






EMPIRICAL STUDIES

The marked body – a qualitative study on survivors embodied experiences of a COVID-19 illness trajectory

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Abstract

Background: Research on COVID-19 has reported data on epidemiology and pathophysiology but less about what it means to be a person living through this illness. Research involving the patients' perspectives may help to improve healthcare professionals' understanding of ways to support patients.

Aims: To gain in-depth understanding of the meaning of a COVID-19 illness trajectory from the patients' perspective.

Methods: Fifteen participants who had undergone an illness trajectory due to confirmed COVID-19 infection participated in individual qualitative interviews. Data collection, analysis and interpretation were inspired by Ricoeur's philosophy and Merleau-Ponty's phenomenology of perception and embodiment has been applied as a theoretical frame.

Findings: Being infected with coronavirus is expressed as an experience in which the participants oscillate between relief, security, imprisonment and raw fear. A predominant focus on the physical dimensions of the diseased body was found in the encounters between patient and healthcare system, and distance may furthermore be a consequence of use of protective equipment. Stigma and fear of infection were also expressed. After COVID-19, an overwhelming feeling of a door opening to freedom is perceived. However, the body is marked, and bears witness to decay from this insidious and frightening virus. The responsibility for assessing their bodily symptoms is placed with the individual patients themselves, who feel lonely and fearful and this keeps them indoors.

Conclusions: During a COVID-19 illness, trajectory concerns about the unknown course of this disease are highlighted. Isolation is confrontational; however, a companionship between patients might emerge. The study shed light on an unavoidable gap between the patients and healthcare professionals due to the use protective equipment. After

COVID-19, the body is labelled as something others fear and become a symbol of awe and alienation for others.

KEY WORDS

SARS-CoV-2, COVID-19, coronavirus, qualitative study, patient perspective, Ricoeur, Merleau-Ponty

INTRODUCTION

COVID-19 is one of the major pathogens that primarily targets the human respiratory system (1). The first cases were reported in December 2019 in China, and the disease was named (2). Symptoms of COVID-19 appear after an incubation period of approximately five days (3). In fatal cases, the period from the onset of COVID-19 symptoms to death is reported to range from 6 to 41 days with a median of 14 days (4). The most common symptoms at onset of COVID-19 are fever, cough and fatigue, while other symptoms include sputum production, headache, diarrhoea and dyspnoea (1). There are no specific antiviral drugs or vaccine against COVID-19 for potential therapy for humans. (5). Remdesivir, a broad spectrum antiviral drug, has shown mixed results in patients with COVID-19 infection but may be a possible treatment option for the infection (6,7). Despite the lack of antiviral treatment, the majority of patients spontaneously recover from the infection, while some may develop various fatal complications (2).

Guidelines aiming to serve healthcare professionals (HCP), for example frontline doctors and nurses, to tackle the suspected COVID-19 infected patients, has been developed (8). Such guidelines describe effective isolation and protection conditions as well as treatment plans and clinical observations. Research has demonstrated the clinical features of patients with pneumonia caused by COVID-19. Some patients may require admission to an intensive care unit due to acute respiratory distress syndrome, and shock or acute kidney injury have been reported (9). Most people infected with the COVID-19 will, however, experience mild to moderate respiratory illness. Older people, and those with underlying or coexisting medical problems, are more likely to develop serious illness (8,10).

Research on COVID-19 infection has reported data on clinical presentation and features, epidemiological risk, and pathophysiology studies performed within a biomedical paradigm. Medical science knows much about the *how* of diseases but less about what it means to be a person living through the illness trajectory. What may be at stake for people who undergo illness from a novel coronavirus has been sparsely investigated. The patients' perspectives of being diagnosed with COVID-19 and undergoing the course of this illness is thus lacking from the research literature. Research involving the patients' perspectives may help to improve our understanding of how people manage problems or phenomena in this illness

and lead to better ways of supporting them in the future. Qualitative research of this kind on the COVID-19 population will provide additional evidence for developing patient-centred supportive interventions. The purpose of this study is therefore to gain in-depth understanding of the meaning of a COVID-19 illness trajectory from the ill person's perspective.

