

Responsibilities of Risk

Living with Mental Illness During COVID-19

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Responsibilities of Risk: Living with Mental Illness During COVID-19

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ABSTRACT

Following the COVID-19 pandemic, Denmark introduced repeated lock-downs of society, including outreach services and visits from social workers for people living with mental illnesses. Based on ethnographic fieldwork, in this article we explore how people with mental illness react to and manage their lives amid COVID-19 mitigations, focusing on how they experience and negotiate vulnerability at personal and community level. We argue, that the subjective management of restrictions implicated in their personal lives notions of risk, vulnerability and agency, and shows a diversity and heterogeneity of responses to the pandemic that allowed the mentally ill to perform good citizenship.

KEYWORDS

Denmark; mental illness;
COVID-19; risk; vulnerability;
citizenship; personhood

It [COVID-19] is not particularly dangerous to me, I'm young, or should I say not *old* (laughing). But it's important that all of us act responsible and take care of the vulnerable, like my 80 years-old neighbour. Linn, 37, diagnosed with schizophrenia.

Matters of life and death are, if not daily life struggles for everyone all the time, fundamentals of being human and dealing with existential issues and challenges. These matters often come to the fore when illness, natural catastrophes, or sudden accidents happen. Ordinary individuals are hit hard and affected at a personal level, as each one of us tries to manage a way of making things bearable and perhaps controllable; to survive or to struggle along. Anthropology has contributed substantially to the understanding of individual experiences and narratives of crises in life, such as chronic disease, death, war, and disrupted relations (e.g., Manderson and Smith-Morris 2010; Martin 2009; Mattingly and Garro 2001). However, such matters cannot be understood solely from an individual perspective, nor can their causes (Manderson and Wahlberg 2020; Singer and Ryko-Bauer 2021). Experiences of crisis encompass structural dimensions and social determinants, which also need to be brought into the picture. *Structural vulnerability* is a term that encompasses not only politico-economic forces, but also social and cultural forces that influence individual lives, disease, and distress. Structural vulnerability points to what constitutes suffering and is a framework for understanding suffering beyond personal conditions (Quesada et al. 2011). With this term, we may speak of the production of vulnerability as a result of social hierarchies, discourses on normativity, and social exclusion derived, for example, through a medical diagnosis. Structural vulnerability is produced by certain social and cultural orders (Quesada et al. 2011) that may change or be restructured.

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Media teaser: We argue that lock-downs during the pandemic created new notions of vulnerability in Denmark, affecting people with mental illness in both positive and negative ways.

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Medical anthropological investigations of mental illness have included suffering and the conditions that cause it in discussions on vulnerability. On the one hand, suffering is given attention both as an existential ground of human experience and as a social phenomenon (e.g. Biehl et al. 2007; Jenkins 2015; Kleinman et al. 1997), which constitutes a focus on what matters and is at stake in peoples' lives. On the other hand, the social, economic and political conditions of adversity that mediate and inform suffering and create positions of vulnerability are crucial to understanding specific social formations of subjectivity (Biehl et al. 2007). Jenkins (2015) makes a strong case for this, pointing to conditions such as warfare, political violence, domestic violence, trauma, abuse, scarcity, and discrimination, while also engaging with complex struggles of healing, social engagement and just living or working despite mental illness and the weight of diagnostic predicaments and socio-structural forces. Others have explored notions of diagnostic classifications and their internalisation into individual lives, their meaning and context, such as bipolar disorders that may be seen as mediated by specific cultural models of production and activity (Martin 2009). Rose (2019) offers a critical view on psychiatry itself and its role in defining mental distress, questioning psychiatric diagnosis, and the role of neurology and brain disease ideologies, while all the time advocating the link between mental illnesses and social factors such as poverty. The issues of interest and urgency are many, and both political economy, social theory and subjective experiences intertwine. According to Kleinman (2012), this intersection engenders the need to pursue specific questions in the future: to investigate how social suffering and illness overlap, to go beyond stigma, to explore global pharmaceuticals, to highlight caregiving for mental health, and to reframe science and society in the light of the dominance of new neurobiology. Following this, ways of struggling, reacting, and trying out life, rather than explicit manifestations of mental illness, are more central to our analysis, as is attention to how the COVID-19 context complicates notions of vulnerability, risk, agency and alterity.

We take as our point of departure Luhman's call for recognizing the existence of mental illnesses in very distinct and diverse forms that influence daily life in different ways, yet acknowledging the unhappiness and disturbance it often brings (Luhmann 2000:12). Our interlocutors live with what are diagnosed as schizophrenic or bipolar disorders, so we focus here on the forms of mental illnesses that require medical treatment, often lifelong, which leave footprints of humiliation and struggle in most aspects of our interlocutors' lives.

