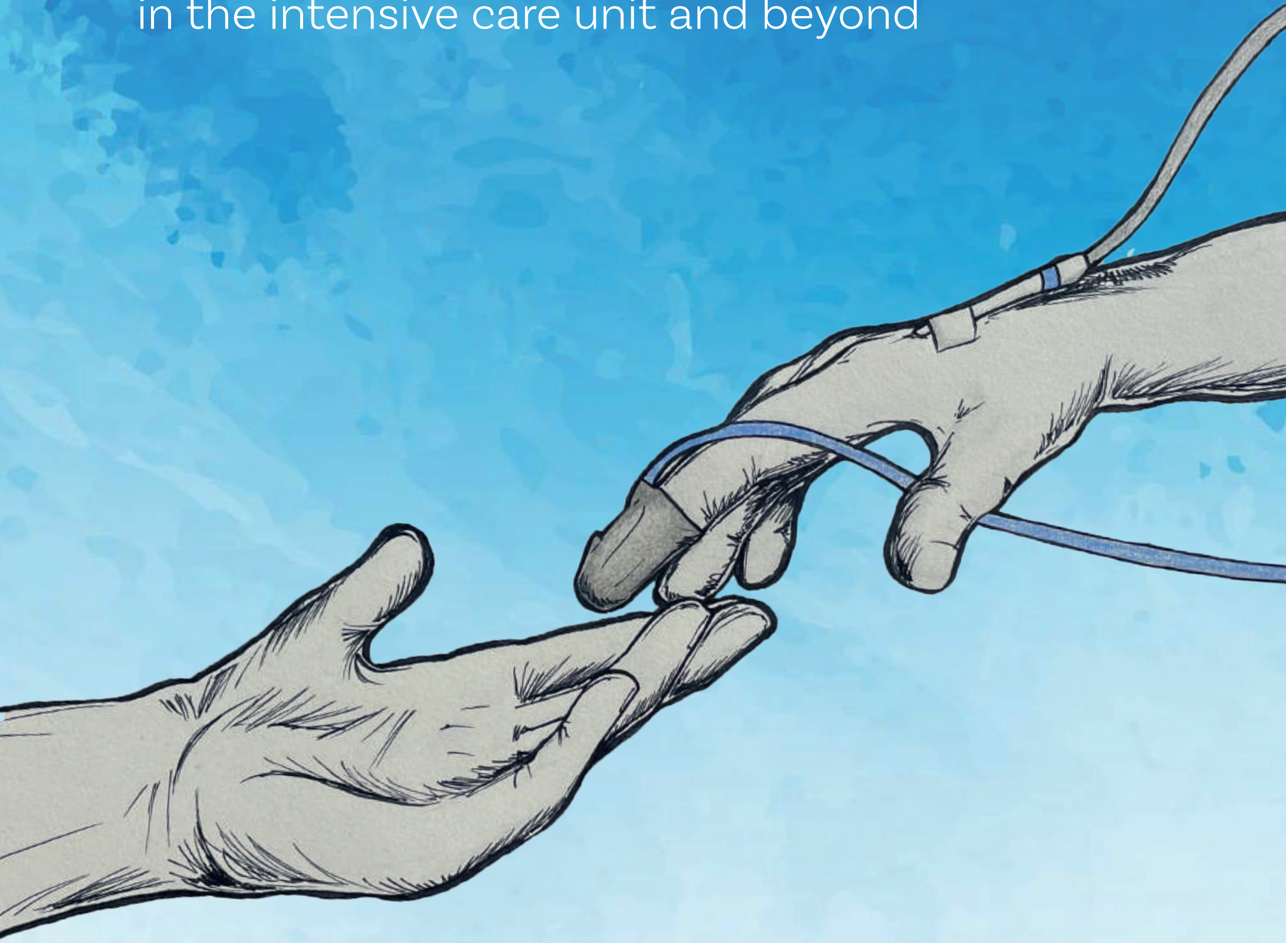
Embodied Recovery

Exploring lifeworld dimensions and the value of physiotherapy in the intensive care unit and beyond



Roel van Oorsouw

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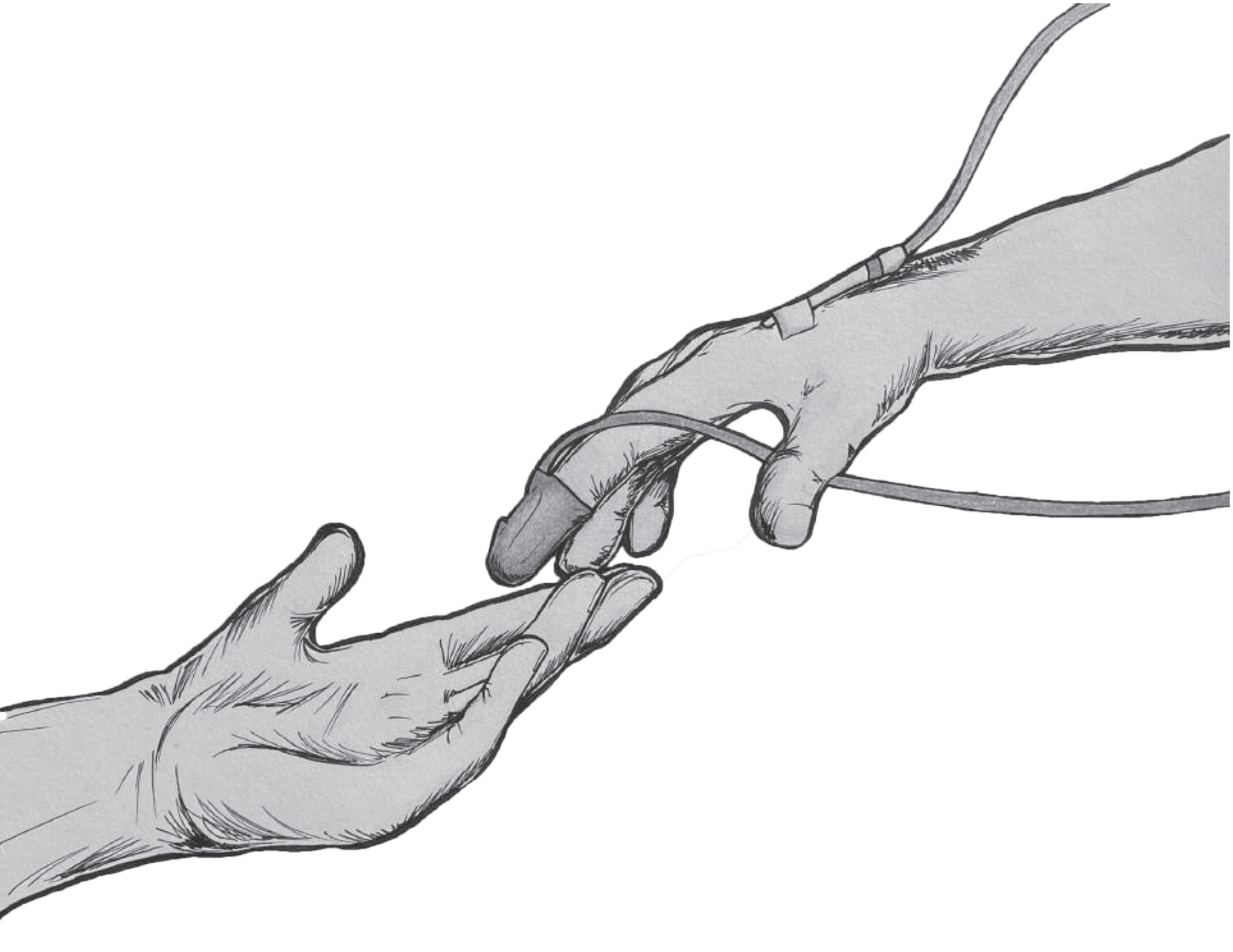
“The body is our general medium for having a world” [1]

Maurice Merleau-Ponty

CONTENTS



1

General Introduction

“I have seen some amazing physiotherapists do some incredible things with patients. […] But for all the wonderful things I have seen, I have also spent much of my professional life wondering why we, as physiotherapists, do not make more of the experiences, skills and manifest opportunities available to us. Why is it that we have chosen to focus on the biomechanical body? […] Why is it that we have willingly embraced quantitative research, but not qualitative? Why have we shown such an abiding passion for complex anatomical and pathological ideas, but turned our professional ‘nose’ up at philosophy and sociology?” [2]

David A. Nicholls

Embodied recovery, lifeworld dimensions, intensive care unit and physiotherapy? These terms may not instantly be clear. In this introduction I hope to clarify why this combination of terms does make sense, and how they form an important topic for scientific inquiry. This introduction starts with my personal involvement with physiotherapy in the intensive care unit (ICU) and beyond. Next, I describe the development of critical care medicine and ICU facilities. Then, I introduce the concepts of deconditioning during ICU stay and typical intensive care related phenomena including intensive care unit acquired weakness (ICUAW) and the post-intensive care syndrome (PICS). Subsequently, I introduce how physiotherapists aim to prevent and decrease deconditioning during ICU stay through early mobilisation, and support patients in gaining back their functional abilities through ICU rehabilitation. I will explain how one can take different perspectives and introduce the terms illness, disease and sickness. Then, I will concentrate on the study of the first-person perspective and introduce phenomenological methodology. Finally, I provide an outline of this thesis together with the overarching aim of the PhD trajectory as a whole and the specific aims of the included studies.

PERSONAL INVOLVEMENT

For the past 15 years I have worked as a hospital-based physiotherapist dedicated to supporting critically ill patients. The assignment was and still is usually quite simple: “mobilise the patient”. However, over the years I have often felt lost and confused while trying to fulfil my clinical role. As acknowledged in literature, mobilisation requires substantial coordination [3, 4], and can be frustrated by organisational factors such as: physician rounds, restrictive technology, insufficient staffing, resting hours, lack of equipment, healthcare professionals’ coffee breaks and so on. However, especially in the ICU, many more factors are of influence, making the work unpredictable and fascinating at the same time. Patients can unexpectedly wake up or show sudden decline. They can be upset and restless or anxious and obviously hallucinating. Attending family can be supportive but also fearful and withholding. I am still so often intrigued by the extraordinary ICU environment, the impressive medical technology available and the impact of critical illness on people’s lives.

To ensure optimal support for patients and their relatives in this setting, the healthcare professionals must form a strong team, which I am proud to be part of. The text in Box 1 exemplifies what I typically say and do during a consultation with a severely weakened mechanically ventilated ICU patient. When reading this example, one may recognise that many of the expressions relate to thoughts, fears or feelings that the patient might have. Some will say that it is a matter of communication skills, but I think that it is not that simple. It seems to me that it requires empathic abilities from the therapist to provide the guidance, safety and support needed to mobilise the patient. Over the years, I have become increasingly aware of the importance to not only optimise my professional technical skills and clinical reasoning but also to invest in, and relate to, the lived world or 'lifeworld' of patients, and of my own. This lifeworld concept is something I missed in my physiotherapy education and appears to be underexplored in rehabilitation practice and literature. It was a relief when I discovered lifeworld dimensions to be much more established in nursing literature and acknowledged in nursing science [5-7].

Since my education in qualitative research, as part of my master's training, I became particularly interested in phenomenology, which is both a philosophy and a qualitative research methodology. As a physiotherapist, and not philosophically educated, it was a challenge to comprehend its concepts and theories. However, I found them to be very helpful in my clinical practice and wished to learn more about them. Especially embodiment theory, and the insight that the body can be experienced as an object, a living thing, but also as subject, as lived through [8], seemed to me essential for understanding the phenomena I came across in the ICU context. This two-sidedness is made tangible in Husserl's famous description of the 'double sensation of the body' (please see Box 2).

In order to make the lifeworld more visible and tangible to myself and my colleagues, I looked for possibilities to study the ICU and rehabilitation setting from a phenomenological perspective. To promote the transfer of knowledge to the practical field of physiotherapy, I present three clinical examples (please see Boxes 3, 4 and 5), which I think illustrate situations that are difficult to explain when we disregard lifeworld dimensions.

Box 1. A physiotherapy consult at the intensive care unit

"Good morning Henk, I am Roel, a physiotherapist. I was here with you yesterday. Then you sat on the side of the bed for the first time. It was hard for you to stay upright. The nurse told me this morning that you had a good night of sleep and that you are now fully rested. I can see that you want to talk, but unfortunately that is not possible because of the tube in your throat. Is something bothering you? Can you point to it? Your mouth? Do you have a dry mouth? Are you thirsty? I cannot give you something to drink, but I can moisten your mouth with this spray, is that better?

In a minute I want you to sit up again so you can get used to this position and so we can exercise your arms and legs. You are shaking your head, you don't agree? I can imagine that you don't look forward to it. I have discussed this with the nurse and physician and we are convinced that you can do this. Don't worry, we will take it step by step and we will support you through it. Yesterday it went very well already.

Before we start, we have to make some arrangements. We will unhook these drips and we can also take off this line. Because of your illness and the lying in bed your body may feel strange. But through movements and exercises this may normalise. Can you try to roll over towards me? If you put your hand here and you push there on your elbow, then you can help yourself, very good. You may become a little dizzy now when you sit up, this is normal, it might go away when you make this movement with your ankles. Does that feel better already? Nice. Now you're sitting up very well, I can tell that you are more in control compared to yesterday. If you cannot keep this position anymore then you can lean on the pillow we put behind you. Can you now try to kick against my hand? I can see that you are trying. You have little strength right, very different to what you were used to.

Your wife told me that you normally have a very active lifestyle, with cycling and working the garden. That can come back you know, we have seen it more often. I know this takes a lot of energy, but it is the only way to go forward. Of course you also need your rest. We made a daily schedule to make sure that your activities are well distributed across the day. We have also discussed this with your wife and kids. They are coming to visit you this afternoon again. Shall I take a picture now you're sitting up? I bet they would love to see that."

Box 2. Husserl's example of the 'double sensation of the body'

"If we touch our left hand with our right hand, both hands can, dependent on our attitude or attention, appear as either the executing instance of touching or the object of touching. We can perceive the touched hand according to its physical or objective attributes, in its smoothness or roughness; it is then the object of perception or touch. But as soon as the localised sensations of the left hand enter the picture, this does not merely add to the characteristics of the physical thing, 'a living body (*Körper*)'; in this very moment, it turns into a 'lived body (*Leib*)' that itself senses" [8].

Box 3. Clinical example: testing strength

Physiotherapists working in the ICU will regularly test skeletal muscle strength using the Medical Research Council SumScore (0-60) to gain insight into patients' muscle strength and to diagnose intensive care unit acquired weakness (MRC-SS < 48). Often, when the patient appears weak this testing takes place with them in their bed. Many times, I have formally tested a patient in bed and the patient scores low, for instance strength 2 (out of 5) on knee extension on both sides (which means that he or she can extend the knee, but not against gravity). The odd thing is that when I then help the patient to a sitting position, on some occasions the patient is able to stand up, and even stand in a stable manner, for which you need more strength in your knee extensors than strength 2. I cannot explain this from either a biological or biomechanical perspective.

Box 4. Clinical example: quick recovery

Physiotherapists working in the ICU will all know examples of patients who were mechanically ventilated and bedridden for weeks and subsequently developed severe muscle weakness. Intensive care unit acquired weakness is described as a combination of polyneuropathy, critical illness polymyopathy or critical illness neuromyopathy, and is typically combined with muscle atrophy. I have seen many patients being incapable of performing any movement or showing any strength on day 1, but with the help of rehabilitation training, on day 14 he or she can walk around the department. I cannot explain this progression from a physiological or biomechanical perspective because muscle and nerve recovery do not progress this quickly.

Box 5. Clinical example: limiting technology

Physiotherapists working in the ICU or at a hospital ward will recognise that patients can have all sorts of lines, cables, drains, catheters attached to their bodies. I have had many experiences when a patient is convinced that these lines are a reason to not mobilise, yet I am convinced that it is actually possible. In many cases it is not enough to just 'tell' them how this can be accomplished. When I 'show' them how it is done and how they can manage the lines while mobilising, then they 'see' the possibilities as well. When we arrive back at the patient's room, typically patients say that they didn't expect this to be possible.

CRITICAL CARE

Critical care is defined as "the identification, monitoring, and treatment of patients with critical illness through the initial and sustained support of vital organ functions" [9]. Modern critical care began with developments in technology, like the iron lung and negative pressure ventilation, which were extensively used during the poliomyelitis epidemic in the 1950s. Poliomyelitis caused many patients to develop respiratory failure due to respiratory muscle paralysis or bulbar palsy [10]. To enable treatment for all these patients, students were staffed, working in shifts, manually ventilating the patients [11]. The Danish anaesthetist Bjorn Ibsen came up with the idea to care for these patients in a dedicated ward, where each patient could have their own nurse [10]. The first ICU was developed as a result.

In the following years, the availability of mechanical ventilators and automated monitoring devices increased [12]. The development of a microprocessor-controlled ventilator in 1971, along with the introduction of a multitude of new equipment and drugs, stimulated the growth of intensive care medicine in the next decades [10]. By the end of the 1980s, in industrialised countries, almost every major hospital had implemented ICU facilities [12]. Initially the care in the ICU was provided solely by physicians and nurses, but over the years many specialties joined in, including dedicated medical specialists, nurses, physiotherapists, pharmacists, dietitians, technicians, radiologists and microbiologists [10].

Nowadays, an ICU can be described as a specially designed department where patients' vital functions are monitored and treated using complex technological devices. If needed, patients' vital functions can be supported or completely taken over. Currently, each year about 70,000 patients are admitted to ICUs in the Netherlands [13]. The COVID-19 pandemic, starting in 2020, resulted in many patients needing ICU treatment. This demanded a quick increase in ICU capacity and led to a broader awareness among the public concerning the work done in ICUs.

Deconditioning during ICU stay

Due to constantly improving medical technology many patients nowadays survive their ICU stay. The one-year mortality rate after ICU stay has decreased from over 70 percent in the 1970s [14] to less than 20 percent in the last decade [13]. Survival, however, is not the same as recovery in good health. After being discharged from the ICU, patients often face a variety of long-term impairments related to the critical illness and its treatment, reducing their quality of life [15-19]. These impairments have been collectively called the post-intensive care syndrome (PICS), defined as: "new or worsened impairments in physical, cognitive or mental health originating after critical illness and persisting beyond acute care hospitalization" [20]. One year after ICU discharge about 50% of patients still suffer from PICS symptoms [21, 22]. Typically occurring impairments in the physical domain include fatigue, weakened condition, muscle weakness, joint stiffness, shortness of breath, joint pain, respiratory complaints, balance problems, sensitivity problems and muscle pains [21]. Risk factors for worse outcome after ICU stay are lengthy hospital stay, female sex, older age, and worse patients' pre-ICU functional status [21, 23].

Major physical impairments can be caused by intensive care unit acquired weakness (ICUAW), which is defined as: “clinically detected weakness in critically ill patients in whom there is no plausible aetiology other than the critical illness and its treatment” [24]. ICUAW affects skeletal, trunk and respiratory muscles. It therefore impedes patients’ ability to perform functional activities like sitting, standing and walking, and hinders weaning from mechanical ventilation [25]. ICUAW can originate from critical illness polyneuropathy, critical illness polymyopathy or critical illness neuromyopathy, and is typically combined with muscle atrophy [26, 27]. Patients in the ICU can lose more than 15% of their muscle mass per week [28]. The exact pathophysiology for ICUAW is still unknown but entails complex structural and/or functional changes in muscle fibres and neurons [26]. Currently there is no effective treatment for ICUAW, although preventive measures have been described including avoiding hyperglycaemia, avoiding early parenteral nutrition, minimising sedation and providing early mobilisation [25, 26].

Early mobilisation and ICU rehabilitation

For decades routine features of critical care included liberal use of sedation and immobilisation because they were thought to be necessary to normalise patients’ physiological function by artificial means [29]. However, around the year 2010 the paradigm shifted towards a ‘less is more’ philosophy for patients in the ICU [10, 29, 30]. Critical care strategies were altered towards lung protective ventilation including lower tidal volumes and airway pressures, the acceptance of lower blood pressure and cardiac output values, fewer blood transfusions and patients were sedated less heavily in order to keep them comfortable instead of comatose [10]. Insights that added to this paradigm shift came from studies that reported the long-term negative effects of bedrest, inactivity, and high doses of sedatives [16, 31]. Moreover, landmark studies by Morris [32], Schweickert [33] and Needham [34] indicated that early mobilisation was feasible, safe and potentially beneficial. Since then, physical training interventions have been broadly implemented in ICUs aiming to prevent patients from deconditioning during ICU stay [35-38]. Mobilisation is “a type of intervention that facilitates the movement of patients and expends energy with a goal of improving patient outcomes” [39]. The definition of ‘early’ strongly differs among authors, ranging from ‘within 24 hours after ICU admission’ to ‘throughout ICU stay’ [40, 41]. An early start of mobilisation is recommended in the PADIS (Pain, Agitation, Delirium, Immobility and Sleep) guideline [42], and the widely acknowledged ABCDEF (Awakening, Breathing, Choice of analgesia, Delirium, Early mobility, Family engagement) bundle [43, 44]. Physiotherapists are part of ICU teams and have their own clinical practice guidelines [45, 46]. The feasibility and safety of early mobilisation have been well established [47], however, the positive effects have not yet convincingly been proved. Multiple systematic reviews found promising effects of early mobilisation [48-63]. Yet, they structurally conclude that there is a high risk of bias in the current literature, and a need for well-designed large randomised controlled trials (RCTs). A recent large RCT, performed by the Team study investigators, showed no effect of increased early active mobilisation among mechanically ventilated patients [64]. However, because the control group in this trial received a relatively high level of early mobility, this result must not be interpreted as a proof that ‘rest is best’, but rather as an indicator that the optimal dose and timing of early mobilisation in the ICU are still unclear [65, 66].

With the knowledge that patients face long-term impairments after hospital discharge, more attention has been given to aftercare. Outreach teams and follow-up clinics have been set up to address patients’ needs for physical, psychological and cognitive recovery [67, 68]. Physical recovery after discharge from the ICU is typically supported by physiotherapists on the hospital ward, in rehabilitation facilities and after patients have been discharged home [38]. This type of therapy is called ICU rehabilitation, where rehabilitation is defined as: “a set of interventions designed to optimise functioning and reduce disability in individuals with a health condition” [69]. In the Netherlands, ICU rehabilitation is guided by consensus found in Delphi studies [70, 71] and the recently published guideline of the Dutch Federation of Medical Specialists [72]. The effectiveness of these kind of interventions remains uncertain [73, 74], and is currently being studied [75-78]. Ideally these efforts result in a continuum of care for patients (and their families) after critical illness, extending from the ICU to community or primary care [79].

TAKING PERSPECTIVES

It seems that the value of early mobilisation and ICU rehabilitation is hard to capture in quantitative research. Therefore, to obtain a broader perspective on these interventions, and to see the story behind these numbers, we need to consider qualitative research. Quantitative research has different qualities than qualitative research. Quantitative research is grounded in positivism and the idea of a single objective reality. It uses deductive reasoning and has the goal of testing theories [80]. Qualitative research is grounded in a variety of philosophical traditions which share the belief in multiple realities. It uses inductive reasoning to build theory and explore the meaning of phenomena [80]. Both research traditions provide different perspectives. Because qualitative research accepts individual context and differences it is particularly suitable to explore the patient perspective, or illness perspective.

In 1967 Andrew Twaddle was the first person to make a distinction between disease, illness, and sickness [81]. Since then, these distinctions have become widely accepted in medical sociology, medical anthropology, and philosophy of medicine [82]. The three terms reflect professional, personal and social perspectives on human ailment [83]. Despite lacking consensus on their exact formulation, the terms can be described as follows:

- "**Disease** can be observed, examined, mediated, and measured, and is objective in this sense. Physiological, biochemical, genetic, and mental entities and events are the basic phenomena of disease. Disease is the target of health professionals who want to classify, detect, control, and treat disease, ultimately in order to cure [82]". This objective neutral stance, or medical gaze has also been called the third-person perspective.

- "**Illness**, on the other hand, has emotions and experience, such as anxiety, fear, pain, and suffering, as its basic phenomena. Although illness is in this sense subjective, it can be argued that we can have access to another person's illness through his or her verbal reports of introspection (phenomenology; [84-87], through a common language (the philosophy of language; [88], or through brain states; [89]. For example, illness is characterised in terms of bodily and/or mental awareness and a feeling of estrangement, unpleasantness, or uncanniness [90]. Health professionals' aim with regard to illness is comfort, care, and/or relief of suffering" [82]. It is the experience from within, also called the first-person perspective.

- "**Sickness** has expectations, conventions, policies, and social norms and roles as basic phenomena. Its criteria are discovered through social interaction, participation, and social studies. Accordingly, the knowledge about sickness is inter-subjective (i.e., it is knowledge shared by a social group). Sickness determines whether a person is entitled to treatment and economic rights, exemption from social duties, such as work (sick leave), but also whether a person is legally accountable for his or her actions" [82]. The term intersubjectivity is also used to indicate the possibility to empathise with the feelings of someone else, which is often referred to as the second-person perspective.

Medical humanities have extensively critiqued the dominance of the medical gaze, taking the objective 'disease' perspective as their main focus [91-94]. From this medicalised view, knowledge of the body can be reduced to a collection of third-person objective facts [95]. Healthcare professionals, taking the biomedical perspective, have been accused of ignoring patients' personhood reducing them to a series of intersecting body parts in order to diagnose and treat disease [96]. Human bodies are seen as machines, in which parts can be fixed or replaced.

By its nature critical care oftentimes requires a mechanistic view of the body to ensure survival and invasive treatment of the critically ill. An ICU is a high-tech environment in which patients are continuously monitored and observed and patients' bodies are reduced to anatomical and biochemical entities [5, 97]. The biomedical perspective, or disease perspective, has the potential to dominate ICU professionals' practice [98].

In physiotherapy literature this body-as-machine or biomechanical approach has also been criticised [2, 95, 99]. The body is at the heart of the profession, yet physiotherapists have a limited view of the body, and physiotherapy literature shows almost no interest in the subjective body [2, 100]. Taking the biomechanical perspective has benefitted the profession a lot, however it is now hampering progress as it prevents the profession from seeing people as a whole [2]. Therefore, physiotherapists should problematise a biomechanical view of the body and seek understanding of the diverse ways in which illness and injury may impact patients' experiences of the world [101].

A biomedical or biomechanical approach is however not all problematic. There are many situations in which we experience our body as a thing or as an object [102]. Moreover, patients come to healthcare professionals to solve their health problem, and sometimes 'impersonal' ways of thinking or speaking are needed to deliver safe and effective care [91, 103, 104]. The mechanistic approach of the healthcare professional, the phenomenological perspective of the patient and the role of the social and physical environment equally add to the wellbeing of humans [91]. They are inter-dependent and inseparable. Each of these entities has its own truth and value, and they should not oppose each other [91].

Rather, healthcare professionals should be able to switch between perspectives [100, 105]. Taking another's perspective, also called perspective-taking or role-taking, is a mental activity imaginarily taking someone else's position or perspective on the world in order to understand their thoughts or behaviour [106, 107]. This perspective-taking implies that healthcare professionals have an eye for the first-person or phenomenological perspective. Yet, despite a scarce exception [108], physiotherapists do not have a large tradition in this field. Also, in the literature on early mobilisation and ICU rehabilitation there has not been much attention given to the first-person perspective. When physiotherapists study experiences in early mobilisation or ICU recovery they typically use a more positivistic approach, like grounded theory [109, 110]. However, phenomenology is the eminent approach to study the first-person perspective.

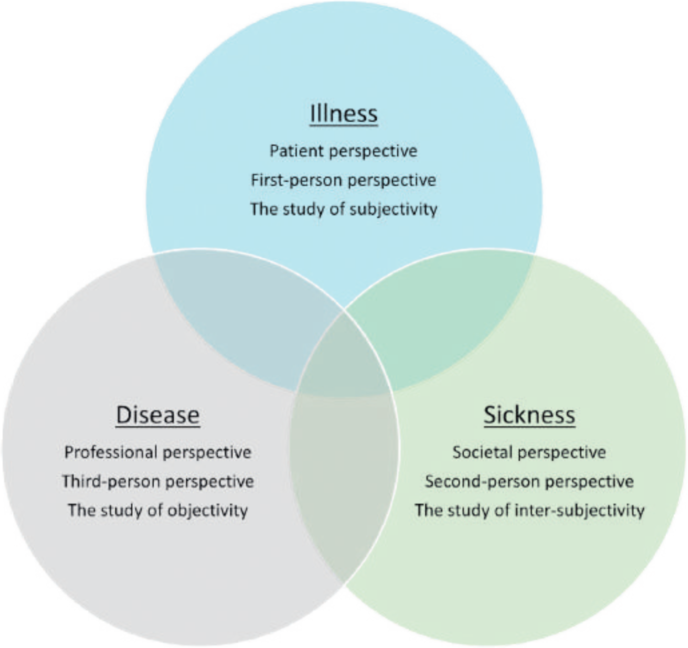


Figure 1. Different perspectives and study directions, adapted from Hofmann [83]

PHENOMENOLOGY AND THE LIFEWORLD

Phenomenology was first established by Edmund Husserl (1859-1938), and further developed by Martin Heidegger (1889-1976), Jean-Paul Sartre (1905-1980), Emmanuel Levinas (1906-1995) and Maurice Merleau-Ponty (1908-1961) [111]. Phenomenology stems etymologically from the Greek words *phenomenon*, which means 'that which shows itself', and *logos,* which means 'to let something be seen' [112]. Phenomenology goes back to the things as they appear to our consciousness, without any presumptions about reality, truth or world. Turning to the things themselves is turning away from theories, interpretations and constructions [111]. Phenomenology is the study of pre-reflective experience, the ordinary experiences that we live in and live through for most of our day-to-day existence [112]. To be able to study these experiences we must leave the 'natural attitude' and take up the 'phenomenological attitude' which is done by 'epoché' and 'phenomenological reduction'. Then, through 'eidetic variation', the essential structures and common meaning of phenomena can be found, which are then presented in a 'thematic description'. These concepts are methodologically important, but for this thesis they do not require further elaboration. In contrast, the concepts of 'intentionality' and 'lifeworld' will be referred to frequently in this thesis and therefore do need further introduction:

- **Intentionality:** Husserl adopted the idea from Franz Brentano (1838-1917) that consciousness is always consciousness of something [113]. This directedness of consciousness is called intentionality [111]. Because all our thinking, feeling, and acting are oriented to the world, we can never step out of the world and view it from a detached standpoint [112]. Intentionality should however not be confused with the more familiar concept of intentionality as having a purpose [111].

- **Lifeworld:** Like fish may take for granted the water they swim in, us humans may find it difficult to notice and articulate the qualitative world we live in [114]. Taking a phenomenological attitude means actively reflecting on the experience as lived through. This world of immediate, 'pre-reflective', experiences, or lived experiences, make our 'lifeworld'. The lifeworld is our every-day experience which is filled with persons, values and meaning [115]. The lifeworld is the world that is there before we reflect on it, before we study it through science or represent it through art [113]. According to Van Manen we can distinguish five fundamental structures of the lifeworld (lived body, lived others, lived time, lived space and lived materials), which he calls 'existentials' [112].

Phenomenology is both a philosophy and a qualitative research tradition. It is one of the well-described qualitative approaches just like grounded theory, ethnography and narrative inquiry [116]. Applied phenomenology, or empirical phenomenological research is mostly done by in-depth interviews but has also been conducted through autoethnography or observations [116-118]. It is characterised by an open attitude and reflexivity of the researcher and of the one who brings in the experience. Theoretical presuppositions and pre-assumptions are made explicit and bracketed [116, 119]. This must not be confused with an objective or distanced position [117]. The researcher is open and invites the participant to co-operatively study experiences [112]. Phenomenological research does not lead to fixed conclusions, but rather to possibilities and variations [117]. Results cannot be generalised to a certain population. However, the reader of a phenomenological study can gain new insights and can decide based on the (thick) description whether it is applicable to their practice.

Phenomenology aims to uncover first-person perspectives via the study of subjective experiences [120, 121]. This however does not mean that phenomenology is the study of the merely subjective, apparent or superficial [111]. Phenomenology is grounded in our direct reality and should not be seen as vague or subjective [122]. Subjective and objective observations are two modes of manifestation but must not be confused with the idea that they are two different worlds. Phenomenologists reject this two-world doctrine and will argue that “the right place to locate objectivity is in, rather than beyond, the appearing world” [111]. By studying consciousness and our modes of being, phenomenology overcomes traditional dichotomies of subjective/objective, perception/action, organism/environment, and mind/body [116, 122].

The phenomenology of illness is a rich tradition which brought insights in the essences of the illness experience [123]. For instance, ill persons, in Western modern culture, feel that something is taken away from them, reflected in five types of losses as described by Toombs [124]: 1) Ill persons experience loss of wholeness, they are alienated of their body and experience loss of integrity. 2) Ill persons experience loss of certainty, they are faced with their own vulnerability. 3) Ill persons experience a loss of control, the disease is unplanned and unasked for, and for treatment they must rely on others. 4) Ill persons experience a loss of freedom to act, their ability to choose freely which course of action (which medical treatment) to pursue is restricted by their lack of knowledge of what the best course of action may be. 5) Ill persons experience the loss of the everyday world, as they can no longer continue with the activities they do in normal daily life.

Phenomenological research can be useful in a healthcare context for several reasons:

- Care can only be meaningfully delivered through an understanding of patients’ experience of illness [125]. Good care includes healthcare professionals’ attempts to understand patients’ perspective [126]. A phenomenological approach portrays the patient as a whole human being and allows holism and caring [5].

- Phenomenology is a way to access another person’s experience of illness. Therefore, it enables healthcare professionals to change perspective and empathise with the illness experience, trigger reflection, and bring about enhanced praxis [122, 127, 128].

- Ill persons are vulnerable to (epistemic and hermeneutical) injustice because they are presumed to be cognitively unreliable or emotionally unstable, and because many aspects of the illness experience are difficult to understand and communicate [129]. Telling stories of illness gives voice to an experience that medicine cannot describe [130]. Phenomenology can therefore be a tool to empower the patient in contact with healthcare professionals [129, 131].

- Studying the healthcare context phenomenologically can be theoretically relevant because it may reveal new and unexpected themes which can encourage new fields of research [117].

- Alongside patient experiences, phenomenology can also be applied to the experiences of healthcare professionals; through growing conscious of their own experiences, they can reflect on their work, learn and see how they can improve their way of working [117].

In the context of early mobilisation and ICU rehabilitation phenomenology can be particularly useful. Being admitted to an ICU due to critical illness is clearly a significant life event. ICU patients often deal with an inability to distinguish reality from hallucinations and dreams, the proximity to death, transformation and perception of the body in illness and transformation, and perception of time [132, 133]. An ICU admission was called an existential crisis, a biographical disruption, a situation of intense vulnerability and is often described as traumatic [134, 135]. Studying patient experiences phenomenologically can highlight these feelings so that they can be addressed [136]. It can add to a recent development called 'humanising ICU' [137-139]. A human-centred approach is deemed essential for good quality hospital-based physiotherapy [140, 141]. Early mobilisation and recovery after critical illness are complex processes which take place in very specific environments [109, 142, 143]. To provide the best rehabilitation care, physiotherapists could benefit from insight in patient experiences [101, 139, 144]. Therefore, there is a need to phenomenologically study the fields of early mobilisation and ICU rehabilitation.

AIMS AND OUTLINE OF THIS THESIS

The overarching aim of this thesis is to uncover lifeworld dimensions in early mobilisation and ICU recovery through first-person experiences collected from patients and healthcare professionals. Findings from this PhD research may result in better understanding of patients' and healthcare professionals' experiences and provide recommendations for critical care, early mobilisation and ICU rehabilitation.

In **Chapter 2**, using a generic phenomenological approach, we aim to create an understanding of the impact of hydrotherapy in critically ill ventilated patients seen from a patient perspective. The Radboudumc has a pool, especially designed to exercise critically ill ventilated patients. The upward force of water enables patients to train functionally despite severe weakness. Patients' experiences during this therapy may provide unique insights relevant to understand lifeworld dimensions in early mobilisation.

In **Chapter 3**, using a meta-ethnographic approach synthesising phenomenological studies, we aim to gain insight into how patients experience their body in the ICU and in recovery from critical illness. This is valuable because meta-ethnographies provide a suitable approach to synthesise patients' embodied experiences, which may bear valuable implications to improve healthcare. However, to date, patients' experiences of their bodies in the ICU or in ICU recovery have not been systematically reviewed. Insights in body experiences can be used to understand people's experiences of illness and inform healthcare professionals about optimal treatment strategies.

The scientific projects in this thesis were strongly affected by the outbreak of the COVID-19 pandemic. The highly contagious SARS-COV-2 virus resulted in a significant increase in the number and duration of hospital and ICU admissions requiring hospitals to expand the number of ICU beds. Patients developing critical illness due to COVID-19 typically needed prolonged periods of mechanical ventilation and showed high incidence of ICUAW [145, 146]. Several organisational changes, including strict infection regulations, source isolation or cohorting and higher patient-to-nurse ratios than normal, led to extraordinary circumstances for patients and healthcare professionals. These developments urged us to consider COVID-19 as a topic for several research projects.

