

An Unexpected Journey: The Lived Experiences of Patients with Long-Term Cognitive Sequelae After Recovering from COVID-19

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Abstract

This current study explored the lived experiences of patients with long-term cognitive sequelae after recovering from COVID-19. A qualitative design with in-depth interviews and an analysis inspired by Ricoeur's interpretation theory was utilised. Contracting COVID-19 and suffering long-term sequelae presented as a life-altering event with significant consequences for one's social, psychological and vocational being in the world in the months following the infection. Patients living with long-term cognitive sequelae after COVID-19 were in an unknown life situation characterised by feelings of anxiety, uncertainty and concerns about the future, significantly disrupting their life trajectory and forcing them to change their ways of life. While awaiting studies on treatment, symptom management and recovery after persistent sequelae of COVID-19, clinicians and researchers may find inspiration in experiences of other health conditions with similar phenomenology, such as ME/chronic fatigue syndrome and chronic headaches.

Keywords

recovery, health behaviour, cognition, fatigue, exhaustion, lived experience, long-term, illness and disease, neurology, qualitative, symptom management, covid-19

Introduction

The COVID-19 pandemic has suddenly and vitally impacted our daily lives (Day et al., 2020; Keller et al., 2020; UN, 2020), influencing our physical, mental, psychosocial and economic health and overall well-being (WHO, 2020). Presenting as a potentially life-threatening condition in the acute phase, while rendering a rising number of patients with severe, long-lasting complications (Huang et al., 2021; Lavery et al., 2020), this virus has challenged our healthcare systems since it emerged. We have yet to see the aftermath as the significance of long-term sequelae and potential interaction with chronic diseases is still unclear (Hacker et al., 2021).

Background

The number of cases involving long-lasting complications of COVID-19 is increasing (Huang et al., 2021; Lavery et al., 2020; Wang et al., 2020), and it is gradually being recognised that some COVID-19 survivors continue to suffer persistent symptoms even after a mild COVID-19

infection. Such complications are thought to affect roughly 10% of priorly infected patients. The most commonly reported sequelae include chest pain, shortness of breath, muscle and joint pain, headaches, cognitive impairment (i.e. 'brain fog') and fatigue (Kingstone et al., 2020).

Several studies have described experiences in people with long-term sequelae after COVID-19, but mainly as quantitative accounts of symptoms. For instance, Davis et al. (2021) conducted a questionnaire among patients with long-term sequelae and found that fatigue, respiratory difficulties and cognitive dysfunction (impaired memory and attention span and difficulty thinking) were

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the predominant symptoms. [Sudre et al. \(2021\)](#) found that fatigue and headaches were common denominators among patients with long-term sequelae after COVID-19 (symptoms lasting longer than 28 days) and a recent systematic review of long-term COVID studies ([Vanderlind et al., 2021](#)) reported a high prevalence of fatigue as long as 6 months after infection. A high prevalence of fatigue was also found in a study ([van den Borst et al., 2021](#)) investigating health status 3 months after recovery from COVID-19: 69% of the 124 patients reported fatigue, 64% reported impairments in daily life and 72% reported impairments in general quality of life. Only a few studies have focused on the lived experiences of patients living with long-term sequelae after COVID-19. [Ladds et al. \(2021\)](#) investigated lived experiences among doctors and other healthcare professionals suffering from long-term sequelae after COVID-19; they reported high frustration with the fact that there was no clear explanation or cause for their long-term symptoms, and they felt rejected by their general practitioner. This led the patients to seek support and information in social media groups and in their immediate networks to feel less alone, thus facilitating a feeling of shared identity and belonging.

[Roberts et al. \(2021\)](#) found a wide range of physical and psychological symptoms reported by their patients, with 'overwhelming fatigue' and lack of energy being the main physical symptoms. In terms of psychological experiences, the patients reported feeling a loss of control, fear of the unknown, anger, anxiety and being stigmatised.

Similar experiences were expressed in a qualitative study by [Kingstone et al. \(2020\)](#) among British patients with persistent symptoms after apparently mild cases of COVID-19. In their study, patients expressed a vicious circle of experiencing fatigue, causing them to spend time and energy on fatigue management, prioritising their time, searching for knowledge about fatigue and fatigue management and trying to gain access to assessment and treatment (further exacerbating their fatigue).

Post-viral symptoms such as fatigue is not an unknown phenomenon as a high prevalence of long-lasting fatigue months and even years after the SARS-CoV epidemic in 2003 was reported ([Islam et al., 2020](#)). Still, limited evidence on how to manage symptoms and the uncertainty of whether future rehabilitation is achievable has been reported to impact patients' distress, and besides the challenges of enduring, understanding and managing symptoms, patients have described difficulty in accessing care ([Kingstone et al., 2020](#)). This even seemed to be the case in a group of doctors describing their experiences as COVID-19 patients. They described feeling stigmatised and illuminated the challenges of enduring symptoms that could not be medically explained ([Taylor et al., 2021](#)). The

difficulty accessing care is explained partially because of altered consulting routines during the COVID-19 pandemic, healthcare professionals not acknowledging patients' symptoms as requiring support or care ([Kingstone et al., 2020](#)) and the lack of a consistent approach to the diagnosis, management and follow-up of patients with long-term sequelae ([Ladds et al., 2020](#)).

