

It's Not Just a Virus! Lived Experiences of People Diagnosed With COVID-19 Infection in Denmark

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Abstract

The purpose of this study was to explore the lived experiences of people infected with the coronavirus in Denmark during the first phase of the pandemic. An explorative qualitative design underpinned by a phenomenological hermeneutical approach was applied. Fifteen individuals with confirmed COVID-19 infection were included and interviewed individually by telephone. Analyses were inspired by Ricoeur's interpretation theory. The study illuminated how being diagnosed with COVID-19 was experienced not just a virus infecting the participants' biology; it was also a threat to their existence and bodily perception as well as an interference in ordinary social relationships. Beyond a supportive approach, the participants experienced being a special case where people around them acted with excitement and curiosity. Responsibility for existential and emotional care after COVID-19 has been placed with the individual ill person and within their ordinary social circle. We suggest follow-up and rehabilitation for people during and after COVID-19 to support recovery.

Keywords

qualitative study; Ricoeur; patient perspective; COVID-19; coronavirus; qualitative; phenomenological hermeneutical; Europe

Introduction

The COVID-19 pandemic will make the year 2020 a once-in-a-century global event. COVID-19 is an infectious disease caused by a newly discovered coronavirus and it is a disease showing no respect for geographical borders. A large amount of research contributing to more efficient clinical management of people infected with the virus, as well as public health preparedness and response has already been published (Dubey et al., 2020; Jean et al., 2020; Pascarella et al., 2020; Rothan & Byrareddy, 2020; Sohrabi et al., 2020). This research mainly deals with the clinical presentation and features of the COVID-19 infection with a focus on COVID-19 pathophysiology, diagnosis, potential treatment options, and prognosis, from a biomedical viewpoint and uses objective scientific methods. Thus, experiences of diagnosis, illness, and treatment from a first-person perspective (the ill persons' perspective) and the meaning they attach to these experiences have been scantily investigated. This study includes participants with COVID-19 infection, both people hospitalized and those who were isolated at home, and offers an in-depth understanding of issues and concerns for these individuals. These findings should be of interest to a broad worldwide readership within health care and will

add knowledge to the growing COVID-19 evidence base and in developing supportive interventions targeted infected people during pandemics in the future.

Background

The global pandemic of COVID-19 originated in China in December 2019 (Sohrabi et al., 2020). It has rapidly spread across China and many other countries and was declared a Public Health Emergency of International Concern by the World Health Organization in January 2020 (World Health Organization, 2020a). Early research reported a link between a single local fish and wild animal market and cases of infection, indicating possible animal-to-human transmission; however, studies have

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increasingly demonstrated human-to-human transmission of COVID-19 through droplets, direct contact, or through contact with contaminated environmental surfaces (Lai et al., 2020; Pascarella et al., 2020). In the case of COVID-19, most people infected with the virus will experience mild to moderate respiratory illness and recover without requiring special treatment. Older people and those with underlying or coexisting medical problems are more likely to develop serious illness (Cruikshank & Shaban, 2020; Jin et al., 2020; World Health Organization, 2020a). Patients will most often present with clinical symptoms of dry cough, dyspnea, fever, and bilateral lung infiltrates on imaging (Pascarella et al., 2020; Rothan & Byrareddy, 2020). Patients with a suspected infection are recommended to be isolated, monitored, and diagnosed in hospital as soon as possible. Patients with mild symptoms are isolated at home (Jin et al., 2020).

There are currently no therapeutics or vaccines available for the COVID-19 disease and, presumably, no pre-existing immunity in the population (Al-Shamsi et al., 2020; Pascarella et al., 2020). Management of the disease is primarily based on supportive therapy and on treating the symptoms and trying to prevent respiratory failure (Pascarella et al., 2020). Research has furthermore suggested that patients might be vulnerable to the emotional impact of coronavirus (Lima et al., 2020) and others have suggested that psychological and humanistic care should be performed for patients with COVID-19 (Jin et al., 2020). To meet the patients' specific needs for such psychological support, there is an urgent need to investigate how the diagnosis and illness impacts the lives of these ill people. Such research will help to identify needs for care interventions from the point of diagnosis and during the hospitalization and recovery periods. The majority of studies on patients with COVID-19 infection apply a predominantly quantitative approach (Vindrola-Padros et al., 2020). While the results of those studies have advanced knowledge in this area, little knowledge exists on the patients' perspective on receiving a COVID-19 diagnosis and its impact on their lives. Illness experienced from the ill person's perspective in its qualitative immediacy is grounded in lived experience and the purpose of this study was therefore to explore the lived experiences of people infected with the coronavirus.

Method

Design

This explorative qualitative study was underpinned by a phenomenological hermeneutical approach inspired by the French philosopher Ricoeur, creating an epistemological stance for exploring first-person accounts of the

experience of undergoing a COVID-19 illness trajectory (Missel & Birkelund, 2019; Ricoeur, 1984, 2002). This approach offers a frame in which participants' lived experiences can be interpreted, and thus, a comprehensive understanding can be achieved. The expression "lived experiences" refers to the phenomenological tradition concerning experiences of the everyday lifeworld. Such experiences from our lifeworld are prereflective and therefore less available to our awareness (Galagher & Zahavi, 2012; Ricoeur, 1984; Zahavi, 2019). The importance of including a perspective and focus on lived experiences and lifeworld is not to reduce human beings to subjects who react according to certain laws that can be observed. Instead, humanistic health research must generate insight into the lifeworld phenomena which are important to ill people. These are phenomena that cannot be captured through objective scientific methods (Galagher & Zahavi, 2012; Missel & Birkelund, 2019).