In **Chapter 4**, using a hermeneutic phenomenological approach, we aim to explore lived experiences of patients recovering from COVID-19-associated ICUAW and to provide phenomenological descriptions of their recovery. This is important as in the first wave of COVID-19, 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.

In **Chapter 5**, using an interpretative phenomenological approach, we aim to explore lived experiences of rehabilitation professionals working in hospitals during the COVID-19 pandemic, including the ethical issues and moral distress that these professionals might have encountered. This is valuable because hospital-based rehabilitation professionals, including dietitians, occupational therapists, physiotherapists, and speech-language therapists, were tasked with a variety of roles in the care of patients with COVID-19 in a working environment that was very different from normal. As earlier outbreaks have shown, decision-making in a time of emergency is associated with ethical issues. Insight into the experiences of rehabilitation professionals could help to empathise with the unusual working situations and identify their requirements during this pandemic or a possible future one.

In **Chapter 6,** using a pragmatic guideline development approach, we aim to provide guidance and detailed recommendations for hospital-based physiotherapists managing patients hospitalised with COVID-19. As physiotherapists play an important role in supporting hospitalised patients through respiratory support and active mobilisation, they were also consulted for patients that developed critical illness due to COVID-19. The development of this guideline was given priority because combining the latest scientific insights with expert opinions could provide clarity and guidance and increase safety in uncertain times.

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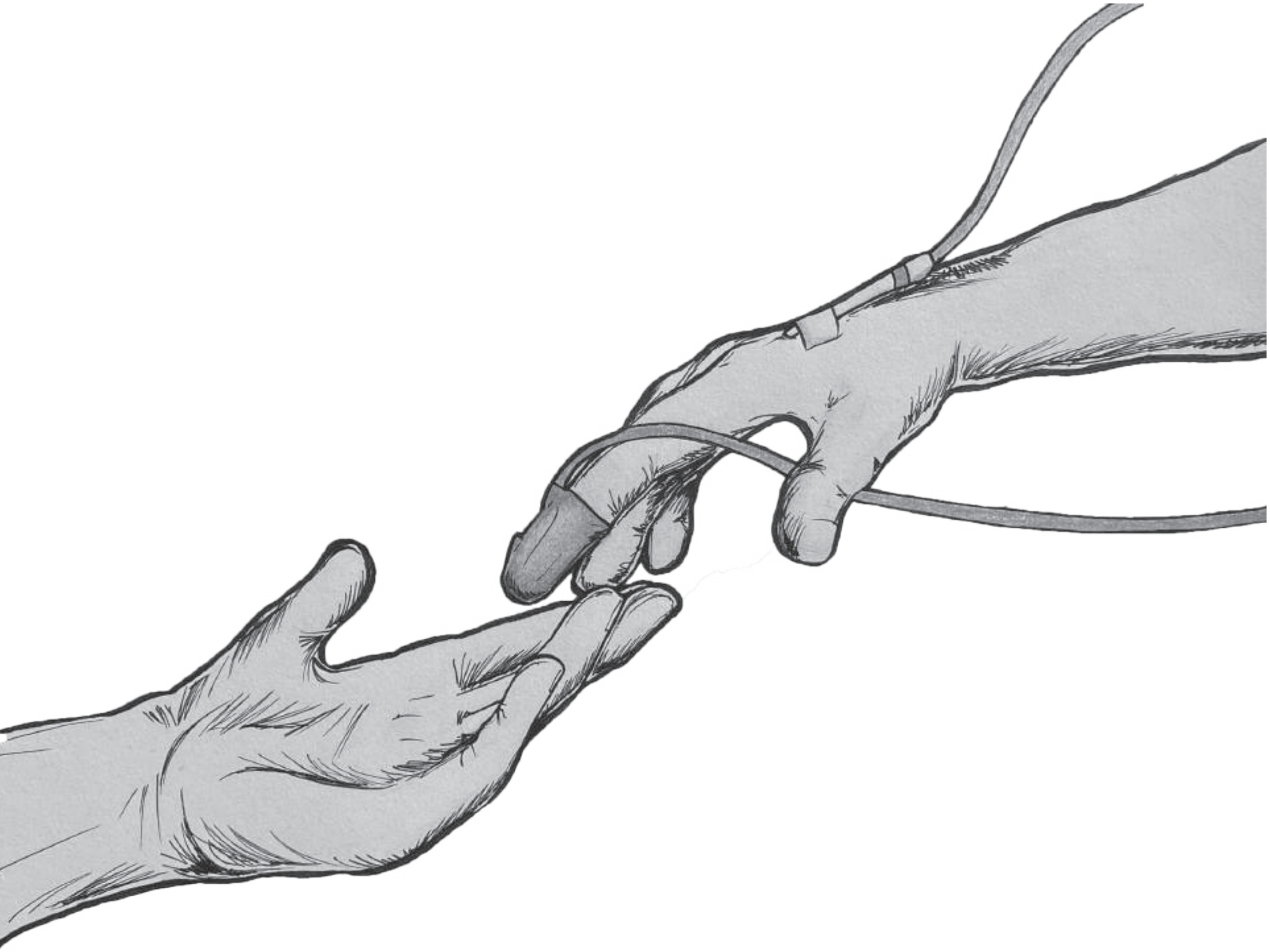

2

Patient views regarding the impact of hydrotherapy on critically ill ventilated patients

A qualitative exploration study

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ABSTRACT

Background

Intensive care unit acquired weakness can be mitigated by early activity and progressive mobilisation. Hydrotherapy enables patients to work on their recovery in a very early stage. This may lead to higher levels of self-efficacy, subsequently higher activity-rates and faster functional recovery. Hydrotherapy might positively affect the regaining of control, hope and trust. Our aim is to explore patient perspective regarding the impact of hydrotherapy on critically ill ventilated patients.

Methods

This qualitative exploration study adopted an interpretative phenomenological approach using in-depth, face to face, semi-structured interviews. Questions covered: pre-admission physical activity, perception of hydrotherapy, affection to water, positive and negative experiences and feelings towards the recovery process. Interviews were analysed using thematic analysis.

Results

Twelve patients were enrolled, of which eight could be interviewed. After analysing, five main themes were found: experiencing consequences of critical illness, feeling safe in the water, being able to move, positive experiences relating to hydrotherapy and experiencing a turning point.

Conclusions

Hydrotherapy seemed to help patients regain control and belief in their recovery. Patients experienced exercising in water as a turning point in their recovery process. This study encourages to continue providing hydrotherapy to critically ill ventilated patients and may stimulate future research.

Keywords

Critical illness, mechanical ventilation, hydrotherapy, physiotherapy, patient experiences.

BACKGROUND

Over 7 million patients are admitted annually to Intensive Care Units (ICU) in the United States [1]. Each year >85.000 adults are admitted to an ICU in the Netherlands [2]. ICU patients who have been mechanically ventilated for >48 h are at risk for (long-lasting) restrictions in physical, social and psychological functioning [3,4]. These problems are caused by an interaction between inactivity, inflammation, use of pharmacologic agents and the presence of neuromuscular syndromes associated with critical illness [5]. Skeletal muscle strength declines with approximately 2% per day of absolute bed rest [6]. Muscle weakness acquired at the ICU is defined as 'Intensive Care Unit Acquired Weakness' (ICUAW) [7,8]. Muscle wasting occurs early in critical illness following complex pathogenesis [9]. Functional decline can be prevented and decreased by early activity and progressive mobilisation [10]. Physiotherapy has an important role in the early progressive mobilisation practice for mechanically ventilated patients [11-15]. However, clear proof for efficacy is not yet established and the optimal mobilisation strategy has still not been defined [13].

Hydrotherapy is a commonly used therapy modality in rehabilitation centres because the upward force of water enables patients to train functional despite muscle weakness [16]. Additionally, water immersion is known for its relaxing and pain modulating effects [16]. Furthermore, staying in (warm) water may reduce anxiety and increases perceived well-being [17].

In 2003, Taylor was the first to describe a mechanically ventilated patient mobilised in a pool [18]. In 2012 the Radboud university medical center (Radboudumc) in Nijmegen, the Netherlands opened a pool designed specifically for the early mobilisation of critically ill ventilated patients. It is located close to the ICU, has a movable floor, a maximum depth of 1.35 m and a water temperature of 30 degrees Celsius. The water is continuously filtered, and the total water content is cleaned at least every two hours.

In 2015 our research group showed that hydrotherapy can safely be applied to critically ill ventilated patients and emphasised the need for studies evaluating potential clinical benefits [19]. The effects of hydrotherapy have been studied in several different populations. Marinho-Buzelli et al. showed fair evidence supporting the use of hydrotherapy for improving mobility in adults with neurological diseases [20]. Hydrotherapy in patients with stable heart failure resulted in improved exercise capacity, muscle strength and quality of life similar to land-based training protocols [21]. Research in patients with knee and hip osteoarthritis showed small effects of hydrotherapy on patient-reported pain, disability and quality of life. However, these patients are very different from our target population [22].

During the application of hydrotherapy to critically ill ventilated patients it struck treating physicians and therapists that the treatment had a particularly large influence on the mental state of patients although there are no studies present to substantiate these findings. Literature shows us that experiencing limited possibilities to act, lack of demands, and being dependent on others are pointed out by ICU-survivors to be the biggest challenges [23,24]. Hydrotherapy enables patients to actively contribute in the recovery process starting from a very early stage. This might help the patient believe in recovery and lead to higher levels of self-efficacy. High levels of self-efficacy result in higher activity rates [25], which might contribute to faster functional recovery. In this qualitative study we aimed to explore patient views on the impact of hydrotherapy in critically ill ventilated patients.

METHODS

Study design

This qualitative study adopted a phenomenological approach to explore the common meaning and lived experiences related to 'the application of hydrotherapy on critically ill ventilated patients' [26]. This approach, based on Husserl's philosophy, enabled us to investigate patients' views on the phenomenon under study [27]. The researchers recognised their knowledge and experience treating critically ill ventilated patients, which could influence their interpretation of data, therefore they worked with a framework of interpretative phenomenology [28,29]. The study protocol was approved by the ethics committee of the Radboudumc (Number 2015-1552).

Setting, participants and recruitment

A purposive convenience sample of critically ill ventilated patients was included at the ICU of the Radboudumc, Nijmegen, the Netherlands. Ventilated patients admitted to the medical, surgical, or thoracic ICU were eligible for hydrotherapy if they were severely weak (unable to walk >5 m on land) and able to respond to verbal commands. Patients were excluded from hydrotherapy if they needed high ventilator support (fractional inspired oxygen >0.6; positive end expiratory pressure >10 cm H2O; inspiratory support >15 cm H2O), were given vasopressive medication, had large wounds, displayed severe agitation or in case of colonisation with multi-resistant bacteria. The hydrotherapy sessions were prepared and subsequently performed according to the Radboudumc hydrotherapy checklist (see Supplement 1).

To be eligible to participate in this study, patients had to partake in hydrotherapy at least once while being mechanically ventilated. Furthermore, they had to be able to communicate in Dutch. From January 2015 to April 2015 the list of patients who took part in hydrotherapy was screened weekly by the coordinating nurse (TH) and researcher (KF) to designate subjects eligible for participation in this study. The goal was to have a diverse sample consisting of patients with diversity in reason for admission, length of stay, gender, age and enthusiasm towards hydrotherapy. The researcher (RO) contacted all patients meeting the inclusion criteria and asked for permission to visit them (at home). This visit was planned 6 to 12 weeks after hospital discharge. Informed consent was signed prior to the interview.

Data collection

In semi-structured interviews with a maximal duration of 45 min, patients were asked about their experiences regarding hydrotherapy. The interview guide is displayed in Table 1. Core questions covered the following areas: pre-admission physical activity, pre-admission experiences with water/swimming, perception of hydrotherapy, positive and negative experiences related to hydrotherapy and feelings towards the recovery process. The interviewers (RO and KF) are experienced physiotherapists who specialise in the field of intensive care medicine. Bracketing was trained during three test-interviews to ensure transcendental subjectivity [30].

Interviews were recorded on tape and transcribed verbatim. Only one interviewer was present during the interviews, patients were allowed to be accompanied by a close relative. There were no previous interactions between interviewer and respondent, except for the invitational phone call.

Table 1. Interview guide

Question number	Question
1	How are you doing (nowadays)?
2	How have things been going since your hospital dismissal?
3	How do you spend your days now?
4	What do you think of your recovery since your hospital dismissal?
5	What do you remember of your ICU stay?
6	What kind of exercises did you perform during your hospital stay?

Table 1. Continued.

Question number	Question
7	During your hospital stay you went into the water, can you tell about your experiences?
8	How did you feel about going into the water?
9	How did the caregivers initiate the practicing in water? How did you react?
10	What did you think of the practicing in water?
11	How was the communication with the therapists during the hydrotherapy?
12	What was the most important additional value of the hydrotherapy?
13	Was it nice to be away from the room and be washed? Is that why you enjoyed the hydrotherapy so much?
14	If you look back, would you choose to go into the water again?
15	Would you recommend the hydrotherapy to other patients?
16	Are you normally someone who likes to be in water?
17	In what way were you physically active before hospital admittance?

Data analysis

Data were open coded, axially coded, selectively coded and then thematised using an inductive approach [31]. To ensure trustworthiness and credibility two researchers (RO and KF) independently analysed the data. In a consensus meeting, disagreements in coding and thematising were discussed [32]. An independent researcher (RN) inspected the preliminary results for the effectuation of peer examination [33]. Analysis was performed using ATLAS.ti (Scientific Software Development GmbH. Version 7, 2012). The results will be presented using direct quotes to provide for rich description of the themes.

All interviews ended with a verbal summary of findings to give the interviewees an opportunity to give comments, make corrections or add additional thoughts. All interviews were tape-recorded and transcribed verbatim. During the interviews, field notes were taken to capture observations, interpretations and behaviour [26]. These notes were added to the data analysis. Demographic data were collected at the time of the interview from all participants. Patients were asked for their age, highest education, whether they were for the first time in hospital (yes/no), current work (yes/no, type), currently sporting (yes/no, type), and use of walking aid (yes/no, type). Health care providers were asked for their age, highest education, work (type), and work experience.

RESULTS

Patient characteristics

Table 2 shows the patient characteristics. Between January and April 2015 a total of 11 patients had an indication for hydrotherapy and met the study inclusion criteria. Of these 11 patients seven could be interviewed These seven patients were all positive about hydrotherapy. Only after one year a patient could be included who expressed negative feelings towards hydrotherapy (patient no. 12). A flow-chart of patient inclusion is displayed in figure 1. For detailed patient descriptions see Supplement 2.

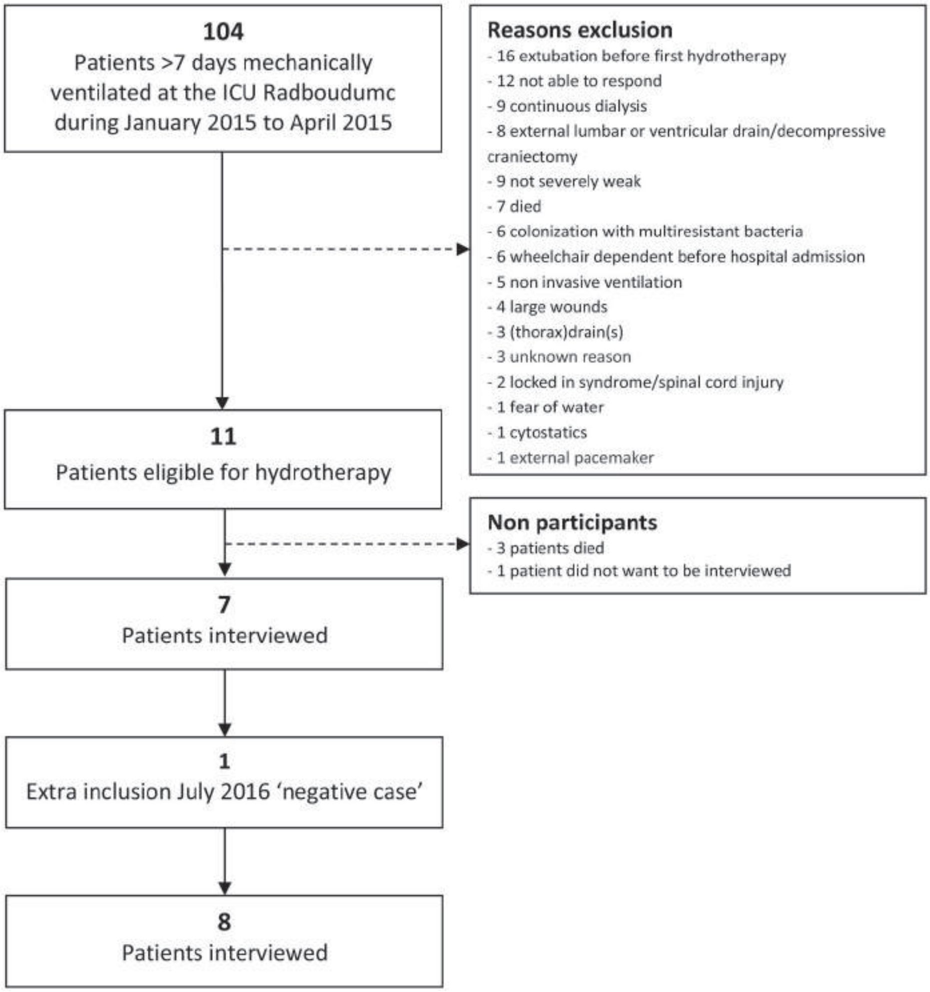

Figure 1. Flow-chart of patient inclusion

Table 2. Patient characteristics

Patient no.	Gender	Age	BMI	APACHE II-score (0-71)	Reason for ICU-admission	ICU length of stay (in days)	MV duration (in days)	Number of HT-sessions	Interview
1*	M	80	30	19	CABG	42	42	8	-
2	M	70	28	24	VSR	29	29	2	+
3	F	44	30	17	Alveolar lung pattern	20	20	3	+
4*	M	75	17	18	Oesophageal resection	22	22	4	-
5	M	72	29	24	Surgery for Gastro-intestinal rupture	38	38	3	+
6	F	33	23	9	Exacerbation asthma	40	36	3	+
7	F	49	30	28	Pneumonia in a patient with COPD GOLD 4	22	22	1	+
8	M	63	28	16	Chest/extremity trauma, surgery for HET with external fixation lower leg	33	32	11	+
9*	M	69	20	21	OHCA, complicated with ARDS	85	69	9	-
10	F	70	22	28	Stem cell transplant in non-Hodgkin Lymphoma	39	32	3	-
11	M	65	25	26	Respiratory failure after cardiac surgery	53	29	8	+
12	F	73	25	#	Chest/extremity trauma, surgery for HET.	98	17	8	+
Totals Mean (SD)	7 M 5 F	64 (14)	26 (4)	21 (6)	3 Cardiac surgery 3 Pulmonary disease 2 HET 2 Gastro-intestinal surgery 1 OHCA 1 Stem cell transplant	38 (29)	27 (18)	5 (3)	8+ 4-

*Abbreviations: BMI = Body Mass Index; APACHE = Acute Physiology and Chronic Health Evaluation; ICU = Intensive Care Unit; MV = Mechanical Ventilation; HT = hydrotherapy; M = Male; F= Female; – = not interviewed; + = interviewed; CABG = Coronary artery bypass grafting; VSR = Ventricular Septal defect Repair; COPD = Chronic Obstructive Pulmonary Disease; GOLD = Global initiative for chronic Obstructive Lung Disease; HET = High Energetic Trauma; OHCA = Out of Hospital Cardiac Arrest; ARDS = Acute Respiratory Distress Syndrome; ICUAW = Intensive Care Unit Acquired Weakness; # = missing; *= Patient died during hospital-stay.*

Patient experiences

Five main themes were found to be important in the recovery process. Table 3 shows the main themes and related quotes.

Experiencing the consequences of critical illness

Experiencing the consequences of critical illness has a big impact on patients. They experience weakness in their arms and legs and realise the severity of their disease. For many activities in daily life they are dependent on their caregivers. Moreover, inability to communicate with people can be very frustrating. Muscle weakness can impair the possibilities to communicate with a letter board or by writing.

Feeling safe in the water

Some people display great enthusiasm when hydrotherapy is suggested. Most of them are experienced swimmers or relate swimming to holidays and happy memories. Others are scared by the idea of going into the water, especially when muscle strength is minimal. The strict protocol, presence of skilled staff and a high-tech swimming environment provide confidence. Patients lose their fear very quickly as they experience the warm water and the relaxation that comes with it. They trust the accompanying staff and follow their instructions.

Being able to move

In the water some people feel a certain kind of pressure on their body, which makes the body feel light. Other patients experience relaxation and pleasant sensations. Patients are able to move their arms and legs and in some cases they are able to stand and/or walk. When patients are able to move by themselves in the water, they experience they can actively contribute to their recovery.

Positive experiences related to hydrotherapy

Patients often have no recollections of their stay in the ICU. Therefore, it was remarkable how many people had good memories relating to the hydrotherapy. Some people were looking forward to their next session and were disappointed when a session was cancelled. One patient said: “when I was in hospital I went in the water twice a week. In the rehabilitation centre they won’t train me in the water for fear of my tracheal cannula. I really miss it.” Another patient said: “Normally I never contribute to research projects, but in this case, I make an exception because the hydrotherapy was very important to me, and I want other patients to be able to get the same treatment.” People are positive about the skilled staff who care about them and the professional organisation around the hydrotherapy sessions. The possibility for family to be present during the hydrotherapy sessions, and in some cases join the patient in the water, was also much appreciated. In several cases telling about the hydrotherapy affected patients so much, they got emotional.

Experiencing a turning point
Many patients experienced exercising in the water as an important turning point in their recovery process. During the sessions they regained confidence in their body and dared to look forward. One patient said: “The nurses and doctors told me I would recover, but I did not believe them. Whenever I exercised in the water I felt that recovery was possible.” Several patients pointed out that exercising in the water gave them a mental boost.

Table 3. Themes and exemplifying patient quotes

Theme	Quotes
Experiencing the consequences of critical illness	“I was laying there and I couldn’t lift my arm. I could not even operate the television remote. (...) A board with letters on it was given to me, but I couldn’t even point at the board. That was so weird, I never realized laying in bed and being held in a coma would make you this weak.” (Patient no. 6) “There was so much going on around me. I was having renal dialysis. I was carrying 40 l of fluid in me, I felt like an inflatable doll. (Patient no. 11) “Only when the cannula was in the right place I could talk, otherwise I couldn’t. You see, when they slid the cannula up I couldn’t say anything. That was incredibly annoying. But, well it was probably necessary. At one point, I thought I was choking, so I pulled the cannula out so I was able to get some air, but then they immediately put it in place. What I also remember is that they tied up my hands for some time, apparently I was too much trouble.” (Patient no. 5) “Your body has failed you, that is how you feel at that point.” (Patient no. 7)
Feeling safe in the water	“The first time I was afraid, because I was not capable of doing anything. I’ve never been a good swimmer, so I was frightened at the beginning. But when we started the fear was gone within a couple of minutes.” (Patient no. 8) “They brought everything. If something happened to me, they could immediately give me oxygen or start mechanical ventilation etcetera, but fortunately that was not necessary. There were always nurses and physiotherapists nearby.” (Patient no. 11) “My wife also went into the water. And the therapist. That really gave me a safe feeling.” (Patient no. 8) “The warm water, the swimming in it (...) it was a kind of relaxation. It was lovely and joyful.” (Patient no. 3) “I had a lot of trust that it would go well. I know I’m a good swimmer. Despite the fact that you’ve no strength at all, you don’t realize that. You think like: if I’m in the water I can just swim away.” (Patient no. 5)

Table 3. Continued.

Theme	Quotes
Being able to move	"I remember at first that I couldn't lift my arms. Swimming is just so nice, after that I was just capable of doing a lot more. I really felt the difference." (Patient no. 6) "I was so weak and unable to stand upright, and in the pool that was not the case at all, I was able to stand and walk." (Patient no. 7) "In the beginning I was unable to move at all and I was thinking and worrying all the time. When you're in the water all those thoughts are gone, it all goes so smooth and easy. It goes by itself. It's all so very light, whatever you do, and that's wonderful." (Patient no. 8) "In the water you can do so much more. Muscles are incredibly more relaxed. You can move in ways you would never be able to do on land." (Patient no. 11) "That pool just made miracles happen. After swimming I could raise my arm and turn my head. Just all these normal things." (Patient no. 6)
Positive experiences related to hydrotherapy	"For me it was of great value, even though I went in the water only once." (Patient no. 7) "Thought the experience in the water was fantastic." (Patient no. 2) "I would do it every day. It really makes you fresh, and the freshness was missing a lot of times. I really made a mess with food and stuff." (Patient no. 5) "In the Radboudumc I went in the water twice a week. Later on even three times a week. I was really looking forward to the swimming sessions." (Patient no. 8) "I think we should go swimming every day." (Patient no. 6)
Experiencing a turning point	"I just had the feeling that I could not walk anymore, not move anymore. Then in the swimming pool they put you on your feet and then you start walking through the pool. Then I thought: if I can walk here, I can do it outside of the pool as well later on." (Patient no. 7) "It was good for body and soul. The swimming really gave me a boost." (Patient no. 6) "I would really recommend to start walking again in the water. It gives you a boost, like: hey I can walk again. The strength is actually there, that's what you experience at that point." (Patient no. 2) "After the swimming session(s) my recovery took a leap forward. That was truly amazing. Everybody was amazed. Yes, then it went really fast." (Patient no. 2) "It did so much for me, I can't tell you how much. It gave me back my confidence, that I could indeed recover the way I wanted. I cried in that pool. It was just fantastic. Yes, for me it was a real turning point." (Patient no. 7)

DISCUSSION

In this small-scale interview study, we explored patient views regarding the impact of hydrotherapy on critically ill ventilated patients. Patients were remarkably positive about exercising in water and thought it to be of great value in the physical and mental recovery from critical illness. Hydrotherapy seemed to help patients regaining control and belief in their recovery. Patients experienced exercising in water as a turning point in their recovery process.

The hydrotherapy treatment was perceived to have strong influence on the recovery process, even by patients who exercised in the water only once. From a physiological perspective it is unlikely that one hydrotherapy session has an actual training effect. However, hydrotherapy treatment enables patients to discover their strength and actively contribute in functional training. It focuses on a person's strength rather than weakness. This could stimulate the individual self-efficacy. This is a major advantage compared to land-based exercise where the patient will continually face his inabilities. This approach fits with the new definition of health according to Huber et al [34]. They define health as "the ability to adapt and self-manage in the face of social, physical, and emotional challenges" [34]. It emphasises that a person is more than his/her illness and still has potential for being healthy. Self-efficacy has been known for a long time as a strong predictor for activity levels and recovery [35,36]. The present study also indicates that self-efficacy, mood and belief in recovery are important factors during recovery from critical illness.

Earlier results from our research group stating that hydrotherapy is feasible and safe on critically ill ventilated patients [19], were confirmed in this study when viewed from a patients' perspective. Safety concerns seemed to be no issue for patients once they were in the water. Furthermore, in this study hydrotherapy was proven feasible in a diverse case mix. The case with an external fixation of the lower leg showed that open wounds are no contra-indication for hydrotherapy as long as wounds can be properly sealed. Based on our earlier study [19], and the results of Wegner et al. [37], these pools are even safe for critically vulnerable patients. This was confirmed in this study by a patient who underwent stem-cell transplantation. These patients have a higher infection-risk. Their treating physicians trusted the quality of the water to be sufficient and permitted this vulnerable patient to partake in hydrotherapy. No negative effects were seen afterwards. These findings implicate that the current safety-criteria may be adequate. As our group reported earlier, biochemical and microbiological analysis of pool water were performed to meet Dutch law standard criteria at any time [19].

Results from qualitative studies are assumed more valid when a deviant case is included [38]. After the inclusion period it was evaluated within the team, whether a patient had negative feelings towards hydrotherapy. Such a patient was admitted in July 2016. This person (patient no. 12) went into the water eight times. Especially the last couple of sessions were a negative experience because she found the hydrotherapy exhausting and the preparations and precautions overdone. During the interview she stated that she would have preferred to stop the hydrotherapy treatment earlier. Our treatment protocol for hydrotherapy demands caregivers to extensively inform patients and relatives about the intended hydrotherapy. Patients are specifically asked whether they want to undergo hydrotherapy treatment or not. However, based on these results we will evaluate patient experiences with hydrotherapy more often, in order to check whether the patient really wants to continue.

Three of the patients included in this study died during ICU stay. These patients all showed prolonged ICU stay, weaning failure, and there was no hope for recovery. Treatment was terminated, resulting in their deaths. These three patients underwent a relatively large amount of hydrotherapy sessions, however hydrotherapy treatment stopped at least seven days before they died. The patients who died could not be interviewed, though it would have been of interest because we know at least one of these patients had negative feelings towards hydrotherapy. It could have been of additive value to have a second divergent case included whereas the majority of the patients was positive about hydrotherapy.

Not only patients suffer from their stay at ICU, the people around them suffer as well. Several studies have reported the importance of providing care to relatives and family of ICU patients [39,40]. In 2007 Davidson et al. published a practice guideline for support of the family in the patient-centred ICU, recommending a flexible and open policy regarding the visits of family and loved ones [39]. In our hospital family is invited to be present during hydrotherapy sessions and, if possible, to join the patient in the water. In this study, family members participated in the water in one third of the cases. Corresponding to the cited literature, this study shows that family and relatives highly appreciated the possibility to participate during hydrotherapy.

Currently, patients can only go for hydrotherapy when admitted to the ICU and being unable to walk more than five meters on land. Patients reported it to be disappointing that hydrotherapy could not be continued in other departments or other healthcare facilities. It is understandable patients want to continue hydrotherapy treatment, certainly when experience an improvement in their recovery. However, the Radboudumc is the only facility providing hydrotherapy to this population and the capacity of the pool is limited to a maximum of five treatments a day. In this context it is very important to manage patient expectations from an early stage, to be able to prevent disappointments. In the ideal situation hydrotherapy is continued on the ward and in other facilities until the patient is able to train on land. Future studies should evaluate cost-effectiveness of hydrotherapy, because it is a time-consuming and labour-intensive therapy demanding a high-tech pool with high structural costs. With more insight in the costs and effects of hydrotherapy, other institutions can determine whether it is eligible and profitable to build their own pool for this population.

Limitations of this study include the lack of triangulation. The use of other methods than taped interviews, for example participant observations or taking field notes, could have enriched the data [33]. In addition, we have not included quantitative functional outcome measures in this study although this could have provided more insight in our sample. We could not include this data because the outcomes were not sufficiently reported in the patient files. Furthermore, patients' memories and cognition were not investigated prior to the interview. During the interviews, several patients declared they had limited memory of their stay in ICU, which might have caused recall bias. Furthermore, we cannot rule out patients might have felt pressured by the one on one interviews. Therefore, they might have given socially desirable answers, despite informed consent procedure and the emphasis on transparency.

Findings from this study encourage to continue providing hydrotherapy to critically ill ventilated patients. We gained insight in patients' views and experiences regarding hydrotherapy. These results can be used to design quantitative research. In order to obtain more thorough understanding of treatment effects and determinants of recovery, we recommend including measurements of self-efficacy, belief in recovery, mood and depression. When there is more clarity on the effects of hydrotherapy in this population it might be easier to select the patients who are more likely to benefit from hydrotherapy treatment. To investigate the effect of hydrotherapy a controlled intervention study should be designed. Since the ICU population is heterogeneous and they receive multiple interventions at the same time it might be complicated to perform a randomised controlled trial. To predict recovery in critically ill ventilated patients, we recommend a cohort design using repeated measurements to compare patient recovery curves and show the influence hydrotherapy has on the recovery process.

CONCLUSIONS

This study gives insight in the views and experiences of eight critically ill ventilated patients who went for hydrotherapy. Hydrotherapy seems to help patients regain control and belief in their recovery. Patients experienced exercising in water as a turning point in their recovery process. Results from this study are an encouragement to continue providing hydrotherapy to critically ill ventilated patients and can be used in designing evaluative research.

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SUPPLEMENT 1. HYDROTHERAPY CHECKLIST

Patient:

Informing patient/family	executed
Announcing patient at Medium Care (location of pool)	executed
Check safety criteria and contra-indications	executed
Patient positioning	optimal
Copy mechanical ventilation parameters	executed
In case of possible faeces incontinence insert anal tampon	executed
Lines disconnected and covered	executed
Nasogastric tube disconnect and flushed	executed
Cover insertional openings	executed
Urine catheter disconnected	executed
Cover wounds with Tegaderm™	executed
Hearing aid removed	executed
Endotracheal suctioning	executed
Subglottis drainage	executed

Material:

Laptop/transport ventilation machine	present
Ventilation machine hose and reserve material	present
Oxygen cylinder	present
Resuscitation balloon	present
Suctioning catheter	present
Cuff Pressure Measuring Syringe	present
Tube tape	present
Vacuumpump	present
Suctioninghose for vacuumpump	present
Pulse-oximeter	present
Tracheal inner cannula and imputational cannula	present
Bathing clothes	present
Showergel/shampoo	present
Extra linen	present
Incontinence material	present

Staff

Physiotherapist	present
Ventilation specialist nurse	present
Intensive care nurse	present

Procedure	
Briefing	executed
Discuss treatment policy	executed
Discuss what to do in case of emergency	executed
After procedure	
Mechanical ventilation check	executed
Reconnect infusion and catheters to patient	executed
Patient minimal 1 hour of rest	executed
Debriefing	executed
Report in digital patient file	executed

SUPPLEMENT 2. PATIENT DESCRIPTIONS

Patient no. 1 was treated after coronary artery bypass grafting (CABG) complicated by pulmonary edema. He was treated with hydrotherapy eight times. There were several weaning attempts but none turned out permanently successful. After clinical decline, ICU treatment was stopped at patients request. Patient died after palliative sedation. Patient could not be interviewed.

Patient no. 2 was treated after emergency surgery for a ventricular septum defect. He was treated with hydrotherapy two times. He was interviewed at his home nine weeks after hospital discharge, 11 weeks after ICU discharge, during the interview he was accompanied by his wife. He was able to walk independently, able to walk the stairs, and started car driving since two weeks. Since two weeks he was visiting the rehabilitation centre two times a week. He could walk and bike (with electrical support) for hours in a row. The admission period had a large impact on him and he kept on telling about the weird and frightening dreams he had since ICU-stay. He was positive about the hydrotherapy and would absolutely recommend it to other patients.

Patient no. 3 was treated for acute respiratory failure. She was treated with hydrotherapy three times but could only remember two sessions. She was interviewed at her home eight weeks after hospital discharge, 11 weeks after ICU discharge, there were no others present during the interview. She was able to walk independently but hardly ever walked stairs. She restarted her volunteering work. She experienced no difference in her physical functioning compared to the period before hospital admission. She was positive about hydrotherapy because of the warmth of the water that felt nice and was relaxing.

Patient no. 4 was in the Radboudumc for a second opinion after a complicated esophageal resection with gastric tube reconstruction. He was treated with hydrotherapy four times. Weaning from mechanical ventilation failed several times. He turned out to have severe lung fibrosis with a dismal prognosis. ICU-treatment was stopped at patient’s request. Patient could not be interviewed.

Patient no. 5 was treated after gastrointestinal surgery. He was treated with hydrotherapy three times. He was interviewed at his home 10 weeks after hospital discharge, 11 weeks after ICU discharge, during the interview he was accompanied by his wife. He was able to walk independently (max 5 minutes) and able to climb stairs. He started biking and car driving already. He was visiting a physiotherapist two times a week for physical training. Before hospital admission he was not functionally limited in any way. He was positive about the hydrotherapy, only thought that he should have been treated in the water more often.

Patient no. 6 was treated for severe acute asthma. She was treated with hydrotherapy three times. She was interviewed at her home seven weeks after hospital discharge, nine weeks after ICU discharge, there were no others present during the interview. She was able to walk independently and able to climb stairs. She got help with kids care but tried to do most of the household herself. She had not started working yet. She was planning to start physical fitness training in two weeks. She felt less energetic compared to the preadmission period. She was very positive about hydrotherapy and wished that she could have trained in the water more often, but thought this was not possible because other patients also needed their time in the water.

Patient no. 7 was treated because of pneumonia. She was treated with hydrotherapy one time. She was interviewed during a visit to the ICU after care policlinic, 11 weeks after hospital discharge, 12 weeks after ICU discharge, during the interview she was accompanied by her daughter. She was able to walk independently and able to climb stairs. She started (electrically supported) biking. She started working already half days (sitting office work). She started fitness training since two weeks now after a physiotherapist visited her at home the first three weeks after hospital discharge. The hydrotherapy session had been very important to her because it gave her confidence that she could recover from her sickness.

