Healthcare seeking for people diagnosed with severe mental illness:

Sensations, symptoms and diagnostic work

Abstract

For people with mental and somatic illnesses, the interpretive process of attending to a multitude of bodily sensations and recognising them as potential symptoms represents daily and `chronic homework´. Based on 16 months of ethnographic fieldwork in Denmark, this study explored diagnostic work and healthcare seeking among people with severe mental and somatic illnesses. As multiple studies have shown, the transformation process for a perceived sensation to become a symptom is a socially constructed interpretation process highly dependent on social legitimisation and shaped by prior cultural knowledge. We found that people with severe mental and somatic illnesses often struggled to "read" the body and its boundaries and to define and distinguish when a symptom becomes a potential sign of illness. Furthermore, they often lacked opportunities for social recognition of symptoms because they lacked social relations. Finally, lifelong experiences with the healthcare system have taught them, that they must distinguish between "mental" and "somatic" symptoms to fit the systemic organisation of the healthcare system. This deeply rooted mind-body dualism in the organisation of healthcare services and the daily struggles of diagnostic work to comply with this organisation impacted the interlocutors' healthcare seeking strategies. Further, even though they "make up their minds" to seek healthcare, they risk being met with diagnostic overshadowing and reductionist clinical approaches.

Keywords: Symptoms, mind-body dualism, ethnographic fieldwork, mental illness, healthcare seeking

Introduction

This paper focuses on everyday life sensations and healthcare seeking by people diagnosed with severe mental illness who simultaneously live with one or several somatic diseases (a condition that manifests in the body, often with observable symptoms, and is influenced or caused by psychological, social, or emotional factors (Kirmayer and Sartorius 2007). `Severe mental´ illness is a term used in the scientific literature when referring to schizophrenia, bipolar disorder and severe depression with a high degree of severity (Corrigan et al. 2014; Lerbaek 2021). Let us take an example: A person lives with paranoid schizophrenia, going in and out of psychiatric wards, takes antipsychotic medications, has been diagnosed with various coexisting conditions such as Parkinson´s disease, depression, asthma and experiences various bodily sensations and must visit different hospitals and doctors for various follow-ups. The

person lives alone and feels isolated and lonely; one of the few social relations in life is the contact person from the supported housing facility. We can only begin to imagine the complexity and precariousness of this way of living. This example is not particularly extreme or fictitious since it illustrates the life of an interlocutor in this study. It serves as an example of the everyday life conditions that people with severe mental and somatic illnesses often struggle to handle, both in respect to navigating the healthcare system and managing several illnesses at the same time. The Danish welfare system is structured into separate domains for somatic healthcare and mental health services (Davidsen et al. 2020). Despite efforts to improve cooperation between these sectors, the division between mental and somatic health remains pronounced (Davidsen et al. 2020; Bento et al. 2020). This paper emerges from this organizational landscape, not from a dualistic approach to disease and health by the authors. Instead, we hope to help dissolve this dichotomy with our analysis of experienced sensations and symptoms.

Over the last decade, the number of people diagnosed with mental disorders has increased dramatically worldwide, and similar tendencies are seen in Denmark (Behandlingsrådet 2023). Research shows that people with mental illness often live with somatic illnesses in addition to their mental illness (Grudniewicz et al. 2022). Several circumstances contribute to the prevalence of comorbidities, such as people ageing, life-prolonging medicine, unhealthy lifestyle, side-effects of medicine and psychopharmacological drugs, and substance abuse (Dieset et al. 2016; Happell et al. 2016). These comorbid conditions contribute to an excess mortality among people with severe mental illness. Research shows that life expectancy is shortened by 15-20 years compared with the general population, and the majority of premature deaths are due to somatic disease, such as cardiovascular disease and other preventable illnesses, which are believed to be underdiagnosed and undertreated (Fiorillo and Sartorius et al. 2021). A recent report in Denmark on health inequalities in somatic treatments in patients with mental disorders (Behandlingsrådet 2023) emphasises how mental disorders increase the risk of premature death, and that patients with mental illness receive less-optimal treatment in the somatic healthcare system, for instance delayed diagnosis and misdiagnosis (Shefer et al. 2014), and they receive fewer health services compared to patients without mental illness (Grudniewicz et al. 2022). The literature identifies various barriers that contribute to these health inequalities. A qualitative Swedish study identifies the main barrier as the gap between patients' healthcare needs and abilities, and the organisation of the healthcare system. It also shows how the system relies on patients' own ability to initiate contact with healthcare, which is also seen as a barrier to accessing somatic healthcare for people diagnosed with mental illness (Brämberg et al. 2018).

Other international studies have explored barriers related to such health inequalities, and what hinders or facilitates access to healthcare for people with mental illness (De Hert et al. 2011). They emphasise stigmatisation, which is believed to delay diagnosis and treatment of somatic illness among patients with mental illness (Happell et al. 2012; Happell et al. 2016), as well as self-stigmatisation (Brämberg et al. 2018), overshadowing (Happell et al. 2016; Jones et al. 2008; Shefer et al. 2014), social isolation (Wang et al. 2017), socioeconomic factors (Ross et al. 2015), initiating healthcare in time (Behandlingsrådet 2023), navigating the healthcare system (Brämberg et al. 2018), and lack of coordination and communication within the healthcare system between somatic and psychiatric care (De Hert et al 2011, Grudniewicz et al. 2022). The latter touches on the well-known division between somatic and psychiatric healthcare. This organizational and structural division of treatment and care illustrates an inherent dualism between body and mind, which is highly relevant to discuss when patients have mental and somatic illnesses simultaneously. A literature review focused on patients with mental illness and their experience with somatic treatment concluded that stigmatisation and somatic healthcare professionals´ lack of knowledge about mental illness caused patients to avoid seeking care (Alzokani and Ronge 2022). Barriers such as scheduling appointments, the actual transportation to the general practitioner (GP) clinic and sitting in a crowded waiting room with other patients may also challenge and impede access to healthcare (Grudniewicz et al. 2022).

Several initiatives have been launched to address the healthcare gap and the somatic health disparities. These primarily focus on lifestyle interventions that aim to change health behaviour among patients suffering from mental illness (Cabassa et al. 2010; Karasz and Dempsey 2008; Moltke 2017). Despite such initiatives, focus on the quality of somatic care in the treatment of patients with mental illness remains neglected, which calls for further research in this area (Behandlingsrådet 2023). Several studies demonstrate the need for more knowledge about barriers to accessing somatic healthcare, and about the context-specific barriers from the patient perspective (Alzokani and Ronge 2022; Grudniewicz et al. 2022).