Participants and Recruitment

The participants were people who had undergone an illness trajectory with a confirmed COVID-19 infection. A convenience sampling strategy was used (Polit & Beck, 2020) by giving out flyers about the study encouraging participants to approach the research team by email, if they were willing to attend an interview. The flyers were posted at corona test facilities, COVID-19 hospital departments, and social media. Snowball sampling (Polit & Beck, 2020) was also utilized to recruit new participants among the existing study participants' acquaintances. Everyone with a confirmed COVID-19 infection, who approached the research team, was invited to participate in the study. Fifteen participants agreed to participate and were interviewed between March 23 and April 1, 2020. Five participants had been hospitalized due to severe symptoms, whereas the remaining 10 participants were isolated at home. The mean age for all participants were 46 (range: 22–67 years), and seven were male. Participants were recruited from three different regions of Denmark.

Data Collection

As human beings, we are able to experience the world in a prethinking way (Missel & Birkelund, 2019; Ricoeur, 1998). Narratives enable us to share the meaning of these unarticulated experiences (Ricoeur, 1976). To gain access to the lived experience of living through COVID-19 illness, a narrative approach was therefore used for data collection during individual interviews. The participants' narratives reflected their experiences as they saw them and wanted to present them. The interviews were open-ended to explore the participants' lived experiences and

emphasized listening to the participants. Participants were asked to narrate how they experienced undergoing illness caused by a COVID-19 infection. Narrative accounts of participant experiences were encouraged but questions such as “How did you feel about and experience the various things that happened or took place during your illness?” and “Can you tell me more about your experiences during hospitalisation/at home/when you came home/after you were free of symptoms/after you got well?” were used during the interviews. When recounting their stories, participants brought about a configuration themselves by summarizing a chain of events or actions. All interviews were conducted by telephone based on ethical accountability to not contribute to the spread of the virus. Three experienced qualitative researchers, who were not part of the clinical care and treatment for COVID-19 infected patients, performed the interviews. The interviews lasted on average 46 minutes (range: 21–70 minutes) and were recorded and transcribed verbatim by the individual interviewer or by a research assistant.

According to Ricoeur, something happens to the language when the spoken words are transformed into written words. He rejects the notion that written text is merely fixed, preserved speech. He emphasizes that the written text is not simply an extension of the spoken words. When writing down the spoken word, the meaning is liberated from the event, which means that the meaning of the text is freed from the author’s underlying intention (Missel & Birkelund, 2019; Ricoeur, 1998). The task of the interpreter is therefore not to look behind the text, for example, to discover the patient’s psychology, but rather to interpretively unfold the issue which the text is pointing to.

Data Analysis

According to Ricoeur, embedded in a language there is always a meaning that extends beyond the direct linguistic expression (Missel & Birkelund, 2019; Ricoeur, 1976, 1998). As such, language, including texts, contains connotations that can only be approached through a process of interpretation. The focus of interpretation is not the text, the transcripts, in themselves, but the issues and meanings which the text points at. Inspired by Ricoeur, the interpretation process has to do with different layers of meaning understood as an endless spiral involving three levels: a naive search for the overarching meaning which the text seeks to convey, a linguistically oriented structural analysis, and an in-depth comprehensive interpretation (Ricoeur, 1976). The spiral process of analysis and interpretation are illustrated in Figure 1.

In the *naive interpretation*, reading and rereading of the narratives took place to gain an initial understanding of