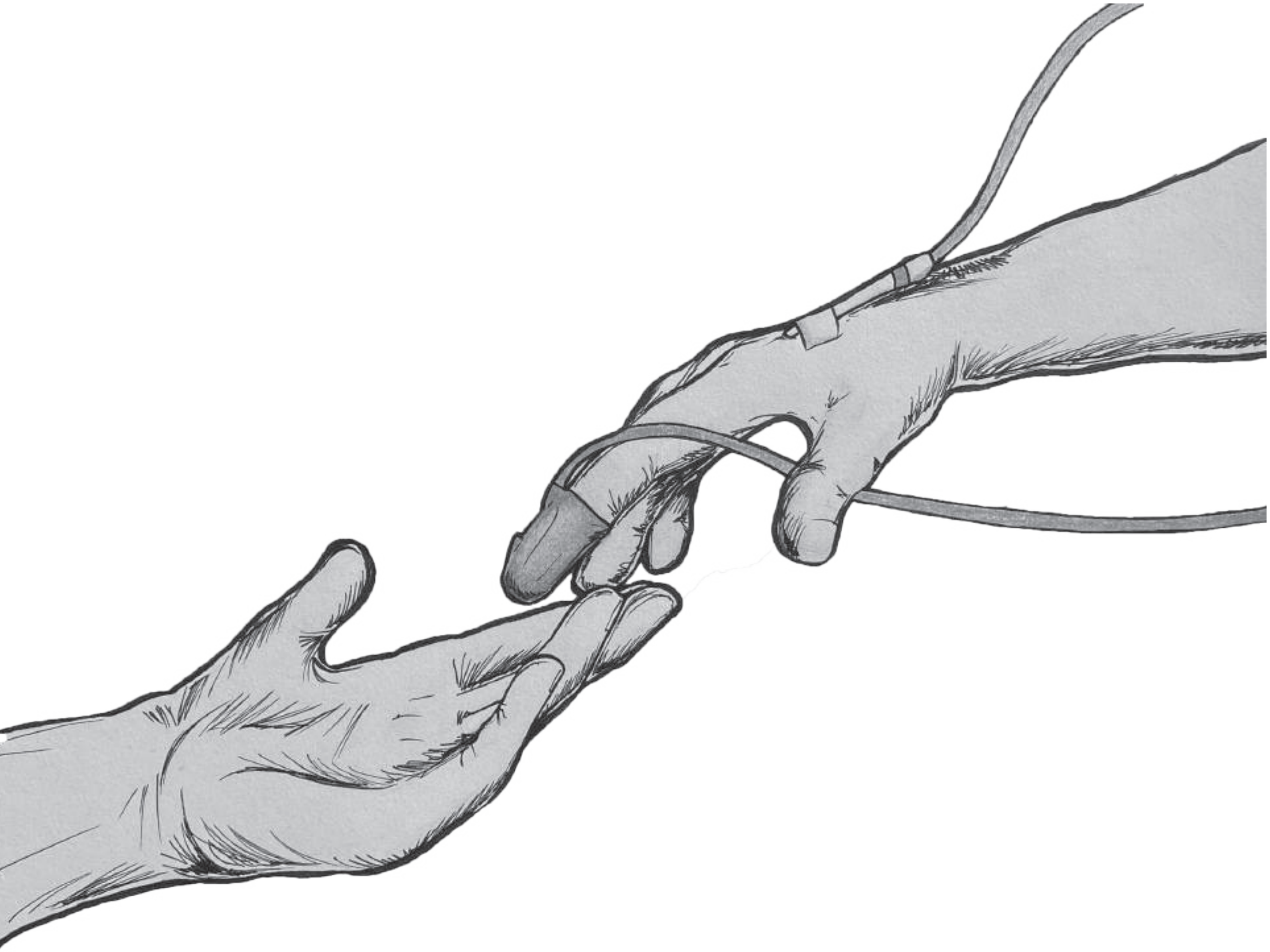
Patient no. 8 was treated after multiple trauma with chest/extremity injury. He was interviewed while being admitted to a rehabilitation centre, six weeks after hospital discharge, eight weeks after ICU discharge, during the interview he was accompanied by his wife. He had a tracheal cannula. He was unable to manage self-care yet. He was following an intensive exercise program including occupational and physiotherapy. He was disappointed that hydrotherapy was not continued at the rehabilitation centre, because he had positive experiences with the training in water. At the centre there were facilities for hydrotherapy, however they could not guarantee safety for patients with a tracheal cannula.

Patient no. 9 was treated for acute respiratory distress syndrome (ARDS) and severe cardiac impairment. During ICU-stay he was treated with hydrotherapy nine times. After months of care the medical treatment was stopped at patient’s request. Patient died after palliative sedation. Patient could not be interviewed.

Patient no. 10 was treated at the ICU after stem cell transplant complicated with pneumonia. She was treated with hydrotherapy three times. She did not want to be interviewed because she did not feel strong enough.

Patient no. 11 was treated after cardiac surgery complicated with respiratory failure. He was treated with hydrotherapy eight times. He was interviewed at his home seven weeks after hospital discharge, nine weeks after ICU discharge, there were no others present during the interview. He was able to walk independently (max 50 meters) and able to walk the stairs. He was visiting a physiotherapist two times a week for physical training. He felt very tired compared to pre hospital admission. He was positive about the hydrotherapy and would certainly recommend it to other patients. He was planning to start swimming for himself.

Patient no. 12 was treated after multiple trauma with chest/extremity injury. She was treated with hydrotherapy eight times. She had been at the ICU for 14 weeks and stayed for three weeks at the nursing ward while being interviewed, there were not others present during the interview. She was dependent to others for practically all activities. She was not able to do self-care, and not able to stand or walk. She was transferred in the chair with a patient lifter. She was specifically asked to give an interview because she was not positive about the hydrotherapy. She experienced it as exhausting and she found the preparations and precautions taken overdone.



3

Patients' lived body experiences in the intensive care unit and beyond

A meta-ethnographic synthesis

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ABSTRACT

Objective
To gain insight in patients' lived body experiences during intensive care unit (ICU) stay and in recovery from critical illness.

Methods
For this meta-ethnography, through a comprehensive systematic literature search 45 empirical phenomenological studies were identified. Patients' lived body experiences were extracted from these studies and synthesised following the seven-phase interpretative and iterative approach as described by Noblit and Hare. Merleau-Ponty's embodiment theory was taken as theoretical perspective.

Results
Three lines of argument were identified: 'recovery from critical illness starts from a situation in which patients experience the lived body as unable', 'patients experience progress in recovery from critical illness when the lived body is empowered' and 'recovery from critical illness results in a lived body changed for life'. These lines of arguments form the overarching concept based on 11 third-order constructs which we formulated as different kinds of bodies: 'an intolerable body', 'an alienated body', 'a powerless body', 'a dependent body', 'a restricted body', 'a muted body', 'a touched body', 'a transforming body', 'a rediscovering body', 'an unhomelike body' and 'a remembering body'.

Conclusion
Patients' lived body experiences during ICU stay and in recovery from critical illness have richly been described in phenomenological studies and were synthesised in this meta-ethnography.

Keywords
Critical illness, intensive care unit, ICU recovery, lived body, patient experiences, meta-ethnography, phenomenology, qualitative research

INTRODUCTION

Critical illness is "a state of ill health with vital organ dysfunction, a high risk of imminent death if care is not provided and the potential for reversibility" (Kayambankadzanja et al, 2022). Critically ill patients are admitted to an intensive care unit (ICU) to enable intensive monitoring and treatment. During ICU stay patients can face unreal experiences and dreams, proximity to death, transformation and perception of the body and time, and dependence and desire for contact with others (Cutler, Hayter, and Ryan, 2013). Moreover, ICU patients may have to endure physical discomfort including pain, sleeplessness, thirst, and breathing difficulties (Topçu, Ecevit Alpar, Gülseven, and Kebapçı, 2017).

Through improved medical technology, nowadays over 90% of patients survive their ICU stay (www.stichting-nice.nl/datainbeeld/public). However, survival and discharge from the ICU do not mean that patients are fully recovered. An ICU admission can dramatically change a patient's life (Tembo, 2017). Many ICU patients suffer from long-lasting symptoms related to their critical illness and ICU treatment, collectively known as post-intensive care syndrome (PICS) (Needham et al, 2012). PICS concerns symptoms in the physical, cognitive or mental domain (Geense, Zegers, and Peters, 2021). To prevent deconditioning during ICU stay, mobility interventions are started as soon as possible, referred to with the term early mobilisation (Boelens, Melchers, and van Zanten, 2022; Devlin et al, 2018). These mobility interventions are continued until hospital discharge. Post-discharge, patients are typically offered ICU rehabilitation, which includes rehabilitation interventions to increase and restore their functional capacities.

The literature on early mobilisation and ICU rehabilitation is mainly focused on safety, feasibility and effectiveness of interventions, emphasising objective outcomes starting from a third-person perspective (Zhang et al, 2022). The first-person perspective, including what it means to patients to mobilise in these situations is often overlooked. However, studying patients' lived experiences can show how illness or impairment affect a person's subjectivity, agency and sense of self (Slatman, 2014). Moreover, they can provide patients with concepts and language with which they can articulate their illness experience (Carel and Kidd, 2014).

Both early mobilisation and later rehabilitation interventions are typically provided by physiotherapists (Lippi et al, 2022). Physiotherapists work with the body and primarily focus on physical symptoms and problems. Nevertheless, physical therapists are known to have negligible philosophical-theoretical underpinnings about the body (Nicholls and Gibson, 2010). Several critical thinkers suggested that the dominant biomedical view on the body in physiotherapy should be complemented with renewed accounts of the body to fill gaps between theory and practice (Halák and Kříž, 2022; Nicholls and Gibson, 2010). Phenomenological studies can be used to explore patients' lived body experiences (Sandström, 2007; Cramp, McClean, and Turton, 2021). To date, only few studies have explicitly studied patients' lived body experiences while being admitted to the ICU or in ICU recovery (Fredriksen, Talseth, and Svensson, 2008; Uotinen, 2011). However, knowing that a substantial amount of phenomenological studies are conducted among this patient group, a thorough synthesis of the lived body experiences from these studies could fill this gap.

Inspiring examples showed that meta-ethnographies provide a suitable approach to synthesise patients' lived body experiences bearing valuable implications to improve healthcare (Bootsma et al, 2020; Øien and Dragesund, 2022). Therefore, the objective of this meta-ethnography is to gain insight in patients' lived body experiences during ICU stay and in recovery from critical illness.

THEORETICAL PERSPECTIVE – THE PHENOMENOLOGY OF EMBODIMENT

Phenomenology is a philosophy and research tradition studying human experiences. It was first developed by Edmund Husserl (1858-1938) who advocated studying the things as they appear, not as they are in itself, but how they are perceived and what they mean to people (Zahavi, 2018). This requires leaving the natural attitude, to bracket off fixed beliefs, and to set aside theoretical assumptions about truth and world. The current study uses the perspective from the phenomenology of embodiment as developed by Merleau-Ponty (1908-1961) (Merleau-Ponty, 2013).

Merleau-Ponty takes embodiment as a fundamental starting point for human experience because in action and perception the body forms our primary relation to the world. He argues that the body is therefore not to be classified as a thing among the things, but a thing that we are ourselves. In other words, we are a body subject (Halák and Kříž, 2022). The notion of intentionality, a key concept in phenomenology, means that a subject's experience is always directed or oriented towards something (Gallagher, 2012). Merleau-Ponty describes that the body itself shows intentionality, a directedness towards things in the world, which is first and foremost a practical and motor intentionality (Weiss, Salamon, and Murphy, 2019). This is in strong contrast with an 'intentionality of representation', which in a mechanistic psychophysical approach envisions realisation of movement (Halák and Kříž, 2022). According to Merleau-Ponty the world appears to us because we perceptually orientate ourselves in the world, not because we think (Slatman, 2014). Consciousness and thinking are not separated from the body, they are intertwined, and are in the world (Doyon and Wehrle, 2020). Therefore, motor intentionality does not correspond to the act of "I think", but to processual awareness of what 'I can' practically do within a situation (Halák and Kříž, 2022; Slatman, 2014).

METHODS

We followed Noblit and Hare's interpretative and iterative approach for conducting a meta-ethnography (Noblit and Hare, 1988). This approach, and the eMERGe reporting guideline (France et al., 2019), provide seven phases: (1) formulating the research question (2) identifying and selecting studies (3) repeated reading of selected studies (4) determining how studies are related through coding and comparing conceptual content (5) translating the studies into one another (6) synthesising the translations, and (7) expressing the synthesis. The author group consisted of a multidisciplinary team including three physiotherapists (RvO, PvdW and NK), a physiotherapist/sociologist (GvO), an ICUnurse (MvdB) and an ethicist (AO). This review protocol was registered in Prospero (CRD42020184593).

Search strategy

After defining the aim of this study (phase 1), we set up a strategy to find relevant studies (phase 2). In collaboration with a librarian (OC) the first author (RvO) conducted a comprehensive systematic literature search (Appendix 1). The following databases were searched from inception until November 2021: MEDLINE, EMBASE, CINAHL, PsychINFO, Web of Science and Google Scholar.

Process of reviewing and selecting potential primary studies

Inclusion criteria were: 1) adult patient experiences during ICU stay or in recovery from critical illness, 2) bodily or embodied experiences and 3) study used phenomenological methodology. Reasons for exclusion were: 1) palliative care, 2) reported in language other than English or Dutch, 3) full text was not available, 4) ineligible study design (e.g. meta-study, test of model) or 5) ineligible article type (e.g. abstract congress, thesis, commentary). After the removal of duplicates, all titles and abstracts (N=11,721) were reviewed against the predetermined eligibility criteria independently by two reviewers (RvO and GvO) and categorised as 'possibly relevant' or 'clearly not relevant'. The 'possibly relevant' abstracts were included in the full-text eligibility assessment. Then the full-texts (N=361) were compared against the eligibility criteria by two reviewers independently (RvO and GvO). Disagreements were resolved in a consensus meeting between both reviewers (RvO and GvO). As displayed in the flow diagram of the study selection process (Figure 1) this resulted in a total of 45 primary studies included in this meta-ethnography.

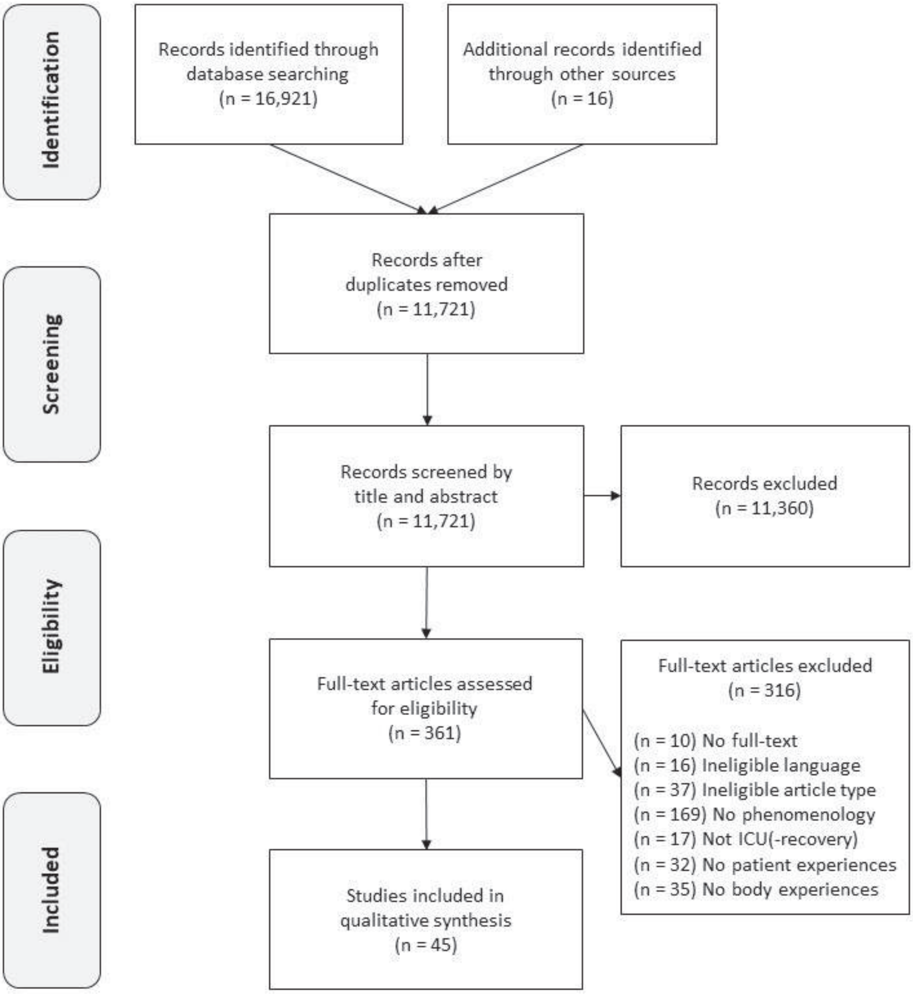

Figure 1. Flow diagram of study selection process.

Quality appraisal

To gain insight into the methodological quality we assessed all studies included using the Critical Appraisal Skills Programme (CASP) qualitative studies checklist (www.casp-uk.net). Included studies were independently assessed by two reviewers (RvO & NK). Disagreements were resolved in a consensus meeting between both reviewers. Outcomes are provided in Appendix 2.

Data-analysis and synthesis

After selection of the studies, study characteristics were extracted by the first author (RvO), which are displayed in table 1. Both analysing authors (RvO & GvO) carefully read and re-read the studies included to gain familiarity with the data (phase 3). In order to determine how the studies were related, two reviewing authors (RvO & GvO) independently selected text sections (phase 4) according to methods as described in the worked example of Britten et al. (2002). First-order constructs, involving patient quotes, were coded in the results sections. Second-order constructs involving authors' interpretations (themes and concepts) about patients' experiences were coded in the results, discussion and conclusion sections. Subsequently, both reviewing authors (RvO & GvO) independently looked for patterns and structures in the data looking through their coded first-and second order constructs selecting keywords, concepts and metaphors. In a consensus meeting, both reviewers' lists were combined. The outcomes of this translation are provided in Appendix 3. The translation led to a general idea of themes, which were then presented in a two-hour group meeting. During the group discussion (RvO, AO, GvO, MvdB, PvdW and NK), we found that these themes seemed associated with specific phases in recovery: crisis, normalisation and post-discharge (Egerod and Christensen, 2009; Jensen et al, 2017). With the outcomes of this group meeting we progressed with the next phase: translating findings from different studies into one another with the goal to create unique meaningful third-order constructs (phase 5). In this phase all first- and second- order constructs were now ordered in the preliminary third-order constructs by going through all studies once more. This resulted in a matrix with on the vertical axis the studies included, and on the horizontal axis the third-order constructs, or body themes. This created a workable document to compare the patients' experiences in the different studies. Through filling in the matrix all first- and second-order constructs were once more analysed concerning differences (refutational translations) and overlap (reciprocal translations). In order to preserve context and meaning of the relationships between concepts, within and across studies analytic memos were written throughout this translation process. The matrix is available to readers upon reasonable request. With the matrix, the authors were able to start writing theme descriptions in the results section. Four of the authors (RvO, AO, GvO and NK) were intensively involved in the writing process. Throughout the writing process, the wording and order of the third-order constructs evolved. Through discussion among all authors potential alternative interpretations were explored. After a first draft of the results section of this manuscript, a second consensus meeting was performed with all authors. In this meeting we evaluated the third-order constructs and discussed possibilities for lines of arguments, as an overarching explanation of patients' lived body experiences during ICU stay and during recovery from critical illness (phase 6) (Bootsma et al., 2020). Conceptual ideas were discussed in the group, trying to avoid bias by consciously reflecting on our individual positions and perspectives. In order to express the synthesis (phase 7) the authors summarised their findings, considered strengths and limitations and reflected on how they, as reviewers, influenced the interpretative process and synthesis findings, which were expressed in the discussion section.

Trustworthiness

To enhance trustworthiness, we rigorously followed Noblit and Hare's method (Noblit and Hare, 1988). We ensured transparency concerning the outcomes of all steps (please see Appendices 2 and 3). Moreover, to promote thoroughness of the data analysis all analysing steps were performed at least by two researchers independently and the final synthesis was performed in panel sessions with an interdisciplinary research group.

Table 1. Study characteristics

First author, year, country, sample size	Setting	Study aim	Age (years)	Critical illness	Theoretical approach	Timing of data collection
Albanesi, 2022, Italy, n=11	The Cardiac ICU of a cardiology research hospital	To describe Cardiac Surgery patients' lived experiences.	Range: 42-75	Eight patients presented with a valve pathology; two of them had a vascular pathology. One patient was suffering from both diseases, and one was hospitalized as an emergency.	A qualitative study, adopting an interpretative phenomenological analysis approach	At least 2 weeks after ICU discharge
Vester, 2021, Denmark, n=12	Two multidisciplinary ICUs in a university hospital	To explore patients' and relatives' experiences of everyday life after critical illness.	18+	Not reported	A phenomenological-hermeneutic approach	After discharge from the hospital or rehabilitation ward.
Lee, 2021, South Korea, n=15	Two university hospitals	To derive an in-depth understanding of the transfer experience of ICU patients in South Korea through a phenomenological analysis.	Range: 29-64	Various	A phenomenological approach according to Colaizzi	3 to 5 days after ICU discharge
Ellingsen, 2021, Norway, n=9	Two hospitals and one patient organisation	To provide a deeper understanding of how former critically ill patients narrate their own experiences of the illness trajectory from the acute stage throughout rehabilitation and long term follow up.	Mean: 60	Various severe circulatory, respiratory or neurological diseases	A study grounded in phenomenological philosophy.	All patients had been admitted to an intensive care unit over the last 5 years

Table 1. Continued.

First author, year, country, sample size	Setting	Study aim	Age (years)	Critical illness	Theoretical approach	Timing of data collection
Alexandersen, 2021, Norway, n=17	A major hospital	To provide insights into what promotes and challenges inner strength and willpower in formerly critically ill patients back home after a long- term ICU stay.	Median: 55 Range: 27– 76	Diagnoses included serious disease, severe trauma and complication	A qualitative hermeneutic-phenomenological approach according to Dahlberg.	6 to 20 months after hospital discharge
Umberger, 2019, USA, n=8	A medical ICU	To explore the experiences of sepsis survivors after 1 year of their index ICU stay.	Range: 37-74	Sepsis	A phenomenological study, guided by Merleau-Ponty's philosophy	At least 1 year after ICU discharge
Alexandersen, 2019, Norway, n=17	A university hospital	To explore aspects that promote and challenge long-term ICU patients' inner strength and willpower.	Mean: 55.2 Range: 27–76	Various	A qualitative, hermeneutic-phenomenological approach	6 to 18 months after ICU discharge
Tingsvikl, 2018, Sweden, n=12	Three different hospitals	To explore the meaning of being a patient on mechanical ventilation during the weaning process in the ICU.	Mean: 66 Range: 43-82	All patients had previously been hospitalised for a variety of medical and surgical diagnoses	A hermeneutic-phenomenological approach according to Van Manen	2 to 4 months after ICU discharge

Table 1. Continued.

First author, year, country, sample size	Setting	Study aim	Age (years)	Critical illness	Theoretical approach	Timing of data collection
Felten-Barentsz 2018, Netherlands, n=12	A university hospital	To explore patient perspective regarding the impact of hydrotherapy on critically ill ventilated patients.	Range: 33-80	Cardiac surgery (n=3); pulmonary disease (n=3); high energetic trauma (n=2); gastro-intestinal surgery (n=2); out of hospital cardiac arrest (n=1); complicated stem cell transplant (n=1)	A phenomenological approach	6 to 12 weeks after hospital discharge.
Holm, 2017, Denmark, n=4	Two multidisciplinary ICUs	To explore adult ICU patients’ experience of being conscious during endotracheal intubation and mechanical ventilation.	Range: 61-86	Pleural effusion, Multi-trauma, Pneumonia, Pleural effusion	A phenomenological-hermeneutic approach	1 to 2 days after extubation
Da Cruz de Castro, 2017, Portugal, n=12	A hospital	To assess the experience of persons with critical condition during hospitalization in an ICU.	Range: 27-77	Not reported	A phenomenological descriptive design	Not reported
Mylénl, 2016, Sweden, n=11	A neurosurgical ICU	To explore the lived experiences of conscious patients in neurosurgical intensive care	Range: 37—81	Not reported	An interpretive phenomenological approach	2 to 14 months after discharge
Whitehorne, 2015, Canada, n=10	Two acute care hospitals	To understand the lived experience of intensive care for critically ill patients who experienced delirium.	Range: 46-70	Critically ill patients who experienced delirium.	Heideggerian hermeneutic phenomenology according to van Manen.	After transfer from the ICU to a medical or surgical unit.

Table 1. Continued.

First author, year, country, sample size	Setting	Study aim	Age (years)	Critical illness	Theoretical approach	Timing of data collection
Tembo, 2015, Australia, n=12	A 16 bed ICU in a large regional referral hospital	To describe the lived experience of people who experienced critical illness in ICU using a hermeneutic phenomenological approach in the DSI context.	Range: 20-76	Diverse	A hermeneutic-phenomenological approach	2 weeks after ICU discharge and 6 to 11 months later.
Stayt, 2015, UK, n=19	A university teaching hospital	To explore patients' experiences of technology in an adult ICU.	Range: 32-86	Elective post-operative admission, sepsis, pneumonia and trauma	Heideggerian phenomenology.	12 weeks after discharge.
Palesjö, 2015, Sweden, n=7	An ICU with six beds	To describe and interpret the essential meaning of the lived experiences of being in a critical illness-recovery process after a life-threatening condition.	Range: 24-61	ARDS, cardiomyopathy, multi-trauma, cardiac arrest, septic shock, aspiration pneumonia after surgery to remove a malignant brain tumour, septic shock	A phenomenological hermeneutic approach	2 to 4 years after ICU discharge
Lykkegaard, 2015, Denmark, n=3	An ICU at a larger university hospital	To explore the perceived meaning of being dependent on care as experienced by intensive care patients.	Range: 27-78	Surgical complication, medical problem	A phenomenological hermeneutic approach	6 to 12 months after ICU discharge
Moen, 2015, Norway, n=7	An average-size ICU accommodating eight patients	What are the experiences of former intensive care patients of having their dignity upheld during their stay in the ICU?	Not reported	Not reported	A phenomenological approach according to Giorgi	5 to 12 months after ICU discharge

Table 1. Continued.

First author, year, country, sample size	Setting	Study aim	Age (years)	Critical illness	Theoretical approach	Timing of data collection
Torheim, 2014, Norway, n=10	Two ICUs	To describe experiences of care of patients with advanced COPD when suffering acute exacerbation in ICUs.	Range 45-85	Patients diagnosed with COPD	A phenomenological descriptive design	After ICU discharge or within 2 weeks after hospital discharge
Alguindy, 2014, Egypt, n=14	The ICU of cardiothoracic surgeries at a University Hospital	What are the personal lived experiences of patients connected to mechanical ventilator during recovery period after open-heart surgery at Al Maniel University Hospital?	Range: 21-53	Patients who underwent cardiothoracic surgery	A qualitative phenomenological design	Not reported
Olausson, 2013, Sweden, n=9	Three general ICUs, two in university hospitals and one in a regional hospital	To reveal the meanings of the ICU settings as a place of care.	Range: 38-80	Septic shock, Guillain-Barré syndrome, respiratory failure, pancreatitis, trauma, ruptured aorta aneurism, respiratory failure, trauma, endocarditis	A phenomenological approach	Not reported
Lykkegaard, 2013, Denmark, n=3	An ICU of a larger university hospital.	To explore the perceived meaning of being dependent on care for intensive care patients.	Range: 22-76	Surgical complications, complicated postoperative course, medical problem	A phenomenological hermeneutic according to Ricoeur	3 to 12 months after discharge

Table 1. Continued.

First author, year, country, sample size	Setting	Study aim	Age (years)	Critical illness	Theoretical approach	Timing of data collection
Locsin, 2013, Thailand, n=10	Not reported	To describe the meaning of the experiences of patients who were dependent on technologies while being cared for in ICUs.	Mean: 44 Range: 22-76	Various	A hermeneutic phenomenology design according to Van Manen	2 months to 5 years after hospital discharge.
Tembo, 2012, Sweden, n=12	A tertiary referral hospital ICU	To enhance understanding experiences based on the descriptions of the participants	Not reported	Not reported	A hermeneutic phenomenological approach according to van Manen	2 weeks after ICU discharge and at 6 to 11 months later.
Karlsson, 2012, Sweden, n=12	An eight-bed ICU in a county hospital	To illuminate the lived experience of patients who were conscious during mechanical ventilation in an ICU.	Mean: 58 Range: 23-88	Epiglottitis throat abscess, stroke, myelitis, laryngeal cancer, multi-trauma, carotid surgery, airway obstruction, sepsis, pneumonia, pneumothorax	A phenomenological-hermeneutic approach according to Ricoeur	4 to 11 days after ICU discharge
Johansson, 2012, Sweden, n=13	A general ICU with eight beds at a county/ regional hospital	To illuminate the meanings of being critically ill in a sound-intense ICU patient room, as disclosed through patients' narratives.	Range: 51-86	Pancreatitis, whipple-surgery, aortic aneurysm, guillain-barre´, pulmonary embolism, rectal cancer surgery, pain treatment, pneumonia, thrombosis, sepsis	A phenomenological hermeneutic approach	2 to 35 days after ICU discharge

Table 1. Continued.

First author, year, country, sample size	**Setting**	**Study aim**	**Age (years)**	**Critical illness**	**Theoretical approach**	**Timing of data collection**
Cypress, 2011, USA, n=5	An adult ICU in an urban, nonprofit, nonsectarian community hospital.	To describe and understand the lived ICU experience of nurses, patients and family members during critical illness.	Range: 23-70	Haemorrhagic stroke, diabetic ketoacidosis, asthma, emphysema, respiratory failure, multiple gunshot wounds, exacerbation of congestive heart failure	A phenomenological approach according to Merleau-Ponty	The first interview was conducted after ICU discharge. The second interview was conducted 4 days after the first interview
Fredriksen, 2010, Norway, n=6	Not reported	To inquire and understand the patients' experience of the body in relation to their significant others during critical illness.	Range: 20-75	Acute infection (n=1); pulmonary disease (n=2); infectious disease (n=1); surgery for cancer (n=1); intoxication due to substance abuse (n=1).	A phenomenological hermeneutic approach according to Kvale	Within 6 months after hospital discharge.
Foster, 2010, UK, n=3	An acute NHS Trust	Describing the experience of tracheostomy tube as lived by a group of people who had this tube inserted as a part of their critical illness or as a procedure related to an acute event	Not reported	Tracheostomy	Scientific phenomenology	Not reported

Table 1. Continued.

First author, year, country, sample size	Setting	Study aim	Age (years)	Critical illness	Theoretical approach	Timing of data collection
Wang, 2009, China, n=11	A six-bed ICU of a university teaching hospital	To understand patients' intensive care experience while receiving mechanical ventilation in ICUs.	Mean: 60 Range: 33-78	The mean score of acute physiology and chronic health evaluation (APACHE) was 21.4 (range: 14–30).	An ontological phenomenological approach according to Heidegger	3 to 14 days after the transfer from the ICU
Storli, 2009, Norway, n=10	A nine-bed general ICU in a university hospital,	To explore the meaning of patients' lived experience of being followed-up in a programme consisting of patient diaries, post-ICU conversations and visits back to the ICU.	Mean: 52 Range: 24-82	Admission diagnoses ranged from multi-trauma and extensive surgery to life-threatening infections	A phenomenological approach according to Kari Martinsen	about 6 months and again about 18 months after hospital discharge
Henricson, 2009, Sweden, n=6	Two general ICUs	To illuminate the meaning of receiving tactile touch when being cared for in an ICU.	Range: 54-78	The patients suffered from heart disease, heart surgery or intestinal surgery	A phenomenological hermeneutic approach according to Ricoeur	3 to 4 months after hospital discharge.
Storli, 2008, Norway, n=10	An ICU at a university hospital	To explore the meaning of living with memories from intensive care.	Range: 18-65	Admission diagnoses ranged from multi-trauma and extensive surgery to life-threatening infections	A phenomenological approach according to van Manen, Dahlberg and Merleau-Ponty	10 years after hospital discharge

Table 1. Continued.

First author, year, country, sample size	Setting	Study aim	Age (years)	Critical illness	Theoretical approach	Timing of data collection
Karlsson, 2008, Sweden, n=8	A rural hospital.	To investigate experiences of being conscious during ventilator treatment in the ICU from a patient perspective.	Mean: 46 Range: 21-81	Epiglottitis (n=3); sepsis due to various causes (n=3); Guillain-Barré syndrome and post-surgical complications involving perforation of the pericardium.	Hermeneutic phenomenology	Not reported
Fredriksen, 2008, Norway, n=7	Three hospitals	To inquire and understand the ways the body and its experience appear when the phenomena of strength and movement are altered.	Range: 34-82	Chronic lung disease with complication (n=2)s; heart surgery with complications (n=1); infectious disease with complications (n=2); orthopaedic surgery with postoperative complications (n=1)	A phenomenological-hermeneutic approach according to Ricoeur	Within 6 months after hospital discharge.
Storli, 2007, Norway, n=3	A nine-bed ICU in a university hospital.	To look more closely into this type of experience by turning to its meaning as reflected on by patients themselves.	Range: 30-60	Sepsis, multi-trauma, post-operative complications	A phenomenological approach	About 6 months after hospital discharge.
Almerud, 2007, Sweden, n=9	A moderately large hospital	To develop a knowledge base of what it means to be critically ill or injured and cared for in technologically intense environments.	Mean: 59 Range: 45-74	Not reported	A phenomenological approach according to Giorgi and Dahlberg	After ICU discharge or a few days after hospital discharge.

Table 1. Continued.

First author, year, country, sample size	Setting	Study aim	Age (years)	Critical illness	Theoretical approach	Timing of data collection
Johnson, 2006, Australia, n=9	CCUs	To describe and interpret the meaning for patients of being on long-term mechanical ventilation in a CCU.	Range: 21-69	Not reported	An ontological-phenomenological approach according to Heidegger	2 weeks to 2 months after hospital discharge
Ballard, 2006, USA, n=11	Seven critical care areas within three suburban hospitals	To determine and describe the remembered experiences of critical care patients who were given neuromuscular blocking agents and sedatives and/or analgesics to facilitate mechanical ventilation, improve hemodynamic stability, and improve oxygenation.	Range: 19-69	Respiratory failure, shock, overdose, COPD, nausea and vomiting, dizziness and weakness, hyperosmolar state	A phenomenological approach.	During admission to the critical care unit or another unit within the hospital
Strahan, 2005, UK, n=10	Not reported	To explore and describe the lived experiences of patients following transfer from the ICU.	Range: 18-77	Trauma (n=4); vascular (n=2); neurology (n=2); thoracic (n=1) and orthopaedic (n=1).	A Husserlian phenomenological approach	3 to 5 days after ICU discharge
Sheen, 2005, Australia, n=5	Not reported	It is easy for health professionals to assume that unresponsive patients are not feeling anything under their sedation. The aim of this research was to explore this phenomenon.	Not reported	Not reported	Phenomenology	6 to 12 months after hospital discharge

Table 1. Continued.

First author, year, country, sample size	Setting	Study aim	Age (years)	Critical illness	Theoretical approach	Timing of data collection
Del Barrio, 2004, Spain, n=10	Not reported	To describe the liver transplant patient's experience in the ICU.	Mean: 55	Liver transplant	A phenomenological descriptive study	1 to 12 months after transplant
Papathanassoglou, 2003, Greece, n=8	Not reported	To explore the lived experience of individuals with a past hospitalization in an ICU, with focus on their dreams.	Not reported	Not reported	An Interpretive hermeneutic phenomenological design	Four participants had been discharged between 12 and 24 months ago, and four between 4 and 6 years ago.
Jordan, 2002, South Africa, n=5	Not reported	To identify, explore and describe the experiences of patients who were connected to a mechanical ventilator.	Range: 22-54	Not reported	A phenomenological approach	12 to 48 hours after discharge from the ICU
Granberg, 1998, Sweden, n=19	A general ICU	To describe and give a deeper insight into patients' experiences and memory recall, both during and after their stay in the ICU.	Range: 25-82	Not reported	A qualitative hermeneutic approach according to Dahlberg and Gadamer	The first interview usually took place in the ward, between 6 and 10 days after ICU discharge. The second interview took place 4 to 8 weeks after the first interview.

Abbreviations: ICU= Intensive Care Unit; N = number; ARDS = Acute respiratory distress syndrome; COPD = chronic obstructive pulmonary disease.

RESULTS

Our meta-synthesis resulted in three lines of argument: ‘recovery from critical illness starts from a situation in which patients experience the lived body as unable’, ‘patients experience progress in recovery from critical illness when the lived body is empowered’ and ‘recovery from critical illness results in a lived body changed for life’. These lines of arguments form the overarching concept based on eleven third-order constructs which we formulated as different kinds of bodies: an intolerable body, an alienated body, a powerless body, a dependent body, a restricted body, a muted body, a touched body, a transforming body, a rediscovering body, an unhomelike body and a remembering body. The kinds of bodies and lines of arguments are related to stages in recovery (crisis, normalisation and post-discharge), as displayed in table 2. However one must not interpret this grouping as static stages, following a linear or sequential order. Recovery comes with moments of success and failure, with breakthrough moments and setbacks, with hope and despair. To clarify the variability, fluidity and ambiguity of the different kinds of bodies we will now describe them in detail.

Table 2. Results of line of argument synthesis with accompanying kinds of bodies.

