse med projektets forskellige aktiviteter.

Din deltagelse
Herunder er en beskrivelse af det, som du siger ja til, hvis du vælger at deltage i undersøgelsen.

1. Observationer
Observationer foregår i perioder, hvor jeg følger med dig i din dagligdag, for at få indblik i dit hverdagsliv, som en person, der er tilknyttet OPUS. Jeg vil særligt have fokus på sundheds- og sygdomsadfærd og på dit samspil med dine nærmeste omgivelser. Periodernes længde aftaler vi undervejs.
Jeg vil være tilstede i kortere eller længere tid, over flere dage og observationerne vil være fordelt over ca. ½ år.

2. Individuelle interview og interview, der beskriver psykisk lidelse (psykiatriske interviews)
Du siger ja til at deltage i interview med mig, hvor der vil være fokus på dine erfaringer med sundhed og sygdom, og på de samspil med andre mennesker, som du er en del af i hverdagen. Interviewene lydoptages.
Du siger også ja til at deltage i 2 interviews, der skal give et indblik i din psykiatriske lidelse. Det ene interview gennemføres af mig og giver indblik i de symptomer, som du oplever. Interviewet tager ca. 1 time.
Det andet interview giver indblik i andre faktorer relateret til at være psykisk sårbar og indsigt i sygdom. Det gennemføres af sundhedsfaglige personer, som er særligt trænede i at udføre denne type interview. Interviewet tager ca. 2 timer.
Begge interviewtyper lydoptages. Interview om din psykiske lidelse optages på video, hvis du giver tilladelse til det.

3. Videregivelse af oplysninger fra relevante journaler
Du giver samtykke til, at jeg kan få adgang til relevant materiale fra sygeplejefaglige og lægefaglige journaler. Det vil give indsigt i de samspil, som du har haft med sundhedsprofessionelle samt i de sundhedsprofessionelle beskriver din sundheds- og sygdomsadfærd.
Materialet vil komme fra de elektroniske journaler, som er oprettet på bosteder, ved ambulante sygehus besøg samt ved indlæggelse på såvel psykiatrisk som somatisk sygehus. Vi aftaler specifikt, hvilke dele du vil give samtykke til, at jeg kan få indsigt i.

4. Tilladelse til at vi må kontakte relevante personer fra dit netværk.
Endeligt giver du tilladelse til at jeg må kontakte 1-2 personer fra dit netværk. Det kan f.eks. være pårørende (familie og venner) eller sundhedsprofessionelle. Hvem det skal være, aftales med dig. De inviteres til at være med i fokusgrupper.

Fordele og ulemper ved at deltage
Det forventes ikke, at du vil opleve nogen former for ubehag ved at deltage i projektet.
Vi laver klare aftaler omkring forløbet og de kan tilpasses undervejs efter behov.

Samtykkeerklæring
Du modtager mundtlig og skriftlig information før du beslutter, om du vil deltage i projektet. Du har mulighed for at have en bisidder ved informationsmødet og du opfordres til at tage dig tid til at overveje om du ønsker at deltage.
Hvis du ønsker at deltage, giver du et skriftligt samtykke ved at underskrive en samtykkeerklæring.

Det er frivilligt at deltage i projektet, og du kan til enhver tid trække dit samtykke tilbage ved henvendelse til mig, uden at give en grund herfor og uden, at det får konsekvenser for nuværende eller fremtidig behandling, eller dine rettigheder i øvrigt.

Dine rettigheder som projektdeltager

Du modtager ikke vederlag for din deltagelse i projektet.

Oplysninger om dine helbredsforhold, øvrige rent private forhold eller andre fortrolige oplysninger, som indgår i eller fremkommer ved dette projekt er omfattet af tavshedspligt.

Projektet er meddelt til Datatilsynet og opbevaring af oplysninger, der indgår i projektet, sker efter reglerne om behandling af personoplysninger.

Der er mulighed for at få agtindsigt i forsøgsprotokoller efter offentlighedslovens bestemmelser. Det betyder, at det er muligt at få adgang til at se papirer, som vedrører din deltagelse i projektet (bortset fra dele, som måtte indeholde fortrolige oplysninger om andre).

Der er desuden generelt i sundhedsvidenskabelige forskningsprojekter mulighed for at klage og få erstatning efter reglerne i lov om klage- og erstatningsadgang for sundhedsvæsenet.