In the spring of 2020, our ongoing fieldwork was (as for so many others) suddenly interrupted, and the pandemic added new perspectives of risks and responsibilities to our interlocutors. In this article, we consider the COVID-19 pandemic from the perspective of our interlocutors, beginning with a discussion about how the implementation of restrictions, such as social distancing, reveal both well-known and new structures of vulnerability (Team and Manderson 2020). Specific groups, such as the elderly and those with severe, chronic, somatic diseases, quickly seemed to be affected hardest by the virus itself, perhaps exaggerating more than defining a *new vulnerable* group. Other more structural issues (also not new) became visible, for example, in terms of poor and overcrowded housing. The politics of housing meant that groups of immigrants, indigenous populations, pensioners, students, and people with disabilities were more easily exposed to infection even though they tried to adhere to regulations. There are many examples in popular news media in Denmark of immigrants being criticized for their lifestyles and living arrangements, which were assumed to contribute to the spread of the virus (see also Dionne and Turkmen 2020; Onoma 2021; Team and Manderson 2020, for international perspectives). This unfair scapegoating ignores structural vulnerabilities and the positions these groups are ascribed due to economics, allocated physical space, and social hierarchies and norms. New vulnerabilities occur too, as we are reminded by Napier (2020), and in this COVID-19 pandemic we need also to look, for example, at people working in service industries and health care, at prisoners and at long-stay hospital patients, who are exposed just by being where they should be, but find themselves in circumstances of unexpected vulnerability.

Following the pandemic, Denmark introduced repeated lock-downs (40 days in 2020, and 40 days during the winter 2020–21), in which all public life, schools, work spaces and non-acute services were sat on hold, including outreach services and visits from social workers for people living with mental illnesses. When society was not locked-down, restrictions were implemented, depending on the number of COVID cases. These consisted mainly of social distancing, requirements to wear facemasks, and a limit of the number of people who could assemble, forcing most social services and meetings to be online.

Compared to other countries in the Global North, Denmark has had a relatively mild pandemic. As of February 2022, 2.4 million Danes have been infected, and 4109 have died with (not necessarily of) a confirmed COVID-19 infection. All citizens above the age of 5 are offered free vaccination (two doses for those under 12 years, three doses for those over 12); 80% of the population has received second dose, and 61.5% has received the third dose, with vaccinations still ongoing.¹

It is argued that Denmark has managed to get through the COVID crisis relatively well because of the population's confidence in the government and their handling of the crisis, and a willingness to change behavior as the pandemic developed (Lindholt et al. 2021). The evocation by the Prime Minister to show community spirit, and the Danish queen's injunction to "stand together but apart" has reverberated throughout the country and created a common national task, speaking to each person's moral responsibility. This has been visible in the recognized need to protect "the vulnerable" whom, in Danish media, have mostly have been limited to the elderly, despite research showing both somatic and mental diseases to increase the mortality risk of COVID-19. Our interlocutors, as well as most Danes, have reproduced popular media's focus on protecting older family members, and particularly considered the well-being of the older population in general. Hence, our interest was on understanding vulnerability from the perspective of our interlocutors, and the extent to which subjective experiences and perceptions, in the context of the pandemic, may have mediated and complicated aspects of vulnerability, risk and agency. Being dependent on policies of care, subject to social norms concerning illness reputations, and suffering existentially, places our interlocutors at the margins and makes it relevant to think of them in terms of structural vulnerability. At the same time, if vulnerability is a position, we may also find ways of reacting to this position and negotiating it. As Whyte reminds us: "Humans are never merely victims of fate: despite the possibility of complete certainty, we actively attempt to create a degree of security or insurance" (Whyte 1997:18).

When confronted with the risk of either contracting COVID or passing it on to others, our interlocutors reacted just as people without mental illnesses; they reflected on how best to manage the risk of infection for the greater good. They responded to risk both emotionally and creatively; at times they were in despair, feeling the absence of touch and hugs, not least when their social services had been transferred online, but, trying to keep their mood up and show community spirit as encouraged by the prime minister, some joined the national singing movement to cheer up fellow citizens. They also demonstrated competency in understanding health information, drawing on years of experiences with health services. As such, both old and new competencies were drawn upon and developed when matters of life and death were at stake. At one level, people may feel aspects of risk, specifically the risk of being infected or of infecting others; but more fundamentally, the risk and uncertainty of what the future may bring and how their lives may end up without, for example, intimacy. At another level, all people manage and adjust as best as they can to avoid risk (Steffen et al. 2005:9), even though they are limited by resources, networks, and living circumstances. At a third level, they may seem to negotiate their position in society. This we find to be particularly relevant to people living on the margins owing to their mental health state, as a crisis like the COVID-19 pandemic may have the potential to instigate changes to their positions in society. All three levels permeate the lives and reactions of the people with mental illness in our study, allowing for further exploration of concepts such as risk, agency, and personhood. Their reactions and

struggles may not change the political economy of mental illness, care policy or neurological ideologies, but they may challenge and meliorate social hierarchies, social positions, and, not least, the “biomedical embrace” and its power of definition (Good 2001).

