

ORIGINAL RESEARCH:
EMPIRICAL RESEARCH - QUALITATIVE

Longing for homelikeness: A hermeneutic phenomenological analysis of patients' lived experiences in recovery from COVID-19-associated intensive care unit acquired weakness

Roel van Oorsouw¹  | Emily Klooster^{2,3} | Niek Koenders¹ | Philip J. Van Der Wees^{1,3} | Mark Van Den Boogaard⁴ | Anke J. M. Oerlemans³

¹Department of Rehabilitation, Radboud University Medical Center, Radboud Institute for Health Sciences, Nijmegen, The Netherlands

²Deventer Hospital, Department of Rehabilitation, Deventer, The Netherlands

³Radboud University Medical Center, Radboud Institute for Health Sciences, IQ Healthcare, Nijmegen, The Netherlands

⁴Department of Intensive Care, Radboud University Medical Center, Radboud Institute for Health Sciences, Nijmegen, The Netherlands

Correspondence

Roel van Oorsouw, Department of Rehabilitation, Radboud University Medical Centre, Radboud Institute for Health Sciences, Nijmegen, The Netherlands.

Email: roel.vanoorsouw@radboudumc.nl

Abstract

Aims: To explore lived experiences of patients recovering from COVID-19-associated intensive care unit acquired weakness and to provide phenomenological descriptions of their recovery.

Design: A qualitative study following hermeneutic phenomenology.

Methods: Through purposeful sampling, 13 participants with COVID-19-associated intensive care unit acquired weakness were recruited with diversity in age, sex, duration of hospitalization and severity of muscle weakness. Semi-structured in-depth interviews were conducted from 4 to 8 months after hospital discharge, between July 2020 and January 2021. Interviews were transcribed verbatim and analysed using hermeneutic phenomenological analysis.

Results: The analysis yielded five themes: 'waking up in alienation', 'valuing human contact in isolation', 'making progress by being challenged', 'coming home but still recovering' and 'finding a new balance'. The phenomenological descriptions reflect a recovery process that does not follow a linear build-up, but comes with moments of success, setbacks, trying new steps and breakthrough moments of achieving mobilizing milestones.

Conclusion: Recovery from COVID-19-associated intensive care unit acquired weakness starts from a situation of alienation. Patients long for familiarity, for security and for recognition. Patients want to return to the familiar situation, back to the old, balanced, bodily self. It seems possible for patients to feel homelike again, not only by changing their outer circumstances but also by changing the understanding of themselves and finding a new balance in the altered situation.

Impact: Muscle weakness impacts many different aspects of ICU recovery in critically ill patients with COVID-19-associated intensive care unit acquired weakness. Their narratives can help nurses and other healthcare professionals, both inside and outside of the intensive care unit, to empathize with patient experiences. When healthcare

This is an open access article under the terms of the [Creative Commons Attribution-NonCommercial-NoDerivs](https://creativecommons.org/licenses/by-nc-nd/4.0/) License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

© 2022 The Authors. *Journal of Advanced Nursing* published by John Wiley & Sons Ltd.

professionals connect to the lifeworld of patients, they will start to act and communicate differently. These insights could lead to optimized care delivery and meeting patients' needs in this pandemic or a possible next.

KEYWORDS

COVID-19, critical care, hermeneutics, qualitative research, rehabilitation

1 | INTRODUCTION

Intensive care unit (ICU) treatment has become topical with the pandemic of coronavirus disease-19 (COVID-19) causing an acute severe illness and ICU admission in 5% of all hospitalized cases (Dong et al., 2020). Critically ill patients with COVID-19 frequently require mechanical ventilation, often combined with prone positioning (Marini & Gattinoni, 2020). Prolonged duration of mechanical ventilation and ICU stay are important factors associated with intensive care unit acquired weakness (ICUAW) (Latronico et al., 2017). ICUAW is defined as “generalized muscle weakness, which develops during the course of ICU admission and for which no other cause can be identified besides the acute illness or its treatment” (Hermans & Van den Berghe, 2015). One study found ICUAW in 26% of the patients with more than 7 days of mechanical ventilation (Ali et al., 2008). Another study found ICUAW in 65% of this patient group (Sharshar et al., 2009). A recent study among patients with COVID-19 requiring mechanical ventilation found ICUAW in 69% of the cases (Medrinal et al., 2021). To prevent long-term problems and symptoms corresponding with the post-intensive care syndrome (PICS), it is important to start recovery as soon as possible (Fuke et al., 2018). Before COVID-19, patients with ICUAW started rehabilitation at the ICU with early mobilization supported by physical therapists in close cooperation with ICU nurses and, ideally, accompanied by patients' close relatives (Lang et al., 2020). However, especially in the first surge of COVID-19, early mobilization and family participation were largely impossible (Thornton, 2020). Due to the highly contagious nature of the virus, patients with COVID-19 were, and still are, cared for in isolation. The strict infection regulations, limited availability of personal protective equipment and lack of staff time together with the complicated and relatively unknown pathophysiology of COVID-19 created extraordinary circumstances (Liu et al., 2021; Maaskant et al., 2021; Marin-Corral et al., 2021). For nurses and other healthcare professionals, this meant that they had to work in changing working environments and experienced high levels of stress (Catania et al., 2021; Nie et al., 2020). For patients with COVID-19-associated ICUAW this meant that they faced sub-optimal rehabilitation.

2 | BACKGROUND

“But that tube in my throat that was shocking. [...] I can still feel it there, but even just the thought of it.

[...] I couldn't talk and I couldn't move [...] they had tied my arms to the bed. [...] It was like a prison... very scary” (Tembo et al., 2015).

This patient quote reflects what it feels like to be treated in an ICU, which can be a restrictive and prisonlike experience. The isolation measures applied to patients with COVID-19 might amplify this feeling of imprisonment. Source isolation comes with a loss of freedom, separation from loved ones, and has been associated with post-traumatic stress symptoms, avoidance behaviour and anger (Brooks et al., 2020). The isolation environment becomes the patient's world, and touch and sounds become heightened in the isolation environment (Vottero & Rittenmeyer, 2012). It is, therefore, likely that being treated for prolonged periods in the restrictive nature of ICU combined with the isolation precautions during ICU and rehabilitation result in major challenges for critically ill patients with COVID-19-associated ICUAW.

For optimal recovery, close interaction and cooperation with caregivers are paramount (Laerkner et al., 2019; Söderberg et al., 2020; Van Willigen et al., 2020), and the presence of loved ones promotes strength and willpower (Engström & Söderberg, 2007; Palesjö et al., 2015). Therefore, we anticipated that the typical challenges of ICU stay and recovery are amplified in the group developing COVID-19-associated ICUAW and that studying their experiences could result in unique insights.

Due to the novelty of the virus, few studies have described the experiences of ICU patients with COVID-19. Recent studies have focused on feelings of anxiety, stress and depression (Berends et al., 2021; Sun et al., 2021), however, the lived experiences of these patients remain unknown. Their narratives can help nurses and other healthcare professionals, both inside and outside the ICU, to gain an enriched understanding of lived patient experiences and allow them to be more empathic (Carel & Kidd, 2014; Van Manen, 2014). Furthermore, these insights could be used to optimize the care delivery and to meet patients' needs in this pandemic or the possible next.