Noticing or feeling something in one's body precedes seeking help in most cases. Nonetheless, research on healthcare seeking seldom touches upon patient work concerning symptoms, and most research is done in the context of diagnostic overshadowing, and how healthcare professionals attribute somatic illnesses in relation to mental illness (Happell et al. 2016; Jones et al. 2008; McCabe and Leas 2008; Shefer et al. 2014). Research on symptoms in relation to people diagnosed with mental illness explores clinical situations of how GPs fail to discuss somatic health

with people suffering from mental health in primary healthcare (McCabe and Leas 2008). Patients' inability to report somatic symptoms is one among several factors preventing them from receiving good somatic healthcare (Phelan et al. 2001). We believe that this points to the need for further research into the perception of sensations and symptom interpretation prior to healthcare seeking. In Brämberg et al. (2018), interviews with patients revealed how patients doubted if somatic symptoms were "real" as part of their self-stigma, and how clinicians found it difficult to understand psychotic patients´ descriptions of their symptoms (Brämberg et al. 2018), but without delving further into interpretation of symptoms and their significance prior to healthcare seeking. In an ethnographic study on managing physical health in everyday life, Lerbaek et al. (2021) touch on symptoms and identify two strategies used by people with schizophrenia to manage physical health. The first strategy is to avoid discomfort and situations caused by physical symptoms. The second strategy is to retreat from everyday life in an attempt to recover, which often worsens their physical health. Lerbaek et al.'s (2021) study raises important issues, but it touches little upon how this self-management of physical health influences healthcare seeking.

Drawing on ethnographic fieldwork, we study the process of healthcare seeking in the context of the diagnostic work done by people with mental and somatic illnesses, and their approach to bodily sensations. The aim of this paper is to explore healthcare seeking by people diagnosed with severe mental illness experiences with an emphasis on how symptom interpretation, perception of sensations and diagnostic work complicates care seeking.

Theoretical framework

According to Karasz and Dempsey (2008), who studied health seeking for ambiguous symptoms by comparing two different culturally diverse communities, healthcare seeking is dependent on cultural models of health and illness which may affect how, when and with what to seek treatment. This "links" specific illnesses with specific health-seeking practices in different cultural, social and moral settings. They argue that illness representation and individual health behaviour are mediated, shaped and limited by structural and societal features, which affect the individual's access to healthcare and resources. Also personal autonomy is connected with specific values, which affect how people make healthcare decisions (Karasz and Dempsey 2008). As argued by Kleinman et al. (1978), our understanding of illness is culturally shaped and the individual´s social position influences how they understand,

perceive and present symptoms of illness. Sensorial anthropology helps us explore "*how sensations are experienced phenomenologically, interpreted culturally, and responded to socially*" (Nichter 2008:166). Hay adds to this that "*sensations form the bases of our recognition that we are well, or, alternatively, that something is wrong*" (Hay 2008). The interpretation process to distinguish "fine" from "sick" is a social transformation process dependent on social legitimisation and influenced by the cultural context shaped by our cultural knowledge (Hay 2008, Offersen et al. 2017).

Within this field of medical and sensorial anthropology and sociology, sensations and symptoms have been widely explored and been subject to several discussions on what sensations and symptoms are, their meanings and how they emerge in culturally mediated processes (Andersen et al. 2017; Eriksen and Risør 2013; Hay 2008; Hinton et al. 2008; Kirmayer 1984; Kirmayer 2008; Kleinman 1981; Nichter 2008). Most of the recent literature on sensations and symptoms has focused on the transformation process from sensations to symptoms (Hay 2008; Offersen et al. 2017). Furthermore, studies on sensations and symptoms have explored cancer patients in Denmark and Norway (Andersen et al. 2010; Seppola-Edvarsen and Risør 2017), related to delayed healthcare seeking in Germany (Brandner et al. 2017), patients with medically unexplained symptoms in Denmark (Kirmayer et al. 2004; Risør 2009), patients with post-traumatic stress disorder in Denmark (Nyboe et al. 2016), somatic symptoms related to experienced traumatic life events in Central America (Waitzkin and Magana 1997) and patients with HIV and trauma in Uganda (Meinert and Whyte 2017). Although various studies have contributed to the understanding of symptom experience, the focus on people with mental illness and how they experience and interpret bodily sensations has been limited in medical anthropology and sociology. Overall, despite increased awareness of mental illness worldwide and the higher occurrence of somatic health issues among people with mental illness, we know little about how healthcare seeking may be fashioned by social predicaments, embodied health practices, and biomedical discourses shaping the understanding of mental illness.

To capture the interpretive process and explore the experience of sensations prior to healthcare seeking in an everyday life perspective, this paper also draws upon concepts of diagnostic work (Fainzang 2018) and the role as a diagnostic agent (Oudshoorn 2008). According to Fainzang, diagnostic work is part of the subject's self-evaluation when transforming a bodily sign into a symptom, and it always involves some sort of interpretation (Fainzang 2018). Inspired by Oudshoorn´s work (2008) we also draw on the concept of the role as diagnostic agent to explore the interlocutors' everyday routines, practices and attempts we classify as invisible work done by the interlocutors when experiencing sensations.

Methods

The analysis is based on sixteen months of ethnographic fieldwork (Atkinson 2015; Marcus 2009) carried out from June 2018 to September 2019 among people who suffer from both severe mental and somatic illnesses in Denmark. The fieldwork is part of a PhD study that explores how people live and cope with both severe mental and somatic illnesses. In this study, the term "interlocutors" is employed to refer to the individuals whose perspectives, experiences, and narratives are central to the research process. While the more commonly used terms "participants" or "informants" denote individuals involved in a study, the choice of "interlocutors" reflects a nuanced understanding of the dynamic nature of the researcher-participant relationship. The term "interlocutors" emphasizes the dialogic nature of the interaction between the researcher and the individuals contributing to the study, and acknowledges that the research process involves not just passive participation, but active engagement in meaningful dialogue (Geertz 1973). By employing the term "interlocutors," the intention is to convey a sense of mutual respect, reciprocity, and collaboration in the co-construction of knowledge (Tedlock 1991; Rabinow 1977).