METHODS

Study design

The methodology applied in this qualitative study was inspired by the phenomenological and hermeneutical aspects of the philosophy of Ricoeur. Phenomenology is seen in this study as an epistemological stance for exploring first-person accounts of what it is like to live through a COVID-19 treatment trajectory. The starting point is about how phenomena are experienced pre-reflexively, namely experiences from the patient's lifeworld. In hermeneutics, understanding and interpretation are a fundamental ontological condition for human existence, and hermeneutics are concerned with interpreting the surplus meaning contained in the human life world and recognition takes place via interpretation. According to Ricoeur, we leave traces when we express ourselves, and traces are formed by the world of meanings and traditions to which we belong. Often, the sense in the traces is hidden, making it impossible to directly understand individual's experiences. Reflection on an individual's lived experiences must take place via the narratives in which the individual expresses themselves (11–13). The centrepiece of Ricoeur's narrative philosophy is the threefold mimesis, which can be seen as an epistemological approach to understanding the meaning of people's lived experiences and which, in this study, has inspired the research process (14,15). It comprises: mimesis I (prefiguration): the life lived before it is formulated as spoken or written narrative (data collection); mimesis II (configuration): the language stage, expressing a story (from speech to text); and mimesis III (refiguration): the actual comprehension stage, when the text is interpreted (analysis and interpretation). Merleau-Ponty's phenomenology of perception and embodiment has inspired the interpretation of the participant narratives. Merleau-Ponty argues that human understanding comes from our bodily experience of the world we perceive. He takes the body as 'the self', stating that, 'I do not *have* a body' but '*I am* a body'. Thus, the

body is not an object but a condition. Merleau-Ponty believes that we as subjects are inseparable from our bodies and our world (embodied) (16,17).

Setting and sample

Participants in this study were recruited from a population of people who had confirmed COVID-19 infection and undergone an illness trajectory with mild to severe symptoms. A convenience sampling strategy was used (18) through encouraging participants to approach the research team by e-mail, if they were willing to attend an interview. Flyers about the study were given out to HCP at departments of infectious diseases in different regions of Denmark. Snowball sampling (18) was also utilised in order to recruit new participants among existing study participants' acquaintances. The interviews were conducted by telephone based on ethical accountability for not contributing to the spread of the virus, and they were scheduled at the participant's convenience. Fifteen participants agreed to participate in the study and were interviewed between 23 March and 1 April 2020. The society of Denmark was on lockdown due to the threat of coronavirus on March 11th. Coronavirus was in this period still relatively new in Denmark, 300-500 patients were hospitalised and 77 patients died due to COVID-19 during week three of the epidemic (19). In the included sample, five participants had been hospitalised due to severe symptoms, mean age for all participants was 46 (range: 22 years – 67 years), and seven were male. Participants were recruited from three different regions of Denmark. In the three regions, it was not possible for relatives to visit the patient during hospitalisation, and the possibilities for contact between patient and relatives at the individual hospitals varied. None of the participants had family or friends who were or had been admitted to the hospital due to COVID-19.

Data collection

According to Ricoeur, insight into lifeworld phenomena can be gained via interpretation of traces left by individuals through their language, attitudes and actions (15,11). To gain insight into the participants' lived experiences of the COVID-19 illness trajectory, they were encouraged to narrate about their life with illness. In terms of Ricoeur, the participants were configuring the preunderstanding of mimesis I. When recounting their narratives about illness, the participants brought about configuration (mimesis II) by summarising a chain of events in their life with illness. As a result, essential phenomena or themes were uncovered. All interviews were collected before the analysis and interpretation of the transcribed texts was undertaken.

Data analysis

Ricoeur emphasises that interpretation is the central methodology in phenomenological hermeneutic work (13,15), arguing that something happens to language when the spoken words are transformed into written text. In this study, narratives were transcribed. The key factor when writing down the spoken word is that meaning is liberated from the event, which means that the description of the lived experiences is freed from the narrators' underlying intention (20), thus allowing the researchers to interpret and unfold the issues the text points towards.