3 | THE STUDY

3.1 | Aims

We aimed to explore the lived experiences of patients recovering from COVID-19-associated ICUAW and to provide phenomenological descriptions of their recovery.

3.2 | Design

We designed a study in accordance with a hermeneutic phenomenological approach (van Manen, 1997; Van Manen, 2014). We aimed to explore the phenomenon 'recovery from COVID-19-associated ICUAW' via staying open to the participants' lifeworld and their meaning. To 'grasp the very nature of the thing' (van Manen, 1997), this sort of inquiry requires suspension of taken-for-granted beliefs and the attitude of science, in other words leaving 'the natural attitude' as described by phenomenology founder Edmund Husserl (Van Manen, 2014). Van Manen states that there is no strict method for phenomenology but he does provide for a methodical structure. In line with his writings, we explored participant experiences through a "dynamic interplay among research activities: turning to the phenomenon, interviewing, reflecting on essential themes, interpreting and writing a description of the phenomenon" (van Manen, 1997). This phenomenological reflection was guided by five existentials that give meaning to the life world: relationality, corporeality, spatiality, temporality and materiality (Van Manen, 2014). Data analysis led to the identification of themes that were worked out in phenomenological descriptions.

Reporting of this study followed the Standards for Reporting Qualitative Research (O'Brien et al., 2014).

3.3 | Participants

Patients were eligible for the study if they were treated for COVID-19 (polymerase chain reaction [PCR] test confirmed) and diagnosed with ICUAW (Medical Research Council-Sum Score [MRC-SS] <48) during hospital stay (Hermans & Van den Berghe, 2015). Patients were excluded if they were unable to speak Dutch, if they did not have access to video-calling equipment, or when they were experiencing psychological symptoms for which they were receiving professional treatment. Through purposive sampling, patients were recruited with diversity in age, sex, duration of hospitalization and severity of ICUAW. Patients were selected for potential study participation using ICU data, including MRC-SS collected during standard care. Patients were approached by the interviewing author (RvO) during their visit to the aftercare clinic. During this appointment, they were given an information letter about the study and an informed consent form. They were asked to read the information at home and to return the signed informed consent form if they wanted to participate in the study, so they had time to overthink their participation without any pressure. If the informed consent form was received, the researcher made a phone call to answer possible questions and to make an appointment for the video-calling interview. This initial sample was complemented with patients selected based on the professional opinion of hospital-based physical therapists treating this patient group.

All study participants were admitted to the ICU between March and June 2020, during the first surge of COVID-19 in the Netherlands. This period can be characterized by the following contextual factors; there were fear and limited knowledge among healthcare professionals about the virus and doubts about whether

patients would recover from COVID-19. A significant increase in the number and duration of hospital and ICU admissions required hospitals to expand the number of ICU beds and impose higher patient-to-nurse ratios than normal. Due to extensive viral spreading in certain regions, many patients were transferred to hospitals in other regions requiring visitors to travel farther. Patients admitted to a hospital or rehabilitation setting were isolated using source isolation or cohorting and could only receive a limited number of family visits.

3.4 | Data collection

Video-calling interviews were conducted from 4 to 8 months after hospital discharge between July 2020 and January 2021. Interviews were performed via Zoom.us, Skype for business, or Microsoft Teams, depending on the preferences of the participant. In one semi-structured in-depth interview, respondents were invited to share their lived experiences. Relatives were allowed to be present if so desired by the patient being interviewed. An interview guide was composed to structure the interview, consisting of the following topics: current situation, ICU, hospital ward and recovery after hospital discharge (Appendix S1). All interviews were conducted by the first author (RvO). The interviewer aimed for experientially rich descriptions, exploring first-person experiences, focusing on the experience itself, asking for detail and avoiding theory-laden questions. Interviews were audio-recorded and transcribed verbatim. In addition, with the participants written consent, data on demographical and participant characteristics were extracted from the electronic medical records.

3.5 | Ethical considerations

During the interviews, recall of intense memories could be distressing to the participants. Our first priority was the comfort and well-being of the participants. At the start of the interview, it was emphasized that the interview could be paused or stopped at any moment without giving a reason. The Radboudumc ethical committee (file number 2020-6708) judged that this study did not fall within the scope of the Dutch Medical Research Involving Human Subjects Act (WMO). General principles from the Declaration of Helsinki and Good Clinical Practice were followed. All participants received written and oral information and signed informed consent. All data, including personal data, audiotapes and transcripts were stored in the digital research environment of the research institute and will be kept for 15 years. The paper-informed consent forms were stored in a secured room at the research institute. Only primary researchers and relevant regulatory bodies had access to the data.

3.6 | Data analysis

For the data analysis, we followed specific steps of hermeneutic phenomenological analysis (van Manen, 1997; Van Manen, 2014). These steps are displayed in Table 1.

TABLE 1 Followed steps in hermeneutic phenomenological analysis

Analysing step	Description
1) Wholistic reading	The first two authors read and re-read the transcripts to fully understand the patient's experiences as a whole.
2) Selective coding	The first two authors selected statements or phrases that seemed particularly essential or revealing about recovery from COVID-19-related ICUAW.
3) Thematic coding	The first two authors took the selected statements and grouped them into themes. In addition, thematic descriptions were constructed.
4) Collaborative discussions	Deeper insights were generated by analysing the themes and thematic descriptions with all authors. In digital meetings, the first two authors presented their selective codes and themes to determine whether their thematic descriptions resonated with the views of the others. In three group sessions, themes were examined, articulated, re-interpreted, omitted, added and reformulated.
5) Textural description	The first author wrote a textural description of 'what' experiences were found including verbatim examples.
6) Structured description	The first author wrote a structural description of 'how' the experience happened, reflecting on the setting and context in which the phenomenon was experienced.
7) Composite description	The first author wrote a composite description of the phenomenon incorporating both the textural and structural descriptions grasping the very nature of recovery from COVID-19-related ICUAW as experienced by patients.
8) Re-writing	The composite descriptions of the experiences were reviewed by all authors and re-written in several rounds until all authors strongly felt that the text grasped the experiences of patients.

3.7 | Rigour

Open and transparent data analysis was promoted using ATLAS.ti software (version 8.4, Scientific Software Development GmbH) for data aggregation and analysis. Authenticity was elevated by extensive use of participant's quotes in the theme descriptions. Transferability was improved by providing context information and thick description.

To optimize thoroughness and to correct for individual blind spots, two different researchers independently read, re-read and coded all data. Both analysing authors (RvO and EK) were hospital-based physical therapists involved in the care of patients with COVID-19-associated ICUAW and trained in qualitative methodology and interviewing. Before the study, they bracketed their personal experiences with the phenomenon under study in a reflection report, to set aside their own experiences related to COVID-19 and to direct their focus to the participants' experiences. The other researchers had a background as ICU nurse (Mvdb), hospital-based physical therapist (NK), physical therapist (PvdW) and ethicist (AO). The group discussions and collaborative writing process improved the rigour and credibility of the data analysis. A professional third-party native English speaker translated all participant quotes.