The existing literature thereby paints a rather discouraging picture of COVID-19 survivors suffering extensively and for a prolonged period of time, while lacking adequate healthcare. To support their recovery, it has been suggested that we prioritize the psychological and humanistic needs in our care ([Missel et al., 2021](#)) as the devastating fatigue, along with feelings of stress, anxiety and even panic ([Jin et al., 2020](#)) seem to blur and extent their healing. However, for healthcare initiatives to be effective, they need to be based on objective research of a disease's course, the efficacy of treatments and research of subjective experiences ([Ladds et al., 2020](#)) as these can help strengthen health services for patients and their families in the current resurgence of COVID-19 and future pandemics ([Liu & Liu, 2021](#)).

So far, research has mainly been conducted from a biomedical viewpoint, and knowledge on the lived experience of contracting COVID-19 from patients' perspective is still lacking ([Missel et al., 2021](#)). The narrative approach contributes to identifying new opportunities for gathering in-depth knowledge of patients' life experiences, which is a necessity for the improvement of quality of care. It further provides healthcare professionals with a valuable insight into the patients' worlds as revealed by the narrative they provide. Narratives of lived experience conveniently grasp the complexity of medical activity and the multidimensional reality of disease. This is essential when addressing health and healthcare, as they are non-linear phenomena which emerge from different components and clinical decisions, and need to be properly refined in order to accommodate the individual patients' needs and circumstances ([Russo, 2021](#)).

Since the perspectives of afflicted COVID-19 patients have yet to be thoroughly understood, this study aimed to explore experiences of patients referred to an outpatient neurological clinic receiving patients with long-term COVID-19 sequelae. The focus was on gaining an in-depth understanding of their lived experiences and overall significance of sequelae in these patients' lives, while contributing to the emerging knowledge that can form future interventions.

Methods

To explore the experiences of patients living with long-term cognitive sequelae (LTCS), we used a qualitative study based on individual in-depth interviews.

Participants

The participants were recruited from an outpatient neurological clinic in a university hospital in the Capital Region of Denmark which receives patients with long-term COVID-19 sequelae. The inclusion criteria were patients experiencing LTCS and the ability to speak and understand Danish. Since LTCS is a rather unknown phenomenon, a strategic sample strategy was applied. We strived for variation in our sample in relation to sex, age, level of education and if the participant had returned to work. Please see [Table 1](#) for patient characteristics.

Recruitment

When attending a consultation at the clinic, the participants were introduced to the study by a member of the clinical staff. If the patient accepted to participate, one of the authors subsequently contacted the patient by phone to make an appointment for the interview. Nineteen patients participated and were interviewed from June to August 2021. Two patients were hospitalised in the acute phase, while the remaining patients did not need healthcare until LTCS occurred. The patients' ages ranged from 29 to 63, and 15 female and four male patients were recruited, which was representative of the patients generally referred to the clinic.

Data Collection

Individual semi-structured interviews were conducted by all authors ([Brinkmann & Kvale, 2014](#)). The authors are all experienced in conducting interviews and were not part of the clinical care. The participants were interviewed in different settings according to their preferences and opportunities. Hence, most of the participants were interviewed at the hospital, some via telephone and some in their homes. The interviews were structured via an interview guide designed for the purpose of the study. The interview guide was divided into different overall areas aiming at getting the patient to narrate their lived experiences with LTCS as they saw them and wanted to present them. Hence, open-ended questions were asked; 'Please tell how you experienced contracting COVID-19', 'How do you experience your COVID-19 sequelae?', 'How do you manage your sequelae?', 'How do you imagine your recovery from now on?', 'How do you experience your pathway in the healthcare system?' An effort was made to cover personal issues around daily life before, during and after COVID-19 illness, illuminating the lived experience of COVID-19 LTCS. All interviews were recorded and transcribed verbatim. The interviews lasted from 19 to 69 minutes for a total of 738 minutes (mean 39 minutes).

Table 1. Patients' Characteristics.

Participant <i>n</i>	Age	Gender	Time since infection
1	29	Female	8 months
2	29	Female	6 months
3	37	Female	6 months
4	50	Male	7 months
5	29	Female	8 months
6	38	Female	7 months
7	60	Male	7 months
8	56	Female	6 months
9	59	Female	8 months
10	29	Female	14 months
11	47	Male	7 months
12	61	Female	16 months
13	25	Female	8 months
14	46	Female	9 months
15	53	Female	17 months
16	42	Female	7 months
17	55	Female	8 months
18	63	Male	9 months
19	35	Female	10 months

Data Analysis

The transcribed interviews were analysed and interpreted using a three-phase phenomenological-hermeneutic approach inspired by Ricoeur's theory of narrative and interpretation ([Pedersen, 1999](#); [Ricoeur, 2002](#); [Ricoeur et al., 1976](#); [Simonÿ et al., 2018](#)). Interpretation of a text is the core of this Ricoeur thinking and is a dynamic process aiming at interpreting what the text says and what it speaks about. When writing down the spoken words from the interviews, the meaning is liberated from the event hence allowing the researchers to interpret the underlying meaning and being-in-the-world. The focus of our study was gaining new and extensive insight into patients' lived experiences and the significance of LTCS in their daily lives; thus, this method and thinking of Ricoeur was suitable because the patients' lived experiences could be interpreted while a comprehensive understanding was achieved ([Missel et al., 2021](#)). The method of analysis takes place on three levels: naïve reading, structural analysis and critical interpretation and discussion. By utilising a three-phased interpretation, we alternately moved from what the text said to what it spoke about in an attempt to grasp the meanings of patients' experiences ([Dreyer & Pedersen, 2009](#); [Pedersen, 2005](#); [Ricoeur et al., 1976](#)).