The interpretation process, understood as an endless spiral, involved three levels: a naive search for the overarching meaning which the text seeks to convey, a linguistically oriented structural analysis and an in-depth critical interpretation (20). The naive interpretation is superficial and involved reading and re-reading the narratives to capture an initial understanding. The structural analysis provided insight into the structure of the text; words and sentences were extracted that pointed towards recurring issues and themes throughout the text. The critical interpretation was directed at understanding the meaning and range of the statements in the text. Interpretive understanding thus allowed us a more profound, sophisticated understanding of the lifeworld phenomena left as traces in the participants' narratives. Data analysis was performed by all authors reflecting and discussing data and interpretations at all levels in the analytical process. One researcher was an experienced clinical nurse specialist in the department of infectious diseases (ID), three authors (MM/CB/SKB) were all experienced qualitative researchers with limited prior clinical knowledge on patients with infectious diseases, and one researcher was an experienced public health research assistant with knowledge on epidemics and pandemics in societies (SWC). Together the analysis and interpretation process reflected the different backgrounds of the researchers.

Findings

In the following, the empirical findings will be presented along with the researchers' critical interpretations, which are divided according to three themes.

The body you cannot trust – being infected by COVID-19

Being ill with COVID-19 was expressed in a variety of ways by the participants. Some experienced mild symptoms and were isolated at home while others had severe symptoms requiring intensive care and respiratory therapy. Common for

the participants, however, were insecurity, anxiety and fright regarding this unknown disease and the threat to their health. They were concerned about the unknown course of illness and questioning whether their body and life would ever be restored. In addition, it felt random to be, 'the person' who has been infected: *'It feels like roulette this virus. After all, it is not only the elderly who are most severely affected. So even younger people are in intensive care... you feel it is a bit random, why is it me who has been the selected...'* (pt9). This uncertainty and experience of an unpredictable course of illness led to unexpected and often unknown reactions in the participants. They narrated how their body, which is usually a source of strength, was now experienced as a limp, tired and melting body that they could not rely on. The participants were living through COVID-19 illness with increased attention to their bodily functions. Experiences of difficulty in breathing were especially expressed as a threatening interference in the body. The perception of a body not performing normal life-sustaining work such as breathing is frightening and very confrontational. Living in such an altered body was approached using different coping strategies. Some participants find themselves fighting against the disease while others adopted an apathetic and indifferent attitude, *'It's scary to be so... totally apathetic. I didn't really care about things...'* (pt10).

Being admitted to hospital was expressed as an experience in which participants oscillated between relief, security, imprisonment and raw fear. They found their body being a physical object that was weighed, measured, observed and monitored. At the same time, their body also expressed subjective feelings, perceptions and sensations, *'I was scared ... I'm 43 years old, can I die? This corona is scary because you are so sick and you have heard that just suddenly, people may die'* (pt15). The participants were isolated during hospitalisation either alone or in groups with other patients affected by COVID-19. Being completely alone could be a relief as the participants were thus not confronted with the bodily decay and reactions of other ill people. On the other hand, it could also lead to a feeling of enormous loneliness. Despite being confronted with other weak and ill people a companionship between strangers might emerge during isolation together in a strange place with an alien and novel illness, *'We gained such a community, between us patients, and got to talk and support each other'* (pt15).

Being a body affected by COVID-19 put participants in a waiting position without anyone able to predict, guide or point out how long the course of the disease will last. Participants described how they waited for the days to go by, waited for infection rates to decrease, waited to be able to return to work and, overall, waited for their familiar body to return. It was described as a frustrating waiting period where they felt left out on the sidelines compared to their ordinary everyday life and routines. A participant described how she tried to separate

herself from her physical body in order to push away the frustrating waiting. *'I had times when in the morning I didn't feel like getting out of bed because I didn't want to feel that I was still ill. I think it was uncomfortable because you keep waiting... when does this turn...'* (pt1). They come to doubt their own body and the body's capabilities of normal functioning.