Design and data collection

The ethnographic fieldwork consisted of participant observation (Spradley 1980) and interviews (Kvale 1997). In terms of the recruitment process different approaches were included in the study. One approach was to use purposeful sampling (Palinkas et al. 2013) to gain access through heads of different social activity centres, supported housing facilities and registered care homes for people suffering from mental illness. Four inclusion criteria were defined in collaboration with a larger research project, of which this study is a part: 1) interlocutors had to be 18 years or older; 2) diagnosed with a severe mental illness such as schizophrenia, bipolar disorder, or severe depression; 3) not acutely suicidal; and 4) able to speak and understand Danish. Using purposive sampling, we adhered to these criteria when recruiting participants for the study. Although the focus was on somatic illness, a formal somatic diagnosis was not required, as we aimed to include participants who might have undiagnosed somatic conditions or symptoms. The majority of the interlocutors were recruited from such centres and houses. IC (the first author) called such centres and houses and explained the aim and purpose of the study, and the heads expressed willingness to establish contact

between IC and potential interlocutors with severe mental illness. Another approach to recruit interlocutors was snowball sampling (Browne 2005). This approach resulted in the recruitment of one interlocutor. The recruitment process may have been unconsciously biased since the heads of the activity centres may have selected "particularly well-suited" interlocutors for IC to speak with. However, we tried to pay attention to this during data collection and analysis. It is important to emphasize that while we actively reached out to the interlocutors, the process was also reciprocal. They had the freedom to choose whether to engage with IC, share their experiences, and invite her into their personal lives. Thus, the recruitment process was marked by a mutual selection dynamic (Otto, 1997).

In total, 22 interlocutors with mental and somatic illnesses were interviewed during two rounds. The interviews were in-depth and semi-structured (Kvale 1997; Spradley 1979). The first round of 13 interviews before the participant observation and the second round of 9 interviews after. Not every interlocutor was interviewed twice during the two rounds. The first interviews were conducted in June 2018, and explored the interlocutors' life stories, focussing on their experiences with the healthcare system. These interviews also served to find and select interlocutors who would participate in the subsequent observation study. Not all interviewed in the first round took part in the observation study since one showed out to be difficult to reach and get hold of. The second round of interviews were conducted in September 2019 with the interlocutors who 1) had accepted during the first interview to be part of the observations study, and 2) interlocutors IC got to know at a social activity centre during the observation study. Not all interlocutors were interviewed in this last round. The reasons for this were numerous: IC was unable to reach some, others were struggling mentally at the time of the interview, and some had already participated in a final conversation with IC. Apart from saying goodbye and end the relation between the interlocutors and IC, the aim of the second round of interviews was also to talk to the interlocutors about the preliminary findings, for instance data on the experience of sensations and symptoms. This gave the interlocutors the opportunity to share their reflections and thoughts about the study. However, in most cases it turned out to be difficult, and it turned out to be more a presentation of the findings than an actually discussion of them since some of the interlocutors had difficulties making these kinds of critical reflections.

The ethnographic observations were conducted among 16 interlocutors. The fieldwork aimed to provide insight into everyday life, including needs, barriers and challenges when living a complicated life and trying to manage several illnesses simultaneously. Furthermore, the fieldwork explored how the interlocutors navigated the healthcare system. IC accompanied the interlocutors in healthcare encounters, such as at somatic hospital departments,

general practices, and psychiatric departments. Through months of spending time with the interlocutors, visiting them in their own homes, participating in different encounters, IC slowly became their confidant and a trusted person in their lives. Every encounter was initiated by the interlocutors themselves and depended on their wellbeing. Overall, IC met, talked on the phone or wrote text messages with each of the interlocutors approximately once a week during a period of 16 months. IC did not spend equal amount of time with each interlocutor, nor did she develop the same relation to them since it differentiated how long time it took to establish trust between the interlocutors and IC. Overall, the study was characterized by a high degree of unpredictability. For instance, it was not possible to predict the interlocutors' state of mind and in some cases an interlocutor was admitted to a psychiatric ward, had a psychosis or could not be reached for a period of time. Therefore, planning an itinerary was not compatible with the interlocutors' lives. Instead, IC tried to "go-along" (Kusenbach 2003) with the interlocutors. This journey carried IC into a horse stable mucking out, into the room of the physiotherapist, into the closed psychiatric ward, to encounter with a neurologist, to drinking coffee in a café, to participating in a music and theatre group, to picking up medicine at the pharmacy and to participating with the interlocutors in countless encounters with general practitioners, various health care professionals in hospitals and other care persons. The explorative nature of the study called for a methodological flexibility. This approach serves as a particular contribution to the field and exploration of living with severe mental illness in Denmark.

The interlocutors

The 16 interlocutors, four men and twelve women between the ages of 27 and69, had either been diagnosed with bipolar disease, schizophrenia or severe depression, and, in addition to their mental illness, all had illnesses such as diabetes, Parkinson's disease, fibromyalgia, arthritis, heart problems, asthma, incontinence and high blood pressure. Some of the interlocutors lived in psychiatric housing facilities, others were able to live in their own homes with social service support. All interlocutors have several common characteristics, such as experiences of being hospitalised in psychiatric wards, being unable to maintain a job, receiving social security such as financial aid and being diagnosed with one or several somatic diseases. The interlocutors were informed of the study by the staff at different sheltered homes and social activity centres, and the heads of institution gave IC (the first author) permission to contact the potential interlocutors. All interlocutors provided informed consent both written and verbally.

To protect the identities of the interlocutors, pseudonymisation was employed by altering their names and omitting specific details about locations, such as city names, social facility centres, psychiatric wards, and hospitals. While the article shares the interlocutors' stories and personal details, these are presented in a manner that poses no risk of compromising their identities. Additionally, certain timeframes and dates have been adjusted, such as the duration of hospitalization in psychiatric facilities. These changes were made to safeguard the interlocutors' anonymity and do not impact the analytical findings.