4 | FINDINGS

A total of 13 participants were enrolled and completed the interview with a mean length of 49 minutes (standard deviation: 9, minimum: 29, maximum: 60). Participant characteristics are displayed in Table 2.

Our analysis yielded five main themes: 'waking up in alienation', 'valuing human contact in isolation', 'making progress by being challenged', 'coming home but still recovering' and 'finding a new balance'. The way in which the themes relate to each other is visualized in Figure 1.

4.1 | Waking up in alienation

All patients woke up at some point after a period of being sedated. They were lying in a hospital bed in an unfamiliar room, unable to move their body and unable to speak. Patients struggled to make sense of their situation. They wondered: 'where am I?', 'what am I doing here?' and 'what happened to me?'. Patients needed answers but could not ask questions because a tube kept them from talking. Their weakness prevented them from producing readable writing or using a letter board, resulting in an inability to communicate, which frustrated patients.

"Waking up was such an odd sensation. And I wondered: where am I, and what happened to me? And because you have something in your throat, you can't ask anything. That was very annoying."

(patient 13)

Patients struggled to process the days/weeks that passed by with them being unconscious. There was little daylight, and patients could not tell day and time. They searched for points of recognition, like

TABLE 2 Participant characteristics

Characteristic N = 13	Value
Gender male/female (n)	7/6
Age at interview (years; mean ± SD, range)	60 ± 10 (39–75)
First reported MRC-SS (mean ± SD, range)	24 ± 16 (0–46)
Initial admission to other hospital (n)	10
Hospital length of stay (days; mean ± SD, range)	41 ± 27 (14–98)
ICU length of stay (days; mean ± SD, range)	30 ± 23 (10–76)
Duration of mechanical ventilation (days; mean ± SD, range)	25 ± 20 (9–70)
Tracheostomy (n)	4
Discharge destination (n)	
Geriatric rehabilitation	6
Specialist rehabilitation	4
Home	3

Abbreviations: ICU, Intensive Care Unit; MRC-SS, Medical Research Council–Sum Score; SD, Standard Deviation.

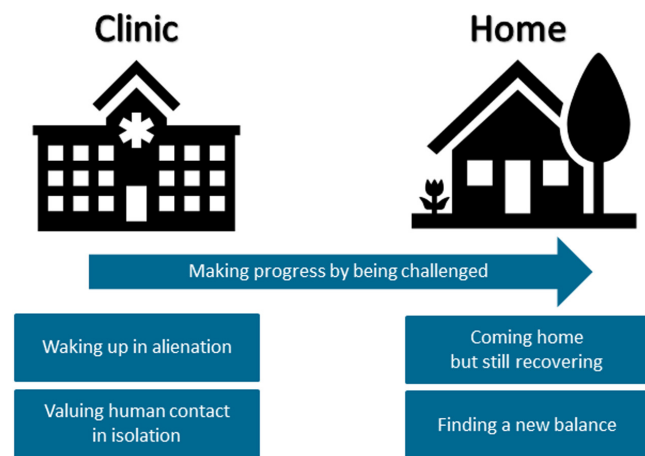


FIGURE 1 Visual display of patients' lived experiences in recovery from COVID-19-associated intensive care unit acquired weakness

hospital logos, but oftentimes, they were in an unfamiliar hospital in a different country region.

"At first I didn't even know where I was. This is where you are they told me. Well yes, but where is that? Where am I? I had no clue where I was. Yes (I knew), they transferred me to [name local hospital] the first week. [...] But then I woke up in [a hospital in a different region], after about five to six weeks."

(patient 4)

The healthcare professionals that helped them turn, wash and change were fully covered in suits, caps and facemasks. Patients referred to them as Martians or astronauts, and some found them scary. No one in the ICU looked like a normal human being, even visiting family members were fully covered.

"Now where did I end up? In heaven or on Mars? [laughs] But I was in the [name hospital] when I came to, people with masks and blue suits, so I thought, shit, am I in heaven or hell?"

(patient 12)

Making sense of the situation was also complicated by the lively delusions that many patients experienced. The strange delirious dreams could sharply be recalled many months later. Typically, these delusions seemed very real and items and sounds in the room were interpreted as part of the dream. For instance, a round medication desk was perceived as an ice-cream machine and beeps produced by room technology seemed to be caused by an old sailing ship.

"I am on an old sailing ship. Everything squeaks and creaks. The squeaking corresponds to the machine, but I do see a lifelike nurse in a suit standing right next to me."

(patient 2)

All patients explained that they felt physically fit before being admitted to the hospital. The contrast with their physical abilities when waking up in the ICU was immense. Patients were unable to move their limbs or change positions. Patients could not control the alarm or the television above the bed. They typically say: 'I could not do anything'. Patients felt as if they woke up in a different body, a body that was not theirs.

"It felt like it [the body] didn't belong to me, and that felt very strange. I couldn't even hold on to a plastic cup, so that was odd. And if they sat me up straight, I felt just like a rag doll, I would collapse again. Now that was a peculiar sensation for sure."

(patient 5)

Additionally, patients had an altered experience of material things. Pencils, cell phones and tableware seemed much heavier than before. Patients were unable to handle these objects like they used to, which meant a strong confrontation with their weakness.

"I couldn't lift a normal cup, like a mug for instance, it was too heavy. I was holding my cell phone, and then I told my son I wanted a new one, as it was too heavy. Everything felt very heavy, I couldn't use my legs, arms or neck."

(patient 11)

4.2 | Valuing human contact in isolation

Patients wanted to be self-sufficient, however, due to their weakness, they were dependent on healthcare professionals for even the simplest activities in daily life. Oftentimes, patients had to wait, and time was going by slowly. They had worrying thoughts like: 'will I survive?', 'how will I

recover'? and 'how long will this take?'. Several patients described feelings of loneliness. This loneliness was reinforced by a sense of being locked up. The isolation precautions required doors to be closed, and patients were prohibited from leaving the room or ward at their own initiative.

"I was lying all alone in that room, I couldn't do anything, I could hardly move, and well, yes, then you feel really lonely. That's when you think: where am I heading?"

(patient 3)

Patients experienced a basic need for human contact. They desired contact with their helpers, and their presence brought feelings of safety and security. Despite the fact that all faces were hidden behind facemasks, patients did recognize different healthcare professionals. They listened to their voices and looked at their eyes, posture and contours. Patients felt the difference in handling and touch between different healthcare professionals.

"What I do recall, and now think of as something I would never do, is the moment I was lying in bed, and I felt very lonely you know, I couldn't talk, I was just lying there. And then someone stood at my bedside, well several people really, but I grabbed the one closest to me by the hand, and I held on, something I would never do normally. But I remember, I had a need to hold on. I think he will think, that person is crazy. Well yes and I held on to him like, I need to hold on to something, something human."

(patient 1)

"When you are lying in a bed you are really aware of whether or not people do it from the heart, and if they are emotionally involved, or whether they just think, I have work to do. They just do their what they have to, their job, and there is no reproach to make on that count. But you are really aware of whether or not someone is doing it from the heart."

(patient 10)

Patients were amazed by the caring attention they received, particularly because these were obviously busy times for healthcare professionals. They valued the kind and patient responses of their professional support. It made them want to express their thankfulness and to find out what the healthcare professionals' faces looked like.