The meeting between the COVID-19 infected body and the healthcare system

The participants were in contact with the healthcare system in various contexts, including testing and assessment for COVID-19, medical assistance at home or in hospital. They spoke of varied experiences, ranging from empathy and security from the healthcare system to experiences of no one wanting to touch, help or support them and instead shy away. The meeting between participants and the healthcare system was perceived as professional and caring when the HCPs balanced between observing and measuring the physical body while at the same time recognising the ill person's lived body and individual bodily perceptions as well. The participants described how in such meetings, they feel they were being taken seriously and the HCPs were supportive in a vulnerable situation, *'It has been very hands-on, trustworthy and confident. And there has been clear support and good communication'* (pt7). In situations where participants perceived the need for urgent help and medical assistance due to severe symptoms of COVID-19, they described how HCPs handled their diseased body in a responsible and professional manner, providing immediate relief and safety. What the HCP in and after such situations might not take much notice of was the ill person's experiences of being an ill body infected with an alien and unknown virus, *'A doctor reviews my symptoms, checks my temperature and listens to my lungs and measures my heart rate, and she says it's just a virus. But I got nervous anyway. It's been a lot of uncertainty'* (pt2). The participants narrated the experiences of their physical body being cared for while in hospital. Receiving antibiotics, monitoring of oxygenation and other vital signs were usually in focus. A distance between the ill person and the HCP was the requirement for protective equipment due to the infectious virus which meant that the ill persons could not see the face of their carers, *'The most annoying thing about protective equipment was that when you had changing nurses, you couldn't recognize them...'* (pt14). The apparently similar face in the encounter might reduce or alter the patient's mood and may tend to overlook the force that HCP have in the relationship with the ill person. One participant, however, described how he found other ways of recognising and relating to the masked HCPs by listening to their different voices and observing their different bodily postures.

Being ill with COVID-19 give rise to the possibility of being considered a human being with a body so toxic and dangerous that no one will come near. Such experiences were present throughout the illness trajectory from being tested and hospitalised and when let out into society again. The extensive uncertainty surrounding the new coronavirus gave rise to excessive restraint by some HCPs. Several participants narrated experiences of contacting the healthcare system but then being denied a visit due to COVID-19. They feel like an individual having the plague and being in a place and situation where nobody dared approach them. In such situations, the participants felt lonely and powerless and this situation bore witness to the seriousness of the illness, *'The porter pushing my bed calls as we enter the department "COVID on the way, COVID on the way!" There I felt extremely poisonous, and I see the nurses smile, and then they all disappear. I was driven into a room which was completely empty. I was left there, and the door closed. There I cried. There I was scared...'* (pt15). The HCPs' reactions to the ill person's infected body had consequences for the participant who felt the discomfort and disgust at her as a person. This participant, like others, felt alone and vulnerable and wished for someone to talk to about such experiences.

The vulnerable and marked body – after COVID-19

When cured of COVID-19, the participants expressed an overwhelming and joyful feeling, almost like a door that opens to freedom again. Through the illness trajectory, participants experienced the loneliness of isolation, which at times felt like being in prison, whereas they now allowed themselves to feel the sparkling happiness in their body, *'I get totally euphoric about coming home. It's so cool to be out in the real world again'* (pt14). While the participants celebrated and appreciated their health, their bodies also bore witness to illness and decline from an insidious, unpredictable and frightening virus. Thinking back and reading own medical records testified to the potentially fatal situation that some of them have been through. Their body responded with sadness, grief and thoughtfulness along with fatigue, lack of energy, loss of appetite and affected breathing. The participants furthermore described an increased awareness in and of their body which in some situations could make them nervous, *'I got a serious pain in my lungs, and then I got nervous again. I never thought about where my lungs are, but suddenly I could feel them... It emphasizes the seriousness'* (pt6). Nervousness and insecurity were also expressed in the transition from hospital to home. When discharged the participants were on their own again and had to rely on own bodily perceptions which might feel scary and lonely, *'You are left to yourself – an*

amateur... It gives some thoughts... Oxygen saturation has been a key focal point of whether it went well and now there are no measures anymore...' (pt14). This participant expressed, like others, how they had to learn to trust and reconnect to their own body again and its sensations.