Ethics

This paper stems from a PhD study that is part of the SOFIA research trial at the University of Copenhagen, which aims at reducing the excess mortality and increasing the quality of life for people with severe mental illness by improving the treatment they receive for somatic conditions in general practice (Rozing et al. 2021). The SOFIA project overall applied for ethical approval of the study to the National Committee on Health Research Ethics in Denmark, which decided that the SOFIA project was to be considered a quality improvement project (cf. journal number H-20003281). According to the Danish legislation at that time, quality improvement projects did not require ethical approval. However, the PhD study received ethical approval from the Ethics Committee at VIVE – The Danish National Center for Social Science Research. This approval ensured that the research adhered to the necessary ethical standards. Also, the study is designed and carried out in accordance with the American Sociological Association's "Code of Ethics" (ASA 2018) and the ethical principles of The Declaration of Helsinki (The World Medical Association 1964). The study is also approved by the Danish Data Protection Agency through a collective notification via the Faculty of Health Sciences at the University of Copenhagen. However, ensuring ethical conduct is not merely about producing informed consent forms and following ethical regulation. Ethnographic fieldwork is unique in its reliance on undesigned relationality, where complex relationships with participants are embraced to understand social worlds (Bell 2019; Lederman 2013, 2016). This open-ended approach, however, creates challenges in navigating institutional ethics reviews, which often require fixed roles, informed consent, and risk assessments that don't align with ethnography's fluid nature (Lederman, 2007). Caring out this research among people with severe mental illness, who are often considered to be vulnerable and stigmatized, required ethical mindfulness and ongoing consent (Pollock 2012). The study was exposed to several ethical challenges. For example, when interlocutors experienced having suicidal thoughts or was admitted to psychiatric wards. These situations raised ethical discussions about how to conduct an ethnographic fieldwork during these vulnerable life

circumstances. However, situations like these also challenged and made accounts on reflexivity in the study in term of the fieldworker´s dual roles (Bell 2019) and position and the sometimes blurred boundaries of being a friend, driver, psychologist etc. to the interlocutors and being a fieldworker with a scientific aim in mind. The "dual relations" where the researcher assumes multiple roles, is often regarded as a problem to be managed, rather than recognized as an essential part of ethnographic work that contributes to understanding different social worlds (Bell 2019). It is undeniable that IC's presence influenced the field, as some interlocutors likely attended more appointments or scheduled them only because IC was there, driving them and participating in their healthcare encounters. However, in ethnographic research, avoiding influence is not necessarily desirable, as data emerge from the interaction between the researcher, the context, and the participants (Hastrup & Ramløv 1988). The following is a simplified example from the fieldwork: While en route to a GP appointment in IC´s car, an interlocutor confided in IC about contemplating suicide due to the current mental challenges he faced. He also considered ending his wife´s life. The interlocutor believed that his wife relied on him for support in daily tasks, as they mutually supported each other with mental health issues. IC pondered the next steps, asking the interlocutor if he would share these thoughts with his GP while grappling with the dilemma of maintaining trust and addressing the seriousness of the situation. The researcher´s ethical stance was in flux as she grappled with the dilemma of disclosing a potentially impactful secret versus maintaining confidentiality simultaneously. The interlocutor opted to confide in his GP, alleviating the researcher of immediate responsibility for his actions – at least for a moment. In this example, an interlocutor shared his dark thoughts, which called for the researcher to interrogate her own biases, values, and assumptions. This position of reflexivity characterized IC's approach to the interlocutors throughout the study, and while it may have fostered an environment of trust and empathy, IC remained acutely aware of the potential implications of her actions and obligations, not least how this influenced the knowledge production of the fieldwork. Eventually, it prompted the researcher to confront the ethical complexities inherent in qualitative research, especially in prolonged fieldwork, particularly concerning the duty to protect interlocutors and other people in this example, while respecting their autonomy and trust. Ethical considerations were continuously discussed with the supervisors associated with the PhD student who conducted the fieldwork. Additionally, the PhD student participated in supervision sessions to talk through experiences during the fieldwork and reflect on the process.

Setting

The ethnographic fieldwork was carried out in Central Denmark Region. The Danish healthcare system is based on a public welfare model with the principle of all citizens having equal rights to care and free social services. Healthcare and social services are free of cost and are subsidised and financed by Danish tax revenues (Rostgaard 2015). The Danish healthcare system is divided into a primary and a secondary health sector. Both sectors provide treatment and care for people diagnosed with mental illness, but are differentiated since the primary sector provides treatment for mild to moderate mental illnesses, whereas the secondary sector treats severe mental illness. The secondary sector provides treatment in different settings, such as the regional psychiatric care, outpatient units and other mental health centres. All citizens refer to a specific GP or general practice clinic, which provides care for somatic symptoms and diseases (Davidsen et al. 2020) and which may refer, recommend and give access to specialised treatment in the secondary sector. In general, the Danish welfare system is divided between somatic healthcare and psychiatric treatment and care. Despite several initiatives to enhance the collaboration between the two sectors, this dualism between mind and body is still evident.

Data analysis

The data material consists of fieldnotes, which were written after every encounter with the interlocutors. Furthermore, data consist of transcriptions since all interviews were recorded and transcribed afterwards. We used the data management program NVivo 12 to code all data, and all data were read thoroughly for content. We used an inductive bottom-up approach in the beginning of the coding process. The first step was an open coding, the second step a systematic coding which was based on themes and patterns found in the empirical data, and the third coding step was an interpretation of the empirical findings, based on developing theoretical inspirations and concepts (Mason 2018). NVivo helped to create basic in-text codes and identify patterns and meanings in the data, without imposing predefined structure or theoretical framework. NVivo is specifically well-suited for inductive analysis, building up e.g. code trees from verbatim words, terms and sentences of the data. Especially during the third coding step and in the final interpretations, we used an abductive approach. Here we aimed at finding empirically based theorizations (Timmermans & Tavory 2012) by moving back and forth between the empirical data and theoretical concepts to create theses and qualified suppositions.

Findings

"You can have mentally broken bones in your body" – patients´ experiences with overlapping symptoms

Mikkel, a 65-year-old man diagnosed with schizoaffective disorder with depression-like symptoms, stated during an interview that "*as mentally ill you are not quite as reliable with your symptoms*". He explained further:

"*My GP took a long time to recognise that I had Parkinson's. And they also had a lot of difficulty with that in the psychiatric hospital. But I pressed on. But after I got the diagnosis, then all symptoms are symptoms of Parkinson's. ´My bad disease´, as he (GP) says. It means that for 3-4 years I have been coughing up a lot of mucus, without getting any treatment for it. And I wondered if there was something wrong with my lungs, but he just brushed it off. Because now it was Parkinson's. But then I went to a health interview offered by the municipality, and they finally found out what was wrong. Now I finally get asthma medicine and it has helped*" (Mikkel).