Level I the Naïve reading. To obtain an initial overall sense of the text, data were read through thoroughly by the authors, while allowing an openness to the text and the potential of becoming emotionally moved by the patients'

experiences of living with LTCS. The naïve reading resulted in an initial phenomenological description of the general meanings of the text (Simonj et al., 2015).

Level 2 Structural analysis. This was followed by a structural analysis guided by the naïve reading. The structural analysis aims at providing insight into the structure of the text. Hence, words and sentences were extracted that pointed towards recurring issues and themes throughout the text (Pedersen, 2005). In this phase, we sought to identify and formulate themes emerging from the data. A theme was comprehended as a pervasive thread of meaning expressing essential content relating to the experience of living with LTCS. To ensure coherence, we continuously reflected on the significance of all the meaning units and whether they resembled the naïve reading. Subsequently, the themes were condensed, which grasped their essential meanings and decontextualised the meaning units from the data (Lindseth & Norberg, 2004).

Level 3 Critical interpretation. When reaching the phase of critical interpretation directed at understanding the meaning and range of the statements in the text (Pedersen, 2005), we discussed and interpreted our findings, focussing on their connections to the theory and existing research and raising them to a level of general significance rather than the individual level.

Trustworthiness

When investigating lived experiences, openness and sensitivity are required. Thus, while trying to grasp the meanings that lie implicitly in the patients' experiences, we intended to have an open attitude, striving to bridle our presumptions (Lindseth & Norberg, 2004). Collected data never has only one meaning or likely interpretation (Dreyer & Pedersen, 2009), but as one interpretation can represent the most suitable one, we sought to obtain credibility in the study by continuously discussing the process through data collection, naïve reading, structural analysis and critical interpretation, which secured the aim of this study and ensured conformability in the elements of interpretation. To ensure full transparency, the quotes are presented in the findings section.

Ethical Approval

This project was reported to the Danish Data Protection Agency (ID-number P-2021-388) and conformed to the ethical principles of the Declaration of Helsinki. All patients were informed about the voluntary nature of the study, and written consent was obtained before each interview. Data were handled anonymously and confidentially. As most patients were in a vulnerable situation, the

authors proceeded with care, especially if a patient became emotional or experienced fatigue while talking about sensitive topics.

Findings

Naïve Reading

The overall impression from the naïve reading was that patients experiencing COVID-19 LTCS were in a new and unknown life situation. This was experienced as a life event and characterised by feelings of anxiety, uncertainty and concerns for the future. Fear of becoming seriously ill or even death was present in the acute phase, while concerns for the future revolved around whether they would ever return to their previous ways of life. Their everyday life had, for months, been marked by significant sequelae such as fatigue, headaches, problems finding words and lack of concentration, flexible thinking and energy. LTCS influenced their work capacity and the roles they play in their social lives. For most patients, experiencing long-term symptoms after an infection was a first-time experience. Hence, they had limited experience in managing their symptoms which seemed to leave them vulnerable and lonely when faced with this severe and prolonged recovery. Although feelings of despondency, sadness and uncertainty were common, they also had hopes for the future.

Structural Analysis

The structural analysis validated and clarified the naïve reading through the following five themes describing the experience of living with sequela after COVID-19: 1) An unexpected journey: How LTCS Conquer Everyday Life, 2) Returning to Work and Surrendering to the Burden of LTCS, 3) A Lonesome Struggle: Managing LTCS Daily, 4) Socialising: An Energy Drain While Striving to Regain a Social Life and finally, and 5) A New Beginning: Navigating Hope and Despair on the Journey Towards a New Normal. Please see [Figure 1](#) for depiction.

An Unexpected Journey: How LTCS Conquer Everyday Life

Surviving the virus was a relief, after which patients expected to return to their previous routines without further ado. However, for some, recovering turned out to be a blurry affair as they could not differentiate when or if they had actually recovered or were still in the acute phase. Others who initially felt they were far beyond the acute phase experienced the delayed onset of COVID-19 LTCS as completely unforeseen. Either way, they were unwillingly led on an unexpected journey when suddenly

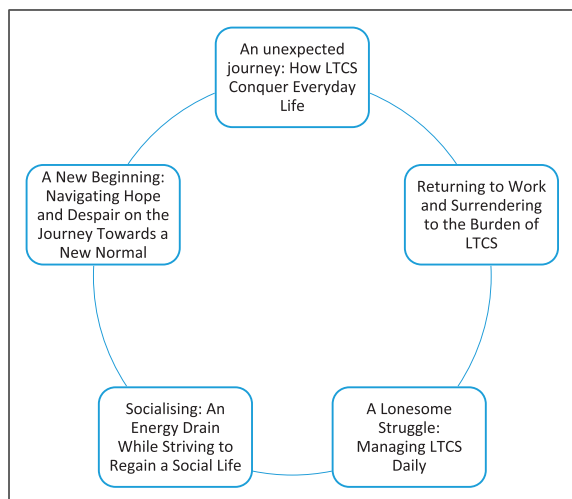


Figure 1. Five themes emerging through the interview data.

facing the prolonged struggles of everyday life dominated by LTCS.

A woman declared how she looked back on her initial recovery:

I thought...yes; I have survived! And then I thought...I can handle everything, and I did not think of sequelae at all...I said to everyone: well, I'm fine...But then it came so suddenly.