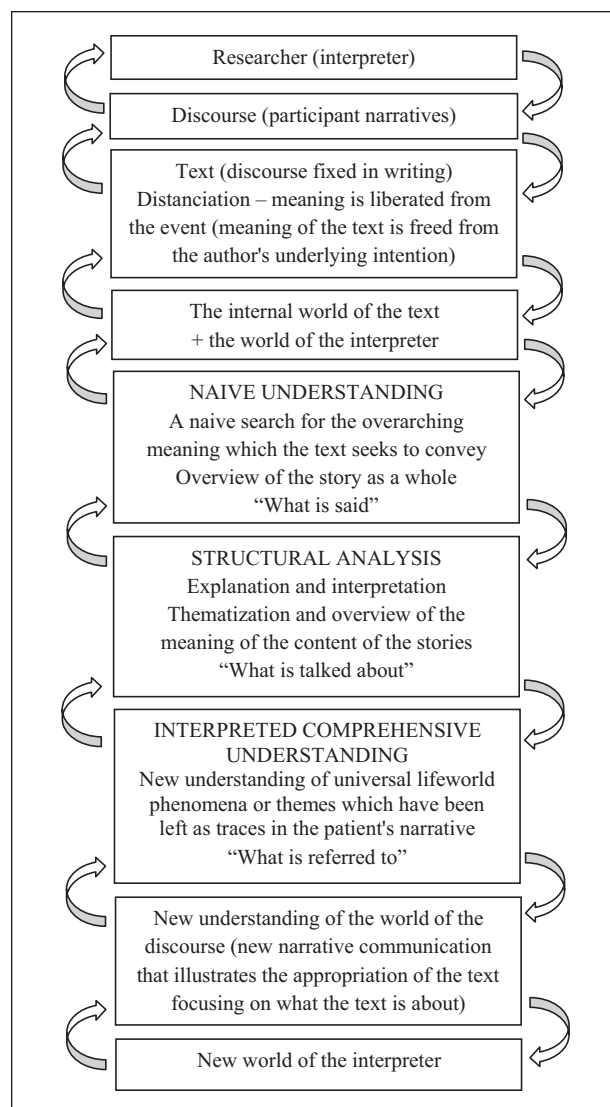


Figure 1. Illustration of the spiral analysis and interpretation process.

Inspiration from Ricoeur (1976).

what the texts were about. This was a surface interpretation that Ricoeur calls a naive grasp of the meaning of the text as a whole. This initial interpretation helped us to provide an overview of the narratives. The *structural analysis* provided an insight into the structure of the text. Describing the structure gave the text an objective content and only the internal nature of the text was considered. From this perspective, it had no context, no external world, and there was no consideration of its having an author or an audience. What arose from this part of the analytic and interpretive process was explanation, which was possible because of the objectivity of the text (distanciation). At this level understanding was relatively immature and took into account the meaning of the words as we understood those. The function of the structural analysis was, however, to proceed from the

initial overview of the stories to enable a more in-depth interpretation, thereby exceeding the naive understanding. Ricoeur expresses this as, “*Interpreting a text means moving beyond understanding what it says to understand what it talks about*” (Ricoeur, 1976, p. 88). The structural analysis led to an opening up of the whole text to make further interpretations possible. The idea, according to Ricoeur (1976), was to first split up the text into “units of meaning” representing “what was said.” Next, units of significance were identified as descriptions of “what the text spoke about.” Thus, the analysis was conducted as a dialectical process, moving from “what was said” to “what the text spoke about” leading to the emergence of patterns, sub-themes, and main theme. This process was carried out as an ongoing internal validation of themes in relation to the naive reading, units of meaning, and units of significance. Hereby, we achieved insight into the meaning of the lived experiences of the participants. The process of deriving units of significance and themes constituted the foundation for describing the findings of this study. The *comprehensive interpretation* had a transcending aim of restoring the narratives to a living communication. Where structural analysis was solely aimed at a closed system, the comprehensive interpretation was aimed at understanding the meaning and range of the texts’ statements. Through interpretation of the world of the text combined with the world of the researchers, something new was formed. In this way, the focus was on what the text was about and what it referred to. To transcend the findings from the individual to a universal level, the structural analysis was discussed in a dialogue that included reference to other relevant theories and studies. As such, we continued with an in-depth interpretation and discussion of the themes we had identified in the structural analysis. Thus, the interpretive understanding elaborated a deeper understanding of the lifeworld phenomena that had been included as traces in the participants’ narratives. This interpretation of factors that are external to the text restored it to a living communication (Ricoeur, 1998).

Ethical Considerations

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 anonymized using identification codes.

Findings

In this section, we present the themes that emerged through the structural analysis of the narrative interviews.

The meaning of receiving a COVID-19 diagnosis was expressed in one main theme comprising three sub-themes. The main theme expressed how the participants experienced the illness not just as a virus infection but also as a threat to their existence and bodily perception as well as an interference in ordinary social relationships. As the participants experienced COVID-19 not just as a virus, they highlight the seriousness of being diagnosed with a new and unknown illness. This ignorance and uncertainty about the coronavirus, transmission routes, illness process, and prognosis meant that getting a COVID-19 infection was expressed as a substantially different experience for the participants than that arising from other well-known virus diseases.

COVID-19 as a Threat to Existence

After being diagnosed with COVID-19, the participants experienced how life’s existential questions suddenly became very present in their awareness. The existential thoughts revolved around questions such as “*why me?*” and “*it simply cannot be true!*” It was hard to believe that it was really happening, and it might feel like a dream. Acknowledging that their lives might be in danger entailed an emotional shift from everyday life, and this experience appeared as surreal as expressed by this woman who was isolated at home: “*It’s actually kinda surreal . . . You have the feeling that tomorrow I’ll wake up, and then it’s all just a dream; it’s hard to believe that this is really happening.*” The participants faced their own mortality and became aware of the fact that something that they did not expect to impact them was now actually doing so. They also described how worldwide news about the virus contributed to a heightened sense of seriousness and threat when they themselves were struck by the COVID-19 infection as narrated by this woman who was hospitalized during illness:

I’ve been stupid and watched so much news . . . And the yellow headlines running across the screen saying that now the amount of dead people is rising in Italy and China . . . So, you got a bit like: God, why me?

Participants switched between thinking that it was a global mass hysteria that has been completely blown out of proportion and then a comparison with the previous SARS outbreaks and COVID-19 high mortality rates activated a wave of considerable concern.