"I was healthy to begin with, and then I couldn't do anything anymore, I couldn't walk, couldn't go to the toilet by myself. That makes you feel very, very small, and very grateful to the male nurses and the female nurses, who did a fantastic job. And who have a lot of patience for you."

(patient 9)

Obviously, the support of loved ones was crucial as well. While visiting policies were restricted in every facility, there were large differences between places, leading to confusion and frustration after transfers. When visitors were allowed, patients felt strengthened by the closeness and connection with their loved ones. Moreover, family members could recognize patient-specific characteristics, which helped alleviate patients' sense of alienation. Patients tried to deal with the restrictions by use of telecommunication, and seeing each other from a distance or behind glass. As time passed, the desire to be close to loved ones was growing stronger, making patients long for the moment that they could leave quarantine.

"When I first woke up, I spoke in dialect so they thought I had a stroke in [different region hospital], because I was not intelligible. Then one of my kids said, well he speaks just like he usually would). [...] I apparently spoke in a, well, language they couldn't understand."

(patient 7)

"My wife and son came to see me almost every day. In the [rehabilitation center], also on Saturdays and Sundays. Yes they invited her in so she could see my progress. Show her that I could walk with a walker, that I could advance alone, and do my thing. That was great, I am very grateful for that."

(patient 12)

4.3 | Making progress by being challenged

From the moment, the patients became aware of their situation they started longing for progress. Their situation was uncomfortable and restricting. As long as patients were unable to actively move their arms or legs, healthcare professionals had to do it for them. Passive motions stimulated limb sensations, which felt nice. Patients referred to this as gaining back their tactile senses.

"The therapist also came to the ICU and she would move my legs and my arms. And that made a difference to my body, just like before, when I used to be on the road a lot, driving a car and I would often go for an hour-long walk or bike ride in the evening. That is when you feel your body recover. Well, that's how this felt too."

(patient 10)

However, being moved by someone else could also feel strange. Patients had no control over their body. Movements and changes in postural positioning were mainly induced by healthcare professionals. Patients felt that they were put straight up, or put on their feet by their helpers and these situations were qualified as weird and scary.

"The nurses would pull me upright in bed, turn me over, take me to the toilet, sit me in a chair, and bring me everywhere. The therapist also came to my bedside with this bike and I could pedal the bike while in bed. Yes, at the beginning when I couldn't really do anything as yet."

(patient 4)

The way in which activities were announced was incoherent with the actual feelings that they gave rise to. The first time sitting up typically came with dizziness or nausea and patients felt inadequately prepared for this. Healthcare professionals used diminutives when referring to mobilizing actions. However, in contrast, patients experienced these activities as huge and exhaustive undertakings.

"Yes that was difficult, with the physical therapists present, holding on to both sides, I had to just sit on the edge of the bed for a little while, yes that was distressing [...] and I did not expect that it would be that difficult."

(patient 3)"

Typically, the idea to try a new step in recovery, like standing or walking, was not suggested by the patient but by a healthcare professional. Patients were encouraged to try actions that they considered impossible. Performing a new step was perceived as scary and came with all sorts of bodily sensations including instability, weakness and shortness of breath. Patients experienced fear of falling and needed the healthcare professionals to stay close to provide safety and support while exploring their abilities. When patients were able to perform such a new action, this was experienced as liberating and as a victory. These moments strengthened their belief in recovery and brought a lot of energy.

"At one point I was able to stand, and a week later he [the physiotherapist] arrived with a walker all of a sudden explaining: "I have a feeling that you will succeed today". I said: "I won't be able to do that." But we were going to do it anyway. My legs swayed in all directions, "but you are walking" he said. That was very motivating. And of course you do make progress and at a certain point when you are actually walking, you continue progressing."

(patient 5)

Patients struggled to see improvement. Progress became particularly obvious when reaching new mobilizing milestones, but patients were not always aware of the small steps in between. They gained confidence when their caregivers pointed to these small steps and emphasized that they did see improvement.

I really wanted to move forward. The initiatives they took, and the positive words they spoke, were very important. And also in my own surroundings, there

were people who told me you can do it. They saw progress when I didn't see it yet, when I thought nothing would change, and that was the worst feeling.

(patient 3)

Patients wanted to work hard for their recovery. They were convinced that they could only recover by putting in a lot of effort. However, at the same time, they experienced their weakness and the need to rest. It was a struggle to find a good balance between exercise and rest. They found out that working hard was not necessarily beneficial. When the dosage of mobilization or therapy was too high, patients felt setback for the rest of the day, or even for a couple of days. Patients talked about this in terms of 'going into the red' or 'being presented with the bill afterwards.' These small setbacks were very frustrating.

"I did get more energy eventually, but it was always two steps forward, and one step back. And that is when I would push my body past its limits, because I would think I was doing really well, but then, unconsciously, I would have crossed my own boundaries and be flat on my back for two days."

(patient 2)

4.4 | Coming home but still recovering

At the time of the interview, all patients were at home. They spoke of coming home as a beautiful moment. At the same time, it was a shocking confrontation, as they were still weak and not anywhere near their old functional capacities. Some patients felt that they might have gone home too early, and wished they had stayed in the hospital because they could hardly manage themselves. Especially those with a busy households had trouble to find the energy to live in harmony with their family and be social.

"I really wanted to go home but when I finally did get home I wanted to return after about an hour and a half. Because then you are very happy to see your children again, but at the same time it is also very tiring. So usually I can handle quite a lot but now I had a very short fuse. I got angry very quickly. And I would flee upstairs. But I would also, for example, like, go upstairs and take a shower, and then I really needed to lie down on the bed afterwards to gather enough strength to go downstairs again."

(patient 2)

Coming home also meant that patients were liberated from quarantine. While admitted they had to follow annoying and in some cases, unreasonable rules, like wearing a facemask outside with nobody around. For many patients leaving quarantine was a big relief.

"You remain in quarantine all the time. If you go out, you put your facemask on, if you are on a bike, you put a facemask on, as well as gloves. Well that is very annoying if you have to make a physical effort. At one point I was sitting on the balcony with my mask on and my gloves on. Yes, outside in the sun. So that feels strange. Sitting there on your own with your mask on. Weird. So I was very happy to finally get out of quarantine."

(patient 8)

Recovery still proceeded after coming home. Some patients went for outpatient treatment in rehabilitation clinics, others were supported by first-line therapists. Patients wanted the best possible treatment and, as COVID-19 was a new disease, they were insecure about which therapist to choose. They looked for therapists experienced with patients with lung problems, or practices with richly equipped training facilities.

While at home, some patients still relied on oxygen therapy, walkers or wheelchairs. These were necessary aids but they also represented the illness period. Patients typically wanted these things out of their house as soon as possible.

"I had a Zimmer frame, a walker, a bed. Basically all the amenities I needed to be at home. A commode, everything I required. By the way, I didn't use the commode, nor the wheelchair. That was also there. I sat in it once. But I wanted that thing out of my house."