Another aspect of being on the road to recovery and reconnecting to the body was also insecurity regarding assessing their own symptoms when they were well again. The participants described how they felt that they were not able to go anywhere because they are unsure if they are completely well, they did not know if they were allowed, *'I'm pretty nervous about going out without having some kind of knowledge of whether I'm really well and can't infect others. I don't know if I am well again, I don't know if I am still contagious. It keeps me indoors'* (pt4). This quote illuminates the confusion about the bodily perceptions of signs to which the participants must relate and trust. They furthermore express how some kind of follow-up from the healthcare system might have supported them in this process of taking control and responsibility of their own body again, *'When I got home, I cried and there I was missing a follow-up. I know that I have to take responsibility for my own health, but I lacked that anyone still cared for me'* (pt15). The participants narrated how the responsibility of assessing their own bodily signs left them alone and therefore expressed the view that some form of support in learning to interpret them might be helpful.

A serious mark of being that person who has been ill with COVID-19 is the reactions of the social surroundings when coming back into society. Keeping extra distance and stigma are suddenly an ordinary daily event when meeting others. The participants' bodies are labelled as something others fear and become a symbol of awe and alienation. They become a diseased body, infected with a creepy and strange virus. Participants feel how their body is marked with suspicion by other people forcing them to keep their distance, *'It was strange coming out among other people again ... they keep extra distance. There's something wrong... or people have respect for it. But it's a strange feeling.... I understand that they protect themselves, but it feels like you have a plague'* (B10). People in the participants' ordinary social networks associate them with both plague and leprosy, and this is experienced as the most unpleasant reaction of all.

DISCUSSION

This study explored the meaning of a COVID-19 illness trajectory from the patients' perspective. Clinical symptoms in patients infected with COVID-19 are frequently reported (21,22). The present study, however, illuminates how individuals affected by COVID-19 experience a body they

cannot trust, and which had become uncooperative leaving them frightened and directing their attention to bodily functions. According to Merleau-Ponty, when something 'goes wrong' with the body, our attention to it then moves from the background to the foreground of our consciousness (17). The bodily symptoms of COVID-19 were brought into the centre of attention for the participants in our study, which contrasts with the healthy body that performs without the need for awareness and reflection.

Narrative medicine offers a model for clinical practice used to understand the meaning and significance of stories (23). This kind of knowledge provides a rich, resonant comprehension of a person's situation. Narrating one's own story is a therapeutically central act because to find the words to contain the disorder and its attendant worries gives shape to and control over the chaos of illness. This approach might be useful in the caring for individuals experiencing COVID-19.

On being admitted to hospital, the participants' body is separated in two: a physical objective body being weighed, measured, observed and monitored and a living body which is the seed of subjective feelings, perceptions and sensations. As subjects we are, says Merleau-Ponty, inseparable from our body and we act through the lived body that we are (16). At the same time, our body can be seen and referred to by others as objects. Treating the physical body with COVID-19 infection is crucial in health care; however, recognising that the lived body is also capable of being hurt is highlighted in the present study. Research studies report how to treat severe pneumonia, acute respiratory distress and septic shock in patients with COVID-19 (24–26), whereas knowledge on how to care for a wounded lived body is sparse (27).

A review of the literature on the psychological impacts of isolation in conjunction with the new coronavirus demonstrated negative psychological effects including post-traumatic stress, confusion and anger (28). In the present study, participants were directly confronted with other weak and ill bodies when they were isolated in groups. The study did, however, also shed light on how a possible community between patients might emerge. The bodies of others are, according to Merleau-Ponty, integral to the process of self-consciousness (17). The presence and awareness of diverse bodies is thus a building block for the awareness of self, and this shows the importance for the patient to interact with other COVID-19 infected people on their way to reconnect to themselves and their bodies. Research including other patient populations has described how a community of understanding might appear when patients are put together with others in the same situation (29–31). Regarding isolation and virus diseases, earlier studies furthermore suggest how to mitigate the consequences of isolation by giving people information, reducing boredom and improving communication (32–34).