Our argument, then, is that with the COVID-19 pandemic, vulnerability is translated and negotiated by people with mental illness in ways that may allow for alternations in citizenship and personhood.

Methods

This article builds on fieldwork interviews with people living with mental illness during the coronavirus outbreak and the subsequent national lockdown of society in Denmark. Our interlocutors are part of a large ongoing study, SOFIA² (Rozing et al. 2021): a randomized controlled trial, which aims to improve the treatment of comorbid somatic conditions in people with mental illness. The SOFIA study is investigating enhanced educational training of general practitioners and their clinical staff, incorporating strategies to change health practice to better accommodate patients with a psychiatric history. This includes longer and holistic consultations with a focus on both quality of life and disease management, and an individualized care plan, considering treatment priorities and the patient’s needs and personal circumstances. Part of the study was to investigate the everyday lives of people with mental illnesses and their encounters with social and health workers. To do so, two authors, Jønsson and Christensen conducted ethnographic fieldwork over a two year period, visiting, interviewing, and participating in the everyday activities of 14 interlocutors recruited through general practice or regional psychiatrists who initiated the contact. Beforehand, these health professionals had screened participants for eligibility ensuring that they would be intellectually able to participate in the study. The fieldwork took place in three of five Danish regions; North, Zealand and Capital Region, and also included observations in psychiatric wards, in general practice and the out-going team of regional psychiatry. Interlocutors are adults (between 25 and 62 years), diagnosed more than ten years ago with schizophrenic and/or bipolar disorders, but who still rely on medication and treatment in the out-patient clinics. All have been hospitalized for longer or shorter periods. All are cognitively well functioning, despite some experiencing episodes of delusions, self-harm, anxiety attacks and other challenges owing to their mental disorders. They all live in rental apartments assigned by the municipality and get weekly visits from the out-going regional psychiatry. Most interlocutors have been granted an early retirement as the municipality had assessed them unable to work, but a few applied for reduced hours work (in which municipality grant financial aid for the hours that the person are not working), and some volunteered as peer-supporters for other, more recently diagnosed, patients. Three of our interlocutors were in a relationship, the rest lived alone and had only limited contact with family members owing to issues often relating to drugs, sexual abuse or other forms of neglect during childhood.

Immediately following lockdown, interlocutors were contacted by phone and, if they agreed, were interviewed every other week during the lockdown online or on the phone. These “corona interviews” were conducted with a particular focus on isolation, relations, disease management, experiences and uncertainties in everyday life, and contact with health and social care professionals. If they agreed interviews being audio recorded, they were transcribed verbatim. Otherwise, researchers’ notes were added to the data. All interlocutors have been anonymized and identifiers have been altered to ensure anonymity.

Combining the ethnography from the ongoing fieldwork with the phone interviews, case descriptions were made for each interlocutor. In this article we focus on five interlocutors who represent different views and experiences of the lock-down, but wider material from the SOFIA study offers ethnographic context, and all interlocutors’ experiences have guided our analysis.

Living with mental illness in Denmark

People with mental illness comprise about 2% of the Danish population (Vive 2018). This is a heterogeneous group whose members do not necessarily have anything in common but their diagnosis. Further, local and cultural contexts influence diagnosis and may even lead to misdiagnosis (Good 1997). Yet, when we talk about mental illness in this article, we speak of people who have been diagnosed with, and are currently being treated for, a schizophrenic disorder, and/or bipolar disorder; and who are all subject to the excruciating impact of these diagnoses on everyday life. Many have experienced symptoms of hearing voices, anxiety, paranoia, distrusting others, and an inability to read the social codes of conduct in most situations, all of which are likely to place them in marginalized and vulnerable positions in society. In Denmark, treatment for mental illness consists of regional mental health centers providing inpatient units, outpatient clinics, community mental health services, outreach services, and specialized treatment (Davidsen et al. 2020). Most patients with mental illness live and take part in the local communities, and their treatment are placed in outpatient services or in general practice. Only when and if needed are they hospitalized, and then often for only short periods.

Acute severe illness is treated at inpatient units, but suicide attempts are treated at emergency clinics. Both can be accessed directly and without payment. People with additional needs can also access social security, which includes the provision of housing or assisted living facilities if relevant, financial aid for those unable to work, and social services to support the individual's everyday life and social functioning.