A broad variation and degree of cognitive obstacles were described. The onset of LTCS differed considerably; it could appear early on or months after a presumed recovery and could either set in abruptly or slowly increase over a longer period. The patients experienced diverse deficits, such as memory difficulties, vertigo, confusion, problems finding words, remembering names, and lack of concentration, flexible thinking and energy. This created a vicious circle of symptoms, where one or two symptoms (e.g. fatigue or headache) initiated other sequelae, such as difficulty concentrating or emotional disturbances, exacerbating the initial fatigue or headache. Light and sound sensitivity were described as part of the experience of living with LTCS. The deficits were revealed in different situations but were characterised by interrupting previously unproblematic activities.

A good illustration of this is a woman who suddenly had trouble baking:

The fact is that I have baked a lot [and] I no longer can. I simply cannot figure out how to read a recipe. There's a cake I've been baking for ten years now, and I [could] remember the recipe in my head [in the past], [but] I no longer [can].

Symptoms such as anosmia, respiratory difficulties, muscle pain and affected vision were also taking a toll

on the patients. Although these could present as pronounced symptoms, the patients agreed that they would prefer these and acute COVID-19 symptoms to LTCS.

LTCS differed by severely influencing their overall life situations, forcing them to make considerable changes in their daily lives. The prolonged course of illness led to feelings of frustration and uncertainty about whether they would ever fully recover. The most severely afflicted patients described how this prolonged course of disease affected their mental states, adding comorbidities such as anxiety, stress and depressive symptoms to their already vulnerable situation. In these distressing circumstances, episodes of uncontrollable crying or outbursts of anger were quite common, and some patients even felt that their personalities had changed:

So, I used to be a happy girl who wanted it all (begins to cry)...I still want it all, but uh...but I cannot...Well, I think it has been hard to [make] heads or tails of all this. There have been so many adjustments...and ways I've had to reinvent myself...I somehow became more and more introverted...Uhm, people said that there was something different about me...I have a colleague that said I seem a bit melancholic (still crying).

Despite the general nature of the symptoms, most people associated their symptoms with LTCS at a rather early stage, and in most cases, their general practitioners would agree when consulted. Depending on the patient's comprehension, cognitive deficits could be perceived as symptoms solely interpreted as LTCS, which, regardless of their perceived origin, tended to conquer their everyday lives extensively. This is illustrated by one woman's reply when asked how LTCS have affected her life:

Well, it affects me by always being in the back of my mind.

Returning to Work and Surrendering to the Burden of LTCS

Returning to work after recovering from the acute phase was a priority for patients and most returned to work after 2–6 weeks of absence due to COVID-19. They either went back full time or immediately realised their reduced ability to work, leading them to a part-time return. Either way, it turned out to be too soon and quite a burden to bear:

I should have stayed home for at least 14 days more. It was the dumbest thing I did...to go to work. I started full time. So, I could hardly [have] been any dumber, but I thought: Now it's over. Now I [won't be] sick anymore, but I [was].

When returning to work after their sick leave, the LTCS intensified. Headache, sleep difficulties and fatigue were common denominators:

Of course, I am really frustrated that it [the LTCS] continues and seems never-ending...I'm suffering from headaches and fatigue...That is what really bothers me.

The intensified LTCS complicated the return to work, and an inability to manage tasks the patients previously found nonchallenging was revealed. In particular, memory difficulties, confusion and lack of concentration, flexible thinking and energy seemed to cause trouble. The patients would typically be more well-functioning in the morning, with symptoms gradually worsening throughout the day. In their work surroundings, LTCS became increasingly tangible, and they struggled to fulfil their own and their workplace's expectations; the patients gave everything they had.

Often, special arrangements in the workplace were necessary to accommodate the patient's needs. Some arranged a gradual return to work, transferring assignments to other colleagues, planning rests during work time or leaving their chair to find peace elsewhere on the worksite until their energy was regained, as described by this man:

I had a great responsibility in a project... and we temporarily transferred that responsibility to a colleague...I have further been able to delegate urgent tasks...so others have been running fast for me. It's been a big help.

A woman expressed:

After every meeting or every class, I just had to lie in bed for at least an hour...And I had no energy for cooking, shopping or cleaning...and doing laundry and all those things.

Suffering from challenges with memory or a lack of flexible thinking was extremely uncomfortable. To compensate for this, some patients began systematically using their calendars, typing things into their mobile phones to help them manage their jobs:

Well, I've tried to put everything on my phone, so I [will] remember...and [make] notes and [use] the alarm and uh...but I still came to a meeting [on the] the wrong day at the hospital and such...because it all became a little too difficult to keep track of.

Whether the patients were cognitively or emotionally challenged, it seemed helpful for them to be open about their struggles:

I have tried to tell my colleagues that I hope they will let me know if they expect anything from me because I really have problems with my memory at the moment.

This also seemed helpful for this man, likewise declaring:

Maybe it was because of my headaches. I was uh...I [had a] short fuse, and I had no patience. But I announced how I felt...I needed transparency...needed them to know.

However, being open and honest required feeling valued and acknowledged in the workplace; this was not always the case, although it was vital to the patients. Not being able to fulfil their job demands or the workplace not recognising their challenges as LTCS-related raised concerns for them about losing their job, which, for some, meant returning to work before they felt ready:

In the beginning, they did [recognise] me, but gradually, I kind of had to ask to extend my sick leave again and again...And I guess it got a lot harder for my manager to understand, and she said to me, "My husband also feels tired when he gets home from work...we all do, right?"...Yes, but I just had to sleep until [the next] morning...So I couldn't do the housekeeping or shop groceries or cook a meal because I was just so tired. And, of course, it also affects you not getting that recognition from your manager, right? Uhm, and it [causes] concern whether it might result in losing your job.