Kontaktoplysninger

Du er altid velkommen til at stille spørgsmål vedrørende projektet og din deltagelse. Jeg kan kontaktes på **tlf. 27 82 75 78** eller **email: birgitte.lerbaek@rn.dk**

Projektets adresse er:
Aalborg Universitetshospital, Psykiatrien
Center for Psykoseforskning, Mølleparkvej
Klinik Psykiatri Syd
Mølleparkvej 12, Indgang 8
Søster Katinkas Hus
9000 Aalborg

Forskningsprojektet finansieres af Psykiatrien i Region Nordjylland og af eksterne fondsbevillinger.

Ph.d. studiet er tilknyttet projektet *Åreforkalkning som årsag til sygelighed og dødelighed hos patienter med skizofreni. Epidemiologi og status med henblik på forebyggelsestiltag og behandling* som er etableret som et formaliseret samarbejde mellem Psykiatrien og Kardiologisk afdeling på Aalborg Universitetshospital.

Information om forskningsprojekt blandt patienterne i Ambulatorium for Unge med Skizofreni (OPUS)

Mit navn er Birgitte Lerbæk. Jeg er ph.d. studerende ved Psykiatrien på Aalborg Universitetshospital. Jeg skal lave et forskningsprojekt blandt patienterne i OPUS og jeg håber, at du vil være med.

Det er et alvorligt problem, at mange personer med alvorlige psykisk lidelse har dårligt fysik helbred. Jeg vil gerne studere, hvad personer med skizofreni tænker om sundhed og sygdom samt hvad de gør, for at holde sig sunde i hverdagen.

Jeg besøger patienter i OPUS fra februar til december 2017 og vil arbejde sammen med 4-6 deltagere herfra. Jeg vil besøge deltagerne i eget hjem og komme i OPUS lokaler, når jeg følger dem. Derudover besøger jeg OPUS for at lære hverdagen her bedre at kende.

Deltagere inviteres personligt til at være en med i studiet og skal underskrive en samtykkeerklæring inden opstart.

Da jeg kan få indblik i ting, der involverer både patienter og ansatte tilknyttet OPUS, når jeg er tilstede i OPUS, er der regler, som jeg skal overholde. Det betyder at:

- Projektet er anmeldt til Datatilsynet og jeg skal overholde deres regler. Det betyder bl.a. at mine notater og udskrevne interviews skal være låst inde og at de ikke må gives videre til andre.

- Jeg har tavshedspligt i forhold til det, jeg oplever i OPUS og i relation til deltagerne i projektet. Jeg må ikke dele min viden med andre end personalegruppen og mine vejledere.

- Når jeg fortæller eller skriver om studiet, vil jeg sløre alle detaljer. På den måde kan ingen genkende dem, der har været med i afrapportering fra projektet.

- I projektet indgår også data fra individuelle interviews, fokusgrupper og skriftligt materiale fra deltagernes journaler.

Hvis du vil vide mere om studiet, er du velkommen til at tage kontakt.

Venlig hilsen
Birgitte Lerbæk
Projektsygeplejerske, ph.d. studerende

birgitte.lerbaek@rn.dk
Tlf. 27 82 75 78

Center for Psykoseforskning
Aalborg Universitetshospital

Appendix E

NAVN: ____

CPR.-NR.: ____________________ **DATO:** __________________

Positiv skala (P)

P1	Vrangforestillinger	1	2	3	4	5	6	7
P2	Begrebsmæssig disorganisering	1	2	3	4	5	6	7
P3	Hallucinatorisk adfærd	1	2	3	4	5	6	7
P4	Ophidselse	1	2	3	4	5	6	7
P5	Grandiositet	1	2	3	4	5	6	7
P6	Mistænksomhed/forfølgelse	1	2	3	4	5	6	7
P7	Fjendtlighed	1	2	3	4	5	6	7

Subscore ☐☐

Negativ skala (N)

N1	Dæmpet affekt	1	2	3	4	5	6	7
N2	Emotionel tilbagetrukkethed	1	2	3	4	5	6	7
N3	Ringe kontakt	1	2	3	4	5	6	7
N4	Passiv/apatisk social tilbagetrukkethed	1	2	3	4	5	6	7
N5	Vanskeligheder med abstrakt tænkning	1	2	3	4	5	6	7
N6	Mangel på spontanitet og flow i samtaler	1	2	3	4	5	6	7
N7	Stereotypisk tænkning	1	2	3	4	5	6	7

Subscore ☐☐

Generel Psykopatologi (G)