(patient 7)

4.5 | Finding a new balance

The extent to which patients recovered their abilities over time strongly differed. Several patients largely regained their old lives. Some started working again. Others still struggled with severe complaints hindering them from participating in social activities. Patients experienced a wide range of complaints including: lack of energy, fatigue, shortness of breath, morning stiffness, hip or shoulder complaints, foot drop, altered feeling in arms and legs, quick acidification in the legs, troubles concentrating and muscle aches. For some complaints, physicians predicted that they would not disappear entirely, for example neuropathic complaints. However, for most complaints, it was unknown to what extent patients might recover and what their final functional abilities would be.

"I suffer from tingling in both feet. And that foot drop, that has also started to play up again. But the tingling in the feet continues day and night. And that bothers me. I've been to the neurologist, and they researched

it [...] and then the neurologist said: "yes, what you have, that's a gift for life, it won't go away."

(patient 4)

Patients talked about their ordeal with their partners and families, oftentimes using the diaries and photos taken during their ICU stay. It was difficult to imagine what it had been like for their families to see them this critically ill and to deal with the isolated circumstances. In the interviews, patients typically became emotional when they spoke about the experiences that their families went through.

"If you look back at the photos and see what you looked like lying in the hospital bed that is when you really know how sick you have been. They even started arrangements for my funeral at home. I still need to process that."

(patient 5)

Several patients expressed a certain degree of acceptance of their situation. They were thankful for the fact that they survived their critical illness, particularly because they also heard about patients not surviving COVID-19. They pointed at this as being a miracle or they felt helped by a higher power. They valued life more than before their illness and recognized an altered mindset of being more generous and loving. These aspects helped them put their actual problems in a different perspective.

"The fact that I got so sick is just part of life. And I want to process it and move on. And when I woke up after being on the ICU, I was so glad I was still alive. At Klimmendaal as well, going outside for the first time, seeing those little flowers, well everything you remember from the past and you get to experience again was wonderful to me. And I am still grateful for that."

(patient 11)

The confidence that one could live on in a meaningful and acceptable manner seemed to grow over time. All progress on a physical level was welcomed, but the urgent striving for progress seemed to slow down. Some patients expressed that they found a new rhythm and balance, which they could accept and live with.

"As weird as it sounds and knowing how damaged my lungs were. I wasn't afraid. And maybe, of course, I say that now I know that my organs have recovered, but I do think that I have become a better person. In retrospect, selfishly, I'm glad I had it. [...] I knew that I should be a little less involved in the hectic work pace. I always had both feet on the ground, but even more so now. I also made an agreement with myself to hold on to this feeling. I do not have to be happy every day,

but I should try to be more realistic, more composed and more balanced overall.”

(patient 2)

5 | DISCUSSION

In this study, we explored patients' lived experiences in recovery from COVID-19-associated ICUAW. Hermeneutic phenomenological analysis yielded five main themes: 'waking up in alienation', 'valuing human contact in isolation', 'making progress by being challenged', 'coming home but still recovering' and 'finding a new balance'. These themes were worked out in phenomenological descriptions reflecting a recovery process that does not follow a linear build-up, but comes with moments of success, setbacks, trying new steps and breakthrough moments of achieving mobilizing milestones.

We found that recovery starts with experiencing a strong sense of alienation. The alienation is applicable to all existentials (lived time, lived space, lived body, lived human relations and lived materials) (Van Manen, 2014). The alienating character of illness found in this study complies with the conceptualization of 'illness as unhomelike being-in-the-world' (Svenaesus, 2011). Patients express that in this alienation they look for familiarity, for security and for recognition. They want to return to the familiar situation, back to the old, balanced, bodily self. Patients long for health and 'homelikeness': "Health is a non-apparent attunement, a rhythmic, balancing mood that supports our understanding in a homelike way without calling for our attention" (Svenaesus, 2000).

In the isolation environment, patients strongly value human contact. The presence and contact with healthcare professionals and family members are crucial in supporting them through desperate moments and to regain belief in recovery. Patients initially have limited control over their body and are being moved by others. They rely on healthcare professionals to create situations in which they can experience improved physical functioning.

At first, this is frightening, requiring much reassurance and support from healthcare professionals. By being challenged, and experiencing some degree of physical activity and control, patients regain confidence. It seems that their body has to be reminded of what it felt like to perform active movements, which suggests that mobility training increases body knowledge. Body knowledge, or body memory, is a noncognitive knowing that guides much of our daily doing and acting. This can be illustrated with the example of a coffee mug: "Our body knows how to pick up a coffee mug from the table with just the right grasp and lift" (Van Manen, 2014).

When patients come back to the familiarity of their homes, leaving the isolation precautions means a big relief, however, in some way they are alienated again. They are confronted with the fact that they are still recovering and are unable to take on their old lives yet. The extent to which patients regain back their abilities over time differs strongly between patients. The same holds true for the extent to which patients find a new rhythm and balance. As acknowledged by recent literature the feeling 'to want to come back' can be strong

and imply a silent form of suffering (Alexandersen et al., 2021). Therefore, patients recovering from ICUAW should be offered health-promoting follow-up support.

5.1 | Relating findings to the existing literature

There is a vast amount of qualitative studies looking into the experiences of patients who are admitted and/or mechanically ventilated in the ICU. In line with our findings, many of these studies have described some form of alienation in the ICU (Almerud et al., 2007; Carruthers et al., 2018; Johansson & Fjellman-Wiklund, 2005; Locsin & Kongsuwan, 2013; Lykkegaard & Delmar, 2013). The importance of human contact and the presence of significant others have also been described previously (Alexandersen et al., 2019; Fredriksen & Svensson, 2010; Karlsson et al., 2012; Lykkegaard & Delmar, 2015; Mylén et al., 2016; Tingsvik et al., 2018). The last decade has seen a growing body of qualitative literature regarding ICU recovery (Abdalahim & Zeilani, 2014; Ågård et al., 2012; Apitzsch et al., 2021; Calkins et al., 2021; Corner et al., 2019; Deacon, 2012; Ewens et al., 2018; Jensen et al., 2017; Kang & Jeong, 2018; Kean et al., 2017; Maley et al., 2016; Nelderup et al., 2018; Palesjö et al., 2015; Thurston et al., 2020; Umberger & Thomas, 2019; Vogel et al., 2021). It is not surprising that our findings show overlap with these studies, such as 'dealing with setbacks' (Vogel et al., 2021), 'learning to live in a changed body' (Palesjö et al., 2015) or 'regaining a mental balance' (Nelderup et al., 2018). However, the phenomenological descriptions provided in this study highlight the immense impact of the isolation precautions that ICU patients with COVID-19 must endure. Moreover, our findings bring across that muscle weakness impacts many different aspects of ICU recovery. This results in specific implications for the care delivery aiming to alleviate these problems.