This quote touches on several important issues. First, living with several illnesses simultaneously and having an "*interplay of mixed symptoms*", as Mikkel also described it, made his perception of sensations and symptom interpretation complicated. Second, it testifies to the delayed diagnosis people with mental illness experience related to somatic illnesses (Behandlingsrådet 2023), which in Mikkel´s case only succeeds due to his own ability to push towards further unravelling of his condition. In the following, we will see how "reading sensations" can be complex and can hamper the process of unravelling of one's condition and healthcare seeking when living with severe mental illness (Hay 2008).

When IC met Pernille for the first time in 2018, Pernille had been diagnosed with bipolar disorder for 10 years. She had knowledge of the disorder because she had grown up with a mother who had bipolar disorder. Pernille was trained as a nurse and had worked until she suffered adverse depression and stress, and spent the next 10 years going in and out of psychiatric wards. Her young daughter was sent to a foster family because Pernille was not able to look after her. Ten years later, 50-year-old Pernille, who was also diagnosed with depression, anxiety and diabetes, was living in her own apartment with home visits from her social worker two times a week aside from monthly visits at the

outpatient clinic. Pernille and IC met at a social activity centre for people with mental challenges. Pernille spoke about her life in general, and she revealed how difficult she thought it was living with daily "symptoms", which was her choice of word for the constant bodily experiences she felt. Pernille talked about her symptoms as if they were clinical realities, but in fact Pernille rarely went to see her GP. On a daily basis, Pernille experienced bodily anxiety, restlessness, stomach pain and rapid heartbeat to mention a few, and from time to time they grew in intensity and amount, and Pernille experienced choking sensations, fever, feeling overwhelmed, feeling lonely, body shaking and seeing flies everywhere.

One day at the activity centre, Pernille showed IC a list, where she had written down her symptoms. The list was made with support from her social worker (picture 1):

Picture 1
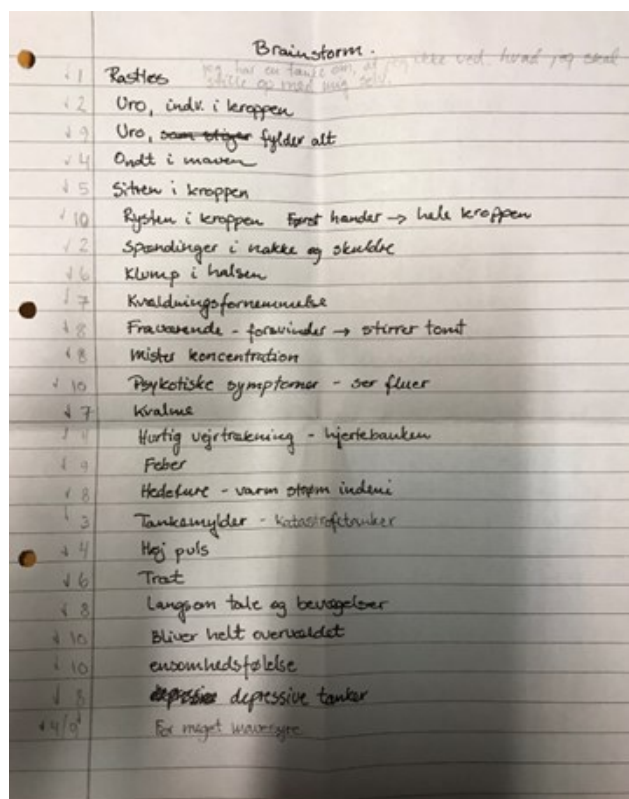
Picture 1 contains the list of Pernille´s experienced symptoms. All symptoms are numbered after their level of paramount importance. For instance feeling "restless" is numbered 1 as being of low importance.

Pernille´s brainstorm of symptoms includes:

Restless, internal restlessness, trembling in the body, shaking in the body, tension in the neck and shoulders, lump in the throat, sensation of choking, absent gaze, loss of concentration, psychotic symptoms such as seeing flies, nausea, rapid breathing, palpitations, fever, hot flashes, racing thoughts, high pulse, fatigue, slow speech and movements, feeling overwhelmed, loneliness, depressive thoughts, and acid reflux.

Looking at Pernille´s list of her symptoms it became obvious why she felt her everyday life was unbearable. Being alone when suddenly experiencing choking sensations, heart pounding and pulse rising, it was understandable how afraid Pernille was. The list was also an example of Pernille´s continuous "chronic homework" (Mattingly et al. 2011) she carried out to visualize and clarify her daily sensations. The concept "chronic homework" (Mattingly et al. 2011) in this context refers to the duties and tasks people with mental illness do in their home on an everyday basis. According to

Pernille, she had struggled with anxiety since the age of seven when "*it became a part of*" her. Pernille was afraid to suffocate and die alone, and her "*fear of anxiety*" reinforced and resulted in her body being on constant alert. Pernille was fully aware of her anxiety and bipolar disorder potentially having physical expressions, however she experienced her bodily and mental sensations as infiltrated in a web, interacting, overlapping and chained together. With Pernille´s own words, her symptoms were "*a spiral*". Pernille used the term when explaining her thoughts about her symptoms as a contentious process of sensations leaving her unable to interpret which sensations were "normal" sensations related to somatic illness or potential signs of one, or physiological expressions of her anxiety rising. According to Hay, "*sensations never start as symptoms. They only become symptoms post-hoc, after an interpretation that they are abnormal*" (Hay 2008). But what is an abnormal symptom when one lives with bipolar disorder? The fine line between being sick and being well, and the distinction between sensations having either normal or abnormal physiological experiences, are put to the extreme when a person has a mental illness. What are abnormal physiological experiences when one experiences fever, fatigue or anxiety on a daily basis?