G1	Somatisk bekymring	1	2	3	4	5	6	7
G2	Angst	1	2	3	4	5	6	7
G3	Skyldfølelse	1	2	3	4	5	6	7
G4	Anspændthed	1	2	3	4	5	6	7
G5	Manierethed og poseren	1	2	3	4	5	6	7
G6	Depression	1	2	3	4	5	6	7
G7	Motorisk langsommelighed	1	2	3	4	5	6	7
G8	Ikke samarbejdsvillig	1	2	3	4	5	6	7
G9	Usædvanligt tankeindhold	1	2	3	4	5	6	7
G10	Disorienterethed	1	2	3	4	5	6	7
G11	Ringe opmærksomhed	1	2	3	4	5	6	7
G12	Mangel på dømmekraft og indsigt	1	2	3	4	5	6	7
G13	Viljeforstyrrelse	1	2	3	4	5	6	7
G14	Ringe impulskontrol	1	2	3	4	5	6	7
G15	Besættelse	1	2	3	4	5	6	7
G16	Aktiv social undgåelse	1	2	3	4	5	6	7

Subscore ☐☐☐

RATERS NAVN: ______________________________

Total PANSS score ☐☐☐

PANSS scores, total scores and sub-scale scores

Participant[1]	**Positive scale**	**Negative scale**	**General psychopathology**	**Total**	**Severity[2]**
1	19	26	42	87	Marked
2	11	23	33	67	Moderate
3	34	20	55	109	Severe
4	24	31	44	99	Severe
5	13	17	37	67	Moderate
6	12	27	38	77	Marked
7	7	20	24	51	Mild
8	-	-	-	-	-
9	20	31	57	108	Severe

Sub-scale scores	**Positive scale**	**Negative scale**	**General psychopathology**	**Total**
Range	7-34	17-31	24-57	51-109
Median [IQR[3]]	16 [11.75 – 21]	24.5 [20 - 28]	40 [36 - 46.75]	82 [67 – 101.25]

[1] One participant was not able to participate in the PANSS interview, [2] Severity based on descriptions in Leucht et al., [3] Inter Quartile Range, calculated in Microsoft Excel.

Appendix F

Display of progressive focusing

FACTORS SUSTAINING PHYSICAL HEALTH ISSUES				
Analysis[1]	**Data materials**	**Key points condensed from the findings**	**Sustaining factor(s)**	**Dimension of social context**
Thematic analysis I	- Field notes - Individual, semi-structured interviews - Audio-recorded conversations - Psychiatric interviews	- Adapting as management strategy - Adapting by avoiding ongoing physical health issues - Induce control and predictability	- **Repeated use of management strategy**	**Individual**
Thematic analysis I	- Field notes - Individual, semi-structured interviews - Audio-recorded conversations - Psychiatric interviews	- Retreating as management strategy - Physical health symptoms as reoccurring, discrete episodes - Negative impact on several aspects of everyday life	- **Repeated use of management strategy**	**Individual**
Discourse analysis	- Transcripts of three focus groups	- MHCPs' approaches to engaging in physical health issues (unsystematic and occasional) - Screening tools (assessing side effects) provide basis for thorough questioning (community) - Based on personal knowledge (residential facilities)	- **MHCPs' approaches to dealing with physical health issues**	**Immediate social context**
Thematic analysis II	- Audio-recordings of five individual, semi-structured interviews	- Lack of MHCPs with health care education and training (residential facilities) - Physical health care based on personal knowledge	- **MHCPs' approaches to dealing with physical health issues** - **Inadequate health care resources available**	**Immediate social context**
Thematic analysis II	- Audio-recordings of five individual, semi-structured interviews	- Physical health is not a priority among mental health users or MHCPs	- **Physical health is not a priority** - **Care focused on social rehabilitation and mental health**	**Individual** **Immediate social context**
Discourse analysis	- Transcripts of three focus groups	- Physical health is not a primary priority in mental health settings - Lack of resources to non-psychiatric issues - Mismatch between intentions and values in care provision	- **Care focused on social rehabilitation and mental health**	**Immediate social context**
Thematic analysis II	- Audio-recordings of five individual, semi-structured interviews	- Physical health needs to be a priority	- **Care focused on social rehabilitation and mental health**	**Immediate social context**