At some point, all but two patients had to surrender to the burden of their LTCS and go on full- or part-time sick leave. Deciding to call in sick was tough. Realising their reduced ability to work hurt the patients' self-image, but once the decision was made, it was a much-needed relief. Colleagues and managers were often the first to suggest sick leave or changes in the work environment to support the patient:

At that point, I was also just fatigued physically, but also mentally, I just couldn't do anything, and then I just started crying; one of my colleagues said to me... 'maybe you should speak to our manager', and I did, and she was actually the one who told me 'I think you need to go on sick leave', and so I did...it was absolutely awful...If my manager had not told me to, I think I would have tried everything else first...I just felt like a total failure.

Another patient similarly expressed:

There was too much noise and [too many] customers calling in. I did not grasp a piece of what they were saying. It was just a big mess for me. Plus, my boss just kept throwing tasks at me, and I kept saying, 'I can't handle anymore. You can't keep

[sending] me tasks all the time'. I ended up on sick leave...He (the boss) called me after a few days and asked how he could help me...We agreed that I move to another location...where no one came running and that I had no phone calls...This worked much better because I could take my breaks...It was so much better to sit there alone. I think I sat there [at the new location] for a month or two.

A Lonesome Struggle: Managing LTCS Daily

Being previously healthy, most patients had no experience with illness influencing their lives for such an extended period. Medications such as analgesics had minimal or no effect. Hence, managing LTCS daily could feel like a lonesome struggle; the patients rarely knew how to address their challenges or which strategies might help them manage their symptoms. Furthermore, as this was a new phenomenon, healthcare professionals were also reluctant to provide strategies as they had no evidence-based practice to rely on. Some had, however, seen on TV that LTCS could be treated like sequelae of a concussion, and this information was considered beneficial:

So, I got an appointment [with my GP]...three weeks after I [called in] sick. So, I was mostly just at home and tired...I didn't quite know how to handle it. It was right after [the sequelae of COVID] being discussed on that TV show and the doctor said to manage it like a concussion...uh...and I've tried that before, so I took this as a bit of a starting point. I tried not to push myself too much, but at the same time, I needed to challenge my limitations... So, I tried to go for a few walks every day and tried to minimise screen usage. It got very boring very fast (laughs)...I really think that lowering your expectations a little bit helps...so you don't get too disappointed.

The feeling of loneliness could be reinforced by most patients having no one with whom they could share their experiences. Many patients experienced scepticism or disbelief from their surroundings because their LTCS symptoms were hidden disabilities, causing them to carefully consider how much of their struggle to reveal. Those who knew others with LTCS felt relief when they shared their LTCS-related stories.

As fatigue was a common symptom, energy management seemed to be the main strategy for dealing with LTCS that could bring relief to everyday life. This could include prioritising activities and planning whether to use energy to exercise or make dinner.

As job performance was a top priority, there was a price to pay when it came to domestic duties and social activities:

Well, I had to prioritise, right? I really had to cut down drastically [and] prioritise...how to spend my energy for

[the] day. And if there was some [energy] left, then that would be just terrific. But then, in the long run, it meant having only energy for my work and my mother.

Other strategies for energy management were taking breaks and naps, meditating, dividing a task into several sub-goals and, in general, by planning:

Yes, yes, I have started using my calendar very much...so I am not so good at remembering, uh, my appointments...so I...so I write down...a lot. Then I can also visually, like, see if they [the appointments] are too close.

The patients reported that engaging in activities could distract their attention or even bring relief from their LTCS. Some resumed to a hobby, such as fixing cars, crocheting or meditating. A common positive distraction was being outside, engaging in nature via walking or, as this man explains, going to the beach:

I started going to the beach with my metal detector...digging in the sand in the ocean. And every time I was out there, my headache disappeared for 2–3 days when I had been in salt water-filled air...Sea air works...at least for me.

Some patients tried to handle their distress by convincing themselves that negative thoughts and reactions were not useful:

Whining doesn't help...I am not much of a whiner...Of course, you can feel that you cannot contribute 100%, but then you must contribute 80%, and that's it, right?

Some patients felt responsible for regaining their health. This could include eating healthy, seeking psychological help or exercising; one patient, despite having respiratory difficulties, insisted on riding her bike 20 km to work to get her 'lungs going'. Some further readjusted their daily routine, striving for a less stressful life, or they would become more conscious about appreciating their lives after surviving the virus:

Yes [it has changed how I view my life]...because I thought...damn...I don't know what happens...all of a sudden, you can die...Such a pandemic is quite terrible...and then I thought, well, you have to live every day...We have to live every day...

Socialising: An Energy Drain While Striving to Regain a Social Life

Living with LTCS influenced not only the patients' working lives but also their family and social lives. Struggling with fatigue and other LTCS, they simply lacked the energy to

socialise in their spare time as they did before. The increased sensitivity to stimuli, such as sounds and lights, was further exhausting and could be an issue when going out.

A woman who previously considered herself an outgoing and socially confident person declared:

I cannot stand being with too many people...It's like I want to say, 'Step away, step away, step away'. I cannot stand when several people are talking simultaneously. I cannot stand noise.

The lack of energy substantially altered patients' social interactions in their workplaces, with their friends and at home with their families. The patients no longer felt they could fulfil their roles in the ways they could before and thus struggled to regain a social life while reconciling with the fact that they were not participating in life as they used to:

I've had a hard time admitting that...that I'm suddenly not able to fulfil the role that I used to...I get a little upset (starts to cry)...so [this] has been the hardest.