5.2 | Implications

Our study bears important practical implications for nurses and other healthcare professionals who work with patients recovering from COVID-19-associated ICUAW. It is in no way our intention to deny the importance of diagnosis and treatment of muscle weakness, neurosensory problems or functional capacities. We argue that both 'technical/objective' as well as 'meaningful/subjective' aspects need to be addressed in patients' recovery. While the language in recovery is mostly directed towards objective and quantifiable outcome measures and therapeutic goals, it is crucial to connect to and empathize with the lifeworld of patients. When healthcare professionals are conscious towards patients' experience, it stands to reason that they start to act and communicate differently (Jones et al., 2020). For example, when the healthcare professional is aware that a patient might see her as an 'astronaut', she could be more inclined to introduce herself and explain what

is going on and what she is there for. Moreover, when one can empathize with the desperate questions that critically ill patients may have such as 'what happened to me?' or 'will I recover?', one might be inclined to explain why someone is experiencing weakness, how one could keep perspective and emphasize small steps of progress.

Understanding of the impaired body knowledge in patients with ICUAW could be vital for their rehabilitation as well. We argue that, because body knowledge plays a role in recovery, rehabilitation training should aim not only to increase muscle strength, but also for the patient to explore and reclaim a bodily knowing. For instance, patients might feel that they are unable to stand up when sitting on the side of the bed. If they are brought in a standing position passively, their bodily knowledge is addressed and awakened. From here on, one can work towards active standing, and phase out support. This might feel counter-intuitive, as one might think that muscles must be strengthened first to create the conditions to take the next step in recovery. However, thinking from bodily knowledge, bringing patients into a new posture could promote the regaining of functional abilities and self-efficacy.

Finally, our study findings imply that healthcare professionals should not only 'explain' patients' weakness but also try to 'understand' what this weakness means to patients (Ahlzén, 2011). This understanding is not self-evident and can be promoted by education. In healthcare education, there are trends to stimulate empathy development through experiential learning (Vanlaere et al., 2010). In experiential learning labs, materials are used to mimic patient experiences like limited mobility or sight. These methods offer opportunities to increase awareness of the uniqueness of every single patient in clinical practice (Honkavuo, 2021). However, to our knowledge, no laboratories have developed materials to mimic ICUAW or critical illness. Lively written accounts of patients' experiences, as we provide here, might be used as a fundament for teaching healthcare professionals.

5.3 | Limitations

There are some limitations related to this study. Methodical choices were constrained by pandemic-related restrictions. Therefore, data triangulation with the use of participant observations was not possible. The restrictive measures were also the reason that all interviews were conducted through video calling. The physical distance between interviewer and participant might have limited data richness through a lack of rapport and non-verbal communication. However, literature indicates that in-person interviews are only marginally superior to video calls (Krouwel et al., 2019). Another limitation concerns the frequent occurrence of delirium among critically ill patients. Some experiences as expressed by the patients in this study could be interpreted as delirious, for instance disorientation in time, place and person. Delirium can disturb memory and evoke amnesia (Jones et al., 2000). The lack of recall as a result of delirious phases during ICU stay could have influenced our findings. One could also

argue that delirious experiences expressed by patients at that moment were not real. However, in phenomenology there is no such thing as an 'unreal experience'. When the patient, for instance interprets himself as being on an old squeaky sailing ship, this is the meaning given to that situation at that point, which undoubtedly adds to a sense of disorientation and alienation.

6 | CONCLUSIONS

In this study, we found that recovery from COVID-19-associated ICUAW starts from a situation of alienation. Patients long for homelikeness and rely on healthcare professionals to regain feelings of familiarity, security and recognition. It seems possible for patients to feel homelike again, not only by changing their outer circumstances but also by changing the understanding of themselves and finding a new balance in the altered situation. Nurses and other healthcare professionals can help them in this process when they not only explain the weakness from a biological perspective, but also try to understand the patient's experiences and empathize with their illness.

ACKNOWLEDGEMENT

The authors express their gratitude to the participants who shared their experiences with the research group.

FUNDING INFORMATION

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

DATA AVAILABILITY STATEMENT

Data can be made available upon reasonable request.

ORCID

Roel van Oorsouw  <https://orcid.org/0000-0002-8328-4277>

REFERENCES

- Abdalahim, M. S., & Zeilani, R. (2014). Jordanian survivors' experiences of recovery from critical illness: A qualitative study. *International Nursing Review*, 61(4), 570-577.
- Ågård, A., Egerod, I., Tønnesen, E., & Lomborg, K. (2012). Struggling for independence: A grounded theory study on convalescence of ICU survivors 12 months post ICU discharge. *Intensive and Critical Care Nursing*, 28(2), 105-113.
- Ahlzén, R. (2011). Illness as unhomelike being-in-the-world? Phenomenology and medical practice. *Medicine, Health Care and Philosophy*, 14(3), 323-331.
- Alexandersen, I., Haugdahl, H. S., Stjern, B., Paulsby, T. E., Lund, S. B., & Haugan, G. (2021). 'I want to get Back!' A qualitative study of long-term critically ill patients' inner strength and willpower: Back home after long-term intensive care. *Journal of Clinical Nursing*, 30, 3023-3035.
- Alexandersen, I., Stjern, B., Eide, R., Haugdahl, H. S., Engan Paulsby, T., Borgen Lund, S., & Haugan, G. (2019). "Never in my mind to