Insights into the life of Elle, a 27 year-old woman who has been part of this study since 2018, illustrates what it can be like to live with a mental illness:

Elle, severely obese, her body covered in tattoos to cover up the scars from former self-induced cuts, is a strong-minded and determined person who, at present, dreams of becoming a singer, model, or actress. Elle had a very traumatic childhood and now lives with schizophrenia, post-traumatic stress disorder, bipolar disorder, and has a track record of suicide attempts. She has confided to Alexandra (first author) that, on average, she tries to commit suicide once every other month. Elle has been hospitalized for most of her adult life. She jokes that the psychiatric ward is where she has had her postal address for the longest period. Nowadays she has an apartment, assigned by the municipality, and, when not hospitalized from her suicide attempts, she has a home visit from her social worker twice a week, to help with everyday living issues like grocery shopping, or just for an informal chat. Once a month or so she has an appointment with her psychiatrist, and also often visits her GP who manages her physical health and, at Elle's request, has made a plan for weight loss. Owing to Elle's severe illness, she is unable to work, and instead receives an early social welfare pension, which gives her enough money for rent, food, going to the movies with her childhood friend, Jane, and pays for transportation for rare visits to mother. Elle's mother is an alcoholic, but sometimes, when her mother is in one of her good periods, Elle visits her for a few days, not least, says Elle, because her mother is all the family she's got. But in general, Elle has very few social contacts; most of them are part of the professional network, including social workers. Sometimes she attends a local club for young people with mental illnesses, which is part of the municipal outreach service, but she dislikes most of the others, and only goes there to meet up with her friend Jane.

Like most people with mental illness, Elle is testimony to, and the corollary of, social inequality in health. She often finds herself stigmatized in social and cultural contexts and speaks of feeling like a "second-rate citizen" who struggles with maintaining a sense of dignity in life. Up until the outbreak of COVID-19, our research focused on how patients like Elle would struggle with behaviors and experience symptoms that were often diffuse and transient, yet devastating if not treated. We were looking into how psychiatric diagnoses create health inequity and generate stigma, with a particular focus on encounters with health professionals. Having a mental disorder and being a psychiatric patient entails changes to both self-perception and treatment by others (Goffman 1990 [1959]). For the patients in our study, it is obvious that different diagnoses carry different moral values and elicit different responses from health professionals (Sartorius 2002), and that this shapes how staff interpret speech, conduct, and distress (Rose 2019:75). Yet, when the new pandemic emerged, current societal roles and categories were turned upside down for our interlocutors, at least for a while.

Negotiating vulnerable positions

Responsibility and adherence to restrictions are all for the common good but focused in particular on protecting the most vulnerable in society, those most likely to suffer from or perhaps die from a COVID-19 infection. Immediately, these groups were characterized by the risk of severe complication due to preexisting conditions, older age, or being in a marginalized position owing to their disadvantages. What were previously referred to as vulnerable groups has changed within coronarhetoric (Napier 2020). This moment in the history of the COVID-19 pandemic exaggerates and creates new or altered forms of vulnerability. For our research group, key questions are: how have our interlocutors responded to the restrictions and mitigations? And, to what extent does this feed into their position as already marginalized and vulnerable people? Throughout the years of fieldwork, we have learned how our interlocutors' daily lives are interwoven with different forms of assistance, social and medical, and this has become part of the individual narrative that naturally follows mental illnesses. Being vulnerable seems to be a ubiquitous description of these patients and their life circumstances are shaped by implicit perceptions that juxtapose mental illness with pain, struggle, and difficulties. Additionally, vulnerability as a term and classification has an impact in itself. As Fawcett (2009) shows, labels like vulnerability are designated as deficits, dependency, and passivity rather than autonomy and self-determination, and they can even result in or amplify exclusion and stigmatization (Brown 2011). In the case of people with mental illness, vulnerability is perhaps taken for granted at the outset and is assumed to have become exaggerated during the pandemic. Yet this response was not seen often. Many of our interlocutors found themselves somehow split between being vulnerable and not being vulnerable: they trusted the government and health authorities, supported the lockdown and restrictions, they were willing to observe measures and take precautions for the sake of the *new vulnerable* people, while also voicing concern that the services on which they depended were diminished, and that they were effectively cutoff from necessary help. One said that it felt like balancing on a knife-edge, both agreeing with the cuts in services for the sake of the common good, yet feeling left alone in trying to “stay sane” without burdening the health care system. Lack of attention toward people with mental illness affected and challenged the established narratives about who is vulnerable and who is not, and *when* a person is vulnerable and when not. Referring to a speech by the Danish prime minister, asking for Danish people to spare the health care system because it needed to use all its resources for people vulnerable to the COVID-19 infection, our interlocutor, Jens, said that he would not describe himself as vulnerable. At the age of 60, with many years behind him featuring drug abuse, suicide attempts, and a generally risky lifestyle, he was surprised to discover that he was categorized as being vulnerable to COVID-19, due to being overweight and having high blood pressure. Jens dismissed this vulnerability, as he had survived so many other diseases and life events, and he did not contact his GP during the lockdown. When asked why not, Jens answered that this was what healthy citizens were asked to do: “We are just doing what we are told”.