Insights into the life of another interlocutor Maiken, a 50-year-old woman diagnosed with schizoaffective disorder, anxiety, autoimmune disease lupus and asthma, may illustrate another interpretative process. Maiken was diagnosed with schizoaffective disorder when she was young, and for as long as she can remember, her mental health had always been challenged. Similar to Pernille, Maiken experienced various bodily sensations daily, and it became obvious to IC that Maiken was in daily pain. When they went for a walk, Maiken had substantial pain in her feet, knees and hip. She did not complain or make a fuss about it, she just began to limp. Mile after mile. Furthermore, Maiken experienced different symptoms in relation to her stomach. It was sore, felt unpleasant, bloated, was hard as stone, and sometimes she suffered from constipation. This was the case during the 16 months of fieldwork, but Maiken´s stomach was always a sensitive subject of conversation. When IC asked Maiken about her sensations, she said that they were part of her "*body capacity*". It became obvious that Maiken thought it was difficult to deal with her body, to relate to it and talk about it, especially her stomach – but not her mental problems or diagnosis, since she happily explained and talked about her schizoaffective disorder. She revealed that she had difficulties feeling her body or allowing herself to feel the stomach pain. Sometimes she fantasised about stabbing a knife into her stomach to release the pain: "*It has to do with my body and my absent body. Maybe it has to do with me actually not wanting to feel my body*". The quote is noteworthy since it described Maiken´s thoughts about her "*absent body*", and her ability or perhaps strategy to attend to her bodily sensations without them becoming of paramount importance in her everyday life, which draws

attention to Leder's work on phenomenology of the body. He argues that we often prefer that the body and its functions remain "absent" since the body in itself is not an object but rather we are a body from which we shape our experiences of the world (Leder 1987).

Talking with the interlocutors about what they did in their daily life when experiencing various bodily sensations, they often used statements such as "*I will try to assess it*" and "*I just wait and see*". It was notable across all interlocutors that they used much time and effort assessing and interpreting sensations prior to healthcare seeking. They assessed sensations and then waited. Time passed week after week, month after month, and the assessment continued as daily chronic homework (Mattingly et al. 2011) that each interlocutors carried out at home in an attempt to assess and interpret sensations. Time was not only spent interpreting sensations but to a great extent on distinguishing, classifying and trying to categorise bodily signs, sensations and symptoms into either mentally or physically related symptoms. "*You can have mentally broken bones in your body*", as Maiken phrased it to explain how her sensations interacted and were not easily separated. It became obvious that all interlocutors experienced their sensations as a unity. In Pernille´s case, it seemed as if she had learned to separate her sensations at least to a degree that made her able to control and manage her sensations in her everyday life, but it was a big task and was not easily done.

"I am not able to understand or communicate that I need help" – patients struggling to speak about symptoms

Sensations are felt embodied experiences and for sensation to become a symptom normally requires a socially constructed interpretation and transformation process (Hay 2008). For sensations to be symptoms the symptoms must be socially legitimated through social interaction and negotiations with others (Hay 2008). As argued by Waxler (1981) and Hay (2008), people typically talk with friends or family about their experienced sensations, share concerns and compare sensations prior to seeking healthcare. Communicating sensations and putting bodily experiences into words, helps the process of altering often vague and indefinable bodily sensation into something more tangible, a symptom. A symptom that has the potential to become a diagnosis (Hay 2008).

People with severe mental illness experience more loneliness and social isolation compared with the general population. They often have smaller networks, fewer friends and less family (Koenders et al. 2017). The interlocutors in this study follow that pattern, as most of the interlocutors' lived alone, experienced loneliness, had few friends, had limited social networks and troubled or broken family ties.

Pernille did not negotiate sensations with family or friends. She lived alone and had limited social contact beside her social worker and staff affiliated with the social activity centre she visited a couple of times a week. She was aware that her sensations might infiltrate and interact with each other, but still, she had trouble grasping them fully and evaluating them. Pernille´s daily sensations often resulted in her calling either her GP or the medical emergency services. Pernille went to the accident and emergency department several times because she thought she was having a heart attack, was choking or had a blood clot. On the advice of a social worker, Pernille had started attending an anxiety support group where she received help from professionals to deal with her anxiety in several steps. The first step was for Pernille to describe her bodily sensations and put them into words, write them down in an order depending on which sensations she felt first. This is also another example of the chronic homework (Mattingly et al. 2011) Pernille carried out and resulted in the "anxiety scale" (picture 2), which started with Pernille becoming restless, and gradually intensified until it felt vital and progressed to psychotic symptoms and paranoid illusions. The second step comprised strategies for what Pernille should do when experiencing the sensations, for example she could focus on her breathing, go for a walk or try different activities to distract her thoughts (picture 3). Also, Pernille could think alternative thoughts, such as "it is not dangerous".
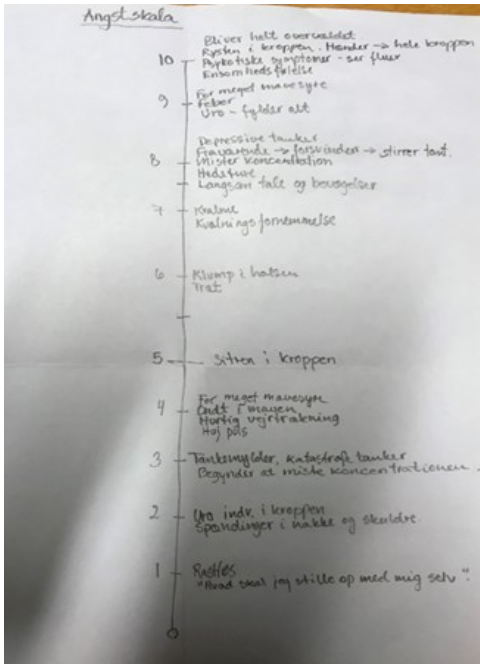
Picture 2   **Picture 3**
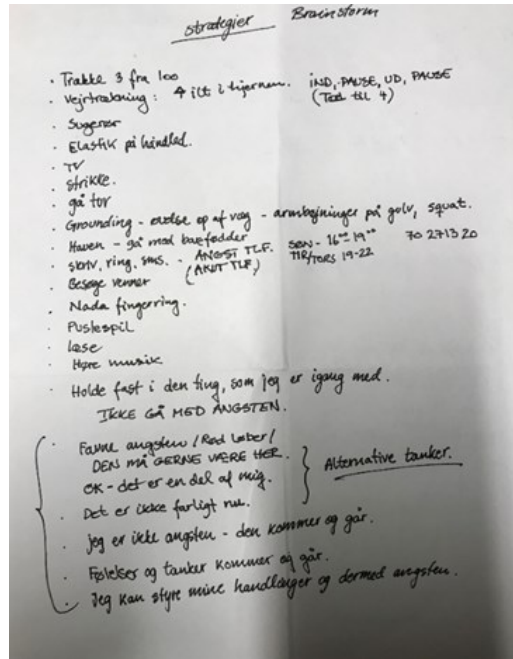
Picture 2 illustrates Pernille´s anxiety scale. Her symptoms are listed in the order they arise starting from the bottom (restlessness and racing thoughts) and up (Feeling completely overwhelmed, body shaking, and depressive thoughts).