Stages in recovery	Crisis	Normalisation	Post-discharge
Kinds of bodies (Third-order constructs)	An intolerable body An alienated body A powerless body A dependent body A restricted body A muted body	A touched body A transforming body A rediscovering body	An unhomelike body A remembering body
Lines of argument	Recovery from critical illness starts from a situation in which patients experience the lived body as unable	Patients experience progress in recovery from critical illness when the lived body is empowered	Recovery from critical illness results in a lived body changed for life

An intolerable body

During ICU stay, patients suffered from pain, difficulty sleeping, breathlessness and inability to move. Moreover, patients described a typical nausea that came with loss of appetite which brought a desire to be left alone and not disturbed (Mylén, Nilsson, and Berterö, 2016). When the suffering was not alleviated this made patients take on ‘a waiting position’ in which they had to tolerate and endure the situation (Holm and Dreyer, 2017). Many distressing experiences were caused by technological applications. Patients were sometimes 'totally unaware' (Johnson, St John, and Moyle, 2006) of the technology and other times irritated or annoyed by its presence. Its presence in itself was a sign of sickness and vulnerability, "am I that ill?" (Granberg, Engberg, and Lundberg, 1998). Mechanical ventilation was experiences as especially discomforting. It gave a continuous strain on the body. The tube was perceived as 'a devil in the throat' (Alexandersen et al, 2019), which came with a sense of 'oppression in the neck' (Albanesi et al, 2022). The mechanical ventilation came with feelings of breathlessness or difficulty getting enough air. Having a tube was also associated with an overwhelming feeling of thirst or a dry mouth. Moreover, airway suctioning to get rid of excretions and mucus brought on 'a sense of suffocation' (Tembo, Parker, and Higgins, 2012). Venous lines and needles were considered as 'fishing-hooks' (Granberg, Engberg, and Lundberg, 1998), which were painful and resulted in numb hands.

> *"I can't bear the thought of having a sore mouth again… I get frightened that it will because that's the worst thing, not being able to breathe and not being able to swallow…" (Foster, 2010)*

ICU treatment could be so intrusive or painful that being in the body was experienced as too difficult and patients dissociated from their bodies. Descriptions typically included a separation of the psyche or the self and the physical body, accompanied with an experience of 'being somewhere else' (Papathanassoglou and Patiraki, 2003). Patients managed to dissociate from the body by shifting the focus from their body to somewhere outside, or to another dimension. They could also experience 'observing the body from a distance' (Fredriksen, Talseth, and Svensson, 2008).

> *"I had to create a zone or a space when they came to do this…I searched for a spot on the wall or a thought I could hold on to… and then they did what they had to do and finished with it." (Fredriksen, Talseth, and Svensson, 2008)*

In this suffering patients experienced that 'their body had failed them' (Felten-Barentsz et al, 2018), and without seeing a future their 'hope for recovery was gone' (Alexandersen et al, 2019). Patients experienced despair or 'being on the brink of giving up' (Tingsvik, Hammarskjold, Martensson, and Henricson, 2018) and 'saw death as an easier alternative' (Lykkegaard and Delmar, 2013).

> *"I was mad at it (the body). And it didn't help (laughing). I have to be honest, there was a time during my stay at the intensive care unit where I thought that if I needed*

> *an injection of some kind then couldn't they just give me a proper dose and then I was gone (crying)." (Lykkegaard and Delmar, 2013)*

An alienated body

In the ICU, patients experienced an alienated body. The body felt different from normal and patients experienced this as weird, strange, unfamiliar or as 'a body that was not theirs' (da Cruz de Castro and Rebelo Botelho, 2017). Patients found it 'incomprehensible' (Almerud, Alapack, Frudlund, and Ekebergh, 2007) how the body had changed during their coma and critical illness. Because of fatigue, weakness and reduced capacities to move, patients experienced 'lack of control' (da Cruz de Castro and Rebelo Botelho, 2017; Fredriksen, Talseth, and Svensson, 2008; Locsin and Kongsuwan, 2013) and their 'routines interrupted' (da Cruz de Castro and Rebelo Botelho, 2017). The body was seen as 'disobedient' (Palesjö, Nordgren, and Asp, 2015) which was frightening. Activities that normally were 'matters of course suddenly needed consideration' (Lykkegaard and Delmar, 2013).

> *"I was laying there and I couldn't lift my arm. I could not even operate the television remote.[…] A board with letters on it was given to me, but I couldn't even point at the board. That was so weird. I never realized lying in bed and being held in a coma would make you this weak." (Felten-Barentsz et al, 2018)*

Not only the weakness and inability to move increased the alienation but also the altered sensations, which were described as a 'feeling of emptiness' (Palesjö, Nordgren, and Asp, 2015). This was linked to being bedridden and being horizontal in bed which affected normal orientation and 'spatial comprehension' (Mylén, Nilsson, and Berterö, 2016). Moreover, patients mentioned a distorted body perception or altered body image, with the body taking 'strange shapes' (Papathanassoglou and Patiraki, 2003).

> *"I felt swollen, huge and very heavy…once they moved me and I felt they were plucking a whole house out… My fingers felt enormous and stiff like gas pipes…" (Papathanassoglou and Patiraki, 2003)*

ICU technology seemed to add to the alienated body and the experience of a 'freakish body' (Locsin and Kongsuwan, 2013). Invasive treatment and techniques were experienced as 'foreign' (da Cruz de Castro and Rebelo Botelho, 2017; Holm and Dreyer, 2017; Johnson, St John, and Moyle, 2006; Tembo, Parker, and Higgins, 2012) and as the body being 'invaded' (da Cruz de Castro and Rebelo Botelho, 2017;

Storli, Lindseth, and Asplund, 2007), which represented a 'violation of the body' (Storli, Lindseth, and Asplund, 2007).

A powerless body

Patients in the ICU experienced a powerless body which could entail different meanings. First, patients felt that they had literally no power. There was no strength, no muscles to perform physical movement. Patients did not have the power to make the body do what they intended to, the body did not respond in the normal way.

> *"I was caught in.. a strange experience.. no power in my torso. I was not able to rise or anything. I wanted a cup of coffee… I saw the cup, but I was not capable of reaching it! They had to help me." (Alexandersen et al, 2019)*

Patients typically said "I could not do anything" (Lykkegaard and Delmar, 2013), or "I could do nothing". These expressions can be taken literally but also figuratively, pointing to the second meaning. Patients were in a powerless state, 'a state of inability' (Stayt, Seers, and Tutton, 2015). Patients used metaphors like "I looked like a plant" (da Cruz de Castro and Rebelo Botelho, 2017; Karlsson and Forsberg, 2008) or "I felt like an infant, unable to walk or talk" (Fredriksen and Svensson, 2010). Their poor condition, their fatigue, their lack of energy, their nausea, pain and dizziness made patients feel passive or 'taken over by others' (Wang, Zhang, Li, and Wang, 2009). This state was also called a state of helplessness, a state of disempowerment, vulnerability and fragility.

> *"But there was nothing to disturb me, nobody asked me to even think, or do anything at all, nothing… no demands whatsoever. I didn't need to eat, breathe or even shit. There was absolutely nothing that I had to do. And when you have nothing to do, you have a lot of time on your hands." (Karlsson and Forsberg, 2008)*

The third meaning of a powerless body relates to the 'power given to the caregiver' (Almerud, Alapack, Frudlund, and Ekebergh, 2007) and a 'lack of agency' (Stayt, Seers, and Tutton, 2015). The caregivers decided when the patient was washed, received meals, and was allowed to have visitors. Patients had a selfcare deficit and were in 'a waiting position' (Alguindy, Mohamed, and Gado, 2014; da Cruz de Castro and Rebelo Botelho, 2017; Holm and Dreyer, 2017; Sheen and Oates, 2005). Patients had lost the potential for action and lacked opportunities to act. They experienced loss of control over their body and over their life. Especially when they were unable to communicate they could not enact choice. It seemed to patients that they were 'not entitled to say "no"' or make demands of the care delivered.

Powerlessness was also evoked by the ICU technology. Patients felt bound and controlled by technology, to which there was an ‘unspoken underlying acceptance’ (Stayt, Seers, and Tutton, 2015). The technology was seen as very important and seemed to dictate clinical decisions such as whether patients could leave their beds.

> *“You have got to do as you are told because they just saved your life// They have got you plugged to machines and it is in their hands.” (Tembo, Parker, and Higgins, 2012)*

A dependent body

Patients in the ICU experienced a dependent body when they needed assistance from others, staff or next of kin, to have their most elementary human needs met. Patients were typically used to being self-sufficient and had trouble accepting help from others. It confronted them with their fragility and dependence.

> *“It was really unpleasant to receive care at first. Anyone would react to that, because it’s not normal. But then you understand it’s necessary, you can’t do it yourself. And then somebody else has got to do it. In the end you appreciate it a lot.” (Moen and Nåden, 2015)*

The technical devices used in the ICU also made patients feel dependent. Paradoxical experiences were described with technology being both distressing and providing a sense of comfort and safety. The technology did not only save patients’ life but also made patients feel dependent and fearful.

> *“When I woke up I had the tube down my throat and I had to depend on the [ventilator] and all the drips and tubes for my very life. It was terrifying at first, because I couldn’t help thinking. ‘What if something goes wrong with one of these machines, and nobody knows? After all, machinery is not infallible, is it? I tried so hard not to panic too much, but your whole life seems to lie in balance in the hand of a bit of machinery.” (Johnson, St John, and Moyle, 2006)*

An important element of the technology used in the ICU are monitoring devices. Being an object of observation could make patients feel marginalised, objectified and humiliated. They could experience a ‘submission of the physical body’, and even ‘subjected to rituals of power’ (Almerud, Alapack, Frudlund, and Ekebergh, 2007).

> *“I felt cared for but it did seem impersonal at times.. well they did examine me but I felt they were more interested in what the machines were telling them.. I felt just separated from it.” (Stayt, Seers, and Tutton, 2015)*

The way in which care was experienced strongly related to the attitude, behaviour and tone setting of the professionals. Receiving care was experienced as 'degrading' (Moen and Nåden, 2015; Lykkegaard and Delmar, 2013; Torheim and Kvangarsnes, 2014) and 'a sign of weakness' (Lykkegaard and Delmar, 2013). Through uncaring actions, cold impersonal care or 'superficial nursing' patients experienced a lack of empathy and felt invisible and neglected. This made patients feel like 'being in a vacuum' or 'being in a void' (Fredriksen, Talseth, and Svensson, 2008).

Despite their limited possibilities to act patients fought to regain power and independence. Patients sought for connection and contact with their caregivers and appreciated caring attentiveness. Patients typically wished to cooperate and contribute in the care process or, if possible, even be in charge. In the vulnerable and helpless situation every small option to participate in care made great difference to patients' sense of autonomy.

> *"Then I asked them to give me one of the long syringes and fill it with water and rest it on my shoulder or chest so that I could push some water through the tube and wet my mouth" (Fredriksen, Talseth, and Svensson, 2008)*

Patients could accept and bear the situation easier when they were met with respect and openness enabling them to grow trust. "Trust means handing over one's body and being confident that somebody will care for it" (Olausson, Lindahl, and Ekebergh, 2013).

A restricted body

Patients in the ICU experienced their body as restricted, restrained, trapped or imprisoned. The restricted body could have different meanings. First, it could mean that patients felt 'locked in a position in life they might not get out of' (Fredriksen, Talseth, and Svensson, 2008), where they had lost control, which increased their sense of dependency.

> *"You are restrained, you can't move. You can't go to the bathroom… you just lie there in your bed." (Almerud, Alapack, Frudlund, and Ekebergh, 2007)*

Second, it could mean that patients were not able to move, immobilised or bedridden. This came from sedation, weakness, tiredness, heaviness in the body, bodily constraints or was due to restrictions related to technical equipment. Patients in the ICU were connected with tubes, lines, catheters and cables and wires to machines, apparatuses and monitors. ICU equipment was restrictive in its nature and forced patients to lie still. They wanted to be a good patient, not disturbing the caregivers. They feared moving or changing position because they did not want to cause disconnection, resulting in alarms.

> *"Tubes and lines all over me, in my arms and legs, forcing me to lie still, they also had lines in my stomach so it was impossible for me to lie on my side. I felt bound and controlled by the equipment, which was both alien and noisy." (Granberg, Engberg, and Lundberg, 1998)*

Third, when patients had physical restraints they 'felt trapped', or 'tied up'. This was a scary, frustrating experience which was also felt as extreme violence. Patients were locked in a position and yearned to leave or escape the situation into freedom.

> *"I wasn't able to do my movement, because I was tied to the bed and was like restrained, so I remained still." (Alguindy, Mohamed, and Gado, 2014)*

Last, the feeling of being trapped or imprisoned could also come from the inability to speak or communicate, or was even linked to the endotracheal tube itself (Tembo, Parker, and Higgins, 2012; Tembo, Higgins, and Parker, 2015).

> *"But that tube in my throat that was shocking. I can still feel it at the back of my throat although it's not there now, I could 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, Higgins, and Parker, 2015)*

A muted body

Patients' inability to communicate and interact with staff and their next of kin made them experience a muted body. Mechanically ventilated patients were not able to speak, they made efforts to speak but did not hear sounds. Patients could not express themselves, could not draw people's attention and could not inform staff about their pain or their need for necessary care. Patients could not ask questions about what was going on. This came with feelings of anxiety, powerlessness, helplessness, anger and frustration, but also with feelings of isolation.

> *"What I thought was worst was that I couldn't talk when I had that plug in my throat, when I hadn't got the speaking valve yet. I thought that was horrible. For instance, my legs hurt a lot, and especially when they were going to turn me around, some of them were quite heavy-handed. And it was painful. So getting that message through was difficult, I thought." (Moen and Nåden, 2015)*

Patients searched for alternative modes of communication. Gestures, incomprehensible sounds and writing were used to attract attention and to express themselves. Writing could help to bring across the message however due to weakness and incoordination patients were not capable of producing readable writing.

> *"I couldn't control my writing which increased my frustration and I can remember throwing it away, across the ward I think…" (Foster, 2010)*

Olausson, Lindahl, and Ekebergh (2013) write about a paradoxical relationship between voice and body: "The body is speaking a language of pain, balancing between wondering and hope but at the same time is in a state of external silence" (Olausson, Lindahl, and Ekebergh, 2013).

A touched body

The way in which patients were touched strongly impacted their experiences. Patients felt violated when caregivers were heavy-handed or applied transgressive touch, when they were forced to participate against their will or when they were patronised. Patients could sense when healthcare professionals were indifferent and felt 'treated instrumentally' (Fredriksen, Talseth, and Svensson, 2008), being reduced to the status of organs, to a 'biological unit' (Almerud, Alapack, Frudlund, and Ekebergh, 2007) or 'just a body' (Lykkegaard and Delmar, 2015)..

> *"It was very transgressive when they touched me all the time. A lot of different people. No one, or maybe they did, but I didn't feel that anybody considered me as a person. It was just a body lying there that they had to get going again. And that was also fine because it meant that I survived but.." (Lykkegaard and Delmar, 2015)*

In a caring relationship, patients experienced touch as comforting, calming and relaxing. Being touched made patients aware of the physical presence of others which helped them to feel safe and less alone. It felt good to patients when they experience others taking care for them in washing, bathing, or smoothing their hair.

> *"One of the things that made me feel the best was when the nurse came in and, uh, she washed my hands, she washed my face, she washed my feet, she held me." (Ballard et al, 2006)*

Patients experienced comfort and wellbeing when they received caring attention for instance when professionals or next of kin rubbed their head or stroked their hands, or gave ‘encouraging pats on the back’ (Mylén, Nilsson, and Berterö, 2016). Within the high technology environment of the ICU, touch ‘reminded patients of their humanness’ (Almerud, Alapack, Frudlund, and Ekebergh, 2007). It made them feel more ‘alive’ (Henricson, Segesten, Berglund, and Määtä, 2009) or experiencing ‘harmony in the body’ (Henricson, Segesten, Berglund, and Määtä, 2009).

> *“Things that I really appreciated were when somebody came and took my hand just like that. You don’t think you can make it without that contact. It’s actually more important than the respirator. It gives you that warmth from another human being, the closeness, and it’s of crucial importance I think.” (Karlsson and Forsberg, 2008)*

Moreover, when patients were in the zone between sleep and wakefulness, bodily contact helped them to perceive the body and maintain contact with reality.

> *“It was so nice to be touched by someone who cared. If I was having an awful dream I would instantly feel safe if someone came up and just reminded me that they were there. I didn’t care if it was by voice or touch. Just as long as I knew I wasn’t alone.” (Sheen and Oates, 2005)*

Patients felt respected when they were confirmed as human beings, when their autonomy was acknowledged and professionals did not do things without asking first. Patients valued a judicious approach, with the caregivers not showing disapproving signals or signs of disgust when caring for them. When patients experienced a holistic approach and interpersonal interaction this enabled recovery and a feeling of being empowered.

> *“It promotes dignity.. to be praised for what little you can do. Even if it’s not much, it can help your confidence. Because my confidence wasn’t sky-high, to put it like that.. I felt small and helpless, I really did” (Moen and Nåden, 2015)*

A transforming body

After surviving a period of critical illness, patients experienced a transforming body. Patients were aware that they lived through a period with a very serious disease and that ‘their life hung by a thread’ (da Cruz de Castro and Rebelo Botelho, 2017), which emphasised the existential nature of being critically ill. Survival meant a lot for patients and they felt that they went through spiritual development and gained new perspectives on life. They spoke of personal transformation, rebirth, feeling like a new-born, with joy and awe for the wonder of life. This came with power and ‘will to get back to life’ (Fredriksen, Talseth, and Svensson, 2008).

> *"I felt really happy that I could come back to life again; I felt very well, much better; I felt strength in my body; I wanted to live." (del Barrio et al, 2004)*

> *"I felt like being reborn again after I died. Like passing the worst point, then (life) got better and better. These technologies are life-giving." (Locsin and Kongsuwan, 2013)*

In this transformation, ICU technology also played a role. Patients could experience technology as a source of security, a necessity for one's survival. When technology was removed patients experienced anxiety again, but at the same time the removal of technologies represented the recovery trajectory.

> *"…so as each drip disappeared and they took off the things from my leg I knew it meant that I could do more for myself." (Stayt, Seers, and Tutton, 2015)*

A re-discovering body

In recovery patients experience a re-discovering body or reclaiming of the body. Minor changes to body, strength and movement were experienced as hopeful developments. Specifically the ability to sit up and 'being removed from the horizontal position' (Fredriksen, Talseth, and Svensson, 2008; Johansson, Bergbom, and Lindahl, 2012; Karlsson, Bergbom, and Forsberg, 2012) was experienced as a huge improvement.

> *"It was almost the biggest thing that happened to me when they helped me get up in that chair, they supported me … to that chair that was there and everything seemed upside down… only so that I could sit and see what was happening around me… and it was almost… although I didn't have any strength… the arms were just lying there and the feet were propped up… yet still I felt that now… something was happening which made… that thing with the chair is one of the greatest things that have happened to me actually." (Fredriksen, Talseth, and Svensson, 2008)*

Assisted movements of patients' arms, legs and head could lead to patients experiencing a regaining of control over their bodies. Moreover, being able to engage in or initiate activities, for instance taking care of personal hygiene, made patients experience a sense of normalisation and self-confidence. Being able to help and assist were interpreted as signs of improvement or 'steps in the right direction' (Tingsvik, Hammarskjold, Martensson, and Henricson, 2018). Through exercise and supported mobilization, patients were able to re-discover the body, or 'get back their body' (Fredriksen, Talseth, and Svensson, 2008). This 'normalization' (Mylén, Nilsson, and Berterö, 2016), and increased ability to move, was called 'building muscles'

(Strahan and Brown, 2005), as ‘discovering body resources’ (Fredriksen, Talseth, and Svensson, 2008), or ‘gaining experience based knowledge’ (Fredriksen, Talseth, and Svensson, 2008).

> *“I didn’t know how to walk anymore. I found that incredible and now it’s coming back again. The muscles are starting to build up in my legs again.” (Strahan and Brown, 2005)*

Through progression, patients regained confidence in the body, regained control, and got more ‘grip on their life’ (Fredriksen, Talseth, and Svensson, 2008). Patients could actively contribute to their recovery. The ability to move, and achieving mobilizing milestones, could mean that patients experienced ‘a turning point’ (Felten-Barentsz et al, 2018; Fredriksen, Talseth, and Svensson, 2008).

> *“the nurses and doctors told me I would recover, but I did not believe them. Whenever I exercised in the water I felt that recovery was possible.” (Felten-Barentsz et al, 2018)*

A new path opened up, allowing patients to look forward and have hope for recovery. In the discovery of their bodily abilities patients dared to set goals and ‘began to have a future’ (Almerud, Alapack, Frudlund, and Ekebergh, 2007). This came with strong motivation and self-confidence, as it stood for life opportunities. Being active, achieving tasks and walking were experienced to be significant and meaningful. Patients wanted to get the body going and wanted to work for it. They experienced that they had only one body which they had to care for.

> *“I am encouraged to get up and go for a walk every hour and I am sticking to that as much as possible... My legs are strengthening up again.” (Strahan and Brown, 2005)*

An unhomelike body

Patients were grateful for surviving the critical illness and being able to return home. However, at home they were confronted with their disabled post-ICU self. They had to learn to live in, and become familiar with, their ‘changed body’ (Ellingsen et al, 2021), ‘uncanny body’ (Ellingsen et al, 2021; Palesjö, Nordgren, and Asp, 2015; Vester, Holm, and Dreyer, 2021) or ‘unhomelike body’ (Ellingsen et al, 2021; Palesjö, Nordgren, and Asp, 2015). Patients wanted to feel normal again and wanted to ‘return to their ordinary life’ (Palesjö, Nordgren, and Asp, 2015), but they had to let go of life as it was, and reconcile with the new body and the new life, into ‘an altered way of existence’ (Tembo, Higgins, and Parker, 2015).

> *"I thought I could do the things I did before. I was so surprised. My body felt so different." (Vester, Holm, and Dreyer, 2021)*

> *"…I suppose it's safe to say that I'm not the same person as before." (Karlsson and Forsberg, 2008)*

The patients' bodies had visible and invisible marks of the critical illness reminding them of their ICU period. Their bodies were weak and fragile. They experienced pain, fatigue, anxiety, and an inability to concentrate. They were uncertain how the body would react. Their bodily senses were easily overstimulated by the environment. Their voices were altered or lost. Moreover, patients experienced dissatisfaction with their bodily appearance.

> *"what… affects me most is my voice, cause I can't talk like I used to…sometimes people can't hear me, and that makes it difficult especially on the phone." (Umberger and Thomas, 2019)*

The bodily changes hindered their previous roles and actions. These problems made patients struggle to regain a sense of their previous self or identity.

> *"I used to do everything, the household, the girls… Things I couldn't do while in hospital. My husband still takes care of everything, leaving me wondering: What am I in this family?" (Vester, Holm, and Dreyer, 2021)*

An extra difficulty to patients was that they were seen as 'healthy at discharge' (Vester, Holm, and Dreyer, 2021). However, with the ICU experience, patients felt that life could no longer be taken for granted. Even years after hospital discharge, patients still perceived their body as vulnerable and unpredictable. Patients experienced insufficient follow-up, lacked help in their 'existential recovery' (Palesjö, Nordgren, and Asp, 2015), and felt "being left in the open" (Ellingsen et al, 2021)

> *"My friends kept commenting on progress in my physical ability. For me, I've felt stuck in a long, endless struggle with other ongoing problems." (Vester, Holm, and Dreyer, 2021)*

A remembering body

In three studies, Storli et al. (2009, 2007 and 2008) described patients experiencing memories stored, or rooted, in the body (Storli and Lind, 2009; Storli, Lindseth, and Asplund, 2007; Storli, Lindseth, and Asplund, 2008). Memories manifested as bodily experiences through bodily expressions of aversion. They experienced feelings of suffocation, tightness in the chest or chills down their back when certain memories were triggered.

> *"I always get a tightness in my chest when the taxi approaches the hospital.." (Storli, Lindseth, and Asplund, 2008)*

Their ICU stay could represent frightening experiences for instance being sexually abused while being held captive in a hotel room (Storli and Lind, 2009).

> *"It's written here that they put in a tube in my rectum, when I had such a bad case of diarrhoea... That's one of the feelings I recall... that something like that was done to me. [...] But all this happened in the hotel room where I was kept captive..." (Storli and Lind, 2009)*

Patients benefited from returning to the ICU, for instance in a follow-up visit, and 'feel the room' (Storli and Lind, 2009). As the body was taken back to the previous situation, deeply stored bodily memories could be awakened and made comprehensible so that bodily experiences could become meaningful and sorted out. This could bring 'harmony felt in the body' (Storli and Lind, 2009).

> *"I got this feeling of being held down, pressed down, that my mother says is maybe real, because I was so restless for a time there, before I really regained consciousness. I've had that feeling with me, but it has been very diffuse. Now I can sort of place it." (Storli, Lindseth, and Asplund, 2008)*

DISCUSSION

In this meta-ethnography, we synthesised the lived body experiences from 45 phenomenological studies. We found that lived body experiences during ICU stay and in recovery from critical illness can be characterised with three lines of arguments: 'recovery from critical illness starts from a situation in which patients experience the lived body as unable', 'patients experience progress in recovery from critical illness when the lived body is empowered', and 'recovery from critical illness results in a lived body changed for life'. These lines of arguments are the overarching concepts of the third-order constructs, or kinds of bodies that we found.

According to Merleau-Ponty, we are a body subject, with motor intentionality corresponding to a practical 'I can' or 'I cannot'. Based on our synthesis, we state in our first line of argument that 'recovery from critical illness starts from a situation in which patients experience the lived body as unable'. In this inability we recognise the "I cannot" from Merleau-Ponty. The motor intentionality, as pre-reflective condition for acting potential, is limited, resulting in critically ill patients having very limited grip on their world or life. The lack of strength and movement, resulting in disempowerment, and loss of control, in the ICU, were previously associated with the ideas of Merleau-Ponty (Almerud, Alapack, Frudlund, and Ekebergh, 2007; Fredriksen, Talseth, and Svensson, 2008).

The care delivered in the ICU is inseparable from the technology being used. Our findings include paradoxical experiences concerning the ICU technology. Patients are supported (they are able to breathe due to mechanical ventilation), and at the same time limited (they are unable to move their arms because it would cause and alarm). It is evident that the lived body experiences during ICU stay are strongly mediated by technology. Mediation means that the appearance of and relation with reality is changed, distorted and alienated (Ihde, 1990). The technology makes that the world appears differently to the patients during ICU stay, and influences capabilities and behaviour.

Our findings have important clinical implications. We are now able to answer questions such as: 'how can I help these patients experiencing a lived body that is unable and mediated by technology?' or in other words: 'how can I help patients experiencing 'I cannot' reach a situation in which they experience 'I can'?' The answer lies in our second line of argument: 'patients experience progress in recovery from critical illness when the lived body is empowered'. Empowering the lived body means for healthcare professionals to support the touched body, the transforming body and the rediscovering body. Our line of argument relates to findings in the recent study of Söderberg et al. (2022), entitled "from fear to fight", which, also, describes an empowerment process (Söderberg et al, 2022). Moreover, we see overlap with studies advocating bringing patients in an active awake state, allowing them to interact and be involved, increasing their sense of agency (Laerkner, Egerod, Olesen, and Hansen, 2017; Wermström, Ryrlén, and Axelsson, 2017). Empowering the lived body of patients during ICU stay is an important step towards recovery, and can be supported by healthcare professionals.

Recovery from critical illness starts early and proceeds long after patients are discharged from the ICU and from the hospital. Patients fight to gain back their old self. However, full recovery is hardly possible. Therefore, we state in our third line of argument: 'recovery from critical illness results in a lived body changed for life'. The body stays unhomelike to some extent, a finding that is also described as the concept of unhomelike-being-in the world by philosopher Fredrik Svenaeus (Svenaeus, 2011). Patients seem recovered, however, they can never return to the life they had before. Therefore, we agree with Ellingsen et al. (2021) that patients surviving critical illness become part of the remission society, a concept of Arthur Frank (Frank, 2013). The memories of being critically ill stay rooted in the body. Patients should be helped to place their experiences in context, so they can start thinking of acceptance and come to terms with their 'new' post-ICU self (Kean et al., 2021).

During the peer-review process for publication, an update of the systematic literature search was requested. The updated search included studies up to June 29, 2023, and yielded 7 relevant studies. Three of the studies collected data in the general ICU population (Tsai et al, 2021; Flinterud, Moi, Gjengedal, and Ellingsen, 2022; Lehmkuhl et al, 2023) and four studies collected data in patients who were admitted to the ICU with COVID-19 (Demir and Seki Öz, 2022; Engstrom et al, 2022; van Oorsouw et al, 2022; Køster, Meyhoff, and Andersen, 2023). In accordance with the findings of this meta-synthesis, these studies described a restricted body calling it a "trapped body" (Tsai et al, 2021), or an "imprisoned body" (Flinterud, Moi, Gjengedal, and Ellingsen, 2022), 'a powerless and dependent body' (Demir and Seki Öz, 2022; Engstrom et al, 2022; Køster, Meyhoff, and Andersen, 2023; Lehmkuhl et al, 2023), and 'a touched body' (Lehmkuhl et al, 2023). New was the reporting of 'an isolated body', expressed by patients admitted to the ICU with COVID-19 (Køster, Meyhoff, and Andersen, 2023; van Oorsouw et al, 2022; Engstrom et al, 2022; Demir and Seki Öz, 2022). It seems important for healthcare professionals to realize that isolation precautions have an impact on how patients experience their body.

Clinical relevance

Based on our findings we distillate several practical implications for physiotherapists and other healthcare professionals working with patients during ICU stay and in recovery from critical illness. When treating these patients, one should be aware of the different ways in which patients can experience their body. Reading our synthesised findings can help to create awareness and empathy for patients' lived body experiences. As lived body experiences are ambiguous and constantly shifting, we encourage healthcare professionals to be curious and sensitive to what the individual patient before them might experience. Using questions like: 'how do you feel?' or 'how does your body feel?' should be part of the clinical routine. A trained and empathic listener will hear many lived body experiences, and will know how to follow up on these expressions. When physical therapists make room for these conversations, they may assist patients to re-discover their body and build a trusting relationship.

Moreover, we found that patients make progress in ICU recovery through empowering actions. When a patient seems uncooperative, the healthcare professional should not simply conclude that the patient is not awake or conscious enough to follow up on commands. When the lived body is unable, 'simple mechanical' commands are often misplaced. In addition to a cognitive approach in the form of telling patients what to do, we recommend bringing patients in situations where they experience their pre-reflective embodied abilities and awaken the non-cognitive body knowledge. In the words of Merleau-Ponty we advocate to bring patients in a situation where they experience 'I can' instead of 'I cannot'.

Knowing that patients' lived body in the long-term can be changed for life, physical therapists should be cautious not to give false hope. Patients will be helped with a realistic prognosis. Acknowledging that patients may feel unhomelike might help patients feel heard, and help verbalize their feelings to their relatives. In line with Kean et al. (2021), physical therapists working with post-discharge patients should have the goal to "move on" and to regain a new sense of normalcy (Kean et al, 2021).

Strengths and weaknesses

To promote thoroughness of the data analysis, all analysing steps were performed by two researchers independently and the final synthesis was performed in panel sessions with an interdisciplinary research group. Herewith, all authors were familiar with the data and were able to critically reflect on the analysis. Moreover, by including a lines-of-argument synthesis, we provided for an overarching explanation of patients' lived body experiences and we were able to formulate clear implications for healthcare professionals.

In this systematic review and meta-ethnographic synthesis we included 45 studies, which is a large sample for a meta-ethnography. Including such a large sample of studies might lead to superficial analysis and synthesis. To ensure sufficient depth of analysis, we reported first-order, second-order, third-order constructs and lines of argument. For thorough analysis and to avoid an even larger sample, we limited ourselves to including only phenomenological studies. Knowing that the collection of lived body experiences among critically ill patients can be very challenging (Rier, 2000; Uotinen, 2011), including studies using other qualitative approaches, for instance general qualitative studies (Hofhuis et al, 2008; Jensen et al, 2017; Ringdal et al, 2018; Samuelson, 2011; Söderberg et al, 2022), grounded theory studies (Corner, Murray, and Brett, 2019; Kang and Jeong, 2018; Vogel et al, 2021), ethnography studies (Laerkner et al, 2019), or auto-ethnography studies (Bowers, 2004; Egerod et al, 2020; Rier, 2000; Uotinen, 2011), might have enriched our findings.

Suggestions for further research

In this study, we found that lived body experiences were related to stages in recovery: crisis, normalization, and post-discharge. There is a large body of qualitative research studying patient experiences during ICU stay (Carruthers, Gomersall, and Astin, 2018; Cutler, Hayter, and Ryan, 2013; Danielis, Povoli, Mattiussi, and Palese, 2020; Maartmann-Moe, Solberg, Larsen, and Steindal, 2021; Topçu, Ecevit Alpar, Gülseven, and Kebapçı, 2017) and around the transfer from the ICU to the nursing ward (Cullinane and Plowright, 2013; Field, Prinjha, and Rowan, 2008; Forsberg, Lindgren, and Engström, 2011; Herling et al, 2020; Karlsson, Eriksson, Lindahl, and Fridh, 2019; Lee and Park, 2021; Major et al, 2019). However, experiences in the post-discharge stage, for instance, in rehabilitation centers or during recovery at home, are less available. In order to give guidance to physical therapists working with patients recovering from critical illness in these settings, more qualitative research should be performed in patients at long-term follow-up.

CONCLUSIONS

Patients lived body experiences during ICU stay and in recovery from critical illness have richly been described in phenomenological studies. Based on a systematic review and thorough meta-ethnographic synthesises we provide a detailed insight into the different situations and kinds of bodies that patients can experience. These insights bear important clinical implications for physiotherapists and other healthcare professionals supporting patients in early mobilisation and ICU recovery. Healthcare professionals should empathise with patients' feeling that their lived body is unable. Subsequently, healthcare professionals should empower the patients' lived body by creating therapeutic situations in which patients experience that they are able. Finally, knowing that the patients' lived body is changed for life, patients recoverying from critical illness should be helped to come to terms with their 'new' self.