The constantly breaking news about the spread, the extent of infected persons, and the increasing number of dead people worldwide due to COVID-19 infection reminded the participants of their own mortality and that they could not take life for granted. The high risk of infection and transmission and total uncertainty and insecurity about how the disease would develop for the

individual further contributed to the COVID-19 infection experience as an existential threat. After a lengthy course of illness and hospitalization, one male participant describing himself as young, healthy, and not at risk of coronavirus recommended the following to his fellow human beings: “Please try to avoid getting infected, because you have no idea where you are going, and you have no way to find out until you are in it [the course of the disease].” While the participants, on one hand, faced the new coronavirus not just as a virus but also as a threat to their existence, they tried on the other, also to distance themselves from acknowledging that they were infected. By doing so they were able to protect themselves from worries and confrontation with the disease and its consequences for themselves and others as described by this woman who was isolated at home:

I had this thought for a moment, that if I didn't say anything to anyone [that she's sick] . . . because I can't handle it . . . and if I've infected others . . . So, if I just didn't say it to anyone, and then they won't find out . . . I really had that kind of thoughts.

This participant described these thoughts as illegal and irresponsible, and she ended up telling the right people that she was infected and ill. Stories like this, where the alien and creepy are pushed away for a while, were pervasive in the participants' narratives, always followed by feelings of guilt. This testifies to the severity of the illness experienced by the participants.

While COVID-19 disease was perceived as unreal, the test situation was a confrontation with the seriousness of the new and unknown virus. The participants narrated how they were met by health care professionals wearing “that moon-base equipment.” The meeting with health care professionals wearing protective equipment gave the participants a feeling of being infected with a very dangerous disease. Thoughts of the scary nature of the disease and possible fatal outcome brought participants to a shaking of the root of their existence which was expressed by this man who was isolated at home: “You can build up a certain awe for corona and for COVID-19 . . . So, with the fact that you have it yourself, you have to comprehend . . .” Generally, the participants, however, experienced the positive test result as a relief. They stuck to the theory that we all need to be infected with coronavirus to form immunity. Therefore, it became an aid for the participants to know that they did not have to fear this particular disease in the future. Despite this relief, an uncertainty was lurking in the background of the participants' consciousness. While they were hoping for immunity, there was also ignorance about whether they could become infected again as narrated by this woman who was isolated at home:

I think it was a relief. Now I've had it . . . I am fortunate, however. Until you read, that it may well be, that you can get it again. So, the confidence you have got that now I am happily over it, then . . . Is it really so, that you can have it again in a few months? When I get out, can I get infected again? It is the uncertainty that makes you feel unsafe. And I think that's unpleasant.

This basic uncertainty and confrontation with their own mortality meant for the participants that they also experienced increased vulnerability. This vulnerability was perceived as surprising and also confrontational, and the participants narrated the awareness that attention to their own mortality was something that they will live with in the future as told by this woman who was hospitalized during illness: “I have a vulnerability that I didn't think I had . . . You are more mortal, than you expect, so it has put thoughts in motion. . . It will always be in my awareness, that I know, I can be hit . . .”

COVID-19 as a Threat to Bodily Perception

With the sudden and dramatic impact of having COVID-19 infection, the participants found themselves disoriented with a loss of the familiar world and a loss of certainty and control. The interviews revealed that the participants' bodies spoke to them now in a more threatening way than previously. The symptoms from the illness lifted the body from the background of the participants' experience to the foreground of their awareness with consequences in terms of an alteration in the perception of the body's signals and expressions as told by this woman who was isolated at home:

At a time when I was just laying down, I counted my heart rate to 170, which was really uncomfortable. Maybe I knew it was because I'm anxious about having this high heart rate, but maybe it's also because my body is trying to fight the disease . . . Maybe it's a combination . . .? Some thoughts went through me . . .

Thus, the participants experienced losing confidence and control of and in their body and they experienced their bodies as having changed capabilities for communicating. Therefore, the participants found it difficult to rely on their bodily perceptions. The participants furthermore described how this altered perception of their own body was making them nervous and insecure. They doubted their own ability to judge well and expressed how their body reacted on its own which was described by this woman who was isolated at home:

It crunches in my chest, and I have a hard time breathing, and then I start to get dizzy and extremely uncomfortable in

my body . . . Because I live alone, I also get scared, because what if I fall, and I don't have anyone to make an emergency call for me? It may well be that it is just the reaction in the body, after so long with uncertainty and with the knowledge that you are ill, and that my body has just reacted.

The participants furthermore described experiences of unfamiliar sensations and emotions, for example, crying, sadness, and worry. They were shocked out of their taken-for-granted way of being and they described how they were living with a confusing mixture of such feelings. When bodily reactions were unfamiliar it felt like a threat to their bodily perception as told by this woman who was isolated at home: *“Psychologically, I get uncomfortable in my own body. And I have never felt that in my life before. But I've noticed this lately. I get unwell and I get anxious.”* Thus, self-understanding, moods, emotions, and thoughts were altered by the illness which seemed to have had consequences for daily activities, including, for example, their joy in watching films, where they currently lacked concentration and were unable to engage in more serious and emotional films. These bodily reactions also interfered with the participants' involvement with the usual stream of news about the pandemic. The participants expressed how they experienced a heightened sensibility and how their body reacted on their behalf when watching the news about the COVID-19 infection. They felt insecure about their bodily expressions as described by this woman who was isolated at home:

I get nervous, and it hurts in the chest, does it have something to do with corona? Is there something wrong? And if I see something serious or hear something, then I can also feel that I am getting a little like . . . that it, for example, hurts a little in the chest . . . I also get a little uneasy, because we have heard about how serious it is in Italy.