In contrast to Jens, Linn had more ambiguous feelings as to whether she was to be considered vulnerable or not.

Linn had been on a positive track lately; she passed the audition for the local choir, was working on her anxiety with her therapist, and her self-harm had lessened. When we met a couple of years ago, 37-year-old Linn had a habit of pouring drain cleaning acids on her wrist so she could focus on physical pain – even if for just a moment – rather than the constant voices that have been her critical companions since schizophrenia first manifested itself during her adolescent years. In January 2020, we were drinking coffee in her living room, and she excitedly shared how her psychiatrist at the outpatient clinic had encouraged her to apply for a peer-to-peer volunteer role on the ward, helping other patients on their recovery journeys. Instead, a few months later, Linn found herself isolated in her apartment, with most community activities on hold. The voices inside Linn's head became increasingly violent and set in motion an increase in her self-harming actions. One week into lockdown, Linn went from self-harming once a day to a strictly structured scheme of self-harm repeated five times a day. “It's the restrictions that I feel most threatening (...) many drop-in centers (væresteder) for people with mental illness have been shut down (...) Yes, those things are what I find the hardest to handle”, Linn said in a sad voice. However, she supported the lockdown and stressed that she thought the authorities were handling it in the right way: “It's all about protecting the vulnerable”, adding – when asked who she meant by that – “the elderly, the

people with chronic illness". We began talking about which chronic illnesses were putting people at greater risk, and Linn assured me that none of her comorbidities would increase her risk of severe illness or death from COVID-19. She had contacted the authorities' hotline with no result, but the Facebook community of people with this particular skin disease she worried about had put up a post stating that they were not to be counted in the group of high-risk people.

To Linn, redefining a vulnerability narrative that had been established by health and social workers in her late teens owing to her mental illness and hence dependency on help, medication and psychiatric and social services, became an emancipating, profound, and radical change. Still, it also caused uncertainty about her special needs (including assistance and psychiatry) being neglected in favor of prioritizing the new vulnerable. This speaks to a certain kind of temporality in the impact of COVID-19 showing vulnerability as a phenomenon that can be negotiated among individuals, in communities, and in public discourse.

As a consequence of restricted movement and social interaction, Jens explained that he was losing basic social competencies. Jens may not have identified himself as being vulnerable at first during the pandemic, but as time passed, his passive resignation from society created a new form of vulnerability.

Both Jens and his partner, Maiken, played in a band at the local activity center for people with mental illnesses. During lockdown in spring 2020, the weekly practice was cancelled, and social activities within the group were put on hold. Jens especially missed members of the music group, whom he described as family members. After several weeks and months spent in isolation at home, not being able to interact, touch, or see other people, Jens told Iben (second author) that he was losing his social skills. According to Jens, it was difficult to maintain social skills, such as communication, detecting and sensing tone, mood, and atmosphere, and understanding codes of conduct without any social interactions. The lockdown made most social interactions impossible, and Jens felt he was withdrawing, becoming more passive, and spending more time on the couch watching TV.

Likewise, Linn's perception of her situation as either vulnerable or taking responsibility for the "new vulnerable" was swinging back and forth like a pendulum. She may not be especially vulnerable to a COVID-19 infection, but her mental illness was getting worse without the appropriate assistance, and she became increasingly uncertain as to what would become of her. How people, who are already involved in more than the usual conditions of uncertainty due to their mental health status, manage to come to terms with the uncertainty provoked by a pandemic that is shared with all Danish citizens, is pivotal to our study. We believe that we see, in this group of people with mental illness, subject positions that are situationally mediated and defined as they forge their lives, their concerns, and what is at stake for them, negotiating uncertainty and possibility through distinct social formations (Biehl et al. 2007). They are concerned with things that matter to them, they care about specifics, expressing subjectivity while taking action and trying to deal with a problem (Whyte 2005); they use what they have available to them to manage uncertainties. As such, our interlocutors do not lean back and await the consequences of the pandemic; instead, they actively assess their positions, conditions, and possibilities. They compare themselves with other vulnerable groups, which they acknowledge while positioning themselves as not strictly vulnerable, and they still try to manage the troubles brought on by the mitigations of the pandemic. Adhering to restrictions, checking out the uncertainties around being at risk, or just reflecting on one's degree of vulnerability and taking precautions accordingly, are examples of agency evoked by the pandemic. Structural vulnerability (Quesada et al. 2011) is still at play and determines basic life conditions for people with mental illness, but if being vulnerable is a position, it is one that may be altered. What we see here is an agency performance that seems to shake the perception of personal everyday vulnerability. The mitigations of the pandemic install new vulnerability, as in Jens' case. However, our interlocutors still act according to what they are up against, and challenge the classification of being vulnerable *per se*.