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APPENDIX 1 SEARCH STRATEGY

	Criteria	Results
S	Sampling strategy	Comprehensive, Boolean search strategy
T	Types of studies	Qualitative research, fully reported
A	Approaches	Systematic electronic search, hand-searching, snowball-searching reference list
R	Range of years	No date limits (Search 1-11-2021 till 12-11-2021)
L	Limits	Language (English/Dutch), publication type (peer reviewed journal)
I	Inclusion and exclusions	Inclusion criteria: -Study includes patient experiences -Study incudes bodily or embodied experiences -Study included experiences during ICU stay or in recovery from critical illness -Adult patients (aged 18 or over) -Study used a phenomenological approach Exclusion criteria: -Palliative care -Article type (e.g. abstract congress, thesis, commentary) -Full text not available -Ineligible language
T	Terms used	Critical Care [MeSH], early goal-directed therapy [MeSH], Intensive Care Units [MeSH], Burn Units [MeSH], Coronary Care Units [MeSH] Recovery Room [MeSH], Respiratory Care Units [MeSH] Critical Illness [MeSH], respiratory distress syndrome, adult [MeSH] Airway Management [MeSH], Extracorporeal Membrane Oxygenation [MeSH], Critical Care Nursing [MeSH], acute ill*, acute respiratory failure, acutely ill, ARDS, artificial respiration, Critical Care, critical ill, critically ill, ECLS, ECMO, extracorporeal life support, Extracorporeal Membrane Oxygenation, ICU, ICUAW, intensive care, intubat*, mechanical respiration, mechanical ventilat*, mechanically ventilat*, medium care, PICS, respirator weaning, respiratory care unit*, respiratory distress syndrome*, ventilator weaning, critical care/psychology [MeSH], critical illness/psychology [MeSH] critical illness/rehabilitation [MeSH], survivors/psychology [MeSH], Life Change Events [MeSH], Self Concept [MeSH], Spirituality[MeSH], qualitative [All Fields], qualitatively [All Fields], qualitatives [All Fields], Grounded Theory [MeSH], Qualitative Research [MeSH]), Interviews as Topic [MeSH], Nursing Methodology Research [MeSH Terms], Focus Groups [MeSH], Narration"[MeSH Terms], Jungian Theory [MeSH] essential meaning, Experience, Experiences, lived experience, phenomenolog*, case stud*, ethnograph, focus group*, Grounded Theory, hermeneutic*, heuristic*, interview*, Jungian Theory, life-world, narrat*, Observation
E	Electronic resources	Pubmed/ Medline, EMBASE, CINAHL, PsycINFO, Web of Science and Google Scholar

APPENDIX 2 METHODOLOGICAL QUALITY ASSESSMENT USING THE CRITICAL APPRAISAL SKILLS PROGRAMME (CASP) CHECKLIST FOR QUALITATIVE RESEARCH

Study	**CASP items**									
	A) Are the results valid?						B) What are the results?			
	1. Aim	2. Methodology	3. Design	4. Recruitment	5. Data collection	6. Relationship	7. Ethics	8. Data analysis	9. Clear findings	10. Local value
Albanesi (2022)	N	Y	Y	Y	Y	N	Y	Y	Y	Y
Vester (2021)	Y	Y	Y	N	Y	N	Y	N	Y	Y
Lee (2021)	Y	N	Y	N	Y	Y	Y	Y	Y	Y
Ellingsen (2021)	Y	Y	Y	N	Y	Y	N	N	Y	Y
Alexandersen (2021)	Y	Y	Y	N	Y	N	Y	Y	Y	Y
Umberger (2019)	Y	Y	Y	N	Y	Y	Y	Y	Y	Y
Alexandersen (2019)	Y	Y	Y	N	Y	Y	Y	Y	Y	Y
Tingsvik (2018)	Y	Y	Y	N	Y	N	Y	Y	Y	Y
Felten-Barentsz (2018)	Y	Y	Y	Y	Y	N	N	N	Y	Y
Holm (2017)	Y	Y	Y	Y	Y	N	Y	N	Y	Y
Cruz de Castro (2017)	Y	Y	Y	N	Y	N	N	Y	N	Y
Mylén (2016)	Y	Y	Y	N	Y	N	Y	Y	Y	Y
Whitehorne (2015)	Y	Y	Y	N	Y	N	N	N	Y	Y
Tembo (2015)	Y	Y	Y	N	Y	Y	N	N	Y	Y
Stayt (2015)	Y	Y	Y	N	Y	N	N	Y	Y	Y
Palesjö (2015)	Y	Y	Y	N	Y	N	Y	Y	Y	Y

Study	CASP items									
	A) Are the results valid?						B) What are the results?			
	1. Aim	2. Methodology	3. Design	4. Recruitment	5. Data collection	6. Relationship	7. Ethics	8. Data analysis	9. Clear findings	10. Local value
Lykkegaard (2015)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Moen (2015)	Y	Y	Y	N	Y	N	Y	Y	Y	Y
Torheim (2014)	Y	Y	Y	N	Y	N	Y	Y	Y	Y
Alguindy (2014)	Y	Y	Y	N	Y	N	Y	Y	N	Y
Olausson (2013)	N	Y	Y	N	Y	N	N	Y	Y	Y
Lykkegaard (2013)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Locsin (2013)	Y	Y	Y	N	Y	N	Y	N	N	Y
Tembo (2012)	Y	Y	Y	N	Y	N	N	N	Y	Y
Karlsson (2012)	Y	Y	Y	N	Y	N	Y	Y	Y	Y
Johansson (2012)	Y	Y	Y	N	Y	N	N	Y	Y	Y
Cypress (2011)	Y	Y	Y	Y	Y	Y	N	Y	N	Y
Fredriksen (2010)	Y	Y	Y	N	Y	N	N	Y	Y	Y
Foster (2010)	Y	Y	Y	Y	Y	N	Y	Y	N	Y
Wang (2009)	Y	Y	Y	N	Y	N	N	N	Y	Y
Storli (2009)	Y	Y	Y	N	Y	Y	N	Y	Y	Y
Henricson (2009)	Y	Y	Y	N	Y	N	Y	Y	Y	Y
Storli (2008)	Y	Y	Y	N	Y	Y	N	Y	Y	Y
Karlsson (2008)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y

Study	CASP items									
	A) Are the results valid?						B) What are the results?			
	1. Aim	2. Methodology	3. Design	4. Recruitment	5. Data collection	6. Relationship	7. Ethics	8. Data analysis	9. Clear findings	10. Local value
Fredriksen (2008)	Y	Y	Y	N	Y	N	N	Y	Y	Y
Storli (2007)	N	Y	Y	Y	Y	Y	Y	Y	Y	Y
Almerud (2007)	N	Y	Y	N	Y	N	N	Y	Y	Y
Johnson (2006)	Y	Y	Y	N	Y	N	N	N	Y	Y
Ballard (2006)	Y	Y	Y	N	Y	N	Y	Y	Y	Y
Strahan (2005)	Y	Y	Y	N	Y	N	N	N	Y	Y
Sheen (2005)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
del Barrio (2004)	Y	Y	Y	Y	Y	N	N	Y	N	Y
Papathanassoglou (2003)	Y	Y	Y	N	Y	N	N	Y	Y	Y
Jordan (2002)	Y	Y	Y	N	Y	Y	Y	N	Y	Y
Granberg (1998)	Y	Y	Y	N	Y	Y	N	Y	Y	Y

Y= Yes; N= No

APPENDIX 3 RELATING STUDIES TO EACH OTHER

Detachment from the body
Detachment from the body
Escaping from the body, having his soul elsewhere
The body as a separate entity
Dissociation from the body
Shift the focus from the body to somewhere outside
A medium with inner spatiality
An altered association between psyche and the physical body
Disorientation
Disembodiment
Unable to grasp what is happening
Being disrupted
Being in limbo
Losing one's map and destination in life

A changed body
Changed body
An altered state
Altered body
Different body
altered bodily perception
Emptiness in the body
The body does not exist
Body image distortion
Alienated body
Feeling misplaced
Distorted perception of body and bodily sensations
Disrupted embodiment
An unfamiliar body
Feeling a stranger cared for by a stranger
Strangeness
Not recognizing the body
Not feeling the body
Loss of the usual and familiar body
Loss of the taken for granted body, which Heidegger referred to as 'the-ready-to-hand'
A freakish body

Unhomelikeness
A disobedient body
A foreign body
A body in silence
A fragmented body
Feeling betrayed by the body
A body completely inert
A body not responding
Transformation of the body

A powerless body
I couldn't do anything
I was paralyzed
Unable to move
Not being able to move
Not able to move arms and legs
Inability to move or express themselves
Unable to communicate
Being in a state of inability
Not being able to go to the toilet, poop in bed
Loss of control
Loss of function
To feel like floating
Traitorous body
Failing body
To feel like a vegetable
To feel like a little child
To feel like an infant unable to walk or talk
Feeling heavy like an elephant
Not knowing how to walk
Self-care deficit
Dysfunctional body
Powerlessness
Living in a bubble
Feelings of disconnection
A debilitated body
No sense of agency

Back to reality
Return to reality
A sense of unreality
Coming back to life
Trying to get it straight
Hope related to life
Bodily contact makes it possible to maintain contact with reality

A hopeless body
Hopelessness
Giving in
Giving up
Capitulation
Being trapped in a black hole
Being locked in a position in life they might not get out of
Uncertainty
Resignation
Feeling dead inside
Feeling like being in de process of dying
Death as an easy alternative
Wanting to die
My useless body
Draining willpower
A body at a breaking point
The confrontation with dead

Dependability
Loss of control
Being out of control
No opportunity to act
Being forced to submit to the will of others
Dependency
Vulnerability
Feeling fragile
Reduced self-confidence
Depersonalisation
No power
Powerless
Power given to the caregiver

The nurse is in charge
Impaired self-worth
Limited autonomy
To feel shamed
A sense of disempowerment
Helplessness
Being helpless
Yearning for independence
Loss of the known self
Degrading, your honour is at stake
No possibility to act
To feel like a child
Feeling left outside community
Experiencing a vulnerable body
Vulnerability
Feeling fragile
Low self-esteem
Inconvenience
Shyness
Illness or injury is a threat not only to the body but also to the person
A lack of agency
A lack of opportunity
A body devoid from its uniqueness
Being in a waiting position, having to tolerate and endure
Lacking strength
Lacking stability and balance in life

Fear, insecurity
Being scared, being terrified
Panic
Anxiety
Fear
Frightening
Terrified
Existential crisis
A need for an existential sphere for the body and self
Insecurity
Distressing thoughts

An imprisoned body

Being captured
Being restricted
Being imprisoned
Being trapped
Feeling trapped
Being controlled
Being tied down
Being tied to the bed
Being bound and drowning
Being unable to move
Being restrained
Being constrained
Feeling limited
Feeling strained
Feeling locked up
Being caught
Being put in straps
Longing to be free
Wanting to contribute
Wishing to cooperate and be in charge
Confinement to the bed
Being pursued
Wanting to escape
Being kept to bed

A suffering body

Suffering
Discomfort
Physical discomfort
Being tortured
Dread
Terror
Grief
Pain
Thirst, mouth dryness
Panic
Tiredness, Fatigue
Choking (when suctioning)

suffocation
Dyspnoea, breathlessness
Seeking air, as if you were underwater
Weakness
Being weakened
Being stiff
Exhaustion
Sleep troubles, sleeplessness
Being hurt
Depression
Waiting

Technology
Technology attached to the body
Technology fixed to the body
Equipment attached to the body
An invaded body
A controlled body
Incomprehensible environment
Awkward situation
Trouble grasping what happens
Being wired
Being tethered
Vulnerability
Dependency
Chaos
Frustration
Fighting staff
Not being yourself
Just taking up space
Feeling like a biological unit
The tube as a foreign object invading the patient's body
Being on MV: A strain on the body
Tube: "a devil in the throat"
A sense of security
Feeling threatened

An objectified body
Being objectified
Being monitored
Being scrutinized
Being marginalized
Infantilizing patient
Diminishing humanness
Feeling like a biological unit
Not feeling seen
Impersonal care
Feeling invisible
Feeling ignored
Feeling neglected
Feeling reduced to the status of organs, objects, or diagnoses.
Feeling ashamed
Being embarrassed
Being exposed
Being violated
Feelings of failure
Feeling disappointed with yourself
Feeling humiliated
Being degraded
Feeling upset
Feeling lost
To feel shut off
Not disturbing the nurse
Feeling degraded
An instrumentalized body
Feeling passive
Feeling taken over by the other or technology

A subjected body
Being subjected to rituals of power
The biological body as an object of observation, supervision, review and control
Being treated instrumentally
Being excluded from having any influence
Not disturbing staff
Pleasing staff / Being a good patient
Blaming oneself

Being in a vacuum
Being in a kind of void
Lack of demands
Lack of stimuli
Perceive lack of value
Being violated
Being denied
Being treated as an object
Being isolated
Being judged
Being punished
Being abandoned
Being forced
Being patronised
Superficial and heavy-handed nurse
No empathy
Complying with an unspoken set of rules
Intimacy is invaded by unravelling the body, surrendering to the professionals' eyes and care

A communicating body
Inability to communicate
Non-verbal communication, gestures, writing
Being muted
Loneliness
Loss of control
Being voiceless
Having lost identity
The body is speaking a language of pain, balancing between wondering and hope but at the same time is in a state of external silence
An unreliable voice, verbal imprisonment
Feeling lost
Waiting to make a connection

Safety/ respect
Feeling safe
Human presence
Human touch
Human voice

Personal integrity
Nurses telling what they do
Nurses caring for you, spending time with you, and just being nice
Holistic approach
Being held by a nurse
Being holistically confirmed
Being connected to oneself
Being in harmony in one's body
Becoming alive
Handing over one's body in trust
The tone and touch of caring
Feeling homelike
Being met with respect
Being met with openness
Deep gratitude
Humbleness
Appreciation
Compassionate care
Bodily touch strengthened identity
Being able to move
The body feeling light
Relaxation
Actively contributing
Regaining confidence in the body
Accepting the situation
Accepting the ICU as an integral part of their lifeworld
Being involved in the care
Experience humanity and respectfulness
Vulnerable interactions

Family
Being attuned to loved ones
Not wanting to be seen
Feeling responsible for the family
Perceiving familiar touch
The conflict between proximity and distance to significant others

Feeling reborn
Feeling strength

Wanting to live, a will to survive
Confident that life goes on
Feeling like a new-born or a baby during recovery
Feelings of rebirth, joy and awe to the wonder of life
Feeling reborn
Inner strength
Willpower

A turning point
Reclaiming life
Re-discovering the body
To experience a turning point
Experiencing a turning point
Stimulated self-efficacy
Regaining control
Regaining a sense of stability and balance
Having both feet firmly on the ground
To get a grip on life
To reach a turning point

Progress
Regaining control
Building muscle
Signs of progress provide confidence and hope
Experiencing relief
To trust
Being able to help
Experiencing hopeful signs of progress as the body was less debilitated
Routines restored
A transfer as sign of progress
A quest to find oneself
The road back to life
Overcoming obstacles

A working body
Goalsetting
Rehabilitation
To hope
To be encouraged

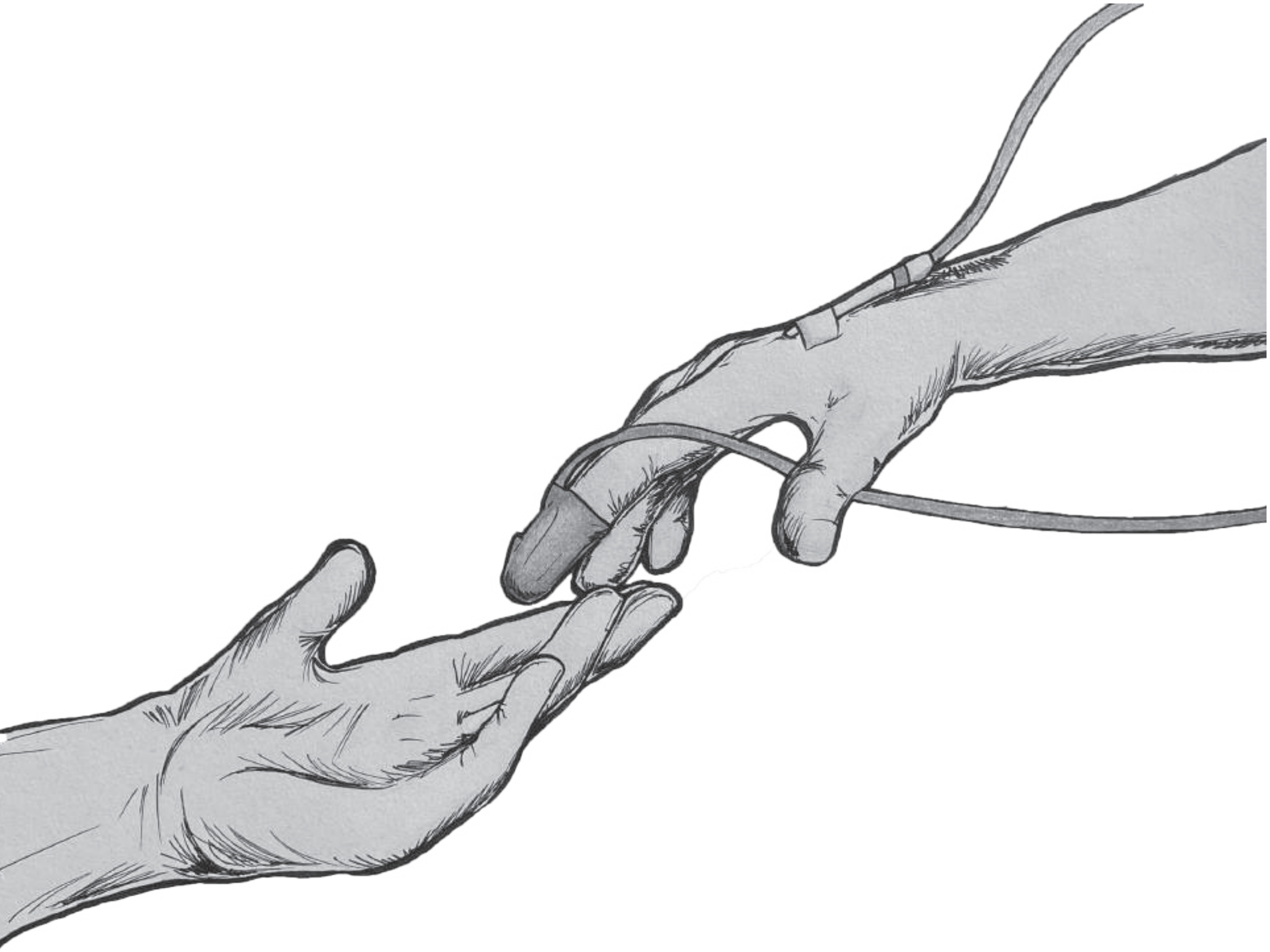
Being in the ward is a milestone in recovery
To be empowered
To be triggered
To have expectations
To find the body intact
To be in touch with one's own body
To be motivated
To be trusted
To achieve
To want
To desire
To be reassured
To gain freedom
Building muscles
Believe in recovery
To shift the gaze outwards into a space and a future
To feel relief
To feel gratitude
Striving for control
To take care of yourself
Striving to regain the old me
Desire for normality
Striving to feel normal
Wanting to work, it's part of identity

After discharge
Feeling forgotten
Being discharged, being left in the open
Having to learn basic things all over again
Being grateful for surviving and not understanding why being depressed
Losing identity when not being able to work
Inability to participate in social roles and activities including hobbies and work
Unhomelike being-in-the-body
An alien body, uncanny body
Regaining familiarity and homelikeness
A vulnerable and unpredictable body
Disintegration of the lived body
Reclaiming the role in the family but being inhibited by fatigue and physical weakness

Slowly reintegrating with the family
To recover in an unfamiliar body

A new self
Living beyond the "ringing bell"
Having to care for yourself in new and different ways
Preserving the self
Treading tentatively in a new world
Fight the battle for survival
Having the courage to meet the life that awaits them
Learning to live in the moment
Learning to live in a changed body
The body has both invisible and visible marks that are reminders of the critical condition
Overcome anxiousness and uncertainty
Existential recovery, learning to live with a changed body
Having lost previous life
Let go the old life, sacrifice life as it was and reconcile with the new body and life
The disabled post-ICU self
Struggle to regain a sense of their previous self/identity
Being born again
A new perspective on life
Life can no longer be taken for granted
A new understanding of oneself
A new orientation on life after critical illness
Redefining oneself

Memories in the body
Memories in the body
Being on a journey
Being on a quest
To encounter one's own expression
To feel the room



4

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

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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 hospitalisation 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 mobilising 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.

Keywords

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

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 hospitalised cases [1]. Critically ill patients with COVID-19 frequently require mechanical ventilation, often combined with prone positioning [2]. Prolonged duration of mechanical ventilation and ICU stay are important factors associated with intensive care unit acquired weakness (ICUAW) [3]. 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" [4]. One study found ICUAW in 26% of the patients with more than 7 days of mechanical ventilation [5]. Another study found ICUAW in 65% of this patient group [6]. A recent study among patients with COVID-19 requiring mechanical ventilation found ICUAW in 69% of the cases [7].

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 [8]. Before COVID-19, patients with ICUAW started rehabilitation at the ICU with early mobilisation supported by physiotherapists in close cooperation with ICU nurses and, ideally, accompanied by patients' close relatives [9]. However, especially in the first surge of COVID-19, early mobilisation and family participation were largely impossible [10]. 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 [11-13]. For nurses and other healthcare professionals this meant that they had to work in changed working environments and experienced high levels of stress [14, 15]. For patients with COVID-19-associated ICUAW this meant that they faced suboptimal rehabilitation.

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"[16].*

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 [17]. The isolation environment becomes the patient's world, and touch and sounds become heightened in the isolation environment [18]. 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 is paramount [19-21], and that the presence of loved ones promotes strength and willpower [22, 23]. 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 focused on feelings of anxiety, stress and depression [24, 25], 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 [26, 27]. Furthermore, these insights could be used to optimise the care delivery and to meet patients' needs in this pandemic or the possible next.

THE STUDY

Aims

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

Design

We designed a study in accordance with a hermeneutic phenomenological approach [26, 28]. We aimed to explore the phenomenon 'recovery from COVID-19-associated ICUAW' via staying open to the participants' life world and their meaning. In order to "grasp the very nature of the thing" [28], 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 [26]. 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" [28]. This phenomenological reflection was guided by five existentials that give meaning to the life world: relationality, corporeality, spatiality, temporality and materiality [26]. 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 [29].

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 [4]. 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 hospitalisation 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 send in 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 physiotherapists 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 characterised by the following contextual factors; there was fear and limited knowledge among healthcare professionals about the virus and doubts 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.

Data collection

Video-calling interviews were conducted four to eight 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 1). 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 demographic and participant characteristics were extracted from the electronic medical records.

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 emphasised 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.

Data analysis

For the data analysis we followed specific steps of hermeneutic phenomenological analysis [26, 28]. 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. Textual 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.

Abbreviations: COVID-19 = Coronavirus disease-19; ICUAW = Intensive care unit acquired weakness

Rigour

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

To optimise 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 physiotherapists involved in the care for 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, in order 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 physiotherapist (NK), physiotherapist (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.

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.

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

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 visualised in Figure 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 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)*

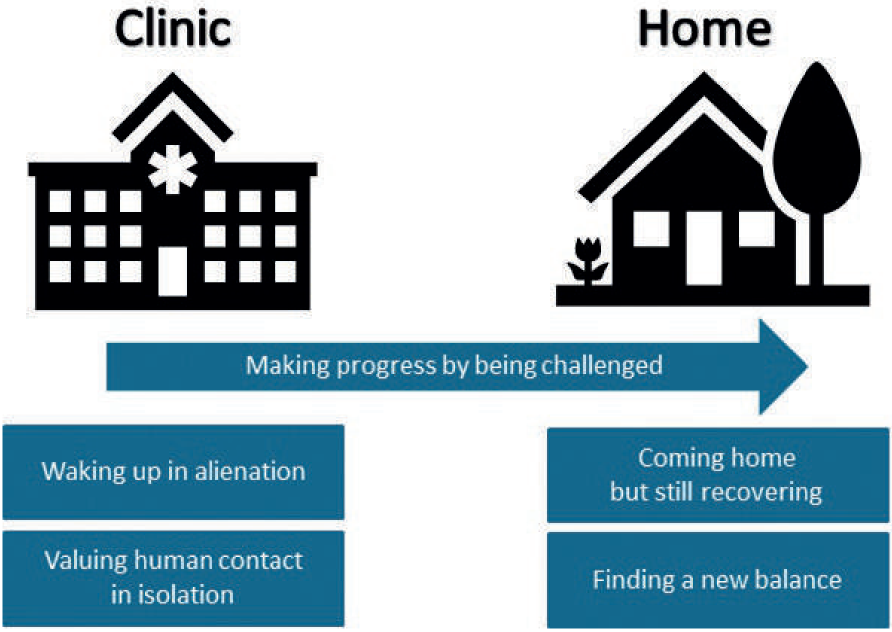

Figure 1. Visual display of patients' lived experiences in recovery from COVID-19-associated intensive care unit acquired weakness

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)*

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 recognise 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 visits were allowed, patients felt strengthened by the closeness and connection with their loved ones. Moreover, family members could recognise 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 centre], 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)*

Making progress by being challenged

From the moment on that 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 his balance 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 mobilising 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 mobilising 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 emphasised 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 mobilisation or therapy was too high, patients felt set back 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)*

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 household 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 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)*

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 en 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 isolation 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 recognised 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 [the rehabilitation centre] 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)*

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 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 mobilising 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) [26]. The alienating character of illness found in this study complies with the conceptualisation of "illness as unhomelike being-in-the-world" [30]. 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" [31].

In the isolation environment, patients strongly value human contact. The presence and contact with healthcare professionals and family members is 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 by 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 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” [26].

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 [32]. Therefore, patients recovering from ICUAW should be offered health-promoting follow-up support.

Relating findings to 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 [33-37]. The importance of human contact and presence of significant others have also been described previously [38-43]. The last decade has seen a growing body of qualitative literature regarding ICU recovery [23, 44-58]. It is not surprising that our findings show overlap with these studies, such as “dealing with setbacks” [44], “learning to live in a changed body” [23] or “regaining a mental balance” [47]. 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.

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 empathise 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 [59]. 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 empathise 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 emphasise 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 a 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 [60]. 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 [61]. 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 [62]. However, to our knowledge, no labs 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.

LIMITATIONS

There are some limitations related to this study. Methodical choices were constrained by pandemic-related restrictions. Therefore, data triangulation with 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 [63]. 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 [64]. 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.

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 experiences and empathise with their illness.

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APPENDIX 1 INTERVIEW GUIDE

Introduction and start recording

Acquaintance
-Can you first tell me something about yourself?
Prompt: How/where do you live? Family? Daily activities? Hobbies? Sports?

Current situation
-Can you tell me how you are doing currently?
Prompt: What does a typical day look like nowadays? To what extent are you able to mobilise? To what extent do you need/receive help? Are there any problems/complaints that you experience? Do you follow treatment? What does the treatment entail?

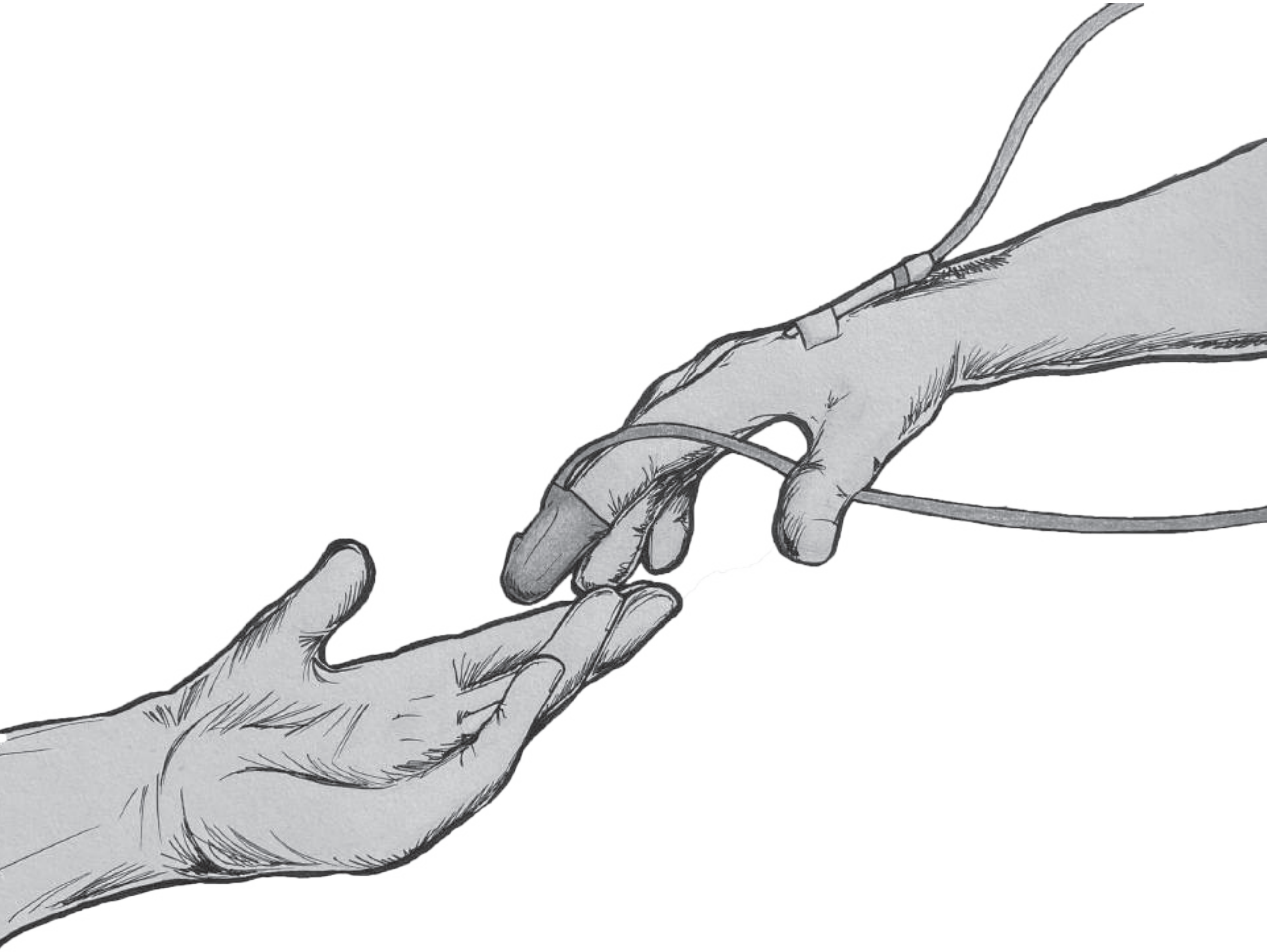
Intensive Care Unit
-Do you have any recall from the ICU period? Can you tell me about your memories?
Prompt: Do you remember waking up? What was it like? Could you move in the ICU? Did you receive help / in what way? Can you describe the surroundings? What did your body feel like? Isolation precautions? Visits?

Hospital ward
-At some point you were transferred to the hospital ward, what do you remember from this?
Prompt: What was it like? Can you describe the surroundings? Were you able to mobilise? Did you receive help / in what way? What did your body feel like? Isolation precautions? Visits?

Recovery after hospital discharge
-Can you tell me what happened after hospital discharge?
Prompt: Where did you go? Rehabilitation centre? What support/therapy did you receive? Mobilisation / activities / sports? What was it like to come home? Family? Work?

-Do you have other experiences related to your recovery not yet discussed?

Ending



5

A sense of being needed

A phenomenological analysis of hospital-based rehabilitation professionals' experiences during the COVID-19 pandemic

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ABSTRACT

Purpose
The purpose of this study was to explore lived experiences of rehabilitation professionals working in hospitals during the COVID-19 pandemic, including the ethical issues and moral distress that these professionals might have encountered.

Methods
An interpretative phenomenological study was performed. First-person experiences of rehabilitation professionals (dieticians, occupational therapists, physiotherapists, and speech-language therapists) were collected with semi-structured interviews and analysed with interpretative phenomenological analysis.

Results
The data of 39 hospital-based rehabilitation professionals revealed 4 themes: a disease with great impact, personal health and safety, staying human in chaotic times, and solidarity and changing roles. Participant experiences show that the virus and COVID-19 measures had a significant impact on the in-hospital working environment due to the massive downscaling of regular care, due to infection prevention measures, and due to unknown risks to rehabilitation professionals' personal health. At the same time, participants experienced a certain freedom, which made room for authentic motives, connection, and solidarity. Participants felt welcomed and appreciated at the COVID-19 wards and intensive care units and were proud that they were able to fulfil their roles. The findings reflect a wide range of situations that were morally complex and led to moral distress.

Conclusion
To diminish the long-lasting negative impact of the COVID-19 pandemic and moral distress, employers should empathise with the experiences of hospital-based rehabilitation professionals and create conditions for ethical reflection. Our data show that hospital-based rehabilitation professionals value professional autonomy. Creating room for professional autonomy helps them feel needed, connected, and energised. However, the needs of hospital-based rehabilitation professionals may conflict with organisational rules and structures.

Keywords
Allied Health Care, COVID-19, Experiences, Moral Distress, Professional Autonomy, Qualitative Research

INTRODUCTION

On March 11, 2020, the World Health Organization declared the outbreak of COVID-19 to be a pandemic. This outbreak, caused by the contagious novel coronavirus (SARS-CoV-2), led to many hospitalisations worldwide [1]. At the peak of hospitalisations in the Netherlands, in the beginning of April 2020, over 1300 patients with COVID-19 were admitted to intensive care units (ICUs) and over 2600 patients were admitted to hospital wards [2].

During this first wave, patients hospitalised with suspected or confirmed COVID-19 were cared for, in full isolation and separated from other patients, using "cohorting." Cohorting allows dedicated staff to work in a ward only with patients who tested positive for COVID-19, so they are unlikely to carry the virus from patients who were positive to patients who were negative. Hospital-based rehabilitation professionals, including dieticians, occupational therapists, physiotherapists, and speech-language therapists, were tasked with a variety of roles in the care of patients with COVID-19 in a working environment very different from normal, with limited availability of personal protection equipment (PPE). They had to make decisions with limited knowledge of optimal precaution and treatment strategies. Due to the crisis, the work process was often task based instead of human based and holistic. Although the professional roles were mostly well delineated, rehabilitation professionals could face roles for which they were not prepared.

As earlier outbreaks have shown, decision-making in a time of emergency is associated with ethical issues [3]. Ethical issues occur when values and norms conflict or when they no longer seem applicable. These conflicts may occur within a person or between different persons, or there may be disagreement with the rules or structures that guide an individual's professional activities [4]. In these situations, it is not possible to avoid acting; therefore, decisions must be made [5]. Making difficult decisions in such troubling situations may result in moral distress [6]. Different definitions of moral distress are used. For the purposes of this study, moral distress is defined as "1 or more negative self-directed emotions or attitudes that arise in response to one's perceived involvement in a situation that one perceives to be morally undesirable" [7]. The core ethical concepts and their operational definitions can be found in Appendix 1. Moral distress among health care professionals can cause professional dissatisfaction, burnout, and shortages in medical staff [6].

Numerous studies have sought to investigate the lived experiences of health care workers in the COVID-19 pandemic; however, they focused predominantly on physicians and nurses [8–10]. Few to none of these studies included rehabilitation professionals [11]; however, some included physiotherapists [12,13]. Insight into their experiences could help to empathise with unusual working situations and identify requirements of rehabilitation professionals during this pandemic or a possible future one. The aim of this study was to explore the lived experiences of rehabilitation professionals working in hospitals during the COVID-19 pandemic, including the ethical issues and moral distress these professionals might have encountered, experienced, or both.

METHODS

Qualitative approach and research paradigm

We performed an interpretative phenomenological study to explain lived experiences of rehabilitation professionals in 4 hospitals in the Netherlands. Phenomenology is a philosophical approach to the study of experiences developed by the German mathematician Edmund Husserl and those who expanded on his views, such as Heidegger, Sartre, and Merleau-Ponty [14]. The aim of phenomenological inquiry is to identify the essential qualities of the experience of a particular phenomenon [15]. It focuses on the appearance of the world to the individual through "going back to the things themselves," which means that experience should be examined in the way that it occurs, respecting individual differences and suspending judgments about what is real [15]. In everyday life, our attention is directed outwards to the activities we are engaged in, and we take for granted our experiences [15]. When we turn inwards and consciously reflect on any of the things we see, think, remember, or wish, then we are being phenomenological and capable of exploring the experiences that we lived through [15]. We collected first-person accounts of experiences with semi-structured interviews and analysed the interview data with interpretative phenomenological analysis [15]. Reporting of this study followed the Standards for Reporting Qualitative Research [16]. The Radboudumc ethical committee (dossier number 2020–6520) judged that this study does not fall under 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 [17,18]. Written informed consent was obtained from all participants prior to the interview.

Researcher characteristics and reflexivity

The interviews were performed by 3 researchers (R.v.O., E.K., and N.K.) who were all hospital-based physiotherapists and involved in health care for patients hospitalised with COVID-19. The interviewers were all educated and experienced in performing qualitative research. Prior to the interviews, the interviewers bracketed their own experiences, opinions, and prejudices on working as a rehabilitation professional in the hospital during the COVID-19 pandemic [19]. They accomplished this by writing a reflection about their own experiences and the issues they encountered. Before the start of the data analysis, the 2 data analysts (R.v.O. and N.K.) bracketed their experiences, opinions, and prejudices once more in a reflection report. The other researchers have backgrounds as an ethicist (A.O.), dietician (M.v.d.B.), speech and language therapist (H.K.), nurse (H.V.), occupational therapist (M.G.), and physiotherapist (P.v.d.W.).

Context

The interviews were performed in June and July 2020. During these months, the numbers of hospitalisations concerning COVID-19-infected persons in the Netherlands were low. The lockdown measures in the Netherlands were less restrictive starting May 2020. In June and July 2020, the basic rules still applied: stay home when sick, work from home by default, wash your hands more often than usual, and maintain 1.5 m distance. Public life had somewhat normalised, with students returning to schools, wearing facemasks in public transport, and cafes and restaurants being open with a maximum of 30 persons. No vaccines were available yet during this period.

Sampling strategy

Through purposeful sampling, rehabilitation professionals were selected for participation in this study. Optimal variation was sought in sex, age, profession, years of work experience, and type of hospital. Potential participants were eligible for study inclusion if they were employed in a hospital as a dietician, occupational therapist, physiotherapist, or speech-language therapist and if they participated in health care for patients hospitalised due to COVID-19 infection. Potential participants were excluded from the study if the professional had no access to digital communication equipment or if the professional suffered from psychological complaints requiring professional support.

Data collection

First-person accounts of experiences were collected to study the lived experiences of rehabilitation professionals, setting aside assumptions and prejudices from participants and interviewers about common sense and science. Participants were asked to share their thoughts and experiences in 1 in-depth semi-structured interview of a maximum 60 minutes. The interviews were structured by an interview guide (Appendix 2) covering the following topics: working in the hospital, working with patients with COVID-19, working at the cohort ward, working at the ICU; screening, diagnostics, treatment, ending treatment, and referral of patients with COVID-19; PPE equipment and infection precautions; and ethical dilemmas, moral distress, and personal health. The interviewers stimulated the participants to describe the experiences as they had lived them and to avoid causal explanations, generalisations, or abstract interpretations [20]. All interviews were held through video calling to avoid the risk of viral spreading. The interviews were audio-recorded.

Data analysis

All interviews were transcribed verbatim by a third party. Data were analysed following interpretative phenomenological analysis, a thoroughly described method situating participants in their specific context, exploring their personal perspective [15]. This method consists of 6 steps; steps 1 to 5 were independently performed by the data analysts (R.v.O. and N.K.), and step 6 was performed by all authors.

1) Reading and re-reading a transcript. For this step, the transcript of 1 interview was read, and the recording was listened to simultaneously.

2) Initial noting. In this step, the interview was coded line by line, looking specifically for experiential claims, concerns, and understandings of the case's lived experiences.