The present study describes how the meeting between the COVID-19 infected body and the healthcare system was

experienced as professional and caring when HCPs balanced observations and measurements of the participants' physical body with at the same time paying attention to their lived body. By contrast, when patient experiences of being an ill body infected with an alien illness were not recognised by HCP, a discrepancy between having a body and being a body was highlighted. Merleau-Ponty states that the body is an aspect of the self (17). If HCP do not get acquainted with the patient's experienced body, there might be a risk of only treating symptoms from 'the outside' and thus contact with how the patient him(her)self makes sense of illness might be lost. Holistic health care has been reported to be concerned with the individual as a whole, complete person and not as an assembly of parts and processes (35,36).

A prominent finding in our study was the consequences of the HCPs' passive faces due to the protective equipment. A gap between the bodies of the carer and patient was unavoidable as a real face-to-face encounter was not possible. In previous studies of experiences of patients suffering infection with multidrug-resistant tuberculosis and vancomycin-resistant enterococcus, patients have reported feeling of anger, anxiety, depression, loneliness, etc., as a result of distanced connection with their carers (33,37–39). The face is ethically compelling, because within its finite perimeter there are an infinite number of possible responses (40). Research has described, how face-to-face moments might lead to an empathic connection in which patients can find hope, meaning and solace (41). Recent evidence reported how HCPs across USA intent on humanising the COVID-19 experience have innovated alternative communication methods to bridge the gap between HCP and patient, and a study describes how a portrait of the HCP could be attached to the protective equipment to help humanise care (42). Data captured during the treatment of Ebola showed that such portraits helped patients feel more connected to their caregivers (43).

Illuminated in our study were experiences of how participants found themselves having a toxic and dangerous body putting a restraint on HCPs who retreat from them. According to Merleau-Ponty, the body is a unit of meaning, an active producer of sense in contexts (16,17). HCPs' responses to the ill body as poisonous is of great concern and a threat to the patient's core of the self. Research on other infectious diseases such as Ebola, hepatitis C and HIV also reported its charismatic ability to ignite fear, anxiety and disgust suggesting specialised training programs in universal precautions for HCPs (44–46).

After COVID-19, participants described how they appreciate their health; however, their bodies are still marked and vulnerable. According to Merleau-Ponty, the healthy body is taken for granted and remains in the background, while by contrast when the body is ill, attention is drawn to its malfunctioning parts (17). This loss of the habitual body makes the present body feel foreign and may have consequences

for the capacity to engage with the world. A sense of meaning might be lost when experiences become focused upon the sensations themselves such as breathing, pain and other symptoms (16). Understood in this way COVID-19 affects human existence as a whole. The participants in the present study thus had to learn to trust and reconnect to their body again and its sensations.

This study illuminated participants' insecurity in assessing own bodily symptoms. It suggests that follow-up from the healthcare system would have supported them in the process of taking control and responsibility for their own body again. Illness is a transformation that suspends everyday routines and conventional action and throws everything into question (16). The participants had to develop new skills and strengthen their perception of body and self, and research has shown how through achieving and advancing knowledge about their own challenges, changes in the body and the consequences in everyday life, patients can gain a new understanding of themselves and their bodily changes (47).

Stigma appeared as a profound mark on the participants who experienced that their body became a symbol of fear. To follow Merleau-Ponty (16,17), the participants' lived body cannot move away from itself or be put in front of itself, and it is always with them and remains on the margins of all their perceptions. However, in the descriptions of the participants' stigmatised embodiment, their body is not on the margins of their perception, but visually foregrounded, both for themselves and others. Experiences of their living body may start to fade, and the body may become a kind of distanced object. Merleau-Ponty's analysis starts from 'one's own body', always supposing that the body experienced is the one *proper* to the self. Feeling stigmatised after COVID-19 may thus be a traumatic experience, one which has been reported in research as well (27,48).