To that end, we may need to re-conceptualize categories of vulnerability as less static and more contextual conditions. Taking steps toward forging and managing fluid vulnerabilities during a crisis may not only affect one's perception of being vulnerable, but they may also create new levels of uncertainty, including new perceptions of what constitutes risk and how to manage it.

Responsibilities of risk

While uncertainty, in many ways, defines the human condition and is not specific to particular situations (Steffen et al. 2005), the pandemic has thrown it into relief, installing a very present notion of uncertainty. We experience uncertainty about what we know about the virus: its extent, how it will develop, the impact it will have on oneself, friends, family, and community. Uncertainty about life and death, and what the future will bring, makes everyone, to some extent, engage in existential deliberations and questions. At the same time, as citizens we are met with governmental and institutional attempts to control a situation of global uncertainty, in the sense of regulations, measures, and restrictions. When COVID-19 began spreading worldwide in the spring of 2020, and after a resurgence of COVID-19 infections in the fall of 2020 and winter 2021, Denmark, like many other countries, introduced restrictions in an attempt to confine the virus. Measures to prevent the increase in COVID-19 cases were largely adhered to and accepted by the Danish population (Lindholt et al. 2021). However, exactly what individuals do in this intersection between structural control and personal agency (Steffen et al. 2005) is what strikes us as essential in the case of people with mental illness and their everyday lives during lockdown.

As we are reminded by Manderson and Wahlberg (2020), the pandemic also resulted in inadequate means, due to emergency resources being spent on bolstering intensive respiratory care capacity in hospitals. In both resource-poor and in rich countries, unemployment rates are rising, and the vulnerable parts of the population are left in precarious living conditions. For the mentally ill in Denmark, all non-acute services were shut down and visits from home assistants were transferred to online meetings, leaving no room for informal chats, a hug, or just the mere presence of another human being. As with the general population, some of our interlocutors were afraid of the virus and the possible consequences that it could have on their bodies, including death. However, though all our interlocutors expressed fear about getting infected, it was the consequences of isolation and possible harm to others that caused stress for most of them.

Pre-pandemic, Linn had been assigned weekly visits from a social worker with whom she had built a trusting relationship. Karen, the social worker, helped Linn with grocery shopping, activities planning, encouragement to get out of the apartment once a day, and she always gave hugs and praised Linn for how well she was doing. During the pandemic, Karen was still allowed to visit Linn in person, but they could no longer hug, and Linn became terrified of catching COVID-19, which put a stop to the visits. “It’s not the disease itself. I’m scared that if I get sick, I can’t see my therapist and I can’t get home visits”, Linn explained over the phone.

Other interlocutors stressed how the risk of being contagious and possibly transmitting the virus to others was the most frightening scenario. When the pandemic broke out in Denmark, Elle was terrified that she would catch the disease. She worried about ways of avoiding the virus, and when the government announced measures, she was willing to observe every one of them, not only for herself but also for the greater good, as she said: “We need to take care of the old ones; everyone should take this seriously”.

Meanwhile, Elle learned that the new precautions also meant that her social assistance was withdrawn for an indefinite period, the local club was shut down, her psychiatrist could only call her on the phone, and she was advised, like all Danes, not to see her GP unnecessarily, and to limit social activities. Yet even so, she explained, that sacrifice was an act of responsibility.

Viruses and risk are part and parcel of the history of mankind, but this particular group of people living with mental illness responds to a more general risk than that of the virus. The lockdown created a great deal of uncertainty in terms of the disease, its consequences, the value of the measures used to limit the spread, and identifying who is at increased risk of severe symptoms or death. Responses to risk are of great interest in shaping the values and possibilities for agency among people with mental illnesses. The affective repertoire for managing risks and the consequences of the pandemic following the Danish lockdown of society sheds light on the implicit responsibilities of risk as performed by so-called vulnerable groups.

Jens, our interlocutor with a wild past, has paranoid schizophrenia and lives with his girlfriend Maiken, a 52-year-old woman with schizoaffective disorder. They have been a couple for more than 25 years; they met on a psychiatric ward and have been together ever since, “against all odds”, as Jens explained: “people with mental illness are usually not in long-term relationships”. Both Jens and Maiken receive early retirement pensions. Pre-pandemic, Jens was well medicated and attended his GP once a month for check-ups. During the lockdown of fall 2020, Maiken suddenly developed a sore throat and felt pain all over her body. Maiken is used to chronic pain, but not combined with a sore throat. Suspecting that she may have coronavirus, she immediately isolated herself and Jens in their apartment. The symptoms were still present after a few days so Maiken called her GP, who advised her to get tested. Maiken has severe anxiety towards computers, phones, and other communication technologies, and it was challenging for her to schedule an appointment at the test center. The couple do not have a car, nor was there extra money to call a cab, which in any case would increase Maiken’s anxiety toward strangers and her obsessive fear of being abducted in a taxi. They had no choice but to take the local bus to the test center. Jens and Maiken thought they were doing something very wrong, being completely irresponsible, and potentially putting other people at risk of infection when taking the local bus. What if Maiken had COVID-19 and infected someone else on the bus? They put on masks, sat at the back of the bus; they tried not to touch their seat, or the seat in front of them, or the door on their way out of the bus at the stop for the test center. Maiken’s test was negative.