COVID-19 was not just a virus, but it was an illness threatening the infected individuals' bodily perception. Thinking back, reading their own Facebook diary or watching photos or videos from the worst period in their illness trajectory reminded the participants about the seriousness of their situation, which awoke bodily reactions as narrated by this man who was hospitalized during illness:

I made a video diary. It was something I filmed while hospitalized. There I sat with my phone and oxygen in my nose and filmed. When I saw it, I got a panic attack because it was my body, right there . . . It just flushed through my body of discomfort because it reminded me that I was just in there . . . It was me a week ago . . .

The unfamiliar reactions from the body were evidenced in this young man's story, frightening reactions that are

beyond his own conscious control. Despite finding their body foreign and unreliable, the participants tried to regain familiarity with their body after illness. They were trying to transform their embodied disruptions into a bodily awareness by use of different strategies. Such strategies included drawings and illustrations of the disease trajectory, as well as of the health care professionals wearing visors and masks and experiences associated with that. Others had a great need to talk about the course of the illness again and again and expressed it as a way of re-connecting to oneself again. Distancing oneself from the virus and imagining how it was possible to fight against it was also described as a strategy to take back control over own body as described by this woman who was isolated at home:

I visualized the nasty virus that was inside my body and I yelled at it; it was disgusting, that it was trying to suck on my cells around in my body. It was really evil . . . I've had many pictures of the virus that went around inside my body.

Despite the described ways of dealing with disrupted bodily perceptions, the participants generally expressed a need to put their experiences into words.

COVID-19 as an Interference With Ordinary Social Relationships

The participants' ordinary social relations became very significant during illness and were a key element of their narrative accounts. They experienced tremendous practical and emotional support and help from their social networks. It was a support beyond the ordinary and which they had never experienced the like of before. Family, friends, neighbors, and colleagues often did a little extra for the ill person, such as bringing flowers, buying a little surprise when shopping, or playing cards through an open window while keeping distance. For the participants, it felt like care, attention, and love, which helped them through the course of the illness. It was extremely supportive in a time of uncertainty and loneliness, and the participants were touched by the immediate participation and compassion for their situation as told by this man who was isolated at home:

I've never seen so many people who would like to help: “Hey we're out shopping, what should I bring for you?” My friend, who lives just around the corner, she put fresh breakfast bread in my driveway . . . I really got a lot of “can we help you with anything?” I've experienced so much helpfulness . . .

The enormous attention testified to the special situation to which the participants were brought by the new COVID-19 disease and confirmed that COVID-19 was

not just a virus. Thus, the encounter with this new and unknown disease caused people in their social network to act almost like the Good Samaritan pushing thoughts of reasonable help aside and participating with empathy and charity for the ill person.

Although the participants greatly appreciated the caring help and support of their close network and acquaintances, it also put them in a situation where they felt unable to repay it. They experienced embarrassment and paid close attention to not being too much trouble. There was a shift in the normal social relationships in which the ill people found themselves in a receiving role and a burden to others as told by this woman who was isolated at home: *“I have not had a problem getting help with shopping, but you are feeling the trouble for others and being a burden to others”* Balancing between receiving help and support while not feeling awkward and inferior in the relationships could thus be a difficult experience for the participants and which required a little extra strength and energy.

The participants furthermore described how supportive it felt to have someone in the surrounding social circle to talk to when they felt anxious and insecure. They experienced the healing of being allowed to share the thoughts and concerns that dominate consciousness and everyday life and expressed it as a kind of coping with the situation as told by this woman who was isolated at home:

It really helped to talk to those I have close to me; to talk to them and talk things through. Also, my family, my mom and dad, those were probably the ones I could talk to for several hours a day because they had plenty of time to listen to my frustrations and how I was feeling. So, they have been a huge support.

It was also particularly important for the participants to have someone to tell their illness story to over and over again as narrated by this woman who was hospitalized during illness:

I wrote to my family that they should allow me to talk about it again and again. You are scared to feel the symptoms that you have read about can be so dangerous, and it is scary to be in the hospital and hear how sick the others were . . .

The course of COVID-19 illness thus forced the relatives to participate in the healing process of the participant, so taking co-responsibility for the ill person being able to handle a life with and after the illness.

Despite the overwhelming attention and care, the participants also described how their social circle was sometimes very curious about the ill person's situation as expressed by this man who was isolated at home: *“It has been both caring at the same time with interest and curiosity,”* as well as this woman who was also isolated at

home *“Wow have you really got . . . ! It is extremely exciting that I have what everyone talks about; it is obviously more exciting than it is scary”* The news and excitement of knowing someone who had coronavirus meant that the participants found themselves becoming a *“special case.”* In such situations, the care, love, and concerns from the participants' social surroundings faded into the background and the insistent curiosity dominated the social bonds and connections interfering with and threatening the ordinary social relationships.