- give up!" a qualitative study of long-term intensive care patients' inner strength and willpower—Promoting and challenging aspects. *Journal of Clinical Nursing*, 28(21–22), 3991–4003.
- Ali, N. A., O'Brien, J. M., Jr., Hoffmann, S. P., Phillips, G., Garland, A., Finley, J. C., Almoosa, K., Hejal, R., Wolf, K. M., Lemeshow, S., Connors, A. F., Jr., Marsh, C. B., & Midwest Critical Care Consortium. (2008). Acquired weakness, handgrip strength, and mortality in critically ill patients. *American Journal of Respiratory and Critical Care Medicine*, 178(3), 261–268.
- Almerud, S., Alapack, R. J., Fridlund, B., & Ekebergh, M. (2007). Of vigilance and invisibility—being a patient in technologically intense environments. *Nursing in Critical Care*, 12(3), 151–158.
- Apitzsch, S., Larsson, L., Larsson, A.-K., & Linder, A. (2021). The physical and mental impact of surviving sepsis—a qualitative study of experiences and perceptions among a Swedish sample. *Archives of Public Health*, 79(1), 1–9.
- Berends, K., Claus, L., De Waele, E., Crunelle, C., Matthys, F., & Vanderbruggen, N. (2021). Experiences of COVID-ICU-survivors: Mixed-methods study of psychological consequences by written survey. *Tijdschrift voor Psychiatrie*, 63(5), 324–330.
- Brooks, S. K., Webster, R. K., Smith, L. E., Woodland, L., Wessely, S., Greenberg, N., & Rubin, G. J. (2020). The psychological impact of quarantine and how to reduce it: Rapid review of the evidence. *The Lancet*, 395(10227), 912–920.
- Calkins, K., Kako, P., & Guttormson, J. (2021). Patients' experiences of recovery: Beyond the intensive care unit and into the community. *Journal of Advanced Nursing*, 77(4), 1867–1877.
- Carel, H., & Kidd, I. J. (2014). Epistemic injustice in healthcare: A philosophical analysis. *Medicine, Health Care and Philosophy*, 17(4), 529–540.
- Carruthers, H., Gomersall, T., & Astin, F. (2018). The work undertaken by mechanically ventilated patients in intensive care: A qualitative meta-ethnography of survivors' experiences. *International Journal of Nursing Studies*, 86, 60–73.
- Catania, G., Zanini, M., Hayter, M., Timmins, F., Dasso, N., Ottonello, G., Aleo, G., Sasso, L., & Bagnasco, A. (2021). Lessons from Italian front-line nurses' experiences during the COVID-19 pandemic: A qualitative descriptive study. *Journal of Nursing Management*, 29(3), 404–411. <https://doi.org/10.1111/jonm.13194>
- Corner, E. J., Murray, E. J., & Brett, S. J. (2019). Qualitative, grounded theory exploration of patients' experience of early mobilisation, rehabilitation and recovery after critical illness. *BMJ Open*, 9(2), e026348.
- Deacon, K. S. (2012). Re-building life after ICU: A qualitative study of the patients' perspective. *Intensive and critical care nursing*, 28(2), 114–122.
- Dong, E., Du, H., & Gardner, L. (2020). An interactive web-based dashboard to track COVID-19 in real time. *The Lancet Infectious Diseases*, 20(5), 533–534.
- Engström, Å., & Söderberg, S. (2007). Receiving power through confirmation: The meaning of close relatives for people who have been critically ill. *Journal of Advanced Nursing*, 59(6), 569–576.
- Ewens, B. A., Hendricks, J. M., & Sundin, D. (2018). Surviving ICU: Stories of recovery. *Journal of Advanced Nursing*, 74(7), 1554–1563.
- Fredriksen, S.-T. D., & Svensson, T. (2010). The bodily presence of significant others: Intensive care patients' experiences in a situation of critical illness. *International Journal of Qualitative Studies on Health and Well-Being*, 5(4), 5120. <https://doi.org/10.3402/qhw.v5i4.5120>
- Fuke, R., Hifumi, T., Kondo, Y., Hatakeyama, J., Takei, T., Yamakawa, K., Inoue, S., & Nishida, O. (2018). Early rehabilitation to prevent postintensive care syndrome in patients with critical illness: A systematic review and meta-analysis. *BMJ Open*, 8(5), e019998.
- Hermans, G., & Van den Berghe, G. (2015). Clinical review: Intensive care unit acquired weakness. *Critical Care*, 19(1), 274.
- Honkavuo, L. (2021). Ethics simulation in nursing education: Nursing students' experiences. *Nursing Ethics*, 28(7–8), 1269–1281.
- Jensen, J. F., Overgaard, D., Bestle, M. H., Christensen, D. F., & Egerod, I. (2017). Towards a new orientation: A qualitative longitudinal study of an intensive care recovery programme. *Journal of Clinical Nursing*, 26(1–2), 77–90.
- Johansson, L., & Fjellman-Wiklund, A. (2005). Ventilated patients' experiences of body awareness at an intensive care unit. *Advances in Physiotherapy*, 7(4), 154–161.
- Jones, C., Griffiths, R. D., & Humphris, G. (2000). Disturbed memory and amnesia related to intensive care. *Memory*, 8(2), 79–94.
- Jones, J., Bion, J., Brown, C., Willars, J., Brookes, O., Tarrant, C., on behalf of the PEARL collaboration. (2020). Reflection in practice: How can patient experience feedback trigger staff reflection in hospital acute care settings? *Health Expectations*, 23(2), 396–404.
- Kang, J., & Jeong, Y. J. (2018). Embracing the new vulnerable self: A grounded theory approach on critical care survivors' post-intensive care syndrome. *Intensive and Critical Care Nursing*, 49, 44–50.
- Karlsson, V., Bergbom, I., & Forsberg, A. (2012). The lived experiences of adult intensive care patients who were conscious during mechanical ventilation: A phenomenological-hermeneutic study. *Intensive and Critical Care Nursing*, 28(1), 6–15.
- Kean, S., Salisbury, L. G., Rattray, J., Walsh, T. S., Huby, G., & Ramsay, P. (2017). 'Intensive care unit survivorship'—a constructivist grounded theory of surviving critical illness. *Journal of Clinical Nursing*, 26(19–20), 3111–3124.
- Krouwel, M., Jolly, K., & Greenfield, S. (2019). Comparing skype (video calling) and in-person qualitative interview modes in a study of people with irritable bowel syndrome—an exploratory comparative analysis. *BMC Medical Research Methodology*, 19(1), 219.
- Laerkner, E., Egerod, I., Olesen, F., Toft, P., & Hansen, H. P. (2019). Negotiated mobilisation: An ethnographic exploration of nurse-patient interactions in an intensive care unit. *Journal of Clinical Nursing*, 28(11–12), 2329–2339.
- Lang, J. K., Paykel, M. S., Haines, K. J., & Hodgson, C. L. (2020). Clinical practice guidelines for early mobilization in the ICU: A systematic review. *Critical Care Medicine*, 48(11), e1121–e1128.
- Latronico, N., Herridge, M., Hopkins, R. O., Angus, D., Hart, N., Hermans, G., Iwashyna, T., Arabi, Y., Citerio, G., Ely, E. W., Hall, J., Mehta, S., Puntillo, K., Van den Hoeven, J., Wunsch, H., Cook, D., Santos, C. D., Rubenfeld, G., Vincent, J.-L., ... Needham, D. M. (2017). The ICM research agenda on intensive care unit-acquired weakness. *Intensive Care Medicine*, 43(9), 1270–1281.
- Liu, K., Nakamura, K., Katsukawa, H., Elhadi, M., Nydahl, P., Ely, E. W., Kudchadkar, S. R., Takahashi, K., Inoue, S., Lefor, A. K., Kesecioglu, J., & Nishida, O. (2021). ABCDEF bundle and supportive ICU practices for patients with coronavirus disease 2019 infection: An international point prevalence study. *Critical Care Explorations*, 3(3), 1–13.
- Locsin, R. C., & Kongsuwan, W. (2013). Lived experience of patients being cared for in ICUs in southern Thailand. *Nursing in Critical Care*, 18(4), 200–211.
- Lykkegaard, K., & Delmar, C. (2013). A threat to the understanding of oneself: Intensive care patients' experiences of dependency. *International Journal of Qualitative Studies on Health and Well-Being*, 8(1), 20934.
- Lykkegaard, K., & Delmar, C. (2015). Between violation and competent care—Lived experiences of dependency on care in the ICU. *International Journal of Qualitative Studies on Health and Well-Being*, 10(1), 26603.
- Maaskant, J., Jongerden, I., Bik, J., Joosten, M., Musters, S., Storm-Versloot, M., Wielenga, J., Eskes, A. M., & FAM-Corona Group. (2021). Strict isolation requires a different approach to the family of hospitalised patients with COVID-19: A rapid qualitative study. *International Journal of Nursing Studies*, 117, 103858.
- Maley, J. H., Brewster, I., Mayoral, I., Siruckova, R., Adams, S., McGraw, K. A., Piech, A. A., Detsky, M., & Mikkelsen, M. E. (2016). Resilience in survivors of critical illness in the context of the survivors' experience and recovery. *Annals of the American Thoracic Society*, 13(8), 1351–1360.