Strengths and limitations

Strategies were employed to demonstrate internal validity (18), including the collection of in-depth data, prolonged involvement with data, and use of the participants' own words to illustrate themes. Ricoeur's steps in the analytical process were defined and followed. The process from prefiguration through configuration to refiguration reflects the shift from lived life to narrative accounts of lived life to the final interpretation, which provides an insight into the individual participants' concrete experiences and into universal phenomena of life for people living through a COVID-19 illness trajectory. The purpose of including inspiration from Merleau-Ponty's philosophy was to develop and deepen the understanding of participant experiences, adding a perspective broader than our own (49).

Telephone interviews were unavoidable due to the risk of virus transmission between the ill person and interviewer. Such interviews do, however, have some disadvantages. They are more impersonal in that it is not possible to have eye contact, and as an interviewer, it is difficult to show that you are interested and involved in what is being said, for example by nod and other body language (18). Despite this, we experienced that participants appreciated telling their illness story, and that they spoke extensively about their experiences. Some also expressed relief when narrating. Talking helped people to understand themselves better or differently (11), and the interviews may thus have had a therapeutic function.

The chosen sampling strategy in this study meant that the participants themselves had to approach the research group if they wanted to join the study and participate in interviews. A potential limitation of this strategy was the risk of including only the 'best/strongest' out of this patient group. Therefore, the treatment trajectory, symptoms and problems for the overall COVID-19 patient group may be more comprehensive than described in this study.

A limitation in order to transfer the findings to other healthcare settings is lacking information on the included sample of patients. We must assume that patients with COVID-19 receiving nasal IPPV will have a far different experience than a patient with just low flow oxygen. Similarly, a patient admitted in hospital for 3-4 days will have a far more different experience than one admitted for 3-4 weeks. Having a table of the hospitalised patients with the duration of admission to hospital, ICU, duration of oxygen, duration of invasive or non-invasive ventilation would have been helpful to understand the spectrum. It was, however, only 5 patients out of the 15 patients in the included sample, who had been hospitalised due to severe symptoms.

CONCLUSIONS

During a COVID-19 illness trajectory, participants experienced a body they could not trust, and they were concerned about the unknown course of this disease. When isolated in groups, participants were confronted with other weak and ill people; however, a companionship between patients was described. The meeting between the COVID-19-infected person and HCPs was found to be a challenging balance between observing and measuring the physical body while at the same time recognising the ill person's lived body and individual bodily perceptions. The study shed light on a gap between patient and HCP due to protective equipment diminishing the possibility for a real face-to-face encounter. The participants experienced their body as vulnerable and marked after COVID-19. They oscillated between a sparkling happiness of being cured and insecurity in assessing their own

symptoms. Their bodies were labelled as something others fear and became a symbol of awe and alienation for others.

Clinical implications

Research involving the patients' perspective of being ill with COVID-19 may help improving understanding and lead to better ways of supporting these people. In order to meet these patients' need for care and support during their COVID-19 treatment trajectory, holistic healthcare follow-up is suggested including physical rehabilitation and psychosocial components. Also, a narrative medicine model might be useful to implement for individuals during and after COVID-19 illness as a therapeutically central act because to find the words to contain the disorder and its attendant worries might give shape to and control over the chaos of illness. Additionally, peer support from others affected by this disease should be considered. A significant task for HCPs is to mitigate the consequences of isolation and stigma for individuals affected by COVID-19. When wearing protective equipment wearing portraits of themselves is suggested.

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CONFLICT OF INTEREST

No conflicts of interest exist.

AUTHOR CONTRIBUTIONS

The research team developed the study protocol and topic list for the interviews together and discussed the themes and subthemes. SKB/CB/MM conducted all in-depth interviews. All the authors did the analyses together. MM drafted the manuscript, and all authors critically reviewed and approved the final manuscript. All the authors had full access to all data in the study and take responsibility for the integrity of data and accuracy of data analysis.

ETHICAL APPROVAL

Approved by the Danish Data Protection Agency (P-2020-276) this study adhered to the Danish Ethics Research Committee guidelines and the Helsinki II Declaration. Participants received written information about the purpose of the study and their right to withdraw at any time with no consequences for their treatment. Participants provided informed oral and written consent before being interviewed and were told that interview data would be treated confidentially. Data were anonymised using identification codes.

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