Picture 3 illustrates Pernille´s strategies when experiencing anxiety such as:

Subtract 3 from 100, breathing exercises, drinking straw, elastic band on the wrist, watching TV, knitting, taking a walk, walking barefoot in the garden, visiting friends, NADA finger ring, puzzles, reading, listening to music, calling the emergency hotline, thinking alternative thoughts such as embracing the anxiety, it's a part of me, it's not dangerous now, I am not the anxiety, emotions and thoughts come and go, and I can control my actions and thus the anxiety.

According to Pernille, both the anxiety scale listed with her bodily sensations and strategies she could

follow helped her to live with the daily sensations. She explained it as follows:

"If I feel anxiety, maybe I have, for example, a tingle around my mouth or tongue or in my right

foot. Then I know 'Okay, now I have had it so many times that now I know it is not dangerous'. It

has to do with the fear of death, and the fear of illness, but it is important to first notice and be

aware of the symptoms and then afterwards think 'Okay, now you know what it is. Then you try

to take the tools you have been given in the group and see if you can get rid of it or at least reduce it'" (interview with Pernille).

This is particularly relevant for our study since it indicated that Pernille over time "learned" in interaction with the anxiety group to interpret and distinguish her sensations. As argued by Hay, sensations are ignored if one interprets them as having normal duration, as tolerable disability or they fit with one´s self perception of vulnerability (Hay 2008). If sensations are not interpreted as such, sensations become worrisome and call for social legitimation to be established as a symptom. As Hay phrases it "*interpretations become stabilized through feedback loops*" (Hay 2008:223). However, Pernille´s "learning" to distinguish sensations seemed different than the one proposed by Hay since Pernille was not able to "ignore" sensations on her own nor were her sensations socially legitimised by friends and families. The group sessions worked to some degree as a social setting giving Pernille a possible relation to interact with and respond to.

In contrast to Pernille, the interlocutor Maiken lived with a partner, Jens. They had been a couple for more than 25 years, which they explained was "*against all odds*". Jens suffered from paranoid schizophrenia, and they met for the first time, when they were both admitted at the same psychiatric ward. Both Jens and Maiken had difficulties putting their bodily sensations into words. It was even more difficult explaining them to each other. As a result, they simply did not. Instead, they knew each other's signals, routines and habits. When Maiken walked around the city centre for hours day after day, Jens knew Maiken was not feeling well. He knew that Maiken was trying to "escape" when Maiken borrowed books at the library, after which she read for days in a row, in solitude. Maiken herself, called this a "strategy" when she was not feeling well. When Jens drew the bedroom curtains, went to bed for four to five days, did not shower or brush his teeth, and pulled the duvet over his head, Maiken knew he had problems. Jens did not need to say anything. Sensations were not exchanged verbally between them. Instead, it seemed that Maiken and Jens could "read" sensations and their manifestations coupled to what they meant to each other and how they each managed getting through overwhelming bodily sensations. Instead of talking to each other, they reacted to one another to manage through mutual efforts. Maiken and Jens did not directly take part in each other's legitimation of sensations, but they still helped each other in difficult times, and they influenced and affected each other's being-in-the-world. They knew when something was off, when they struggled individually with "something" unidentifiable for them. The partnership between Maiken and Jens, and their ability to see each other's sensations, formed a special relation

between them, of love and belonging, but also seemed to form and re-invent a sociality and kinship between them that reinforced their ability to manage and cope with both their own and each other's sensations.

Similar to Pernille, Maiken reached out to professionals in her everyday life. Maiken had weekly conversations with her contact person, who was a great support for Maiken, and they talked about issues and strategies on how to cope with everyday life. Discussion of symptoms was not the centre of attention during their conversations, but occasionally Maiken spoke with the contact person about a consultation Maiken had had with her GP, and the contact person asked Maiken questions about it, such as "*what did your GP say was the next step*?" or "*What did your GP advise you to do?,*" but taking part in the interpretative process and socially legitimising sensations was minimal.

Despite experiencing various symptoms, both Jens and Maiken were reluctant to seek healthcare. In fact, most of the interlocutors in this study thought this was difficult. Taking initiative was associated with anxiety about the encounter and the potential risk of not being taken seriously, fear of being labelled, doubting one´s body, and fear of not being able to express what was wrong. Therefore, daily symptoms did not necessarily lead to healthcare seeking. As Maiken said: "*I am not able to understand or communicate that I need help*".

As shown, the interlocutors in this study did not negotiate sensations with friends and family prior to healthcare seeking. Instead, most of their diagnostic work was carried out alone, or as nonverbal recognition between partners. Also, sensations were on some occasions recognised by health professionals, but even then negotiation was limited. From the first tenuous bodily sensation to the point of healthcare seeking, several months had usually passed with interlocutors experiencing worries and suffering. It was not uncommon for the interlocutors to experience sensations for 3-6 months prior to healthcare seeking despite the fact that they had done great amounts of chronic homework and diagnostic work to interpret symptoms. Seeking healthcare was still a barrier to overcome.

"It is just psychosomatic" - patients' experiences of not being taken seriously

While driving to an appointment at Mikkel's doctor, IC and Mikkel spoke about the upcoming appointment and Mikkel showed IC a piece of paper with detailed questions he had prepared. The encounter between Mikkel and the doctor was observed by IC, who noted that Mikkel had not asked the questions he had prepared. When

IC asked Mikkel why he had not asked the questions, he was unable to give a reason. Several interlocutors reported similar preparations prior to an encounter, but questions about physical health and symptoms were rarely put into words. Reasons for this may be attributed to healthcare professionals´ non-recognition of somatic illnesses in patients who suffer from mental illness (Happell et al. 2016). Happell et al. (2016) argued that patients with mental illness were often uncertain about talking about somatic issues in the somatic healthcare system because they experienced they were rarely believed, because healthcare professionals ignored or questioned physically related problems and because it was difficult to get assessments or screening. Similar tendencies are found in our study, for example, the interlocutor Jens experienced healthcare encounters as follows: *"No matter what I come with, well, is it just psychosomatic"*.

Jens was not the only interlocutor using this exact word. "*Psychosomatic*" was frequently used by the interlocutors to describe the situations when healthcare professionals attributed symptoms to their mental illnesses. Jens further explained *"I sometimes think that some of my physical symptoms, when I go to the doctor with them, that I have a hard time getting through. They shrug it off… all down to two things. Now I'm overweight, as you can see, so they either end up labelling it as being overweight or psychosomatic"* (Jens).