A paramount consequence of being infected with coronavirus was the participants' fear of having infected others in their social circle. They narrated about how frightened they were about the risk of hurting others and being *that* person who, by infection and transmission, could threaten the health of other people as told by this man who was isolated at home: *“What has filled me the most, it has not been concerns about myself, but concerns about who I may have dragged down when I got sick”* The participants felt like ticking bombs and they had stopped touching others and were isolating and distancing themselves long after they had felt any symptoms of COVID-19. This continued distancing had consequences for the participants' social and emotional daily life as described by this woman who was isolated at home:

I'm not dying from the pandemic, I'm dying of skin hunger . . . We dare not touch each other, I dare not give the hug which actually means a lot in everyday life. I can really feel the spontaneous need to give people you like a hug. Then one step forward, and then “oh no,” and then one step back again. We've lost something . . .

The lost emotional closeness and intimacy that this participant talked about were due to her not daring to touch other people because of the danger of infecting them.

Comprehensive Understanding and Discussion

This is one of the first studies to explore the lived experiences of people infected with the new coronavirus which causes the disease COVID-19. Three themes emerged that identified the meaning of the illness from the participants' perspectives: COVID-19 as a threat to existence, COVID-19 as a threat to bodily perception, and COVID-19 as an interference in ordinary social relationships. The themes highlight that COVID-19 is not just a virus for the affected people. In the following, we elaborate on what people with COVID-19 infection experience during and after illness, derived from the themes. Selected aspects of theory are used to interpret the findings to achieve a further, deeper, and comprehensive understanding of the participants' lived experiences.

Of crucial importance for the participants' lived experiences of receiving a COVID-19 infection was the narrations of the threat this new and unknown virus had to their existence. Existential thoughts and questions were strongly present in their stories of illness, and COVID-19 as a surreal experience was underlined. Thus, death as a condition of life was transformed from being something abstract that concerned others to becoming something real, concrete, and relevant. According to the Danish philosopher Kierkegaard, existence means both existence in itself, being, but it also means coming forward and taking responsibility for one's own life (Kierkegaard, 1962). The most difficult thing for human beings in the process of dealing with responsibility for one's own life is the confrontation with being and nonbeing. Relating to one's possible nonbeing is something most people will push away; death only happens to others. However, when hit by serious illness, they are often more clearly confronted with the basic or existential living conditions such as death, freedom, loneliness, and the question of meaning (Kierkegaard, 1962), which is also reported in research of patients with other illnesses (Damsgaard et al., 2016; Lee, 2008; Simoný et al., 2015). The participants in the present study were trying to push away thoughts about illness and possible consequences for a while. The test situation and meeting health care professionals wearing protective equipment, however, confronted them with the seriousness of the situation and forced them to act accordingly. Research has highlighted that in the early phase of the SARS (severe acute respiratory syndrome) virus outbreak in 2003, a range of psychiatric morbidities including persistent depression, anxiety, and panic attacks were observed (Cheung et al., 2008; Su et al., 2007). Drawing parallels with COVID-19, other research, therefore, suggests that mental health care should be provided to COVID-19 patients (Taquet et al., 2020; Yi et al., 2020). Our study findings do not support or confirm any psychiatric morbidities due to the different research paradigm and approach applied, but COVID-19 as a threat to existence as illuminated in our study might complement studies suggesting the need for mental health care. A response to experiences of COVID-19 as a threat to existence may, following Kierkegaard, be not to quieten them, much less to remove them, but to live alongside such thoughts and relate to oneself through the presence of and conversation with other people (Kierkegaard, 1962).

COVID-19 illness was in the present study also shown to be a threat to the participants' bodily perceptions. The participants described in different ways how signals and expressions from their body were altered and how they were losing confidence and control of and in their body. Embodiment is a fundamental phenomenon in the French philosopher Merleau-Ponty's philosophy and is defined by him as the ways in which meanings, expectations,

and habits are experienced and expressed in the body (Merleau-Ponty, 2009). The body is a physical thing, an object that can be weighed, measured, and described using purely physical or naturalistic terms, but the body is also the source of subjective feelings, perceptions, and sensations, according to Merleau-Ponty it is the seat of subjectivity. Understood in the light of Merleau-Ponty, COVID-19 illness was therefore not merely a matter of dysfunction of the participants' physical body but was also about a transformation of the ways in which the participants experienced, reacted to, and performed daily tasks. The participants experienced their illness as a disruption of their daily routines and the familiar embodied actions that helped to understand and cope with the world. As a result, the participants lost their sense of security and control and came to see the world through a new prism, namely as unpredictable. Frontloading the concept of embodiment from Merleau-Ponty thus highlights that all parts of the body are integral to the human being and that no part can be separated from the rest or objectified (Merleau-Ponty, 2004). In this way, it is possible to understand how COVID-19 illness affects the whole person and that the illness is not just a virus with objective symptoms or dysfunctions, but rather that there is a complex relationship between meaning, body, and the situation in which participants had their own perception of the illness.