3) Developing emergent themes. The initial codes from step 2 were turned into themes through interpretation by the data analysts. The analysts looked for the essences of what participants said.

4) Searching for connections across emergent themes. The data analysts fit together the themes and selected the themes relevant to the research question. Connections between themes were noted in 1 case description per case.

5) Moving to the next case. Steps 1 to 4 were repeated for each case.

6) Looking for patterns across cases. Patterns across cases were searched in 2 consensus meetings using the transcripts (step 1) and case descriptions (step 4).

The 2 analysts presented and explained their case descriptions. All authors looked for similarities and differences between the 2 case descriptions. After 3 unique cases, they hypothesised patterns across cases by looking for connections, potential themes, certain orders, and key emergent themes. Finally, the first author (R.v.O.) examined the individual case descriptions once more to check whether they were adequately reflected by the established themes. An example illustrating the analytic process can be found in Appendix 3.

Techniques to enhance trustworthiness

The transcripts were aggregated and analysed using ATLAS.ti software (ATLAS.ti version 8.4, Scientific Software Development GmbH, Berlin, Germany) supporting open and transparent data analysis. An audit trail was used to continually check the interviewers' interpretations with the original data in an iterative process of analysis. Furthermore, credibility and trustworthiness of interviews were enhanced by the timing of the data collection. There was a maximum of 3 months between the lived experiences in the work situation and the interview. Two different researchers independently collected and analysed data to maximise credibility and authenticity. By using a heterogeneous sample of 4 different types of rehabilitation professionals, we created an interprofessional understanding of lived experiences. Moreover, the consensus meetings with the multi-disciplinary research team improved transparency and thoroughness of the data analysis. Transferability was improved by the provision of thick description of results, including vignette quoting. All participant quotes were translated by a third-party native English speaker.

Role of funding source

The funders played no role in the design, conduct, or reporting of this study.

RESULTS

Participants

Forty-two potential participants were contacted, 3 of whom did not respond to the study invitation. In total, 39 rehabilitation professionals enrolled in the study and completed the interview. The sample consisted of 9 dieticians, 7 occupational therapists, 13 physiotherapists, and 10 speech therapists. Two of the 39 interviews were held through a phone call with audio recording without video connection because of technical failure. Interviews had a mean duration of 48 minutes (SD = 6 min). Participant characteristics are displayed in Table 1.

Table 1. Participant characteristics

Characteristic N=39	Value
Sex (n)	
Male	10 (26%)
Female	29 (74%)
Age at interview (years; mean ± SD, range)	39 ± 11 (24-64)
Profession (n)	
Dietician	9 (23%)
Occupational therapist	7 (18%)
Physiotherapist	13 (33%)
Speech-language therapist	10 (26%)
Work experience in the hospital (years; mean ± SD, range)	15 ± 11 (1-42)
Type of hospital (n)	
University hospital	22 (56%)
General hospital	17 (44%)

Abbreviation: SD = Standard Deviation

Theme descriptions

Four themes emerged from the data analysis: a disease with great impact, personal health and safety, staying human in chaotic times, and solidarity and changing professional roles. Thorough descriptions of the themes are provided below to elucidate their meaning. Participant quotes are used to exemplify particulars of the phenomenon. They are numbered in correspondence to the numbers in the open access database [21]. The theme descriptions contain ethical issues as experienced by the participants. Themes, ethical issues, and accompanying values at stake are displayed in Table 2.

Table 2. Themes, Ethical Issues, and Accompanying Values at Stake

Themes	Ethical questions	Values and principles at stake
A disease with great impact	How ought I treat patients without sufficient knowledge of the disease?	Beneficence, non-maleficence, professionalism
Personal health and safety	Is it safe to work in the hospital? Am I putting my loved ones at risk?	Patient health, personal health, responsibility
Staying human in chaotic times	How do I keep a healthy work/life balance? How do I stay human in these conditions? How can I treat patients in a humane way?	Personal health, duty, humanity, dignity
Solidarity and changing professional roles	What role should I take on? How can I support my colleagues? Am I a general health care professional or a specialised hospital-based rehabilitation professional?	Responsibility, solidarity, competence

A disease with great impact

One of the first encounters of Dutch rehabilitation professionals with COVID-19 was media footage of Italian ICUs with many patients mechanically ventilated in prone position. At the end of February 2020, the first case of COVID-19 in the Netherlands was confirmed. Participants pointed out that they knew many very sick patients could come their way and heavily impact their work, which made them apprehensive. In some cases, rehabilitation professionals were trained and briefed to be able to help nurses. Non-acute care was scaled down, and rehabilitation professionals working in outpatient clinics had to call their patients to cancel appointments. Some participants experienced some very quiet shifts in which they were waiting for patients to arrive. They sensed a quiet before the storm and a looming threat (Table 3, Quote 1).

When the number of hospitalised patients increased, participants reported that things changed very quickly. Hospital wards were restructured to provide cohort treatment, and nursing staff was shuffled around. When hospitals reached their patient ward limits, patients were transferred to other hospitals. Participants felt like they were in a bad movie. There was a sense of disbelief and being taken by surprise (Table 3, Quote 2).

The rehabilitation professionals talked about a crisis mode and, among nurses and physicians, a survival mode. There was uncertainty and questions such as: What is happening? Will we be able to cope with all these patients? Participants explained that they felt anxious, especially those who witnessed severe illness due to COVID-19 among loved ones, or rehabilitation professionals living in areas with a large number of patients with COVID-19. The streets were empty because of the government measures, which made going to their work weird and surreal. Hospitalised patients were very sick, requiring high doses of oxygen; many patients were mechanically ventilated in prone position, and many patients died. The participants were overwhelmed by the severity of the illness. Some patients had great impact on the well-being of participants, especially when patients were of a similar age (Table 3, Quote 3).

The rehabilitation professionals saw patients being lonely and felt the urge to help and comfort them. This feeling was amplified by the fact that family and close relatives of patients were often forbidden from visiting as a result of infection precaution measures. Rehabilitation professionals saw patients in fear and panic and witnessed sad moments, which made them feel powerless. Concerning the treatment of patients with COVID-19, there was uncertainty about what to do.

Rehabilitation professionals had little information about the disease. Participants did not dare to rely on their clinical experience because the disease showed an unpredictable course, very different from normal. They faced ethical issues, including how to treat patients without sufficient knowledge of the disease and its unpredictable course. Rehabilitation professionals tried to solve these ethical issues by being more careful and by including more checks and balances. Some participants felt they were failing the patients because they did not have the expert knowledge needed to effectively treat them. The participants wondered if patients would ever recover and what would be left of their quality of life (Table 3, Quote 4).

The participants experienced a sharp contrast between being inside and outside of the hospital. From the outside, the situation seemed eerie due to the stories being told in the media. Being inside the hospital put things into perspective according to rehabilitation professionals. There was a feeling of dread, a feeling of pressure, but at the same an excitement before and while entering the wards. Participants typically mentioned they were curious and wondering: What is happening behind those closed doors? This made it even more rousing to go through the doors or sluices (Table 3, Quote 5).

The participants explained that they stepped into a different world when they entered the cohort wards or ICUs. The PPE measures impacted the look and feel of the wards, creating an unpleasant personal distance between patients and professionals and causing them to lose their “human touch.” In a short time, people were used to the situation inside. It was relatively quiet in contrast to the chaotic context pictured in the media. The participants said they saw “with their own eyes that patients were still humans, irrespective of their condition.” Despite the isolation precautions, it was the scenery and work with which they were familiar. The allied health professionals noticed a difference between colleagues that had seen the wards from the inside and those who had not. According to the participants, the anxiety and feeling of threat were lower among those who had been on the inside. They wished that the other colleagues would be allowed to see the patients and wards with their own eyes, because it would put things in perspective (Table 3, Quote 6).

Some participants suddenly had to work from home, a change that was very abrupt and felt strange. The participants expressed feelings of emptiness, resignation, and guilt towards colleagues working in the hospital. Participants pointed out that it felt safe to be able to work from home; however, on the other hand it was disappointing that they could not take part in the clinical work. The possibilities to work remotely were seen as positive and offered good solutions. However, participants typically missed their connection with patients, certainly when they had to work with "patients from paper" (Table 3, Quote 7).

Table 3. Quotes related to "A Disease With Great Impact"

Quote 1	"That was surreal. I came in, and it was actually very quiet from eight to ten and then between ten and twelve we suddenly had emergency admissions and scheduled admissions and that's when you saw the nurses panic, because the nursing team had to be completely reorganised as they suddenly had 6 patients instead of 3." (participant 10,320)
Quote 2	"During one of my shifts at the ICU a helicopter landed on the front lawn 3 times to take patients from the ICU to another hospital because we were full. It was also quite intense to see a long line of ambulances loading and unloading people." (participant 36,412)
Quote 3	"One of the most intense moments [I experienced] took place on that first Friday when a man my own age was being intubated. I was born in the year '79 so when I heard him come in and I heard the staff say that there would soon be a man admitted that was born in '79, I thought, oof, he is my age. [...] In the end he did make it after 3 days. He was also off the ventilator after 3 days. I checked up on him for a while. Some people get under your skin a little." (participant 10,320)
Quote 4	"What really got to me is seeing patients panic, but not really being able to reassure those patients, to say don't worry, it will all work out, we know what we are doing. When it comes to other patients in the hospital you often know the course [of illness] so you can also assume a more reassuring role. So I thought that was, well, I found it quite strenuous mentally." (participant 38,684)
Quote 5	"At one point it was like that for a few weeks and then I thought well, I would actually like to be more involved because I am getting afraid here at home, because I am not there (in the hospital). Because at home it all seems very spooky, but when you are there it is all very different." (participant 84,710)
Quote 6	"Once you are passed the sluice room, and you arrive at the department itself, well, that felt strange, but the kind of distress or madness that you see on television and in the media, was not present at all." (participant 33,394)
Quote 7	"It felt like you were about to be fired. Not that I was afraid of my dismissal, but it felt very weird. Because you sort of say goodbye to your colleagues and you do not know when you will see each other again. So, we ended up calling each other every day. We did plan a sort of meeting at the end of each working day and eventually it turned out that this was not necessary, instead we often connected by app and by mail. But it felt very strange." (participant 84,710)

Personal health and safety

During the first COVID-19 wave in the Netherlands, there was little information about the seriousness of the disease. There were stories that approximately 25% of the hospitalised patients would die. There were cases of health care professionals who got sick and were admitted to their own ICU. Furthermore, there was uncertainty about the way the virus spread. Participants pointed out that they were very aware of the danger of the virus, and that they took action to avoid becoming infected. They felt a great responsibility for the health and well-being of their loved ones. Participants faced the question: I want to help in the hospital, but is it safe? If I do, will I put my loved ones in danger? This made participants meticulous regarding their hygiene. Suits were changed more often, hands were washed more often, keyboards were cleaned more regularly, and they hugged their children only after first taking a shower. Some participants chose to be in very strict self-isolation to solve this issue and stayed available for work in the hospital. Participants who had to work in the hospital while they had expressed concerns to their supervisors about being infected with the virus felt guilt towards patients and colleagues who they might have exposed, which made them feel angry and frustrated (Table 4, Quote 1).

In addition, close relatives of participants also raised concerns about the safety of their work. They asked whether participants formed a risk because they were in contact with infected persons and asked if the participants did not feel scared to take on face-to-face contact with patients with COVID-19. Overall, participants felt safe using the PPE in the cohort wards and ICUs. Some stated that they were aware of the relatively luxurious position compared with the dearth of PPE in the primary care setting (Table 4, Quote 2).

Some situations caused participants to worry that they had been exposed to the virus, in particular when they witnessed disconnection of mechanical ventilation, when they questioned whether they had pressed the nose pads of the mask sufficiently, or when their skin was not fully covered by the PPE. One participant stated that she wore extra high socks to avoid skin contact. Some participants knew themselves to be hypochondriac and recognised anxiety about becoming infected as a continuing threat. Many participants opted for a healthy lifestyle to be more resilient to the virus and stay available for work in the hospital (Table 4, Quote 3).

The rehabilitation professionals felt anger towards people not following the rules or not keeping the required social distance. This anger was aimed at people outside the hospital, for instance in the supermarket, and also at colleagues in the hospital. Participants feeling vulnerable were extra keen regarding the measures and felt troubled when colleagues were not as compliant; however, they did not want to be the one to keep correcting them. Other participants feeling vulnerable due to previous illness considered it as a personal victory that they were able to keep working during COVID. This made professionals feel strong and energetic (Table 4, Quote 4).

Table 4. Quotes related to "Personal health and safety"

Quote 1	"My wife is a little older than I am and she has some lung problems, so she might be susceptible, and I didn't want to infect her. I know that at my age I am not a big risk to my kids, but the situation I am in means that I can catch it more easily because I am exposed all day, if I take proper hygiene measures, this also applies to my grandchildren and my parents. So yes, I consciously said that I am going to go into quarantine and stay 1.5 meters away from others at home and that is quite easy to do, but you have to be aware of it and we were [....] I didn't want to be the one to spread it, to infect vulnerable people and loved ones so that was my main motive." (participant 51,388)
Quote 2	"At one point I really felt much safer here in the hospital than in the supermarket. I was often asked if I was not afraid, and about wearing a suit, and how it must be quite stressful, but to be honest, I would rather be in a suit than in the supermarket." (participant 37,470)
Quote 3	"Then I agreed with my boyfriend not to drink alcohol anymore because we felt like we wanted to stay healthy, we both work with COVID-19 patients, so we stopped [drinking]. And we started exercising, 3 times a week, together with our colleagues. That worked out very well, because it stopped us from only talking about COVID-19 at work, and changed the subject to sports. Never in my life have I exercised so much, ate that healthy, and abstained from any alcohol. [...] so strangely enough I came out fitter than I went in. No COVID-19 pounds." [participant laughing] (participant 30,952)
Quote 4	"For me it really is like I told you, about having been ill, and at that time, it was questioned whether I could ever lead a normal life. And that took about 2 years. And then I slowly started living a normal life again. But I never dared to dream that I could do this. And now I've done it, so now I feel like I can take on the world." (participant 13,293)

Staying human in chaotic times

In a short period of time, adjustments were made in the hospitals, including restructuring departments for cohort, replacing staff, and implementing new treatment guidelines and protocols. Participants felt a need for clarity and leadership. Some participants recognised aspects from previous epidemics, such as coping with patients with HIV. The restructuring came with a continuous stream of information. There were many newsletters, emails, and webinars to update the health care professionals. Participants pointed out that frequent changes in policy made the situation chaotic, and they spoke of excessive information through all different channels. It was difficult to separate main from side issues. In addition, it took much time to distil what information was relevant for their work (Table 5, Quote 1).

Rules and policies changed repeatedly. The rehabilitation professionals experienced this period as chaotic and hectic; they were required to be alert all day. This also concerned PPE usage. Patients required care in full isolation, and at the same time scarcity of PPE material resulted in orders to avoid patient contact unless strictly necessary. Rehabilitation professionals felt pressure to not use any materials unless it was very urgent. Working with the PPE was physically challenging: participants mentioned they felt dehydrated, and experienced headaches in the evening. They had to be creative in unfamiliar circumstances, avoid entering and exiting rooms and departments, and find solutions in the use of materials because the normal instruments were not available at cohort wards and ICUs or could not be used due to limited options for cleaning. Moreover, they had to work with inexperienced teams and colleagues because nurses were oftentimes relocated. With many factors different, participants were happy to recognise their colleagues on the work floor. Working in this new situation and with this new disease, participants explained that they could no longer rely on their routine, which made their workdays intense and exhausting (Table 5, Quote 2).

The period was experienced as intense and stressful, but on the other hand also valuable. After work they might feel tired, irritable, and hot-tempered. Some participants experienced difficulty sleeping. They took their work home and had to process their experiences. Participants were confronted with the question: I want to fulfil my job in the best possible way, but how do I keep a healthy work/life balance? It helped to share stories and feelings with loved ones. Others explained that they had to write things down or take time to ponder to process things. After the COVID period, they felt tired and needed a period to relax. Participants experienced the workload in different ways. Those with small children explained that it was a very busy period due to the home situation with home schooling. Others stated that the period was quite relaxed because a lot of meetings were cancelled and appointments with friends and family were cancelled (Table 5, Quote 3).

The unfamiliar chaotic situations, with all professionals dressed in PPE and with many sick, often sedated, patients with COVID-19, made the work at the wards and the ICUs feel less humane than normal. During the crisis, there was high turnover, and many patients died. Therefore, some participants felt that they blocked their emotions. They experienced a “robot mode,” and the work felt factory-like. This typically was the case for rehabilitation professionals participating in teams that supported ICU nurses turning patients in prone position. Participants felt that they were treating bodies, or human-like dolls, rather than people. Some situations were referred to as disgraceful. Patients were oftentimes naked, smelly, bloated, and affected by severe decubitus, which rehabilitation professionals had not experienced before. There was a lack of personal information in the rooms, which made it impossible to provide person-centred care. This felt wrong, and some participants felt guilt towards those patients. They wondered: how do I stay human in these conditions? And how can I treat patients in a humane way? They coped with this by talking to patients and by showing dignity and respect, even when patients were deeply sedated and were not expected to hear anything of the things said (Table 5, Quote 4).

The rehabilitation professionals wanted to restore and promote the patients’ dignity as much as possible. Some participants explained that they worked in health care because they wanted to care for people. They felt the need for human contact and empathised with the lack of contact patients received (Table 5, Quote 5).

The participants stressed the importance of a personal connection when motivating patients. Participants found creative ways to establish human contact despite the PPE boundaries. They sought eye contact more consciously and frequently or used their voice in particular ways. Some participants explained that they very deliberately showed their face to the patient before entering the room.

Table 5. Quotes related to “Staying human in chaotic times”

Quote 1	“You don’t dare not to read it because you might miss something you need to know. So, I always read everything but, in the end, I thought hmm, does this actually make a difference for me?” (participant 58,414)
Quote 2	“Usually the door is open so you walk in and start treating someone and you occasionally do consult with the nursing staff of course, but that happened more often now because the door is closed and you don’t really want to waste materials [PPE], so you ask in advance, who’s behind the door? How are they doing? What should we do? What do we want to do? We need to make choices. So, we actually added a step [to the process] in order to choose what is necessary and what is not, and where I should go” (participant 58,247)
Quote 3	“I also quite liked the fact that a lot of meetings that you usually had to attend had been cancelled. So, it certainly has advantages. So yes, I do hope we can hold onto some things from this period of time.” (participant 26,976)
Quote 4	“What really, well, what really affected me was the 1 nurse who addressed people by name and told them [what we were doing] we will now do this or do that. I really liked that, so I picked it up and started doing it myself. I started addressing people too. Otherwise, it feels like a rag doll lying there.” (participant 58,414)
Quote 5	“People also feel really lonely don’t they, and as I said, all doors are closed, you have to rely on that one moment when someone comes in, all suited up, well then, that real contact, that real human contact is not there really and it is that human interest that I think we need to make sure we hold on to.” (participant 66,521)

Solidarity and changing professional roles

The period of crisis was experienced as a time of solidarity. Participants typically felt an urge to support their colleagues, to relieve busy physicians and nurses, and to help keep the hospital up and running. Participants speak of a caring reflex, a duty, a calling, a feeling of commitment, a need to stand by when needed, to be of service. They felt drawn to the hospital. They felt that this was why they had become a health care professional. Many hospital-based rehabilitation professionals were deployed as general health care professionals. Some helped transport patients through the hospital, and others were stationed at the nursing ward to support nursing staff. They helped with washing, replenishing stocks, distributing medication, and so on (Table 6, Quote 1).

Some participants stated they felt frustration when they were not allowed to help on the wards due to rules or management choices. When coming to and working on the wards or ICUs, they felt welcomed and appreciated. There was a strong sense of team spirit among health care workers. The participants felt proud that they were able to fulfil their role (Table 6, Quote 2).

From outside the hospital, participants also felt gratitude and respect in the form of banners, messages, fruit baskets, and gifts sent to the wards. There were 2 negative cases in this theme: 2 participants explained that they did not see any role for themselves. They felt that, in a time of life and death, rehabilitation professionals should exercise restraint and not place themselves in the foreground (Table 6, Quote 3).

Other rehabilitation professionals helped turn patients in the ICUs because there were many patients being mechanically ventilated in prone position. They were staffed to assist nurses, whereas they are accustomed to being in lead positions. Some participants explained that this was strange and confusing. It was not clear what was expected from them and what role they should take. They questioned: What role should I take? Rehabilitation professionals also had questions regarding their identity, for example: “Am I a general health care professional or a specialised rehabilitation professional?” As a general health care professional, they particularly wanted to support nurses and physicians to reduce their workload. As a rehabilitation professional, they critically considered what care ought to be provided (Table 6, Quote 4).

Sometimes, based on their skill and knowledge, rehabilitation professionals saw room for improvement in the situation; however, they were not sure whether feedback was appreciated in this situation. They were aware of the workload among the nurses and did not want to be an additional burden. Some participants ensured work would not be delegated to nurses on the floor. On the other hand, participants had difficulty not perceiving the situation through their allied health lenses. The new disease also raised some professional curiosity. They wanted to add their knowledge and skills where they thought they could be beneficial to the patient. They felt pride in their profession and sought recognition for it. Several participants pointed out that they felt capable of taking a role as an expert during the COVID-19 crisis. They took this opportunity to show health care professionals in other disciplines what they were capable of. For instance, the dieticians helped determine the food demand of patients in the ICU to relieve ICU physicians from this task. It felt like a victory when this was established and appreciated. In several different ways, participants felt room to adopt roles they were normally not able to. Some were national experts and taught webinars. Others experienced that they could finally have substantive talks with physicians. The hierarchy seemed to vanish. Moreover, during the crisis period, many factors could be organised within a short time. These elements together made the period energising, exciting, and instructive (Table 6, Quote 5).

It was curious to note all the possibilities and opportunities in this period, which made possible the accomplishment of tasks that had long been desired. This felt refreshing and provided an energy boost. Participants wished they could maintain aspects of this new atmosphere. After the crisis period, participants felt recognition and goodwill on the wards. However, some participants pointed out that the hierarchy and bureaucratic procedures started to return, which felt frustrating (Table 6, Quote 6).

Table 6. Quotes related to “Solidarity and changing professional roles”

Quote 1	“On my first day off, I went cycling. That is my hobby, so I went for a leisurely ride, reducing stress. And I as cycled towards [city name], I was inclined to ride to the hospital. At that moment you realise that you are constantly taking on the assisting role. It didn’t matter what you did, either. I even bathed a patient; those are nursing duties. The nurse asked me if I wanted to bathe the patient, and I said I never did that before but—by then I’d also seen a lot of feces, and at that point that doesn’t matter as long as you can help the nurses. They are very busy.” (participant 10,320)
Quote 2	“You just do it. In my opinion the risk you took was small compared with the gains of work satisfaction. So, you help the more vulnerable, the very sick, and that feels like a small investment you can make in order to contribute to society. I was very proud of my work at that time.” (participant 96,116)
Quote 3	“In matters of life and death, what should an occupational therapist come around for? It was like, family became very important, as did social work and spiritual guidance, they are very important. It was very medical and then, well, within the entire ICU, at that level of care, there is nothing for you to do as an occupational therapist.” (participant 48,827)
Quote 4	“On the ICU you usually take the lead as a physiotherapist and the nurse has a supportive role and now, we had to, well, search for a new division of roles in which the nurse actually wanted to take the lead. I noticed, especially in that first week, that the nurses were really taken aback, and it took a bit of getting used to, like oh, the tube might come off and no, you can’t touch anything. […] And as you are a physiotherapist at heart, you will not simply turn the patient over, but you also look at the overall mobility to get a bit of a feeling. Because you don’t know that [patient] population either.” (participant 40,447)
Quote 5	“The theme leader nutritionist discussed with a privacy officer whether we could also view the patients’ files without referral. And because it was to the benefit of the patient’s treatment, I think we actually received approval for it that same day. When usually you have to get approval from 3 committees, so to speak, it was now arranged within a day. So that is something that changed with Covid-19, now things could be arranged more quickly.” (participant 83,109)
Quote 6	“Now we are back to normal and I actually had that feeling already after 3 weeks at the ICU when I thought, ah, okay, we have returned to our regular hierarchy.” (participant 40,447)

DISCUSSION

This qualitative study using interpretative phenomenological analysis to explore the lived experiences of rehabilitation professionals working in a hospital during the COVID-19 pandemic revealed 4 themes: disease with great impact, personal health and safety, staying human in chaotic times, and solidarity and changing professional roles. Rehabilitation professionals felt welcomed and appreciated at the COVID-19 wards and ICUs and were proud that they were able to fulfil their roles. The themes and accompanying ethical issues reflect a wide range of situations that were morally complex and led to moral distress.

Participating rehabilitation professionals indicated that, during the first wave of the COVID-19 crisis in the Netherlands, the virus had a great impact on the in-hospital working environment due to the massive downscaling of regular care, infection prevention measures, and unknown risks to rehabilitation professionals' personal health. Normal structures, frameworks, protocols, agreements, roles, and certainties did not meet the crisis requirements. This was frightening for the rehabilitation professionals and was accompanied by a need for structure and leadership. New work structures and guidelines were developed, which generated excessive information. The rehabilitation professionals had difficulty to distinguish main from side issues and to distil what information was actually relevant for their work. At the same time, participants experienced a certain freedom, which made room for authentic motives, connection, and solidarity. In the chaotic situations, rehabilitation professionals were urged to rely on their intuition and started acting accordingly. Rehabilitation professionals felt a calling, experienced a sense of being needed, and felt which parts of their work were particularly meaningful, such as therapy for patients and support of nurses. These aspects were pointed to as being beautiful, inspiring, and providing energy. Organisational changes could be arranged within a short time, including changes otherwise impossible to achieve under normal circumstances. Rehabilitation professionals were keen on sharing their expertise and were professionally interested to treat this new patient group as well as possible. Despite the difficult conditions and isolation precautions, they sought ways to remain human in line with their fundamental attitudes to care for people and engage in human interactions. Rehabilitation professionals hoped that these meaningful changes from the crisis period would remain. However, they recognised that when the crisis waned, previous hierarchy and bureaucratic procedures seemed to reappear.

Our findings are in line with the experiences of 22 professionals caring for patients with COVID-19, so-called "soldiers on the front," between May and August 2020 [12]. Rehabilitation professionals have also been working on the so-called front line and discuss the same challenges, such as balancing between "being part of something bigger" (in this study: being needed) and "putting family at risk" (in this study: personal health and safety). Our findings are also consistent with other studies reporting experiences of health care professionals treating patients during a pandemic [11]. This makes it clear to us that past lessons learned contribute to current health care and that lessons learned now contribute to better health care in the future.

In the participant experiences in this study, several types of moral distress as described by Morley et al can be recognised [22]. Moral dilemma distress was present when allied health professionals experienced the dilemma that they wanted to help nurses and physicians but did not know whether it was safe to work in the hospital, not wanting to put their loved ones at home at risk. Moral values and principles such as professional loyalty and personal health were at stake, because participating in health care would be loyal, though it could lead to viral spread to loved ones. Moral uncertainty distress was present in the lack of knowledge of the disease, expressed in the values competence, beneficence, and non-maleficence relating to rehabilitation professionals' insecurity about how to treat patients in the best way; they did not dare to trust their clinical experience. Moral constraint distress occurred in relation to values such as professionalism, responsibility, and duty, for instance, when rehabilitation professionals were not able to treat patients due to isolation restrictions and shortages in PPE material.

Moral distress is a natural response to morally difficult encounters in the provision of patient care [22]. Ethical conflicts and moral distress will always exist in health care, especially in high-intensity settings with ethical decision-making [23]. To avoid the long-lasting negative impact of moral distress, efforts should be made to mitigate its effects. Until now, only a few evidence-based interventions have been studied, with limited effectiveness [24]. Yet, some promising practices can be suggested [22,23,25]. The recently developed SUPPORT model enables organisations to simultaneously develop ethical skills and facilitate team-based dialogue while creating policies shaped by standards of healthy work environments [23]. Based on this model, ethical issues should be recognised and acknowledged. Ethical dialogue should become normal practice, and safety should be established for discussions among team members. The organisation should encourage debriefing and create conditions to engage in ethical reflection. The importance of ethical reflection is also stressed in Kunneman's concept of normative professionalism [26]. It enables professionals to create room and reflect on "slow questions" [27]. Slow questions concern life questions about relations, health, loss, violence or longings, issues that cannot be solved by quick technological solutions. The ethical issues faced by rehabilitation professionals in the COVID-19 crisis were morally complex, requiring a pragmatic trade-off of values in the search for good care and therefore requiring recognition and acknowledgment.

Limitations of this study include the lack of data triangulation. The use of other data collection methods, for instance participatory observations, could have enriched the data. However, due to the limited availability of PPE and the risk of virus transmission, this was not an option. Because of the risk of viral spreading, interviews had to be performed through video calls. Video calling might have limited the richness of the interviews because of less rapport between interviewer and participant and less non-verbal communication. However, recent studies suggest that in-person interviews are only marginally superior to video calls [28,29]. No test interviews were performed before the start of data collection, which might have influenced the data collection during the first couple of interviews. However, because all authors had been involved in caring for patients hospitalised with COVID-19, they possessed a clear vision on the topic, and, over time, the interview guide was only marginally adjusted.

For this study, we interviewed rehabilitation professionals in 4 different disciplines, creating an interprofessional understanding of lived experiences. However, only the perspective of employees was sought, whereas the perspectives of managers of organisations, or politicians countrywide might be opposing. All study participants were rehabilitation professionals employed in Dutch hospitals. The generalisability of findings might be limited because rehabilitation professionals in other countries might have been working under different circumstances. Furthermore, the severity of the COVID-19 crisis differed across countries. However, the curve of hospitalisations was similar to other countries, at least in Western Europe. Furthermore, with the aid of thick description of the results, readers can decide for themselves to what extent our findings are transferable to the reader's situation.

In conclusion, during the COVID-19 crisis, rehabilitation professionals faced a wide range of situations that were morally complex and led to moral distress, requiring a pragmatic trade-off of values in the search for good care and therefore requiring recognition and acknowledgement. To diminish the long-lasting negative impact of the COVID-19 pandemic and moral distress, employers should empathise with the experiences of hospital-based rehabilitation professionals and create conditions for ethical reflection. Our data underline that hospital-based rehabilitation professionals value professional autonomy; hence, creating room for professional autonomy helps them feel needed, connected, and energised. However, the needs of hospital-based rehabilitation professionals may conflict with organisational rules and structures.

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APPENDIX 1 OPERATIONAL DEFINITIONS OF ETHICAL CONCEPTS

Term	Operational definition
Norms	Rules that prescribe which actions are permitted, forbidden, or required [1].
Values	Moral values are lasting matters or convictions that people feel should be strived for in general to realize a just society or lead a good life [1].
Ethical principles	The four principles of medical ethics, formulated by Beauchamp and Childress in 1979, are respect for autonomy, beneficence, non-maleficence, and justice [2]. These mid-level moral norms together form a framework to guide ethical judgment.
Ethical issue, ethical conflict	Ethical issues or conflicts occur when values and norms conflict, or when they no longer seem applicable. These conflicts may occur within a person, between different persons, or there may be disagreement with the rules or structures that guide this person's professional activities [3,4].
Ethical dilemma	An ethical dilemma is a particular type of ethical problem, in which there are two (or more) options for action and whatever the person chooses, a moral wrong is committed [1].
Moral distress	Campbell et al. define moral distress as: "One or more negative self-directed emotions or attitudes that arise in response to one's perceived involvement in a situation that one perceives to be morally undesirable" [5].

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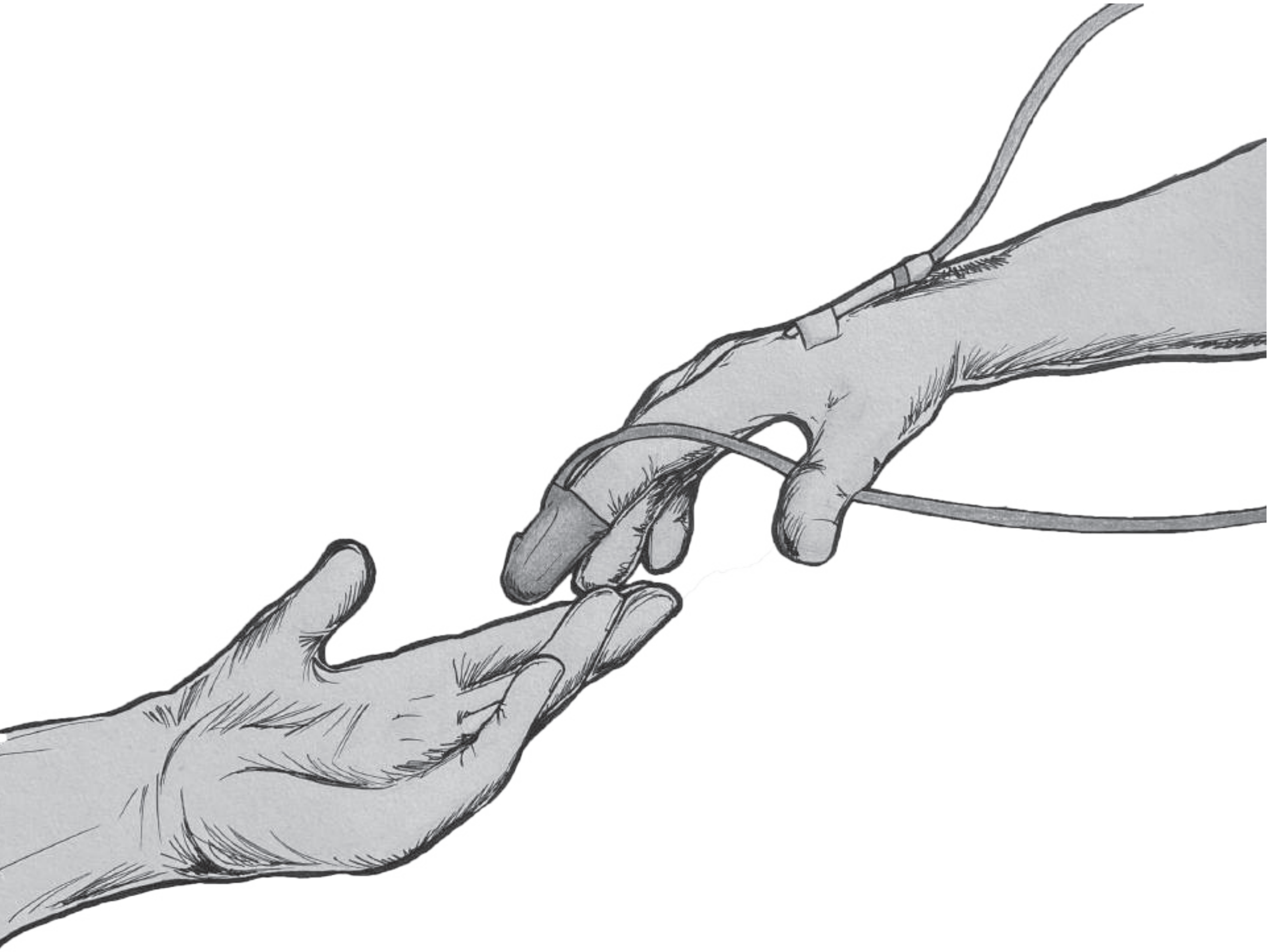
APPENDIX 2 INTERVIEW GUIDE

Topic	Questions
Introduction and start recording	I would like to ask you to answer as comprehensively as possible during the interview. This gives me a picture of your experiences and the meaning you give to them.
Working in the hospital	Can you tell me about your work in the hospital as a dietician/ occupational therapist/physiotherapist/speech-language therapist during the COVID-19 crisis? Prompts: Can you describe a working day? / How was it to work in the hospital? / How was it to be in the hospital?
Working at the COVID-19 ward	How was it to work at the COVID-19 ward? Prompts: Differences to other wards during that time? Differences to normal times? Example? Impressions? Things you missed? Things you could not do? Difficult decisions?
Working at the COVID-19 ICU (when relevant)	Did you work at the COVID-19 ICU? How was it to work at the COVID-19 ICU? Prompts: Differences to the wards during that time? Differences to normal times? Example? Impressions? Things you missed? Things you could not do? Difficult decisions?
Screening, evaluating and testing	How did you screen, evaluate and test patients with COVID-19? Prompts: What actions did you take? Examples? Difficulties? Changes over time?
Treatment	How did you treat patients with COVID-19? Prompts: What treatments? Examples? Difficulties? Changes over time?
Ending treatment and arranging hand-over	How did you end your treatment and arrange a hand-over? Prompts: Which patients received after-care? What was your role? Difficulties? Changes over time?
Personal protection equipment	How was it to work with personal protection equipment? Prompt: Differences to normal? Changes over time? Communication difficulties?
Ethical issues	Can you tell me about possible difficult situations or difficult choices that you had to make during your work? Prompts: Example? Causes? Solutions? How did you feel in these situations? How did you deal with these situations?
Health	How did you experience your own health before and during the crisis? Prompts: Fitness? Insecurities? Work load? Changes over time?
Participant characteristics	What is your gender and age? How many years of experience do you have in this profession?
Closing and stop recording	Would you like to say something in general about your experiences as a rehabilitation professional with patients with COVID-19? Is there a topic or event that has not yet been addressed during the interview?