Douglas’s seminal work shows how risk is not only the probability of an event but also the probable magnitude of its outcome (Douglas 1992). According to Douglas, we need to understand risk in terms of how people classify something as a risk and as a danger (Douglas 1990), and how the notions associated with risk are culturally rooted in society. Douglas argued for the importance of exploring the values associated with a risk to be able to understand people’s perceptions and actions (Douglas 1992). Daily life decisions about risk are taken by comparing many risks and different factors, and their probable good and bad outcomes. Douglas argued that risk must not be isolated as a technical problem but should comprise moral and political implications. In this regard, Maiken and Jens classified the risk of infecting others with COVID-19 as high. Following Douglas, they experienced themselves as being out of order; what they did by taking the bus was morally unacceptable – they became matter out of place. Most of our interlocutors, including Maiken, were not greatly concerned about getting the coronavirus infection themselves, rather it was the moral risk of exposing others to the virus that dominated their thinking. We argue that what is at stake is not risk in itself, but the responsibilities risk encompasses, which juxtaposes our interlocutors with other citizens, regardless of their mental diagnoses. Taking on such responsibilities may trouble the potentials of personhood and create new possibilities for acting along with new uncertainties in terms of how to behave and navigate in this new landscape.

As such, general uncertainty about what the future may hold in terms of restrictions and isolation is transformed into something profoundly political and moral (Douglas 1992). Could it be that this group of interlocutors has grown accustomed to risk and uncertainty, and thus they are, per se, better equipped to manage crises like the COVID-19 pandemic – even to the extent that the responsibilities of risk create an altered sense of belonging in society?

Altered personhood

We use the notion of personhood here, in short, to describe a person’s specific social roles and moral responsibilities, duties, virtues and rights, as well as to how one practices and lives with social relations. However, agency and personhood is not a given individual trait and perception is continuously negotiated in relation to specific contexts and subject to socio-cultural contingencies and relations (Appell-Warren 2014; Carrithers et al. 1985). People with mental illness tend to feel excluded from established society and the general community, leaving them with feelings of being outsiders (Erdner et al. 2005). It has been argued that people with mental illness feel different from other people, and that they have felt this way since childhood, although they want to be equal to everyone else (Nilsson 2004). These experiences of being estranged from society, of social exclusion, and being different are confirmed by our interlocutors and also challenged by the changed

perception of who is at risk, who is vulnerable, and why. The pandemic creates a new form of equality, and everyone is asked to observe the new measures and restrictions. This makes people with mental illness no different from people without mental illnesses; they are reintroduced to the community, for once, on equal terms. One example, as shown by Wilkinson (2020), when interlocutors wear a mask, it not only protects them and others from spreading the infection, but it also shows a civic responsibility equal to other citizens, as wearing a mask also symbolizes that one takes measures to protect others.

The shift in focus away from our interlocutors as not contributing to society and taking up too much of the social and health services, and toward acting as responsible citizens for the common good, is an emancipating moment for changing the narrative. The lockdown period not only affects the loss of skills for some, it also contributes to the reinforcement of existing skills and the improvement of new ones.

This is illustrated by the case of Pernille, from a small town in the Central Denmark Region, who was part of Christensen's fieldwork for 2 years.

Pernille is a 52-year-old woman diagnosed with bipolar disease, depression, and anxiety. She is divorced from her husband of 20 years and lives alone. Every other weekend she has a visit from her 12-year-old daughter, who lives with a foster family owing to Pernille's ups and downs and her difficulties taking care of the daughter. Twice a week Pernille is visited by her social worker who helps her with everyday life struggles, such as grocery shopping, but most of the time they just talk. During the first Danish lockdown in spring 2020, Pernille was very frightened and her anxiety increased significantly. She explained over the phone how living alone was reinforcing her anxiety, and she was haunted by thoughts of becoming ill with coronavirus while no one was looking after her; she spoke of nightmares of dying alone or being choked. Anxiety increased and resulted in different physical symptoms, which made the anxiety even greater. Due to lockdown, Pernille's social worker and home care service were not allowed to visit her in person, leaving Pernille in a new situation. Despite her experience of having stress, anxiety, feeling lonely, and worried, Pernille realized that lockdown would force her to try new things, thus making her aware that she was capable of much more than she thought. Usually, the home care service visited Pernille three times a week to administer her medication, but during lockdown Pernille had to do it herself and showed both herself and others that she was capable of handling her own medicine. Furthermore, before lockdown, the municipality had offered Pernille an iPad so that she could make calls to her social worker when physical visits were not possible for whatever reason, but Pernille declined. During lockdown Pernille agreed to try the iPad, and to her surprise it worked out for her as a replacement.