- Marin-Corral, J., Garcia-Sanz, À., & Masclans, J. R. (2021). Humanizing ICU coronavirus disease 2019 care. *Chest*, *159*(2), 489.
- Marini, J. J., & Gattinoni, L. (2020). Management of COVID-19 respiratory distress. *JAMA*, *323*(22), 2329–2330.
- Medrinal, C., Prieur, G., Bonnevie, T., Gravier, F.-E., Mayard, D., Desmalles, E., Smondack, P., Lamia, B., Combret, Y., & Fossat, G. (2021). Muscle weakness, functional capacities and recovery for COVID-19 ICU survivors. *BMC Anesthesiology*, *21*(1), 1–5.
- Mylén, J., Nilsson, M., & Berterö, C. (2016). To feel strong in an unfamiliar situation; Patients' lived experiences of neurosurgical intensive care. A qualitative study. *Intensive and Critical Care Nursing*, *32*, 42–48.
- Nelderup, M., Simonsson, A., & Samuelson, K. (2018). Intensive care survivors' experiences of recovery after hospital discharge: A qualitative interview study. *Nordic Journal of Nursing Research*, *38*(4), 196–203.
- Nie, A., Su, X., Zhang, S., Guan, W., & Li, J. (2020). Psychological impact of COVID-19 outbreak on frontline nurses: A cross-sectional survey study. *Journal of Clinical Nursing*, *29*(21–22), 4217–4226.
- O'Brien, B. C., Harris, I. B., Beckman, T. J., Reed, D. A., & Cook, D. A. (2014). Standards for reporting qualitative research: A synthesis of recommendations. *Academic Medicine*, *89*(9), 1245–1251.
- Palesjö, C., Nordgren, L., & Asp, M. (2015). Being in a critical illness-recovery process: A phenomenological hermeneutical study. *Journal of Clinical Nursing*, *24*(23–24), 3494–3502.
- Sharshar, T., Bastuji-Garin, S., Stevens, R. D., Durand, M.-C., Malissin, I., Rodriguez, P., Cerf, C., Outin, H., De Jonghe, B., & Groupe de Réflexion et d'Etude des Neuromyopathies En Réanimation. (2009). Presence and severity of intensive care unit-acquired paresis at time of awakening are associated with increased intensive care unit and hospital mortality. *Critical Care Medicine*, *37*(12), 3047–3053.
- Söderberg, A., Karlsson, V., Ahlberg, B. M., Johansson, A., & Thelandersson, A. (2020). From fear to fight: Patients experiences of early mobilization in intensive care. A qualitative interview study. *Physiotherapy Theory and Practice*, *38*(6), 1–9.
- Sun, N., Wei, L., Wang, H., Wang, X., Gao, M., Hu, X., & Shi, S. (2021). Qualitative study of the psychological experience of COVID-19 patients during hospitalization. *Journal of Affective Disorders*, *278*, 15–22.
- Svenaesus, F. (2000). *The hermeneutics of medicine and the phenomenology of health: Steps towards a philosophy of medical practice* (Vol. 5). Springer Science & Business Media.
- Svenaesus, F. (2011). Illness as unhomelike being-in-the-world: Heidegger and the phenomenology of medicine. *Medicine, Health Care and Philosophy*, *14*(3), 333–343.
- Tembo, A. C., Higgins, I., & Parker, V. (2015). The experience of communication difficulties in critically ill patients in and beyond intensive care: Findings from a larger phenomenological study. *Intensive and Critical Care Nursing*, *31*(3), 171–178.
- Thornton, J. (2020). Covid-19: How coronavirus will change the face of general practice forever. *BMJ*, *368*, 1–2.
- Thurston, L. M., Milnes, S. L., Hodgson, C. L., Berkovic, D. E., Ayton, D. R., Iwashyna, T. J., & Orford, N. R. (2020). Defining patient-centered recovery after critical illness—a qualitative study. *Journal of Critical Care*, *57*, 84–90.
- Tingsvik, C., Hammarskjöld, F., Mårtensson, J., & Henricson, M. (2018). Patients' lived experience of intensive care when being on mechanical ventilation during the weaning process: A hermeneutic phenomenological study. *Intensive and Critical Care Nursing*, *47*, 46–53.
- Umberger, R. A., & Thomas, S. P. (2019). Survivor but not fully recovered: The lived experience after 1 year of surviving sepsis. *Dimensions of Critical Care Nursing*, *38*(6), 317–327.
- van Manen, M. (1997). *Researching lived experience: Human science for an action sensitive pedagogy* (2nd ed.). Routledge.
- Van Manen, M. (2014). *Phenomenology of practice: Meaning-giving methods in phenomenological research and writing*. Left Coast Press.
- Van Willigen, Z., Ostler, C., Thackray, D., & Cusack, R. (2020). Patient and family experience of physical rehabilitation on the intensive care unit: A qualitative exploration. *Physiotherapy*, *109*, 102–110.
- Vanlaere, L., Coucke, T., & Gastmans, C. (2010). Experiential learning of empathy in a care-ethics lab. *Nursing Ethics*, *17*(3), 325–336.
- Vogel, G., Joelsson-Alm, E., Forinder, U., Svensen, C., & Sandgren, A. (2021). Stabilizing life: A grounded theory of surviving critical illness. *Intensive and Critical Care Nursing*, *67*, 103096.
- Vottero, B., & Rittenmeyer, L. (2012). The hospitalised patients' experience of being in protective/source isolation: A systematic review of qualitative evidence. *JBI Evidence Synthesis*, *10*(16), 935–976.

SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

How to cite this article: van Oorsouw, R., Klooster, E., Koenders, N., Van Der Wees, P. J., Van Den Boogaard, M., & Oerlemans, A. J. M. (2022). Longing for homelikeness: A hermeneutic phenomenological analysis of patients' lived experiences in recovery from COVID-19-associated intensive care unit acquired weakness. *Journal of Advanced Nursing*, *00*, 1–13. <https://doi.org/10.1111/jan.15338>

The *Journal of Advanced Nursing (JAN)* is an international, peer-reviewed, scientific journal. *JAN* contributes to the advancement of evidence-based nursing, midwifery and health care by disseminating high quality research and scholarship of contemporary relevance and with potential to advance knowledge for practice, education, management or policy. *JAN* publishes research reviews, original research reports and methodological and theoretical papers.

For further information, please visit *JAN* on the Wiley Online Library website: www.wileyonlinelibrary.com/journal/jan

Reasons to publish your work in *JAN*:

- High-impact forum: the world's most cited nursing journal, with an Impact Factor of 2.561 – ranked 6/123 in the 2019 ISI Journal Citation Reports © (Nursing; Social Science).
- Most read nursing journal in the world: over 3 million articles downloaded online per year and accessible in over 10,000 libraries worldwide (including over 6,000 in developing countries with free or low cost access).
- Fast and easy online submission: online submission at <http://mc.manuscriptcentral.com/jan>.
- Positive publishing experience: rapid double-blind peer review with constructive feedback.
- Rapid online publication in five weeks: average time from final manuscript arriving in production to online publication.
- Online Open: the option to pay to make your article freely and openly accessible to non-subscribers upon publication on Wiley Online Library, as well as the option to deposit the article in your own or your funding agency's preferred archive (e.g. PubMed).