APPENDIX 3 EXAMPLE THEMATIC PROCESS

Initial noting	Developing emergent theme	Case description (fragment)	Key emergent theme
We were overloaded by the many sick people despite the warnings from Italy and China.	Being overloaded by the number of sick patients.	This physiotherapist worked at the intensive care unit. The virus heavily hit the region and they were overloaded by the large number of sick patients. It was bizarre to see the department full of severely ill and mechanically ventilated patients, oftentimes in prone position. At some point the hospital almost only treated patients with COVID-19.	A disease with great impact
The amount of newly admitted patients and dying patients with COVID-19 really got to me.			
I found it very disturbing to see the ambulances line up in front of the hospital.			
In the intensive care unit we are used to very sick people, but I have never seen so many.			
The helicopter landed several times in the garden that day to transport patients to other hospitals, that was impressive.			



6

Recommendations for hospital-based physical therapists managing patients with COVID-19

A clinical practice guideline

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ABSTRACT

Objective

The COVID-19 pandemic is rapidly evolving and has led to increased numbers of hospitalisations worldwide. Hospitalised patients with COVID-19 experience a variety of symptoms, including fever, muscle pain, tiredness, cough, and difficulty breathing. Elderly people and those with underlying health conditions are considered to be more at risk of developing severe symptoms and have a higher risk of physical deconditioning during their hospital stay. Physiotherapists have an important role in supporting hospitalised patients with COVID-19 but also need to be aware of challenges when treating these patients. In line with international initiatives, this article aims to provide guidance and detailed recommendations for hospital-based physiotherapists managing patients hospitalised with COVID-19 through a national approach in the Netherlands.

Methods

A pragmatic approach was used. A working group conducted a purposive scan of the literature and drafted initial recommendations based on the knowledge of symptoms in patients with COVID-19 and current practice for physiotherapist management for patients hospitalised with lung disease and patients admitted to the intensive care unit. An expert group of hospital-based physiotherapists in the Netherlands provided feedback on the recommendations, which were finalised when consensus was reached among the members of the working group.

Results

The recommendations include safety recommendations, treatment recommendations, discharge recommendations, and staffing recommendations. Treatment recommendations address 2 phases of hospitalisation: when patients are critically ill and admitted to the intensive care unit, and when patients are severely ill and admitted to the COVID ward. Physiotherapy management for patients hospitalised with COVID-19 comprises elements of respiratory support and active mobilisation. Respiratory support includes breathing control, thoracic expansion exercises, airway clearance techniques, and respiratory muscle strength training. Recommendations toward active mobilisation include bed mobility activities, active range-of-motion exercises, active (assisted) limb exercises, activities-of-daily-living training, transfer training, cycle ergometer, pre-gait exercises, and ambulation.

INTRODUCTION

As of publication date, the number of patients with respiratory syndrome caused by coronavirus 2 (SARS-CoV-2), the virus that causes coronavirus disease 2019 (COVID-19), is still increasing rapidly worldwide. Spreading of COVID-19 occurs mainly through respiratory droplets and aerosols produced when an infected person coughs or sneezes [1]. To our knowledge, there is currently no consensus on the period the virus is transmissible to other humans; however, the duration and transmissibility seem to differ between patients with differing severity of illness [2]. Even after resolution of symptoms, individuals might keep shedding the virus [3]. Diagnosis of COVID-19 requires detection of SARS-CoV-2 RNA using a combination of nasopharynx and throat sample [4,5], but SARS-CoV-2 RNA can also be detected in stool and blood [4]. Chest computed tomography images from patients with COVID-19 typically demonstrate bilateral, peripheral ground glass opacities. Unfortunately, this pattern is non-specific and overlaps with other infections; therefore, the diagnostic value of chest computed tomography imaging for COVID-19 may be low [4,5].

Recent data from China and Italy indicate that in 80% of cases COVID-19 infection causes “mild and moderate illness,” approximately 15% of cases develop “severe illness” leading to hospitalisation, and 5% develop “critical illness” requiring ICU treatment [2,4–6]. Hospitalised patients with COVID-19 experience a variety of symptoms, including fever, muscle pain, tiredness, cough, and difficulty breathing [7]. Elderly people and those with underlying health conditions are considered to be more at risk of developing severe symptoms [4] and have a higher risk of physical deconditioning during their hospital stay [8,9]. Physiotherapists have an important role in supporting hospitalised patients through respiratory support and active mobilisation. Physiotherapy management should be tailored to the individual patient’s needs concerning frequency, intensity, type, and timing of the interventions, in particular for those with severe/critical illness, older than 70 years of age, obesity, comorbidity, and other complications [10,11]. Yet, physiotherapists need to be aware of potential challenges when treating patients with COVID-19. In a recent study, an international group of authors described the physiotherapist management for COVID-19 in an acute hospital setting, including workforce planning, screening, delivery of physiotherapist interventions, and personal protective equipment (PPE) [12].

In line with this international study [12] and the consensus statement of Italian respiratory therapists [13], we aim to provide guidance and detailed recommendations for hospital-based physiotherapists managing patients hospitalised with COVID-19 through a national approach in the Netherlands.

SCOPE

This study focuses on adult patients admitted to an (acute) hospital setting due to COVID-19. In general, patients with COVID-19 experience the following signs and symptoms: fever (83%–99%), cough (59%–82%), fatigue (44%–70%), weight loss (40%–84%), shortness of breath (31%–40%), secretion production (28%–33%), and myalgias (11%–35%) [4,6]. Recent studies showed that illness severity can range from mild to critical: [2,4–6]

- Mild to moderate (mild symptoms up to mild pneumonia): 80%
- Severe (dyspnea, hypoxia, or >50% lung involvement on imaging): 15%
- Critical (respiratory failure, shock, or multiorgan system dysfunction): 5%

Critical cases, needing ICU treatment, may show symptoms of Acute Respiratory Distress Syndrome (ARDS) such as lung disease, with widespread inflammation in the lungs [5]. Consolidation lesions also remain at long term and can leave fibrotic changes in the lungs [5]. Furthermore, patients who are critically ill needing ICU treatment are at risk of developing post-intensive care syndrome (PICS), including ICU-acquired weakness (ICU-AW) [13–15]. Mortality among patients admitted to the ICU ranges from 39% to 72% [4].

Health care professionals should be aware that the clinical progression of symptoms might occur 1 week after illness onset [5,13,14]. Important subgroups are elderly people (≥70 years of age) and those with underlying health conditions (e.g., hypertension, diabetes, cardiovascular disease, chronic respiratory disease, and cancer), who are considered to be more at risk of developing severe symptoms [4] but also at risk of physical deconditioning during hospital stay [8,9].

Figure 1 is based on recent literature and shows the flow of patients with COVID-19 with their signs and symptoms before [4,6,7] and during hospital admission [4,5,7–9,13,15,16], the severity classification [2,4–6], and the physiotherapy goals during hospital stay [10–13,17]. These recommendations focus on the physiotherapist management for adult patients with COVID-19 admitted to the (acute) hospital setting. Recommendations contain specific physiotherapy goals concerning respiratory problems and deconditioning, including ICU-AW and PICS. The recommendations are outlined in 2 sections:

- Section 1: Patients who are critically ill with COVID-19 admitted to the ICU.
- Section 2: Patients who are severely ill with COVID-19 admitted to the COVID ward

We used existing international recommendations [12,13] as the basis for further specification and contextualisation. When our recommendations diverge from the international recommendations, we clarified this in the main text and through a separate paragraph with reflections. The recommendations are structured in the following order: safety recommendations, treatment recommendations (specified for different phases of hospitalisation), discharge recommendations, and staffing recommendations.

PRAGMATIC METHODOLOGY

Due to the acute and sudden spreading of COVID-19, the evidence base for optimal treatment for this group of patients is evolving rapidly and new insights are emerging at a similar pace. Nevertheless, clear recommendations for hospital-based physiotherapy management, either based on evidence or best practices, are crucial to support the recovery of patients and safety of health care professionals. These recommendations will be updated periodically based on new evidence and experience and will be made available through the website of the Royal Dutch Society for Physical Therapy and the World Confederation for Physical Therapy.

To cope with this rapidly evolving evidence base, we utilised a pragmatic approach, rather than a formal approach (such as Grading of Recommendations Assessment, Development and Evaluation [GRADE]) [18], to formulate our recommendations. First a working group was installed comprising experts on content (K.F., R.v.O., E.K., N.K., M.S., E.H.) and experts on guideline methodology (F.D., T.H., P.W.). The working group members conducted a purposive scan of the literature and drafted the initial recommendations based on the knowledge of symptoms in patients with COVID-19 and current practice for physiotherapy management in patients hospitalised with lung diseases and in patients admitted to the ICU. Simultaneously, an expert group of hospital-based physiotherapists in the Netherlands (see Acknowledgments) was formed based on the formal and informal networks of the working group. This expert group served as a sounding board group. Recommendations drafted by the working group based on available evidence and best practices were discussed with the expert group. Considerations by the expert group were discussed in the working group. Recommendations were finalised when consensus, in terms of no opposing votes, was reached among the members of the working group.

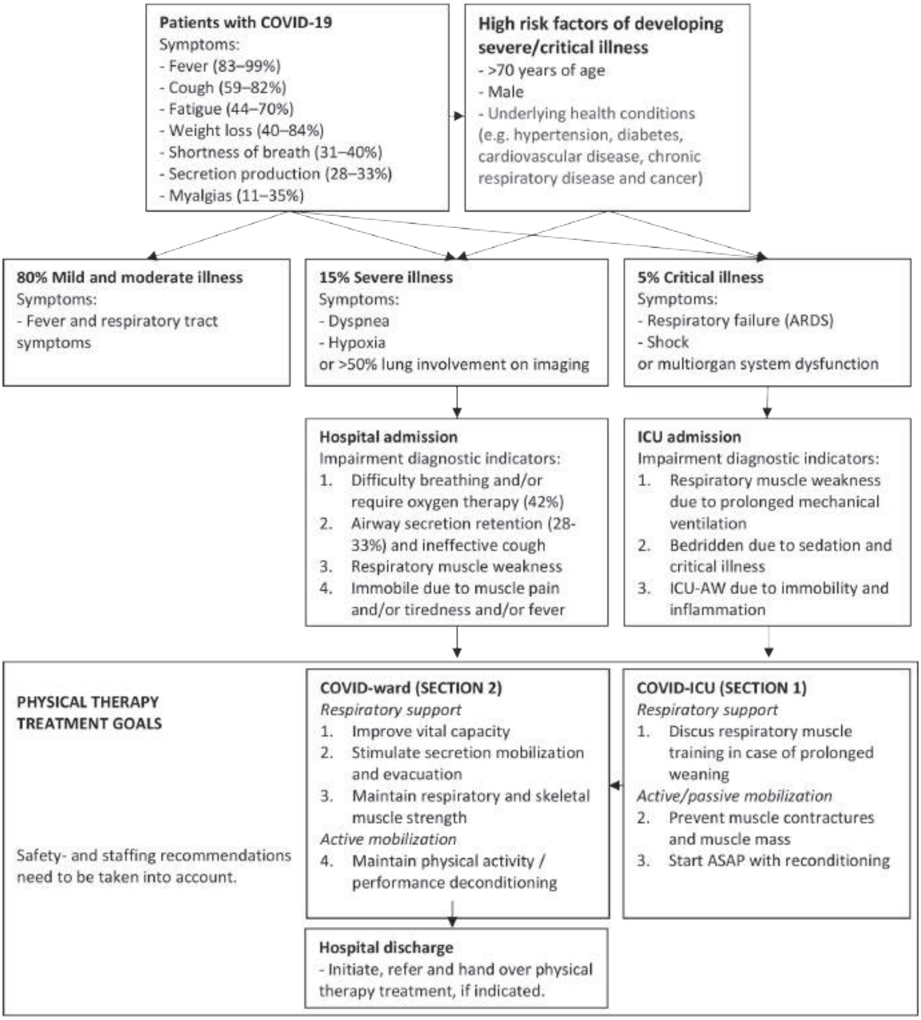

Figure 1. The flow of patients with COVID-19 with their signs and symptoms before [4,6,7] and during hospital admission [4,5,7,8,13,16]; the severity classification [2,4–6] and the physiotherapy goals during hospital stay [10–13,17].

The final recommendations are summarised in Figure 2. We sought and received endorsements for our recommendations from 40 hospital-based physiotherapists from over 20 Dutch hospitals, the Royal Dutch Society for Physical Therapy, the Dutch Association for Hospital-Based Physical Therapists, the Association for Cardiovascular and Respiratory Physical Therapists, and the Dutch Society for Intensive Care Medicine. The authors and consulted experts were all based in the Netherlands; therefore, generalisability to hospital-based physiotherapy settings in other countries, with different health care organisations, different task profiles, and different scope of practice, could be limited.

RECOMMENDATIONS: SAFETY

Respiratory droplets and aerosols may be released from patients during physiotherapist interventions and may cause further spread of the virus. Direct contact between physiotherapists and patients with COVID-19, therefore, should be minimised to avoid risk of virus transmission and reduce usage of scarce PPE. Therefore, we recommend physiotherapists make optimal use of telecommunication and written information material. If direct (face-to-face) contact with patients with COVID-19 is required, physiotherapists should use PPE. Recommended PPE include a gown, gloves, eye protection, and a facemask [4]. Procedures for the use of PPE vary between hospitals; therefore, the use of PPE should be checked locally with hospital officers for hygiene and infection prevention.

Concerning adequate use of PPE, treating physiotherapists should be informed that certain treatment modalities can lead to extra viral exposure. The following procedures can induce the release of droplets and aerosols [12,13,19]:

- Noninvasive assisted ventilation or high-flow nasal oxygen therapy;
- Manual techniques for respiratory support, including compression, which may lead to coughing and secretion mobilisation;
- Secretion mobilisation devices, such as positive expiratory pressure, Flutter Mucus Clearance Device (Allergan Pharmaceutical Company, Dublin, Ireland); Acapella DM & DH Vibratory PEP Therapy System (Smiths Medical Inc, Carlsbad, CA); and high-frequency chest wall oscillation devices;
- Endotracheal suctioning;
- Active mobilisation, which may lead to coughing and secretion mobilisation or disconnection of the mechanical ventilation.

If one of the above mentioned procedures is performed, physiotherapists are recommended to wear a facemask that filters at least 95% of airborne particles (i.e., FFP2 mask, N95 facemasks). Physiotherapists should ensure that they are fully competent in the use of PPE [4]. Safety recommendations need to be taken into account during all steps in physiotherapy management. Benefits of hands-on physiotherapy management should always be weighed against the potential risks of virus transmission.

→ Recommendation: Minimise contact with patients with COVID-19; always consider the benefits of hands-on physiotherapist treatment vs the risks of virus transmission and the use of scarce PPE.

→ Recommendation: Make optimal use of digital and/or written information for the instruction of patients.

Safety recommendations	
Minimise contact with patients with COVID-19, always consider the benefits of hands-on physiotherapy management versus the risks of virus transmission and the use of personal protective equipment.	
Make optimal use of digital and/or written information for the instruction of patients.	
Treatment recommendations	
SECTION 1: Patient is critically ill and admitted to the Intensive Care Unit	
Phase A. Patient is unconscious	Physiotherapy management for respiratory support and active mobilisation is not required due to a lack of therapeutic goals in this phase, the risk of transmission of the virus, and the limited availability of personal protective equipment.
	If contractures are suspected, nurses can consult physiotherapists for advice on passive movements, limb positioning or splinting.
Phase B. Patient is conscious and able to cooperate	Discuss with the multidisciplinary team whether to pragmatically initiate respiratory muscle strengthening in patients with prolonged weaning.
	Stimulate active mobilisation including bed mobility activities. In case safety recommendations for physiotherapy management cannot be met, instruct nurses to combine active mobilisation with their daily care activities.
	Monitor patients' respiratory and hemodynamic functions continuously, when performing active mobilisation.
SECTION 2: Patient is severely ill and admitted to the COVID-ward	
Respiratory support	Use breathing control and thoracic expansion exercises to improve vital capacity.
	Use Active Cycle of Breathing Techniques in patients in need of airway clearance to stimulate secretion mobilisation and evacuation.
	Use inspiratory and expiratory respiratory muscle training in patients recovering from critical illness with suspected respiratory muscle weakness.
Active mobilisation	Use bed mobility activities to improve physical functioning and respiratory functioning.
	Stimulate active mobilisation as much as possible based on patients' needs, preferences and physical functioning.

Discharge recommendations
Initiate, refer, and hand over patients to physiotherapists in primary care practices, rehabilitation clinics, nursing homes or recovery centres in order to continue physiotherapy management, if required.
Staffing recommendations
Deploy physiotherapists with sufficient skills, knowledge and self-confidence in care for severely ill patients at a COVID-19 ward or at the Intensive Care Unit.
Provide psychosocial support for hospital-based physiotherapists.

Figure 2. Summary of recommendations for hospital-based physiotherapists managing patients with COVID-19.

RECOMMENDATIONS: TREATMENT

Physiotherapy management for patients hospitalised with COVID-19 comprises elements of respiratory support and active mobilisation [20,21]. Recommendations toward respiratory support, defined as the “proactive approach to minimise respiratory symptoms during the acute phase of a pulmonary disease,” [22] are presented in detail. In the treatment of patients with COVID-19, respiratory support can consist of breathing control, thoracic expansion exercises, airway clearance techniques, and respiratory muscle strength training. Recommendations toward active mobilisation concern the “proactive approach to support any physical activity where patients assist with the activity using their own strength and control: patients may need assistance from staff or equipment, but they are actively participating in the exercise.”[21]. Examples of active mobilisation are bed mobility activities (e.g., bridging, rolling, lying to sitting), active range-of-motion exercises, active (assisted) limb exercises, activities of daily living (ADL) training, transfer training, cycle ergometer, pre-gait exercises, and ambulation [23].

Section 1: Patient Is Critically Ill and Admitted to ICU

Recommendations for physiotherapy during mechanical ventilation in the ICU depend on the level of consciousness and cooperation of the patient.17 Therefore, the recommendations for physiotherapist management differ between Phase A, where the “patient is unconscious’” (Richmond Agitation and Sedation Score [RASS] < –2 and Standardized 5 Questions [S5Q] < 3; and Phase B, where the “patient is conscious and able to cooperate” (RASS ≥ –2 and S5Q ≥ 3) [17].

Phase A: Patient is unconscious: respiratory support.

Patients with critical illness due to COVID-19 may develop ARDS-like symptoms, requiring admission to the ICU [24]. Initially, the majority of patients are deeply sedated (RASS ≤ –4) and mechanically ventilated in prone position [25]. These patients often receive neuromuscular blocking agents to support mechanical ventilation, as this drug application can improve chest wall compliance, eliminate ventilator dyssynchrony, and reduce intraabdominal pressures [26]. Given the lack of therapeutic goals in this phase, physiotherapist management concerning respiratory support is not recommended. This might be different for physiotherapists outside the Netherlands with other scope of practice concerning respiratory support.

Phase A: Patient is unconscious: active mobilisation.
Patients who are deeply sedated cannot actively participate in mobilisation. Physiotherapy management in this phase focuses on maintaining joint mobility and preventing (soft tissue) contractures. The administering of neuromuscular blocking agents, however, reduces the risk of contractures [27]. Additionally, the evidence base for preventive stretching is limited [28]. Based on these considerations, we think that the risk of transmission of the virus and the limited availability of PPE do not outweigh the benefits of regular joint mobility screening by physiotherapists. When neuromuscular blocking agents are discontinued, the risk for developing contractures increases. If contractures are suspected, nurses can consult physiotherapists for advice on passive movements, limb positioning, or splinting [17].

→ Recommendation: Physiotherapy management for respiratory support and active mobilisation is not required due to a lack of therapeutic goals in this phase, due to the risk of transmission of the virus, and due to the limited availability of PPE.

→ Recommendation: If contractures are suspected, nurses can consult physiotherapists for advice on passive movements, limb positioning, or splinting.

Phase B: Patient is conscious and able to cooperate: respiratory support.
The moment sedation is reduced (RASS ≥ –2) and the patient is conscious and able to cooperate (S5Q ≥ 3), a new phase starts [25]. Normally, this is the phase to start active mobilisation and respiratory support; however, in patients with COVID-19, detachment of the closed mechanical ventilation system circuit should always be avoided due to the risk of virus transmission. Even in the case of weaning from mechanical ventilation, where physiotherapists typically aim to ensure sufficient inspiratory muscle strength [29,30], the risk of virus transmission via droplets or aerosols in using medical assistive testing devices is too high. Therefore, we recommend not detaching the ventilation system for the purpose of respiratory function testing, respiratory muscle training, or breathing exercises [19]. To our knowledge, it remains unclear if both droplets and aerosols are filtered by

disposable bacterial filters [31]. In case of prolonged weaning, patients who fail more than 3 weaning attempts or require more than 7 days of weaning after the first spontaneous breathing trail [32], respiratory muscle training should be discussed in the multidisciplinary team [30]. The team may decide that benefits of respiratory muscle training outweigh the safety risks. In the phase after prolonged (assisted) mechanical ventilation, inspiratory (IMT) and expiratory muscle training can be used to counterbalance the weakness of the respiratory muscles [29,33]. Moreover, additional benefits of strengthening are increased exercise tolerance and cough strength. Usually, noninvasive handheld manometers to assess maximal static inspiratory pressure can help quantify respiratory muscle strength and initiate training [34,35]. Usually, scores lower than 30 cmH2O may indicate a degree of inspiratory muscle weakness that could impact on weaning and recovery [36]. However, the use of these devices is not recommended in patients with COVID-19 due to the increased risk of virus transmission. In this situation, training can be started pragmatically (i.e., without respiratory testing results) using a threshold training device with low resistance (<10 cmH2O) and can be increased on clinical presence, experienced dyspnea, and Borg score for perceived exhaustion [37].

For respiratory muscle strengthening, a combination of both IMT and expiratory muscle training is recommended, as this combination is superior to IMT alone in improving respiratory muscle strength [33]. As respiratory muscle training devices could carry the virus (prolonged), the use of these devices should be discussed with hospital officers for hygiene and infection prevention.

→ Recommendation: Discuss with the multidisciplinary team whether to pragmatically initiate respiratory muscle strengthening in patients with prolonged weaning.

Phase B: Patient is conscious and able to cooperate: active mobilisation.
When patients become conscious and cooperative, active mobilisation can be considered. Active mobilisation should aim to prevent ICU-AW and deconditioning from immobilisation and illness. The Medical Research Council Sum-Score is widely used to diagnose ICU-AW, which is defined as an Medical Research Council Sum-Score < 48 [38]. It is assumed that patients diagnosed with ICU-AW may benefit from active mobilisation also following their ICU admission [39]. These physical activities for patients who are critically ill should be planned and targeted following the evidence-based statement for physiotherapist management in the ICU as much as possible [17]. Patient safety criteria according to Sommers et al [17] for active mobilisation that always need to be considered at the ICU are presented in Figure 3.

Close monitoring of respiratory and hemodynamic functions of patients is crucial to ensure patients' safety [17,21]. As a first step, bed mobility activities can be performed by assisting bridging, rolling, and transferring from supine to sitting [23]. Medical assistive devices (eg, a bed cycle) might be used to support active mobilisation. However, use of these devices should be discussed with hospital officers for hygiene and infection prevention. To evaluate and increase training intensity, frequency, and/or activities, criteria of American College of Sports Medicine guidelines for exercise testing and prescription [40], Modified Borg Dyspnea Scale [37], and/or the evidence-based statement of Sommers et al [17] can be used. Figure 4 shows our expert opinion suggestions for active mobilisation sessions in patients with COVID-19 at the ICU. Ideally, the physiotherapist is the leading health care professional to guide active mobilisation. However, safety recommendations can also be decisive in initiating physiotherapist management. If safety recommendations for health care providers do not warrant direct physiotherapy contact, we recommend instructing nurses to combine active mobilisation with daily care activities. In this case, the physiotherapist has a coaching role.

→ Recommendation: Stimulate active mobilisation including bed mobility activities; in case safety recommendations for physiotherapist management cannot be met, instruct nurses to combine active mobilisation with their daily care activities.

→ Recommendation: Monitor patients' respiratory and hemodynamic functions continuously when performing active mobilisation.

It is recommended to screen every patient on the presence of red flags (contraindications) and relative contra-indications to consider (possible) risks and benefits before and during every physiotherapy treatment session. The criteria mentioned below are (relative) contra-indications for mobilisations out of bed and physical activities of intensive care patients and have to be taken into consideration during the clinical reasoning process. An intensivist need to be consulted in case of a patient showing one of the following conditions before mobilisation/physical activities.

Red Flags (evidence level 1)

Heart rate
- Recent myocardial ischemia
- Heart rate < 40 and > 130 beats/min

Blood pressure
- Mean Arterial Pressure (MAP) < 60 mmHg and > 110 mmHg

Oxygen desaturation
- ≤ 90%

Parameters of ventilation
- Fractional concentration of inspired oxygen (FiO2) ≥ 0.6
- Positive End Expiratory Pressure (PEEP): ≥ 10 cm H2O

Respiratory frequency
- Respiratory frequency > 40 breath/min

Level of consciousness of patient
- Richmond Agitation Sedation Scale (RASS) score: -4, -5, 3, 4

Doses inotropic
- High inotrope doses
  - Dopamine ≥ 10 mcg/kg/min
  - Nor/adrenaline ≥ 0,1 mcg/kg/min

Temperature
- ≥ 38.5°C
- ≤ 36°C

Relative contra-indications (evidence levels 3 and 4)
- Clinical View
  - Decreased level of awareness/consciousness
  - Sweating
  - Abnormal face color
  - Pain
  - Fatigue
- Unstable fractures
- Presence of lines that make mobilisation unsafe.
- Neurological instability: Intra Cranial Pressure (ICP) ≥ 20 cmH2O

Figure 3. Criteria for safety of treatment according to Sommers et al [17]. Level of evidence of the literature and clinical expertise: level 1 = recommendation based on evidence of research of level A1 (systematic review) or at least 2 independent studies of level A2 (randomised controlled trial of good quality and size); level 2 = recommendation based on 1 study of level A2 or at least 2 independent studies of level B (randomised controlled trial of moderate or weak quality or insufficient size, or other comparative studies, e.g., patient controlled and longitudinal cohort studies); level 3 = recommendation based on 1 study of level B or level C (non-comparative studies); level 4 = recommendation based on expert opinion.

Step 1:

Condition: Patient safety criteria should be met throughout the entire session.

- **Bed mobility activities** for example: (assisted) bridging and rolling.
- **(Assisted) exercises while lying supine** such as: cervical rotation, shoulder elevation, biceps flexion, finger flexion and extension, and ankle pumps.
    - Starting with 5 repetitions in 1 set, with progression to 10-15 repetitions in 3 sets.

Step 2:

Conditions: Active mobilisation in supine should be well tolerated and patient safety criteria should be met throughout the entire session.

Termination criteria should be considered with the following *relative* contra-indications: heart rate < 40 and > 130 beats/min, blood pressure (MAP) < 65 and > 110 mmHg, respiratory frequency > 40 breaths per minute, oxygen saturation < 85%, cardiac arrhythmia, and clinical symptoms (decreased level of awareness/consciousness, sweating, abnormal face colour, pain, fatigue, discomfort).

- **Bed mobility exercises** might be increased to (assisted) transferring from supine to sitting.
- **(Assisted) exercised while sitting** such as: cervical flexion and extension, thoracic rotation, weight bearing with arms (to increase postural control), and knee extension.
    - Starting with 5 repetitions in 1 set, with progression to 10-15 repetitions in 3 sets.
- **Passive or active bed cycling for 20 minutes** might also be considered, however, the use of medical assisted devices should also be discussed with hospital officers for hygiene and infection prevention.

Figure 4. Expert opinion suggestions for active mobilisation sessions in patients who are critically ill with COVID-19 in the intensive care unit (ICU), Phase B.

Section 2: Patient Is Severely Ill and Admitted to the COVID Ward

Patients who are severely ill with COVID-19 who require hospitalisation can present with complications such as pneumonia, hypoxemic respiratory failure/ARDS, sepsis and septic shock, cardiomyopathy and arrhythmia, acute kidney injury, and complications from prolonged hospitalisation, including secondary bacterial infections [4]. Because the consequences of the infection impact the respiratory system, one of the goals of physiotherapist management is to optimise respiratory function. Therefore, respiratory support aims to improve breathing control, thoracic expansion, and mobilisation/evacuation of secretion. Active mobilisation aims to increase (or maintain) physical functioning and independence in ADL. These recommendations also apply for patients recovering from critical illness due to COVID-19. Additionally, in patients recovering from critical illness, respiratory muscle strength/endurance training can be continued.

Respiratory support

Respiratory support serves several purposes: to improve vital capacity, to evacuate secretion, and to strengthen respiratory muscle. Techniques and goals are briefly introduced as follows:

- Improvement of vital capacity: To relax the airways and relieve the symptoms of wheezing and tightness that normally occur after coughing or breathlessness (respiratory frequency >25 breath/min, Modified Borg Dyspnea Scale >4), breathing control is used. Breathing control can help if patients with COVID-19 are experiencing shortness of breath, fear, or anxiety or are in a panic [41]. It stimulates tidal volume breathing, with neck and shoulders relaxed and the diaphragm contracting for inspiration. Patients should be encouraged to breathe in through their nose to humidify, warm, and filter the air and to decrease the turbulence of inspired flow [42]. The length of time spent performing breathing control may vary depending on how breathless patients feel [41]. Difficulty of breathing can be evaluated using the Modified Borg Dyspnea Scale [37]. Thoracic expansion exercises are recommended to improve ventilation also in the lower lung fields. This increases the vital capacity and improves lung function, especially if atelectasis is present [43]. Patients should be stimulated to inhale deeply and slowly, combined with chest expansion and shoulder expansion [8]. Extra stimuli can be provided through visual feedback using incentive spirometry [43]. Thoracic hyperinflation should be prevented using adequate monitoring of performance.

- Evacuation of secretion: Early reports indicate that patients with COVID-19 do not show airway mucus hypersecretion [24,44], however, patients with specific comorbidities (e.g., chronic obstructive pulmonary disease, cystic fibrosis, neuromuscular disease) might actually need respiratory support due to airway secretion retention or ineffective cough [13]. In case of clinical signs for presence of airway secretion (by hearing, feeling, or chest x-ray), different techniques and devices can be applied to mobilisation or evacuation. When using these techniques, please keep the safety recommendations in mind. The active cycle of breathing techniques (ACBT) are the preferred procedure. This also includes the breathing control and thoracic expansion exercises, and combines these with huffing and coughing [41,42,45]. Huffing and coughing contribute to the formation of respiratory droplets and aerosols and should be avoided in direct contact with health care professionals. Therefore, these manoeuvres are only recommended in case of airway obstruction due to excess secretions. The multidisciplinary team should carefully evaluate whether airway obstruction is present through medical history taking (e.g., the presence of productive cough), physical examination (e.g., the presence of pulmonary rhonchus), and observations. Telecommunication and/or written instruction material can be used to support the use of ACBT. If patients fail to effectively use ACBT, teaching these techniques under direct supervision of a physiotherapist can be considered.

- Strengthening of respiratory muscle: Patients with COVID-19 might have suspected respiratory muscle weakness caused by prolonged mechanical ventilation during ICU stay. After transfer to the COVID ward, respiratory muscle strengthening can be continued for patients recovering from critical illness according to the recommendations in Section 1, Phase B. Training protocols typically use resistive loads ranging between 30% and 80% of maximal static inspiratory pressure [46]. However, the use of noninvasive handheld manometers is not recommended in patients hospitalised with COVID-19 due to the increased risk of virus transmission. According to Section 1, Phase B, training can be started pragmatically (i.e., without respiratory testing results) using a threshold training device with low resistance (experienced dyspnea, and Borg score for perceived exhaustion [37]. One of the unique advantages of respiratory muscle training is that it can be implemented in shorter intervals (30 breaths, 2 times/d). Training effects from respiratory muscle training have been observed for multiple protocols lasting only 4 weeks [46]. A telehealth or mobile app–based model would allow for the opportunity for real-time remote monitoring of compliance and assessment. Telehealth and home-based models for respiratory muscle training have been studied with similar effects [47].

→ Recommendation: Use breathing control and thoracic expansion exercises to improve vital capacity.

→ Recommendation: Use active cycle of breathing techniques in patients who need airway clearance to stimulate secretion mobilisation and evacuation.

→ Recommendation: Use inspiratory and expiratory respiratory muscle training in patients recovering from critical illness with suspected respiratory muscle weakness.

Active mobilisation

If patients are bedridden and suffering from COVID-19, pulmonary ventilation can be stimulated by bed mobility activities through bridging, rolling, and sitting [11]. If possible, patients might assist with their own strength and control. If needed, staff and equipment can be used to support the activity. A vertical position can be obtained with less support of patients by tilting the bed or using a tilt table. To prevent further deconditioning, patients should be stimulated to be physically active through active mobilisation as much as possible through the hospitalisation period. Physiotherapists can provide specific exercises and training that meet the needs and preferences of patients with COVID-19. Maintaining or improving physical functioning should be executed following common safety recommendations, monitoring, and guidance [17,21]. Based on our expert opinion, at least patient's saturation and heart rate should be monitored before and during active mobilisation due to the low and fluctuating vital capacity of patients with COVID-19. Active mobilisation interventions that need to be considered are bed mobility activities, active range of motion exercises, active (assisted) limb exercises, ADL training, transfer training, cycle ergometer, pre-gait exercises, and ambulation [23]. Sitting and standing are the preferred postures for patients, if possible. To evaluate and increase training intensity, frequency, and/or activities, criteria of American College of Sports Medicine guidelines for exercise testing and prescription [40], Borg score [37], and/or the evidence-based statement of Sommers et al [17] can be used. Figure 5 shows our expert opinion suggestions for active mobilisation sessions in patients with COVID-19 in the COVID ward. Instructions can be provided through telecommunication, flyers, and/or videos when patients are physically and cognitively capable to exercise independently. If patients with COVID-19 are unable to exercise independently, for example as the result of ICU-AW, and safety recommendations by physiotherapists cannot be met, it is recommended to instruct nurses how to support active mobilisation. It is a decision of the interprofessional team of health care professionals to assess benefits of support by a physiotherapist vs the risks of viral transmission and limited use of PPE.

→ Recommendation: Use bed mobility activities to improve physical functioning and respiratory functioning.

→ Recommendation: Stimulate active mobilisation as much as possible based on patients' needs, preferences, and physical functioning.

Step 1:

Condition: Patient safety criteria should be met throughout the entire session.

- **(Assisted) exercises while lying supine** such as: cervical rotation, shoulder elevation, biceps flexion, finger flexion and extension, and ankle pumps.
  - Start with 5 repetitions in 1 set, with progression to 8-10 repetitions in 3 sets.
  - Use criteria of American College of Sports Medicine (ACSM) or moderate intensity:
    - Patients should be able to talk but not sing
    - Perceived exertion 3-4 out of 10, metabolic equivalent tasks level 3-6.

Step 2:

Conditions: Active mobilisation in supine should be well tolerated and patient safety criteria should be met throughout the entire session.

Termination criteria should be considered with the following *relative* contra-indications: heart rate < 40 and > 130 beats/min, blood pressure (MAP) < 65 and > 110 mmHg, respiratory frequency > 40 breaths per minute, oxygen saturation < 85%, cardiac arrhythmia, and clinical symptoms (decreased level of awareness/consciousness, sweating, abnormal face colour, pain, fatigue, discomfort).

- **(Assisted) exercises while sitting**, such as: hip flexion, knee extension, shoulder anteflexion and abduction, and going from sit to stand.
  - Start with 5 repetitions in 1 set, with progression to 8-10 repetitions in 3 sets.
  - Use criteria of American College of Sports Medicine (ACSM) or moderate intensity:
    - Patients should be able to talk but not sing
    - Perceived exertion 3-4 out of 10, metabolic equivalent tasks level 3-6.

Step 3:

Conditions: Active mobilisation while sitting should be well tolerated patient safety criteria should be met throughout the entire session.

Termination criteria should be considered with the following *relative* contra-indications: heart rate < 40 and > 130 beats/min, blood pressure (MAP) < 65 and > 110 mmHg, respiratory frequency > 40 breaths per minute, oxygen saturation < 85%, cardiac arrhythmia, and clinical symptoms (decreased level of awareness/consciousness, sweating, abnormal face colour, pain, fatigue, discomfort).

- **Exercises while standing** such as: hip flexion, knee flexion, shoulder anteflexion, shoulder abduction, stepping in place.
  - Start with 5 repetitions in 1 set, with progression to 8-10 repetitions in 3 sets.
  - Use criteria of American College of Sports Medicine (ACSM) or moderate intensity:
    - Patients should be able to talk but not sing
    - Perceived exertion 3-4 out of 10, metabolic equivalent tasks level 3-6.

- Additional active mobilisation interventions that need to be considered: ADL training (i.e. eating and washing), ambulation, cycle ergometer.

Figure 5. Expert opinion suggestions for active mobilisation sessions in patients who are severely ill with COVID-19 in the COVID ward.