This happened while taking care of children, doing household chores, seeing friends and attending family gatherings. The patients described an unfamiliar feeling of depending on their spouses and families, which, for some, was connected to feelings of peace of mind and thankfulness, while it made others feel sad and uncomfortable:

I feel really dependent on my boyfriend...uhh...which...is deeply frustrating...It is very disabling being so dependent on another human being...yes...in some periods when I have many deadlines...at work...then I am still completely exhausted...then I still become dependent on him to go shopping and cooking for me...Fortunately, it has got a little better.

Being confronted with their limitations was tough. Hence, the ongoing national COVID-19 restrictions, which curbed social activities in society, were welcomed by the patients because they relieved some of the pressure of having to socialise. Still, maintaining a balance between a satisfying social life and not getting overwhelmed was extremely difficult. Careful planning, reducing the number of appointments and household chores and making room for rest were an absolute necessity, leaving no room for being spontaneous:

This [being social] I must plan. I need to plan time for recovery afterwards. Because it's very exhausting to be social...Um...yes...So, I cannot just see people every day as I could before.

When socialising, patients found it especially successful when the time to rest before or afterwards was planned to manage their energy:

Well, it [the LTCS] affects me so much that I cannot...be as social as I was before...It really does affect how I am social...it's like having batteries...I do not have any extra battery I can just plug in, so I only have one and that uh...that one needs to be charged at home (laughs).

These measures seemed to work, but despite planning, the patients often had to cancel appointments on short notice. This could strain their relationships, although this was often met by caring responses from friends and family members, making it bearable. Yet, when cancelling an appointment or not getting a planned activity done, it awakened feelings of guilt.

For some, seeing other people evoked positive feelings and generated energy. However, being social often drained the patients' energy and caused physical and emotional problems afterwards:

I try not to burden myself too much, too fast, even though I might want to socialise more...but I just have experienced it backfiring too many times, so I try to take it easy...Then [when it backfires] the next day I have a terrible headache, and I am just so tired...and I feel like I can't do anything...I have also had some mild depressive symptoms when it [the symptoms] was at its worst.

A New Beginning: Navigating Hope and Despair on the Journey Towards a New Normal

Navigating the healthcare system was quite a challenge for the patients, and acquiring recognition from their general practitioner, on whom they depended for a referral, was considered vital. Not feeling acknowledged could eventually lead patients to change to a new doctor. When referred to the LTCS clinic, the patients met a rather prolonged healthcare pathway, with an initial several months of waiting time. While waiting for the clinic to reach out, the patients were on their own, navigating through hope and despair unless fortunate enough to access psychological aid through their private or workplace health insurance. Although most of the patients, rather early on, associated their symptoms with COVID-19 LTCS, several simultaneously described a common lurking fear. What if the symptoms they experienced were not LTCS – what if they came from something else?

A male patient explained:

I have to admit...I have been going around thinking: 'Do you have a tumour in your head or what the hell is this?' And I must admit that I would actually like to be checked...It amazes me a little that you can keep on having constant headaches...that it can just keep on aching 24-7...That, I think, is strange.

The patients mostly feared that symptoms were covering up unknown cancer or cardiovascular disease, such as stroke. When finally attending the LTCS clinic, a neurological examination could appear as a double-edged sword. The occurring sequelae could not be confirmed by any tests, which eased the patients' worries since no serious underlying illness was suspected. However, this also meant no available treatments; hence, after visiting the clinic, living with COVID-19 LTCS was still a lonely experience:

There is no support available to help manage my symptoms. It is difficult to offer healthcare when you cannot identify the problem, so [in] that matter, I feel a little bit on my own.

Although most of the patients appreciated their visits to the LTCS clinic, some did not feel that their worries were sufficiently acknowledged and, generally, additional techniques to manage their symptoms were requested. Asked about their anticipated future everyday life, most of the patients revealed this as a sensitive matter, causing them great concern:

It's really frustrating not knowing when this will end or what the future holds. Whether it's going to be like this...going to continue forever...because...uh...I'm so young but I feel like an old lady who's just tired and doesn't have the energy to do anything.

Despite the lack of support and answers that could medically explain their experiences with LTCS, they were quite hopeful about their future recovery, as this man, experiencing progress for the last couple of months, stated:

Things will get better in time. There is no doubt about that.

Even when not sure if symptoms were getting better, as was the case with this woman, a narrow sense of hope was revealed:

Had you asked me half a year ago [about the future], I would never have believed I would have ended up here...um...so where I will be in a year (tearful)...hopefully I'm back at work and happy at work...uh (sniffing)...Hopefully, I have resumed some of the activities that make me happy.

Some patients reflected on this rather positive way of thinking, suggesting that it might be a consequence of adapting to their circumstances. The uncertainty of whether they would ever fully recover had led some patients on a journey towards settling in a new normal: an everyday life characterised by low demands adjusted their current state of health:

I don't think I will return to the same level as I was before...but it's not something my body wants either...Something has happened [to me].

Critical Interpretation and Discussion

Through in-depth interviews with the patients, it became evident that contracting COVID-19 and suffering long-term sequelae was life-altering with significant consequences for their social, psychological and vocational well-being in the months following the infection, thus affecting all aspects of their lives. While the patients initially considered their course of disease finished upon the immediate remission of symptoms, many found their levels of functioning significantly altered once they returned to their jobs and the demands of everyday life, such as in parenting, coworking and organising home duties.