As this case shows, Pernille managed to find new ways of handling her situation. In the unpredictable world of living under a pandemic when everything is put to the test, Pernille was left with a sense of being able to regulate something; to manage something on her own, and, we argue, to take control in an uncontrollable world. This left Pernille with a feeling of self-control and the power of self-care and regulation to a degree she was not used to in her everyday life. This, we argue, gave Pernille a new personhood both in terms of a positive self-image and of being a responsible citizen.

As shown, observing pandemic measures emphasizes a group-belongingness and responsibility in which our interlocutors are equal to other citizens, contrary to the stigmatized and excluded positions in society many had previously experienced. As argued by Pillay (2021), the pandemic puts collective cultures over individualist cultures, as one of the core tools to overcome the pandemic is for all to live accordingly to the broader needs of their communities. Here, there is no division or hierarchy, all need to equally perform for the greater good, and hence, what was initially perceived as a threat and a risk, grew for some interlocutors to be a way of entering an altered personhood:

Usually, when they got up in the morning, Maiken would put on her vividly coloured outfit and hat of the day and go window shopping, sometimes for hours, in an attempt to "keep her thoughts fully occupied", she said, while Jens would go to play with the band. During lockdown, the club and non-essential shops were closed and it was, therefore, impossible for Jens and Maiken to sustain their normal activities and routines. Danish national television aired "the community singing movement: singing together apart" every morning and on Friday nights, inviting all Danes to join in. This inspired Maiken and Jens to incorporate a new routine of waking up early to start the day with community singing. Suddenly, they had something to look forward to, singing together with the rest of Denmark from their living room. They described it as being a part of something bigger and strengthening their sense of community.

This form of altered personhood resonates with bio-citizenship in Denmark, by enforcing the link between moral health behavior and solidarity: displayed through the valued autonomy of citizens (Krøijer 2011) and of being responsible for one's health. Good bio-citizenship is now performed visibly by observing measures like keeping social distance and calling out unacceptable behavior in others, such as, getting too close or sneezing into hands, not elbows. The pandemic juxtaposes people with mental illness with others and, for the first time, allows them to perform good citizenship.

Conclusion

With the Covid-19 related lockdown, many services were cut off resulting in a great sense of uncertainty, not least in the lives of people living with mental illness, most of whom were dependent on home assistance and social workers. In this article, we have shown the diversity and heterogeneity of responses to the pandemic, based on personal history and experience, context, emotional ties, and calculative strategies. Our interlocutors' actions can be understood as attempts to conjure up a sense of relative order and control during a very uncertain time. We have argued, in line with Douglas, that risk as a phenomenon is profoundly social, and exists within particular contexts. What our research adds to the debate is that risk is not only about the dangers themselves, but also about how risk is perceived and managed: that adherence to the moral modalities underlying risk has the effect of protecting society from risk. As such, we show how community may take a central position during the pandemic, but it has also highlighted social inequality and structural violence (Dionne and Turkmen 2020; Napier 2020; Pillay 2021; Singer and Rylko-Bauer 2021). Considering this, we have looked at the notion of being vulnerable – a category within which people with mental illness are often placed – but which has been troubled by subjective strategies partly instigated by the pandemic. The experiences of our interlocutors demonstrated how vulnerability has become a more fluid term, one that could even be discarded, affecting self-image and newly discovered skills. In addition, by adhering to the lockdown restrictions and taking extra precautions to avoid disease, our interlocutors could be seen as displaying good citizenship by being extremely responsible and taking their role seriously in limiting the spread of the infection. This could give them back a sense of belonging to society and being part of a greater good, allowing for trends of changes in citizenship and social personhood through a mutable vulnerability. Our interlocutors still have mental illnesses, which will continue to limit their social lives, affect their bodies and souls, interfere in relations, and futures; but we argue that the pandemic has made the fluidity of vulnerability more visible in a formerly marginalized group. It is important to remember, however, that any positive development in the lives of our interlocutors needs to be situated in the context of a worldwide crisis. As the pandemic continues to restrain society, people with mental illness are subject to worsening symptoms and social lives. It might be hoped that a change in the narrative of what it means to be vulnerable and what it means to be a good citizen will have the effect of a more empathetic understanding of what it means to live with mental illness not only during a global pandemic but also in the future.

Notes

1. Daily updated status of the epidemic in Denmark can be accessed in English here: <https://www.sst.dk/en/English/Corona-eng/Status-of-the-epidemic/COVID-19-updates-Statistics-and-charts>.
2. SOFIA is an abbreviation for *Sammen Om Fysisk og psykisk helbred I Almen praksis* (In English: shared care for physical and mental health in general practice).

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