The interlocutors´ experience with the word "*psychosomatic*" carried a negative connotation when they used it to describe the situations where they felt symptoms were not taken seriously as sign of potential illness and were ascribed as side-effects in relation to their mental illnesses. All interlocutors shared stories about not being heard, being treated differently and inadequately both in the somatic and psychiatric healthcare system. "Diagnostic overshadowing" is a term used to describe the processes by which healthcare professionals – acting intentionally or unintentionally – give patients with mental illnesses inadequate, delayed and differential treatment on account of the attribution of somatic symptoms to their mental illness (Happell et al. 2016; Jones et al. 2008; Shefer et al. 2014). As the term implies, mental illness potentially overshadows somatic illnesses or signs of one. All interlocutors shared stories about how their mental illness interfered with the diagnosis of potential somatic illness in both the somatic and psychiatric healthcare system. Their stories were emotionally intense and surprisingly numerous in our data. Some experiences served as very severe cases of overshadowing, a matter of life-and-death and were of paramount importance for the interlocutors' negative experiences of "the system". Overshadowing is often related to words being misunderstood, and the choice of words being ascribed to their mental illnesses:

"I tried to explain my suffering to my GP as ´it tugs and pulls inside´. One month after, I find out that he (the GP) had not assigned it as physical pain. Then I was just devastated and shocked. What does it mean that something tugs and pulls inside? Is that not painful? It is correct… I did not say painful or suffering in that context, and then my GP did not interpret it as physical pain" (Hanne).

Hanne was not the only interlocutor with these experiences. Certainly, not only people suffering from mental illness find it difficult to perceive sensations and distinguish "fine" from "sick "(Hay 2008), since most people may find it difficult to distinguish between sensations and symptoms. We argue here that people with mental illness phrase and talk about sensations and symptoms in a particular and special way that is affected by their social relations, their everyday life with social isolation and limited sharing of concerns on symptoms, which in turn seems to affect and complicate healthcare seeking. They experience blurred, diffuse and constantly changeable sensations that leave them with limited possibilities of having them interpreted culturally or responded to socially (Nichter 2008). The individual negotiation of sensations, isolated and with limited social contact apart from a wide range of healthcare professionals, makes them hesitant to seek healthcare and complicates presentation of symptoms in clinical encounters. These experiences and embodied knowledge are mediated and sharpened by the continued mind-body dualism within the biomedical context, which is illustrated by the organisation of the healthcare system and the division between somatic and psychiatric healthcare (Lerbaek et al. 2021). Despite the fact that distinguishing sensations and symptoms into either mental or somatic symptoms does not make sense for people suffering from mental illness, they are aware of the necessity to do so as diagnostic agents to get access and receive proper treatment. In other words, they have to "make up their minds" before they initiate contact and seek treatment.

Conclusion

In this paper, we have explored and discussed healthcare seeking for people diagnosed with severe mental and somatic illnesses and their experiences with how perception of sensations, symptom interpretation, and diagnostic work complicates their healthcare seeking. First, we focused on how sensations appear in everyday life, and the amount of various bodily signs and sensations they feel and experience on a daily basis. They perform chronic homework (Mattingly et al. 2011) to assess and interpret bodily sensations that are experienced as overlapping and

infiltrated, not easily distinguished. Second, we explored how people with mental illness engage in a different interpretation process in contrast to Hay's (2008) argument that sensations are socially legitimated through social interaction. Due to social isolation and limited social ties and relations, most of the diagnostic work was done alone, or as a non-verbal recognition between kindred spirits. Occasionally, health professionals were used to recognise and legitimise specific symptoms of illness, especially those health professionals who acted as care persons at support units. Third, we showed how the interlocutors prepared questions prior to encounters in the healthcare system, but struggled to ask them and to communicate their sensations to healthcare professionals. As diagnostic agents they struggled to "make up their mind", to classify and distinguish symptoms into manageable categories, which seemed to delay their healthcare seeking.

Perception of sensations and symptom interpretation were complicated and time-consuming in the sense of the interlocutor´ constant attention and reflection towards sensations and signs from their bodies. Challenges in distinguishing and interpreting bodily sensations are well-documented among various patient groups, including socially disadvantaged individuals (Merrild et al. 2017), cancer patients (Andersen et al., 2010), and those experiencing medically unexplained symptoms (Kirmayer et al. 2004; Risør 2009), who face similar challenges in the interpretation processes and recognition of potentially severe or alarming symptoms. The almost non-existing social negotiation of sensations affects how and when people diagnosed with severe mental illness seek healthcare, and their challenging chronic homework and diagnostic work is time consuming and may delay healthcare seeking. Moreover, the interlocutors´ healthcare-seeking practices, mediated and shaped by the social structures within the healthcare system (Karasz and Dempsey (2008), seem to affect not just their symptom interpretation process, but also their challenges with expressing and communicating symptoms in medical encounters. Still, the interlocutors have learned the "approved" way of being ill and seeking treatment, navigating the healthcare system in an attempt to seek either somatic or psychiatric treatment. The attempt to fit into the systemic organisation of the healthcare system can be understood as them trying to be morally competent "good citizens," who take responsibility for their own health and wellbeing (Offersen et al. 2017). Their year-long illness trajectories as patients navigating a sectionalised and fragmented healthcare system have provided them with an awareness of the necessity to follow the right path to receive proper treatment. However, even if they "make up their minds" to seek healthcare, they risk being met with diagnostic overshadowing and reductionist clinical approaches. Because somatic illness is underdiagnosed and undertreated in patients suffering from mental illness, healthcare professionals need to be aware of and recognise the crucial process

of patients' perceptions of bodily sensations and symptoms that exists prior to healthcare seeking. If we wish to reduce the health inequalities in somatic treatment of patients with mental disorders, it is important to acknowledge the importance of a holistic approach in the organisation and treatment of patients with both somatic and mental illnesses, and not just leave it to patients to "make up their minds".

Author Contributions

The ethnographic fieldwork was carried out by IC, the first author, as part of her PhD study. All authors contributed to the study conception and design. IC wrote the first version of the manuscript. All authors collaborated on developing the analyses and argument of this article, commented and wrote on previous versions of the manuscript, and read and approved the final manuscript.

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