Ongoing fatigue, headache and problems with memory, flexible thinking, multi-tasking and planning skills have negatively impacted the participants' abilities to carry out everyday tasks at home and at work. This has caused frustration, temperamentality, sadness, worries about the future and a sense of loss of control of their lives. Many participants worried that they would never fully recover, that they would lose their job or become permanently dependent on the help of other people, such as a spouse. Many felt alone, with no similar cases in their network, while experiencing other people's scepticism and disbelief in their condition, and they were frustrated that they did not receive sufficient counselling from the established healthcare system on how to handle their symptoms.

Others expressed hope and found symptom relief by intense energy management and/or engaging in physical or other activities, either in peaceful indoor surroundings or outside in nature. However, the overall impression of their narratives is that contracting COVID-19 represents a significant disruption in their life course because of a decreased level of physical, cognitive and psychological functioning and high uncertainty about their health and their future. Furthermore, the patients expressed frustration about the reactions of their surroundings, including healthcare professionals, from whom they felt high scepticism and disbelief.

In a study by [Ladds et al. \(2020\)](#), similar perspectives were found, but their study also stressed that the novelty of COVID-19 exacerbated the feeling of uncertainty, with the patients not knowing what to expect in terms of recovery. Feelings of fear and uncertainty may have been further exacerbated by intense media coverage and social media interactions, as was pointed out in a qualitative study by [Missel et al. \(2021\)](#).

In a study among Iranian COVID-19 survivors with long-term sequelae, [Jesmi et al. \(2021\)](#) also found high

uncertainty and worry about symptoms of aggravation, losing their job and thus their income and the future for their children if they, as primary caretakers, died; this caused a significant degree of mental strain and anxiety. In the Scandinavian setting in which our study took place, which has high societal and financial security because of a strong welfare system, the nature of the patients' worries was somewhat different, with them stressing their independence and meaningful roles at home and at work. This may suggest that the reasons for the worries is influenced by the sociocultural context in which the patients live, but high worry about the consequences of the long-term sequelae seems similar across sociocultural boundaries.

Interestingly, most of the patients reported that they did not discover the extent of their sequelae until they returned to work. Trying to meet the demands of their work tasks, their expectations of themselves and their obligations to colleagues and managers turned out to reveal more cognitive problems, fatigue and pain than they had discovered while still recovering at home. This understates the idea that we, as humans, do not simply exist; rather, we exist in relation to *someone* and *something*. Heidegger (1962) and Van Deurzen (1997) theorised upon this idea by emphasising the existence of humans as *Dasein*, 'being there', as opposed to simply 'being'. As humans, we do not have an *essence* that can be objectively studied, but rather an *existence*, and this is a personal, subjective existence in relation to what we find meaningful in our lives (Heidegger, 1962). The everyday averageness constitutes *Dasein* (Heidegger, 1962); being there, being in the world, means constituting an everyday arena laden with value according to what and whom one finds meaningful and valuable. Experiencing a threat to one's meaningful and valuable relationships and activities and facing the limitations and finality of living and of life itself may cause anxiety and insecurity for one's *Dasein* (Van Deurzen, 1997).

All our patients experienced several limitations in returning to their meaningful and valuable everyday life, causing anxiety about their future and whether they could again fulfil their roles as parents, co-workers and friends. The predominant symptom was fatigue, which constituted a significant limitation to their endurance and everyday activities, causing them to withdraw from vocational and social obligations. Thus, experiencing sequelae from COVID-19 constituted a loss of identity and forced them to alter their being in the world and face the limitations of their ways of life, causing concern and anxiety about the future.

From an existential perspective, not only those who have contracted COVID-19 have felt anxious because of the limitations and restrictions following the pandemic. Morin et al.'s (2021) international 13-country collaborative study found a high prevalence of insomnia, anxiety

and depression in the general population during the pandemic. This illustrates that a pandemic such as COVID-19 has physical, psychological and existential consequences not only for those who contract the virus, but in the general population because of disrupted life trajectories and altered being in the world.

Our data contribute significantly to the growing body of knowledge about long-term sequelae after COVID-19, particularly with the phenomenological-hermeneutic approach taken in our study which ensures a focus on patients' lived experience and what they consider most important to their trajectory. Through our open-ended interviews, the patients have provided us with invaluable knowledge about their illness perception, everyday struggles, attempts at symptom management and considerations about their future. Furthermore, the open-ended nature of our approach ensured that the patients, not the researchers, defined which subjects were most important to focus on in the interviews, thus avoiding a predetermined approach to this complex issue.

Although few studies have focused on lived experience and the consequences of a disrupted life course after COVID-19, this approach is well known in disciplines such as health psychology and nursing research. Qualitative approaches focussing on the everyday experiences of illness from a patient-centred perspective have contributed significantly to illness research and provided insight into symptom trajectory across time and space, management strategies and psychosocial consequences of various illnesses. Similarly, this study provides valuable insight into the long-term sequelae after COVID-19 and the effects on their everyday lives, contributing significantly to constructing meaningful intervention strategies.

Particularly relevant for our present study, qualitative studies on the conditions of chronic fatigue, such as ME/chronic fatigue syndrome, and studies on chronic headaches focussing on lived experience reveal several themes like those found in our study. Dickson et al. (2008) investigated lived experience in patients with chronic fatigue syndrome (i.e. ME) and found three main themes expressed in the interviews: identity crisis in terms of loss of control of their lives because the illness affected all aspects of their everyday lives and constituted a significant biographical disruption; other people's scepticism towards their condition, causing them to feel alone and isolated and doubt their own experiences; and finally, acceptance and adapting to new ways of life as a coping strategy to move forward in their lives.