Thematic analysis II	• Audio-recordings of five individual, semi-structured interviews	• Physical health is not a priority	• **Care focused on social rehabilitation and mental health** • **Lack of general awareness of physical health**	**Immediate social context**
Thematic analysis I	• Field notes • Individual, semi-structured interviews • Audio-recorded conversations • Psychiatric interviews	• Social setting as promotor of management strategy • Support provided is delayed	• **Delayed support intervention**	**Immediate social context**

FACTORS SUSTAINING MANAGEMENT STRATEGIES

Analysis[1]	**Data materials**	**Key points condensed from the findings**	**Sustaining factor(s)**	**Dimension of social context**
Thematic analysis I	• Field notes • Individual, semi-structured interviews • Audio-recorded conversations • Psychiatric interviews	• Repeated pattern • No positive change in health • Potential worsening in health	• **Lack of help-seeking**	**Individual**
Thematic analysis I	• Field notes • Individual, semi-structured interviews • Audio-recorded conversations • Psychiatric interviews	• Lack of help-seeking initiatives	• **Exclusion of care givers** • **Lack of help-seeking**	**Individual**
Thematic analysis I	• Field notes • Individual, semi-structured interviews • Audio-recorded conversations • Psychiatric interviews	• Not recognising physical health issues as important or serious • Verified by limited engagement from MHCPs	• **Lack of recognition of seriousness of physical health issues** • **Exclusion of care givers**	**Individual** **Immediate social context**
Thematic analysis I	• Field notes • Individual, semi-structured interviews • Audio-recorded conversations • Psychiatric interviews	• Psychiatric interviews Social setting as promotor of management strategy	• **Delayed support intervention**	**Immediate social context**
Discourse analysis	• Transcripts of three focus groups	• MHCPs provide motivational support • Providing physical health care as balancing act (accept autonomy – risk providing insufficient care) • Respecting individual choice used as justification for not engaging in physical health issues.	• **Limited engagement in physical health issues from MHCPs**	**Immediate social context**
Discourse analysis	• Transcripts of three focus groups	• Severe mental illness used as justification for not engaging in physical health issues	• **Limited engagement in physical health issues from MHCPs**	**Immediate social context**
Discourse analysis	• Transcripts of three focus groups	• Severe and persistent mental illness is a barrier to physical health care • Justification for not engaging in physical health issues	• **Limited engagement in physical health issues from MHCPs**	**Immediate social context**

			• Negative expectations associated with persistent and severe mental illness	
Thematic analysis II	• Audio-recordings of five individual, semi-structured interviews	• Severe mental illness is a barrier to physical health care	**• Limited engagement in physical health issues from MHCPs**	**Immediate social context**
Thematic analysis II	• Audio-recordings of five individual, semi-structured interviews	• Severe mental illness used as justification for MHCPs not engaging with physical health issues	**• Limited engagement in physical health issues from MHCPs**	**Immediate social context**
Discourse analysis	• Transcripts of three focus groups	• Undertreatment of physical health issues • Stigmatisation • Fragmentation of general health care and mental health care services	**• Limited engagement in physical health issues from MHCPs** **• Lack of general awareness of physical health**	**Immediate social context**
Thematic analysis II	• Audio-recordings of five individual, semi-structured interviews	• Complex health issues call for staff with training and education to manage these • More health care qualified staff could have a positive effect (residential facilities)	**• Inadequate health care resources available** **• Lack of general awareness of physical health**	**Immediate social context**
Thematic analysis II	• Audio-recordings of five individual, semi-structured interviews	• Dealing with physical health issues requires engagement (shared responsibility)	**• Limited engagement in physical health issues from MHCPs**	**Immediate social context**
Thematic analysis II	• Audio-recordings of five individual, semi-structured interviews	• Resistance among both mental health users and MHCPs	**• Negative attitude among MHCPs towards physical health care**	**Immediate social context**
Thematic analysis II	• Audio-recordings of five individual, semi-structured interviews	• MHCPs negative attitude towards physical health care • Increased focus on physical health in care as a trigger of conflicts among colleagues	**• Negative attitude among MHCPs towards physical health care**	**Immediate social context**
Thematic analysis II	• Audio-recordings of five individual, semi-structured interviews	• Managers' responsibility • What is expected of staff? • The group of MHCPs need to reflect the support needs of the mental health users.	**• Lack of managerial support** **• Lack of managerial focus on physical health issues** **• Lack of recognition of seriousness of physical health issues**	**Immediate social context** **Indirect social context**

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[1] This column refers to the three analyses conducted as part of this research. They each appear several times to illustrate they contribution into various key points.

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