The findings in our study also indicate that daily news about the COVID-19 infection had an impact on the participants' bodily reactions. Participants expressed how they experienced increased sensations and how their body responded on their behalf as they watched the news of the spread of the virus and death rates. This is the first major disease outbreak that poses a global threat in the age of social media. Accounts vary, but research reports that social media and sensationalist reporting of the outbreak may have generated panic and mistrust in the general public (Dubey et al., 2020; Smith & Li, 2020) which has also been reported during other epidemics (Glowacki & Taylor, 2020). A consequence of laying out unchecked mind-boggling rumors, flamboyant news propaganda, and sensationalism may be fake information as well as negatively skewed misinformation which may metastasize faster than the coronavirus itself (Dubey et al., 2020). Social media also helps users "celebrate" COVID-19 symptoms for easy popularity, which can, however, cause a lot of confusion and panic for others. Other research, therefore, forces health care professionals to take responsibility for providing the correct information and creating effective communication with the citizens to curb this infodemic and mitigate the risk for their inappropriate behavior (Shimizu, 2020; World Health Organization, 2020b). Despite such challenges it is worth noticing how social media also may create a community for the involved individuals (Berard & Smith, 2019).

In a reformulating of their perception of themselves the participants in the present study described how strategies such as “talking about their experiences with the illness,” as well as illustrating or visualizing illness experiences helped them to work the physical forms of expression and unfamiliar sensations and feelings into their embodied being. Furthermore, they generally expressed a great need to put experiences into words. Narrative approaches to support people in a process of emotional and existential healing after illness have been comprehensively investigated (Henshall et al., 2017; Kirkevold et al., 2014; Roikjær et al., 2019) and are widely recommended (Charon, 2017; Frank, 2001, 2012) as well as creative expressions as a way of meaning-making in illness (Stuckey & Tisdell, 2010).

The participants described experiences of interacting with other people differently than prior to illness and as such COVID-19 interfered in the ordinary social relationships. On one hand, the participants described how they received tremendous practical and emotional support from their social circle in an empathetic, caring, and compassionate way, whereas they, on the other hand, at times could be overwhelmed by feelings of not being able to pay back and a fear of being a burden to others. According to the Austrian philosopher and sociologist Schutz (1972), the everyday lifeworld is fundamentally intersubjective and there is a relational association between people. The lifeworld is not private for any individual but rather it is “a world of our common experience” (Schutz & Luckman, 1974, p. 68). Normally, an individual sees himself or herself as being at the center of his or her social world, and groups of people surround that core in layers that reflect varying degrees of intimacy and anonymity to the individual. However, when the participants in the present study were affected by COVID-19 infection, the relationships with others appeared to change across the layers. Our study thus sheds light on the fact that someone quite anonymous in the participant’s social circle may suddenly be very present in a different way than previously and act as a Good Samaritan. The parable about the Good Samaritan is known from the Gospel According to Luke and is reinterpreted by the Danish philosopher Løgstrup among others (Løgstrup, 1991). Løgstrup claims that the Samaritan initially acted quite spontaneously. He did not even realize that it was his duty to help. It was instead out of immediate compassion that he comes to the aid of the assaulted person. And, furthermore, says Løgstrup, such immediate compassion for a vulnerable person is something we all have. And when we act spontaneously with compassion, we let ourselves seize what Løgstrup calls “sovereign expression of life” (Løgstrup, 1996, p. 21). This is different from perceiving help and support as a duty that one as a fellow human being should perform. Mercy is a sovereign expression of life and such

a phenomenon can people not master or create. Those phenomena creep up behind us without our consciously knowing or taking part. When a crisis arises, for example, a novel and unknown coronavirus, only then do we become aware of their existence or nonexistence. Løgstrup also states that sovereign expressions of life are spontaneous, that is, they can neither be substantiated nor explained (Løgstrup, 1991). The participants’ stories in the present study recount their experiences of how their social relationships spontaneously and mercifully supported them through the course of their illness. According to Løgstrup, it is a human precondition to be entangled with each other, which means that a person “always has some of the other person’s life in his hands” (Løgstrup, 1991, p. 25). If, however, this person tries to take over the other person’s individuality, will, and personality, this is an encroachment. We are all, in other words, independent and responsible individuals, but are also widely dependent on each other, but by providing a positive and mutual influence, the person will develop independence and act accordingly (Løgstrup, 1991). The individual may thus accept assistance from others and remain independent. By extension, however, the participants in our study had a fear of being a burden to others which is an aspect of illness also reported in other research studies (Bech et al., 2019; McPherson et al., 2007; Rodríguez-Prat et al., 2019).

The findings of our study furthermore illuminated how the participants also experienced people in their social surroundings acting with curiosity and excitement about knowing someone with COVID-19 illness. In such situations, the care, love, and concern the participants had otherwise experienced unfortunately faded into the background. Research has reported how social media has a raw potential during a public health disaster suggesting it to be a strange comforting sensation of searching for the big catastrophe story (Asmundson & Taylor, 2020). Stigma may be a consequence of being regarded as “the special case infected with coronavirus” (Yusen & Xue, 2020); however, a study conducted during and after the SARS epidemic witness how stigma did not decrease over time (Siu, 2008). Stigma occurs when someone is labeled as less desirable based on an attribute that marks them as different (Kleinman & Hall-Clifford, 2009). According to the American sociologist Kleinman, stigma is embedded in moral experiences. Morality for an individual or group is determined by their local social world, and maintaining moral status is dependent on meeting social obligations and norms. People with stigmatized conditions are in fact unable to meet social demands. Thus, stigma impairs the ability to hold on to what matters most to ordinary people in their local social world. The stigmatized and those who stigmatize are interconnected through local social networks (Kleinman, 2011). When people with a COVID-19 infection in our study

described how the illness interfered in ordinary social relationships, stigma might be present as they, during the period of illness, were marked as different special cases and are thereby not able to meet ordinary social requirements. A recent research study has, however, described how individuals may try to reduce stigma by acting as normal or selectively disclosing their stigmatized attributes (Seo & Song, 2019).