In a study by Nichols et al. (2017), which focused on the lived experience of people with chronic headaches (≥ 15 days per month), the direct consequence of having a chronic headache was a change in behaviour in terms of taking medication and experiencing side effects, avoiding social contact, avoiding planning ahead, ceasing activities

and changing sleep patterns. Subsequent effects were strained relationships, worries of being a burden to others, the stress of the unpredictability of the headache condition and worries about the future and more serious diseases such as a brain tumour. Thus, previous studies focussing on lived experiences of fatigue and headaches have illustrated that such conditions have severe direct and indirect consequences, and these studies expressed similar themes to our patients in terms of the physical and psychological consequences in their everyday lives. Although the aetiology of recurrent fatigue and headaches may be different in our patients, phenomenology and lived experiences reveal several common themes that may open up new perspectives in understanding sequelae and developing treatment strategies for people living with long-term sequelae of COVID-19.

The focus of our study was on lived experiences, not investigating diagnoses or comorbidities. It is, however, important to note that several studies have found a high prevalence of anxiety and depression among people with long-term sequelae of COVID-19 (Davis et al., 2021; Roberts et al., 2021; Taquet et al., 2021; Vanderlind et al., 2021). Almeria et al. (2020) found an association between cognitive complaints, anxiety and depression in people with long-term sequelae after COVID-19. Interestingly, patients with cognitive complaints had significantly higher scores for anxiety and depression, despite not differing in cognitive test performance from other patients without anxiety and depression. Thus, the associations between cognitive performance, cognitive complaints and affective disorder are complex and point to the importance of considering affective disorders among people with long-term sequelae after COVID-19 and simultaneous cognitive complaints.

Our data point to the importance of formulating intervention strategies based on the experience of the patients, thus ensuring a person-centred approach with relevant content for each patient. Fatigue seemed to be a common denominator in most interviews, but how it plays out in patients' everyday lives and how they attempted to manage their fatigue were individual, thus pointing to the importance of a thorough fatigue assessment before initiating intervention. Furthermore, many patients felt a high degree of emotional stress, underscoring the need for psychosocial support or psychotherapy, enabling patients to develop personal and individualized coping strategies to deal with everyday emotional distress. Finally, many complained of recurring headaches, which should be treated by their GP or a neurologist.

In conclusion, it is clear from our study and others that long-term sequelae after COVID-19 represent a significant disruption in people's life trajectories, forcing them to change their ways of life and causing worry about the future. The extent of long-term sequelae, even in those

with apparently mild illness, is evident in quantitative studies, which have reported a high prevalence of fatigue, but also headache, cognitive impairment, anxiety and depression. Meanwhile, qualitative studies, such as ours, have focused on lived experiences and personal accounts of the consequences on daily life, as well as nascent strategies for managing symptoms and redefining identities and being-in-the-world in relation to the activities and social relationships they find meaningful. While awaiting further studies on treatments, symptom management and recovery after persistent sequelae of COVID-19, clinicians and researchers may find inspiration in the experiences of other conditions with a similar phenomenology, such as ME/chronic fatigue syndrome and chronic headaches, although the aetiology is different. Based on our findings, we strongly encourage constructing person-centred intervention strategies that take patients' lived experience into account, thus making the intervention relevant and effective for each patient.

Strengths and Weaknesses of This Study

The open-ended nature of our research approach allowed the patients to narrate their experiences of living with long-term sequelae, thus being experts in their own experiences. Using a Ricoeur-inspired approach further ensures that researchers do not simply confirm or disprove their biased preconceptions of a field of study, but let the patients – the experts – unfold their everyday experiences, thus broadening perspectives beyond a researcher's knowledge, experience and imagination through interpretation of transcribed interviews. Simultaneously, reflecting on and replying to questions asked by researchers may facilitate new perspectives on participants' own experiences, thus creating a space for the dialectical investigation of the experiences of the patients and the researcher.

Teti et al. (2020) also encouraged qualitative research approaches in health research in general and research on the sequelae of COVID-19 in particular. They pointed out that qualitative approaches facilitate further understanding of the reasons for behaviours and social interactions that may reduce or increase disease infection and understand why certain strategies may or may not work. Thus, qualitative research is useful for investigating psychosocial, behavioural and subjective/experiential facets of illness.

This study has several limitations. First, patients were recruited from an inpatient clinic to which they had been referred after contacting their general practitioner, proactively seeking assessment and treatment for debilitating sequelae. Recruiting patients from the general population might have included more perspectives on lived experiences, including those from

patients with milder sequelae and those who have found more efficient symptom management than our patients, thus not needing contact with healthcare professionals. Second, we only interviewed our patients once. Follow-up interviews would contribute to further knowledge and understanding of the outcomes of their management and coping strategies and how their lived experiences may have evolved. We strongly encourage longitudinal qualitative research to further qualify the assessment, treatment and counselling for people who have long-term sequelae after COVID-19. Finally, our study is retrospective, meaning that patients' recollections of their past levels of functioning and the trajectories of symptoms and sequelae development may be affected by biased or deficient memory. However, focussing on lived experiences does not require 'truthful' responses as our phenomenological approach was not about investigating any measurable or objective symptoms load but focused on the patients' accounts of their current being in the world.

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