The interference of COVID-19 in the participants' social relationships is also about the participants' fear of infecting others with this novel coronavirus. Consequently, the participants in our study distanced themselves from physical social contact. Withdrawing from social events or physical encounters has been researched, and a review of the scientific literature about virus epidemics such as SARS and Ebola suggests that affected individuals may experience a sense of isolation from the rest of the world, while they may continue to engage in avoidance behaviors such as social distancing for a longer time than necessary (Brooks et al., 2020; Siu, 2008). Proximity and regular physical touch are essential for us as human beings to do well both mentally and physically. Loving hugs and emotional closeness not only feel nice here and now but are a fundamental human desire, kick-starting several beneficial processes in the body that are of great importance to our overall state of health (Kelly et al., 2018; Montagu, 1986). If we are not physically touched we will wither, which can lead to a condition popularly known as skin hunger. The lost emotional closeness and intimacy because of being infected with COVID-19 was expressed as skin hunger by participants in our study and is, as such, a phenomenon requiring focus when caring for people with COVID-19 illness.

Study Strength and Limitations

This study is one of a few qualitative studies exploring the lived experiences of people undergoing an illness trajectory with COVID-19 infection. The interview method provided insight into participants' perspectives and illuminated how these individuals experienced the COVID-19 illness not just as a virus. The internal validity (Malterud, 2011) of the findings and interpretations was ensured due to the in-depth data collection and prolonged engagement with the data. All authors performed all stages of data analysis and interpretation in a reflexive and dialogical process. The strength of this approach was that all authors participated with their individual preconceptions and horizon of understanding forcing the research team to move forth and back between the parts and the whole in the interpretive spiral. A challenge was, however, that it took time for certain key issues to emerge in the transcriptions due to the different backgrounds and preunderstandings of the researchers. To deepen our

knowledge of the participants' lived experiences, theoretical perspectives were applied. The purpose of including theoretical perspectives was solely to develop and make more profound the understanding of the participants' experiences, adding a perspective broader than our own (Missel & Birkelund, 2019). With regard to the applied analysis and interpretation, it is important to note that there is always more than one way to interpret a text. The interpreted comprehensive understanding in this article is what we found most probable from what the participants told in the narratives based on the researchers' preunderstandings (Ricoeur, 1976).

Telephone interviews in this study were unavoidable due to the risk of virus transmission between the ill person and the interviewer. Such interviews do, however, have some disadvantages (Davies et al., 2020). 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 included in what is being said, for example, by nods and other body language. In addition, breaks are generally less acceptable (Polit & Beck, 2020). We used a convenience sampling strategy, as it was a rapid way to address COVID-19 illness experiences, and thus a relatively quick way to get data collected in a situation where such data are highly relevant and urgently needed. The disadvantages of this sampling method are, however, that it may be people with resources and mental surplus that are included, which means that more vulnerable people's experiences are not considered (Crabtree & Miller, 1999), which the reader should consider when transferring the findings to other settings. Despite the limitations of this approach, we found the included sample very varied in terms of age, gender, illness trajectory, and narrative competencies, resulting in different and nuanced descriptions of their experiences.

Conclusion

In everyday life we do not, as human beings, think much about being here; however, in particular situations in life, we are confronted with our existence. Being diagnosed with COVID-19 was illuminated in the present study not just as a virus infecting the participants' biology but also as a threat to existence, bodily perceptions, and the participants' social relationships. People infected with COVID-19 were confronted with existential questions and were facing uncertainty and confrontation with their own mortality. The worldwide news contributed to a heightened sense of seriousness and threat. These people experienced how their self-understanding, moods, emotions, and thoughts were altered by the illness and they could not rely on their bodily perceptions. Signals and expressions from the ill persons' bodies were hard to interpret and understand, and they had a great need to put

such experiences into words. COVID-19 illness interfered in the ill persons' social relationships. Tremendous practical and emotional support from the social network was described. People in their social circle pushed away their own thoughts of reasonable help aside and participated with empathy. Beyond this charitable approach, the ill persons also experienced being a special case where people around them acted with excitement and curiosity toward them, meaning that the care, love, and concern from their social network faded into the background.

Relevance to Clinical Practice

COVID-19 illness is illuminated in this study not just to be a virus; it is also expressed as a surreal experience confronting the affected persons with their own mortality. The body presents itself with unknown sensations and a heightened sensibility and vulnerability. Responsibility for existential and emotional healing after illness has so far been placed with the individual ill person and within their ordinary social circle, imposing the duty for rehabilitating the ill person on the family and friends. Based on this study's findings, it is therefore strongly recommended to implement follow-up and rehabilitation for people during and after COVID-19 infection to prevent morbid outcomes and to support recovery. It is particularly necessary that health care professionals take responsibility for the follow-up to COVID-19-infected people.

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Data Availability

All authors have full control of all primary raw data (in Danish) and allow the journal to review our data if requested.

Declaration of Conflicting Interests

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