DISCHARGE RECOMMENDATIONS

The hospital-based physiotherapist should screen patients with severe illness due to COVID-19 on whether physiotherapy management should be continued after hospital discharge [48]. Patients may experience loss of function and independence due to hospitalisation and in severe cases develop a PICS, including physical, cognitive, and mental impairments, as a result of their prolonged stay in the ICU [14,49–51]. Based on earlier experiences and knowledge from the SARS epidemic (SARS-CoV) [52], substantial increases can be expected in long-term health care need for patients with COVID-19. Continuing care based on patients' needs after hospital discharge is important. The hospital-based physiotherapist has an important role in warranting continuity of physiotherapist management. When hospital discharge is forthcoming, sufficient hand-over of patient information to physiotherapists working in primary care practices, rehabilitation clinics, nursing homes, or recovery centre is needed. Based on clinical expertise with post-ICU rehabilitation, it is recommended that discharge information should at least contain anamnestic information (medical, psychosocial), patient's clinical question, goals and provided physiotherapy and recovery process, current limitations in functioning and daily life activities, and other involved health care professionals [49–51].

→ Recommendation: Initiate, refer, and hand-over patients to physiotherapists in primary care practices, rehabilitation clinics, nursing homes, or recovery centres to continue physiotherapist management, if required.

STAFFING RECOMMENDATIONS

Professional Expertise

Careful planning is required when physiotherapists are deployed in departments where they are not used to work, such as the ICU. Hospital-based physiotherapists should have adequate knowledge, skills, and attitude in terms of self-confidence to treat patients in isolation, with complex respiratory problems, low physical functioning and with complex acute care needs. The deployment of physiotherapists in a COVID-19 ward or ICU with sufficient skills, knowledge and attitude (self-confidence) and experience in critical care should be optimised [19]. Hospital-based physiotherapists with these skills and knowledge should be tasked with training of less experienced colleagues to provide them with the necessary skills, knowledge and self-confidence for physiotherapist management of patients with COVID-19.

→ Recommendation: Deploy physiotherapists with sufficient skills, knowledge and self-confidence in care for patients who are severely ill at a COVID-19 ward or in the ICU.

Psychosocial Support

The COVID-19 outbreak presents new challenges for health care professionals. Physiotherapists will work intensively with patients who are severely ill, which can lead to mental health distress. It is recommended for managers to plan sufficient recovery time between work shifts of physiotherapists and to let less experienced colleagues carefully be supervised by experienced peers. In these turbulent times, provision of psychosocial support should be considered.

→ Recommendation: Provide psychosocial support for hospital-based physiotherapists.

REFLECTIONS

In this manuscript, we provide detailed recommendations and intervention descriptions for hospital-based physiotherapists managing patients hospitalised with COVID-19 in the Netherlands. Our recommendations are generally in line with the recent international clinical practice recommendations of Thomas et al [12] and the consensus statement of Italian respiratory therapists [13]. However, there are a number of differences in physiotherapist interventions:

- We do not recommend neuromuscular electrical stimulation in bedridden patients with COVID-19 because of the lack of robust evidence of effectiveness, the hygienic aspect, the absence of the equipment in most Dutch hospitals, and our concerns about the feasibility during the hectic care of patients who are severely or critically ill.

- We do not recommend providing certain aspects of respiratory therapy care such as endotracheal suctioning or adjusting oxygen therapy, because these procedures are outside the scope of practice of Dutch physiotherapists. In our recommendations, we focused on physioherapists managing hospitalised patients with COVID-19. However, it is important that recommendations will be provided for the multidisciplinary care after hospital discharge given the physical, cognitive, and mental impairments of patients with COVID-19. In addition, COVID-19 is a novel disease and our understanding of the symptomatology, clinical course, recovery, and transmissibility is emerging. Thus, treatment paradigms need to be evaluated and updated as new information becomes available.

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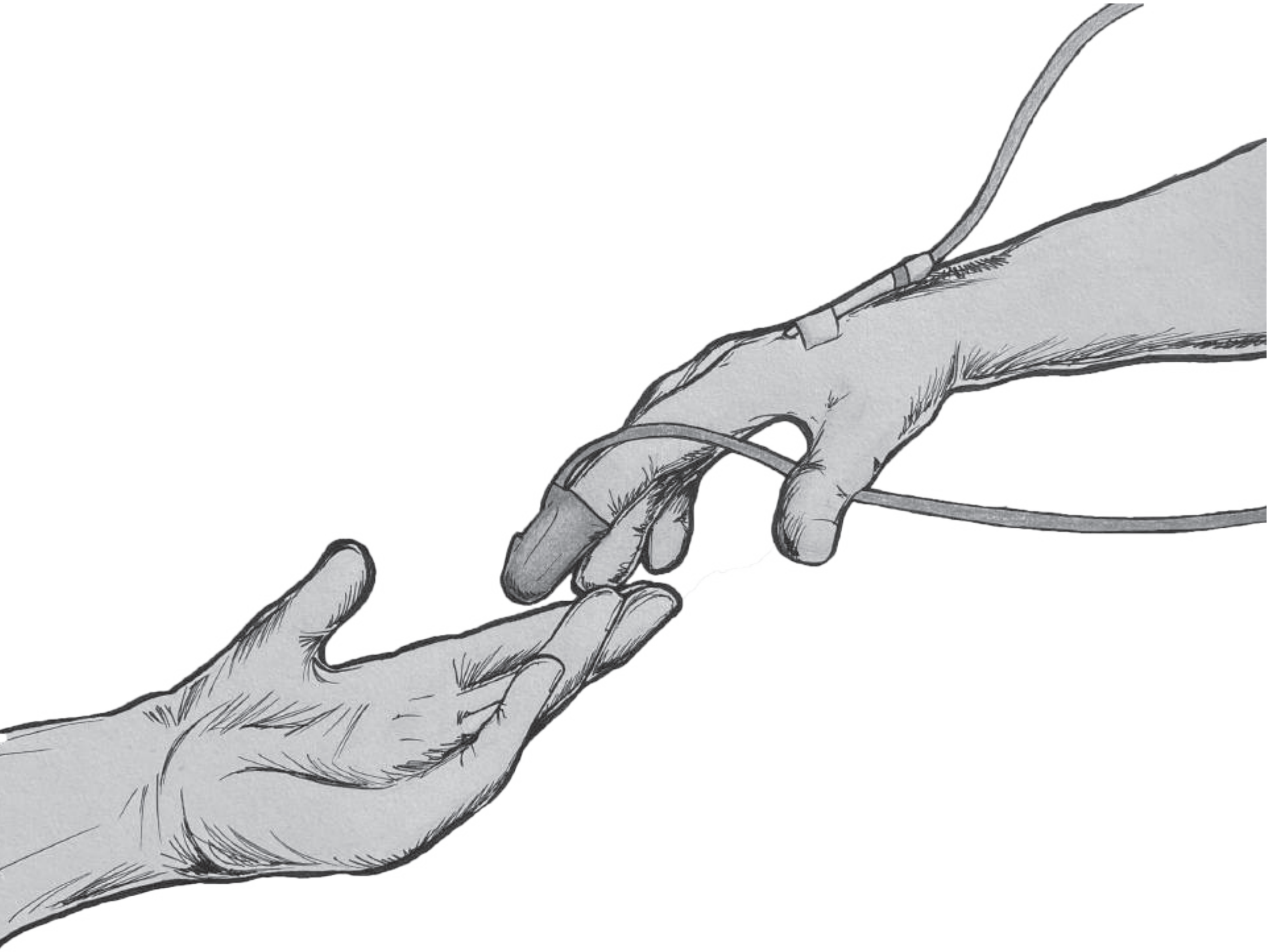

7

General Discussion

"Only a caricature cartesianism would imagine a head compartmentalized away from the disease, talking about the sick body beneath it. The head is tied to that body through pathways that science is only beginning to comprehend, but the general principle is clear: the mind does not rest above the body but is diffused throughout it." [1]

Arthur W. Frank

The overarching aim of this thesis was to uncover lifeworld dimensions in early mobilisation and intensive care unit (ICU) recovery, through first-person experiences collected from patients and healthcare professionals. To achieve this, we used multiple phenomenological approaches. In this general discussion I reflect on the previous research chapters and discuss their findings from a bird's eye view. Firstly, I expound on the main findings. Then, to enable accurate interpretation of the main findings, I discuss the methodological considerations and limitations of the studies included. Lastly, based on the findings discussed, I offer implications for clinical practice, education and research. In boxes 3, 4, and 5, I will outline the clinical examples as introduced in Chapter 1 and consider them from new perspectives.

MAIN FINDINGS

An overview of our main findings is displayed in Table 1. The extent to which the findings are applicable to individual patients can vary as the severity of illness, the duration of ICU-stay, the deconditioning and development of ICU acquired weakness, strongly varies among patients. In general, we assume that the more intense the ICU period then the more our findings are of relevance for these patients. The reflection on the main findings is structured by 'existentials'. According to Van Manen, we can differentiate five existentials (lived body, lived others, lived time, lived space and lived materials), which can be seen as fundamental structures of our lifeworld [2]. To improve clarity regarding the existentials, I will introduce them below.

The role of the **body** in experience is widely acknowledged by phenomenological thinkers [3]. As we are bodily situated beings, our bodies provide a zero-point for our experiences [4]. Our bodies are in continuous relation with the world through our kinaesthetic, sensory, visceral and 'felt sense' capacities [5]. The body can be perceived as a thing, 'a living body (*Körper*)', but also as lived through, 'a lived body (*Leib*)' [3].

Humans are not alone in the world, they live together with **others**, and are social in nature [6]. Lived others concerns the interpersonal world filled with relationships [7]. Examples of feelings that concern the lived others are friendship, love, a sense of belonging and community, but also dedication, sacrifice or loneliness [2]. Lived others can humanise or dehumanise us, such as through kindness or violence [7].

Lived **time** is the subjective or felt time as opposed to chronological time or clock time [8]. Dependent on our mood, time can pass by slowly when we are bored or anxious or can fly by when we enjoy ourselves [8]. The way we experience time is largely impacted by our wishes, plans and the goals we strive for in life [2]. A person's lived time is constituted by the past, present, and future [8]. In contrast to continuous time, we can also have the sense of the 'right timing' or 'right moment' [9].

Lived **space** is defined as felt space [10]. It does not concern the mathematical space, the length, height and depth dimensions of space [8]. Instead, lived space refers to the world or landscape in which human beings move and where they, for example, feel safe and by themselves (home), or feel small and impressed (cathedral) [2].

In his later work Van Manen added a fifth existential called lived **materials** [2]. Lived materials concern our experience of the material things around us, for instance books, fruit or animals [11]. Things can be extensions of our bodies and minds. They can be experienced as intimate or as alien [2]. Things, including technological applications, are not neutral. They have agency just as humans do, and therefore we can experience the moral force they exert on our lives [2]. In our findings, the lived space and lived materials are both strongly influenced by ICU technology and therefore I will discuss them in combination.

The five existentials can be differentiated but not separated. Together they form an intricate unity which we call the lifeworld. In research, we can temporarily study the existentials in their differentiated aspects, while realising that one existential always calls for the other aspects [8].

In order to clarify terms and concepts used in this chapter, I have outlined operational definitions in Box 1. Many of these terms and concepts relate to embodiment theory as developed by Maurice Merleau-Ponty. In Box 2, I give a short description how his embodiment theory contributed to the shift from a substantial to a relational view on the body and how it has been built upon by more recent theories.

Box 1. Operational definitions

- Agency: “The capability and freedom to exercise choice and opportunity for change” [13].

- Bodily dialogue: “One’s corporeality is ‘communicable’ or ‘participable’, which means that bodily subjects are originally capable of positioning their experiences in relation with others’. […] Our bodily capacity for intercorporeal transposition allows us to learn to execute never before performed bodily actions through our perceptions of others’ execution of such actions. In a bodily interaction process so understood, therapists use their own bodies, environmental elements and relevant working aids to organise learning situations tailored to patients’ precise needs” [14].

- Bodily knowledge: A noncognitive knowing that guides much of our daily doing and acting. [2]. “Merleau-Ponty emphasises the bodily, prethematic way of understanding, which is prior and basic to intellectual interpretation and explanation. This prereflexive understanding has its place in the context of operational [bodily] intentionality. Children have learnt things through and in their bodies before they are able to reflect on what they have learnt” [15]

- Bodily intentionality: A processual awareness of what ‘I can’ (or cannot) practically do within a situation, as opposed to an act of ‘I think that’ an object has such and such properties [14].

- Embodiment: “A lens through which physiotherapists might view their approach to practice. At its heart, embodiment emphasises an orientation towards the whole person (an attitude towards the full richness of human life), and a rejection of singular, reductionistic views of the body common to the biomedical sciences. Embodiment is about respecting diversity, eclecticism, deviation, and difference, and having an inclusive attitude to the ways people view their own embodiment” [16].

- Embodiment theory: “For Merleau-Ponty the original human relation to the world is a relation of perception. This perception takes place at a primal, corporeal, and preconscious level. The body-subject is already interlaced with the flesh of the world before having reflective knowledge of it. Or, to say it differently, our knowledge of the world—of others and things—is corporeal, rather than intellectual. We know the world bodily and through our embodied actions” [2].

- Embodied cognition: “A theory or approach in cognitive science that emphasises the role of embodiment (i.e. a wide range of bodily processes, including sensory-motor and affective processes) in cognition” [13].

- Empathy: In the literature many characterisations of empathy are available often distinguishing cognitive and affective empathy [17]. For this thesis I will not separate the two and define empathy as: “The ability to take on the perspective of another and as a result have similar feelings (and perhaps thoughts)” [18]. In line with this definition, in this thesis perspective-taking and empathising are considered the same.

- Enaction: “A dynamic process (or coupling) between a cognitive organism/agent and its environment. The agent actively participates in the generation of meaning through entering an active embodied engagement with the environment or process of interaction with other people” [13].

- Enactivism: “Enactivists think that a living being constitutes a system of interrelated processes that continually interact with its surroundings to maintain its unity and provide the necessary energetic and material resources. Consequently, enactivists understand sensorimotor actions as relational phenomena” [14].

- Intercorporeality: Concerning Merleau-Ponty “we do not have to put in an effort to be empathic, to understand what she/he/they feel: this is immediately expressed in the bodily expressions and gestures themselves” [3].

- Pre-reflective experience: “The way a subject or agent experiences things (including one’s body) without (or prior to) thinking or reflecting about it” [13].

- Technological mediation: “Technologies, when they are used, help to shape the relations between human beings and the world. Rather approaching technologies as material objects opposed to human subjects, or as mere extensions of human beings, it sees them as mediators of human-world relations. Mediation theory is rooted in the ‘post-phenomenological’ approach in philosophy of technology, which was founded by Don Ihde” [19].

Box 2. From a substantial to a relational view on the body

Physiotherapists are specialists in the analysis, promotion, and support of human movement. They have profound knowledge of human anatomy, physiology and biomechanics. Working from the International Classification of Functioning and the biopsychosocial model they will typically say that they are well equipped for their tasks. However, human movement can be constrained by many more factors (for instance cultural, emotional, environmental, governmental or social factors) [16]. The profession could benefit from a critical stance towards the dominant body-as-machine thinking [13, 16, 20]. The philosopher René Descartes (1596-1650) is often named as the person who introduced a mechanistic conception of the world. This idea was reinforced by successes in physics, for instance with the discovery of physical laws by Isaac Newton (1643-1727), who assumed that the world could 'substantially' be explained with small solid, isolated parts that mechanically worked with each other [21]. The dominance of the natural sciences had a large impact on healthcare, and medicine adopted an objectivated and mechanised view of the body [22]. This 'substantial' objective mechanised view on the body has major implications. Machines are passive instruments, and have no interaction with the outside world, which means that they can be studied in isolation [23]. Moreover, movements are seen as mechanical responses to a stimulus from inside or outside the body [21]. In contrast, Merleau-Ponty described the body not as a mechanical object, but primarily as a body-subject [3]. This body-subject cannot be separated from the world as it is in the world and toward the world, captured in the concept of bodily intentionality [3]. The philosophy of Merleau-Ponty has had a great influence on the cognitive sciences but also on the movement sciences. Examples of scientific streams building on his theory are James Gibson's 'ecological psychology' [24, 25], 'enactivism' [3, 26], 'radical enactivism' [27], 'embodied cognition' [28] and 'radical embodied cognitive science' [29]. These different streams bear different nuances, but they all acknowledge that the body plays a fundamental role in our conscious life, including in our cognition. Another commonality is that they all reject the idea of internal representation: the idea of an outside world, which is filtered through the senses and then represented in an inside image. Instead, they emphasise the inseparability of perception and action: body and world act on each other. Although perhaps counterintuitive, perception is an active process as it is something that one does, instead of something that one has [30]. Information is not passively imposed but actively acquired. Environmental and corporeal processes should therefore not be considered as existing in and of themselves but rather as relational phenomena [14]. The relational view entails a shift from objects to relationships, and has led several authors to describe an embodied-enactive relational approach of physiotherapy [13, 14, 31].

Table 1. Overview of main findings structured according to the existentials as described by Van Manen [2]. Some findings are related to stages in ICU recovery (crisis, turning point, normalisation, and post-discharge) as described by Jensen et al. [12].

Lived body	Lived others
• Critically ill patients experience their lived body as unable (*crisis*) • Patients' lived body is empowered through 'I can' experiences and caring actions (*normalisation*) • After hospital discharge, patients experience their lived body as changed for life (*post-discharge*)	• Critically ill patients experience an essential need for human contact • Rehabilitation professionals empathise with their patients and wish to provide human-centred care • Physiotherapists can help patients rehabilitate from critical illness through bodily communication
Lived time	**Lived space and lived materials**
• Critically ill patients often must wait, tolerate, and endure the situation and can feel that time is passing by slowly (*crisis*) • Patients typically experience a turning point in recovery (*turning point*) • When patients take steps in recovery, a new path opens up for them, allowing patients to look forward and have hope for recovery (*normalisation / post-discharge*)	• Critically ill patients experience alienation and long for 'homelikeness' • Critically ill patients experience restriction and long for freedom • These feelings were amplified by the COVID-19 isolation precautions • Critically ill patients have paradoxical experiences concerning ICU technology, with it being both distressing and providing a sense of comfort and safety

Lived body

After waking up in the ICU, at some point patients will start to be aware of their illness and weakness **(Chapter 2).** They experience their body as intolerable, alienated, powerless, dependent, restricted and muted **(Chapter 3).** They feel like they are waking up in a different body, a body that is not theirs **(Chapter 4)**. When combining these findings, we can see that critically ill patients come from a situation in which their lived body is unable. Patients typically express this by saying "I couldn't do anything" **(Chapters 2, 3, and 4).** In this experience of inability, we recognise the 'I cannot' from Merleau-Ponty. For Merleau-Ponty we fundamentally *are* our bodies, as opposed to being consciousnesses that inhabit and *have* bodies [32]. Consciousness to Merleau-Ponty is not an abstract 'I think that', but it is in the world, and it is a space in which we can act. Intentionality for Merleau-Ponty is bodily intentionality [14, 33, 34]. Actions are intentional in the sense that they are directed at some goal or project [35]. Merleau-Ponty speaks of a processual awareness of what 'I can' practically do within a situation [14, 36]. Normally the body does not stand out as a thematic object of experience, but instead remains in the background [37]. In contrast, illness, pain and impairments draw our consciousness towards the body, disrupt the attention towards our goals and actions, and therefore reduce our 'I can' [38]. Moreover, Illness can cause a shift from a spontaneous 'I can' to an unfamiliar 'I cannot' [3, 39, 40]. The 'I cannot', in this case the critically ill patients' inability, was earlier described in literature as patients experiencing 'limited possibilities to act' [41]. Because the 'I can' and 'I cannot' are pre-reflective in nature, a cognitive approach does not do justice to the impaired bodily intentionality. Therefore, when mobilising these patients we would propose to withhold mechanical tasks like "can you extend your knee" for example.

Instead, our findings imply that we should take patients into situations where they are able to re-discover their bodily abilities (**Chapters 2, 3 and 4**). For instance, during hydrotherapy, which seemed a strong way to empower patients **(Chapter 2).** We could say that these actions have a positive influence on both physical and mental states. However, when we stay with the embodiment theory of Merleau-Ponty and avoid mind-body dualism, we see that the lived body is empowered through 'I can' experiences and caring actions. We found that these 'I can' experiences strengthen patients' belief in recovery and bring a lot of energy. Being able to initiate and engage in activities, for instance taking care of personal hygiene, helps patients experience a sense of normalisation and self-confidence **(Chapter 2, 3 and 4)**. Coming from a lived body that is restricted, powerless, dependent and muted (**Chapter 3**), the 'I can' experiences can make patients feel liberated, increasingly independent and experience an improved sense of agency. This increased sense of agency and confidence appear crucial in ICU recovery [42, 43]. To optimise the sense of agency, active exercise is preferred over passive treatments [44]. Haughdahl et al. described this as: "in a way you have to pull them out of that [passive] state" [45]. Söderberg et al. described this as "bringing patients from fear to fight" [42]. We argue that therapists should strive to facilitate 'I can' experiences in this process of activating patients. The body itself has to grasp, to catch or to understand movement to be able to perform it [31]. Bodily knowledge should be awakened not solely by cognitively advising patients how to move their bodies, but also by bringing patients into situations in which they can pre-reflexively experience their bodies and bodily abilities **(Chapters 2,3 and 4).** This process of normalisation starts in the ICU and proceeds after transfer to the nursing ward and after discharge home.

Recovery from critical illness continues long after hospital discharge. We found that patients experience their lived body as changed for life, including experiences of an unhomelike body, an alienated body and a remembering body **(Chapters 3 and 4).** Patients struggle to return to their ordinary life. They experience difficulties in performing everyday activities after intensive care which affects their understanding of themselves, their families and their ability to resume their pre-ICU life [46]. They want to return to the familiar situation, back to the old, balanced, bodily self. Patients long for health and 'homelikeness' **(Chapter 4).** 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 their now altered situation **(Chapter 4).** This is in line with a recent study defining ICU survivorship as: "a dynamic process which starts with the survival of a critical illness and incorporates changes in self, biography, and identity based on the individual patients' experiences of critical illness and their families" [47]. These changes are captured in the process of 'moving on': not striving to gain back the old life, but for a new sense of normality [47]. Getting used to long-lasting physical impairments can be seen as a process where the body is placed back to the background, and where the impairments are 'incorporated' [38].

Lived others

Critically ill patients experience an essential need for human contact. They long to be in touch with their close relatives **(Chapters 2, 3 and 4**). It is highly appreciated when there is the possibility for family members to join in during hydrotherapy **(Chapter 2).** However, for patients with COVID-19, contact with their loved ones was often restricted due to isolation policies. Patients tried to deal with these restrictions using telecommunication and seeing each other from a distance or behind glass **(Chapter 4**). We know from the literature that contact with close relatives is emphasised as crucial to endure and survive critical illness [48]. Patients can feel an alienating isolation when experiencing fear and loneliness [49]. In contrast, patients feel secure when they have a loved one close by. Our findings also imply that contact with attending staff makes a tremendous difference to patients' lived experiences. Patients typically look for connection and contact with the healthcare professionals and appreciate when they are caring and attentive. Even when the COVID-19 regulations required healthcare professionals to be fully covered, patients were still able to recognise them (**Chapter 4**). Patients value a judicious approach, with caregivers not showing any negative signals or signs of disgust when caring for them. When patients experience respect and interpersonal interaction it enables recovery and a feeling of being empowered **(Chapter 3**). In vulnerable and helpless situations every small opportunity to participate in care makes a huge difference to patients' sense of autonomy. Patients are reliant on others for their progression and need to be challenged **(Chapters 3 and 4).** These findings are in line with many studies emphasising the importance of ICU healthcare professionals to be competent, caring, respectful, nurturing and vigilant [48, 50-54].

In **Chapter 5** we found that rehabilitation professionals empathise with their patients and wish to provide human-centred care. However, during the first wave of COVID-19 pandemic, this was oftentimes impossible **(Chapter 5)**. Despite the difficult conditions and isolation precautions, rehabilitation professionals sought ways to remain human, in line with their fundamental attitudes to care for people and engage in human interactions. We found that rehabilitation professionals empathised with the patients' feelings and found it difficult to see them fearful or panicking, lonely or losing their dignity **(Chapter 5)**. They blocked their emotions and took up a detached and robotic mode while taking care of the patients' bodies. In some situations, the rehabilitation professionals had to treat patients' bodies in an instrumental way. This came with feelings of guilt towards their patients because they did not address their personhood **(Chapter 5)**. In the literature it is acknowledged that healthcare professionals can experience moral distress when they feel that they cannot live up to their own standards [55]. Moreover, healthcare professionals can have ambiguous attitudes towards dealing with patients' bodies [56]. They need to find a balance between being empathic and being defensive. Empathy is typically supposed to be a positive quality because it benefits the communication and the relation between patient and healthcare professional. However, empathy can also have negative effects and be a burden for healthcare professionals as they can become emotionally distressed [57].

Physiotherapists can help patients rehabilitate from critical illness through bodily communication. By passive movements, assisted movements, and assisted active mobilisation patients regain their tactile senses, regain control over their bodies and rediscover their body **(Chapter 3 and 4)**. When trying new mobilising actions, patients can be fearful and need the therapist to stay close to provide the necessary support and safety **(Chapter 4)**. Patients can feel a difference between healthcare professionals in handling and touch **(Chapter 4)**. Touch can be experienced as transgressive but also as caring and empowering **(Chapter 3)** and patients can sense when healthcare professionals are indifferent, and they may feel treated instrumentally. However, in a caring relationship patients experience touch as comforting, calming and relaxing. We found that patients feel respected when they are confirmed as human beings, when their autonomy is acknowledged and when professionals do not do things without asking first **(Chapters 3 and 4)**. It is well described in the literature that communication and dialogue, both verbal and tactile, play a central role in physiotherapy [58, 59]. Through hands-on interactions, therapists can feel and incorporate the patients' posture and way of moving, and at the same time patients can experience the therapists' touch and movement facilitation [13]. Through touch and movements, physiotherapists can invite their patients to participate in a silent, moving, touching collaborative dance [58]. In their paper about ‘phenomenological physiotherapy’ Halak and Kriz also used this dance metaphor and described empathy between physiotherapists’ and patients’ bodily intentionalities as an open-ended bodily dialogue [14].

Lived time

When patients wake up in the ICU, they struggle to process the days/weeks that passed by whilst they were unconscious or delirious. There is little daylight, and patients cannot tell the day and time **(Chapter 4).** It is well known that patients can have a memory gap concerning their sedation period and can be disoriented in time [60]. This was also described as a biographical disruption, reducing the patients’ sense of coherence [12, 61], which has a strong impact on the ICU period but also on the recovery period. When awake, patients want to be self-sufficient, however, due to their weakness, they are dependent on healthcare professionals for even the simplest activities in daily life **(Chapter 3 and 4)**. Often, patients must wait, tolerate and endure the situation and time passes by slowly (**Chapters 3 and 4**). Critically ill patients worry about the future. They have thoughts like: ‘will I survive?’, ‘how will I recover’? and ‘how long will this take’? (**Chapter 4**).

We found that critically ill patients at some point have the experience of a turning point. Small changes in posture or movement are experienced as huge steps forward and can be a turning point in the recovery of critically ill patients (**Chapters 2, 3, and 4**). When patients become aware that they can actively move, for instance during hydrotherapy **(Chapter 2)**, a new time stage is introduced where they can re-discover their bodily abilities **(Chapter 3).** Patients can feel liberated, empowered and gain a new perspective on their life, daring to look forward. These experiences can be transformative in character including feelings of rebirth and an increase in willpower to get back to life (**Chapters 2, 3, and 4**). As inner strength and willpower are essential to endure and survive critical illnesses [62, 63], these experiences could be lifesaving.

Making steps in recovery allows patients to look forward and to have hope for recovery. In the discovery of their bodily abilities patients dare to set goals and ‘begin to have a future’ **(Chapters 3 and 4).** This is in line with other lifeworld studies among ICU patients describing that at some point patients can experience a future orientation and a wanting to recover [49]. When reflecting on their recovery process patients typically structure their memories around mobilising milestones and changes of scenery. For instance, the first time sitting up, or the first time walking are important milestones mentioned by patients **(Chapters 3 and 4**). Also changes of scenery, like the transfer from the ICU to the ward, or hospital discharge, make important orientation points for patients. Transfers to other wards have been linked with progress and have meant patients making improvement [48].

Lived space and lived materials

We found that critically ill patients experience alienation **(Chapter 3 and 4**). During the COVID-19 pandemic, the hospital rooms were especially unrecognisable due to the isolation precautions. There was no personalisation with photos or anything similar, and the people walking into the rooms were fully dressed in personal protection equipment making them look like 'martians' **(Chapter 4).** An altered experience of materials was seen as pencils, mobile phones and tableware seemed much heavier than before and patients were unable to handle these objects like they used to **(Chapters 3 and 4**). In this alienation patients long for 'homelikeness', a space where they can feel protected and in balance **(Chapter 4**). In the literature concerning the phenomenology of illness, feelings of alienation have been extensively described [64]. The hospital context has also been described as alien, in contrast to the home situation which represents familiarity, protection and safety [65]. Illness was called 'unhomelike being-in-the world' by Svenaeus [66], and was previously related to the ICU context [49]. The ICU environment has been acknowledged to negatively impact the well-being of both ICU patients [67] and healthcare professionals [68, 69].

Alongside alienation, we found that patients in the ICU can feel restricted or even imprisoned **(Chapters 3 and 4)**. These feelings were amplified by the isolation precautions for COVID-19. Patients admitted to the ICU with COVID-19 were not allowed to leave the room and the doors had to stay closed. The isolation precautions came with feelings of loneliness and a sense of being locked up. After transfer to the nursing wards or rehabilitation facilities, isolation measures were still being applied **(Chapter 4)**. When patients could be discharged home, this meant that patients were liberated from quarantine, which was a great relief **(Chapter 4**). Liberation seems like a strong word but is not uncommon to use in the field of ICU medicine. For instance, we know the ICU liberation bundle, which aims to liberate patients from the harmful effects of ICU stay [70, 71]. According to Merleau-Ponty, our relation to our environment is not to think about it, but to move and act in it. The 'I can' is anchored in the relation between body and environment. The space and materials, therefore, have a strong influence on the extent to which patients experience 'I can'. Therefore, physiotherapists should account for a living body's relationship with its environment [14]. Knowing that the ICU environment adds to feelings of 'spatial imprisonment' [49], physiotherapists should take efforts to adjust the environment to create a more inviting and movement-friendly setting.

An important aspect of the ICU environment is the present medical technology. In **Chapter 3** we found paradoxical experiences concerning ICU technology, with it being both distressing and providing a sense of comfort and safety. Technology is known to have a large impact on our lifeworld. In his book 'Technology and the lifeworld', the philosopher Don Ihde presents what he calls post-phenomenology [72, 73]. Referring to the insights of phenomenology, which emphasised the direct relation between human and world, post-phenomenologists emphasise that technologies actively mediate how the world becomes present to us [72]. It is not the medical technology that deprives patients of their individuality, subjectivity and dignity but instead it is the careless use of technique and the technological attitude adopted by healthcare professionals that causes these problems [74]. ICU technology has the potential to dominate healthcare professionals' practice [75] and therefore these professionals should be conscious and reflective towards this risk. They should know when to heighten the importance of the objective and measurable dimensions provided by technology, and when to magnify the patients' lived experiences [74].

METHODOLOGICAL CONSIDERATIONS

This thesis includes three qualitative interview studies **(Chapters 2, 4 and 5),** one meta-ethnographic synthesis of qualitative studies (**Chapter 3**) and one clinical practice guideline using a pragmatic guideline development approach, including a literature review and a consensus procedure (**Chapter 6**). A large part of this thesis concerns qualitative research projects. Qualitative research has different features than quantitative research. Qualitative research uses inductive reasoning to build theory and explore the meaning of phenomena and quantitative research uses deductive reasoning and has the goal to test theory [76]. Some will say that qualitative research is therefore less reliable than quantitative research. I would say that it depends on the research question as to whether a quantitative or qualitative approach is better suitable. The research topics in **Chapters 2, 4 and 5** concerned, at that time, new phenomena: hydrotherapy with mechanically ventilated patients **(Chapter 2)**, recovery from COVID-19-associated ICUAW **(Chapter 4)** and working as hospital-based rehabilitation professional during the COVID-19 crisis **(Chapter 5).** The novelty of the research topic, in combination with the explorative nature of the research questions, warranted a qualitative research approach. Furthermore, the questions were directed to the participants' first-person perspective and therefore a phenomenological approach was also appropriate (**Chapters 2,4 and 5**).

Choosing a well-defined methodology is helpful in data collection and data analysis and could result in richer findings [77]. Yet, to date there is no consensus on an optimal methodology for empirical phenomenological studies [14]. In **Chapter 2** we described to take a Husserlian approach, but in hindsight we could have chosen a more specific phenomenological approach. In **Chapter 4** we followed the phenomenology of practice as described by Van Manen [2] and in **Chapter 5** we followed interpretative phenomenological analysis as described by Smith [78]. Both methods are frequently used in healthcare research, however, they have been criticised for being inconsistent in their methodology and not being sufficiently rooted in phenomenological philosophy [79, 80]. We agree with these critics that phenomenology methodology is not always specific enough. Especially in the later phases of the analysis, where one starts to interpret and formulate the themes, we sought ways to enhance the rigour of the process and the credibility of our findings. For the data analysis in **Chapters 4 and 5** we chose to include consensus meetings with the multidisciplinary author group. Both contributing authors, who independently analysed the data, presented their findings and ideas to the group before these were then discussed and clarified. In this way we organised our own critical questioning. Whilst this might not appear to be efficient, and indeed these meetings and preparations were time-intensive, we find that it enriched our analysis, it enhanced all authors' familiarity with the data, and increased trustworthiness of the findings. We had satisfying experiences with this method and would advocate other researchers to use this.

Another methodological limitation of our phenomenological studies is the lack of data triangulation **(Chapters 2, 4 and 5)**. In order to optimally capture lived body experiences, in-depth interviewing should ideally be combined with participant observations. Especially when studying lived body experiences, future research should add other data collection methods to complement the verbal accounts. For example, participant observation, shadowing, 'walking with' exercises or video recording could be used to collect nonverbal information about bodily movement and gestures [81]. However, for **Chapters 4 and 5** this was not an option as they were performed during the COVID-19 pandemic and there was high risk of virus transmission and a shortage of personal protective equipment. Therefore, the interviews for **Chapter 4 and 5** had to be performed through video calls. In theory, video calling restricts the richness of the interviews because it could limit rapport between the interviewer and participant, it hampers nonverbal communication and bodily resonance, and the researcher is not able to visually assess the participant's environment and collect contextual data [82, 83]. Though, video calling is accessible, it lowers the barrier for study participation, and recent studies show that in-person interviews are only marginally superior to video calls [84, 85].

A final methodological consideration concerns the profundity to which all lifeworld dimensions were addressed in this thesis. In hindsight, in the empirical phenomenological studies (**Chapters 2, 4 and 5**), not all existentials might have been explored in equal depth. Being a physiotherapist, I might have been more sensitive towards lived body experiences than the lived space experiences, for example. Subsequently, the lived body experiences may provide the most points of engagements for physiotherapists and are therefore strongly represented in the implications section.

IMPLICATIONS

The lifeworld dimensions found in this thesis bear important implications for healthcare professionals working with patients in the ICU and beyond. Here, I distinguish clinical, educational and research implications. The bullet points listed are aimed towards physiotherapists specifically, however they may also be applicable to other healthcare professionals.

Clinical

- Physiotherapists should be aware of the different ways in which patients can experience their body. Using questions like ‘How do you feel?’ or ‘How does your body feel?’ should be part of the clinical routine. A trained and embodied listener will hear many lived body experiences and will know how to follow up on these expressions. When physiotherapists make room for these conversations, they can help patients re-discover their (lived) body and build a trusting relationship.

- Physiotherapists should be sensitive to patients’ bodily expressions including tone, posture and habitual movements. As we do not usually reflect on and describe our own movements, physiotherapists should remark non-verbal ‘embodied narratives’, expressions of the patients lived body. Especially in the ICU, the patient’s first-person perspective might not be easy or possible to communicate through words, but can be communicated through the body [13]. By capturing the cues, signs and symptoms of the patient, the physiotherapist can focus on the patients’ needs and coordinate and facilitate them in optimal form [13].

- Physiotherapists should be aware that patients can feel so weak that they are overwhelmed by the idea of mobilising. Patients can feel misunderstood and frustrated. They often feel exhausted and fear an increase of pain and shortness of breath when mobilising. They can be anxious to fall or to dislocate important lines or the endotracheal tube. Furthermore, they often have no control over their body and must fully trust the healthcare professionals. When patients are informed about the importance of mobilisation, when they have a say in the duration and timing of early mobilisation and when the agreements are lived up to, they can be convinced to cooperate [86, 87].

- Physiotherapists should empower patients through body experiences. When the lived body is unable, ‘simple mechanical’ commands are often misplaced. In a way it is unfair to ask these patients rationally to help and cooperate with the mobilisation actions. Instead, patients should be taken into the situation in which they experience their ‘I can’ and so that their bodily knowledge is evoked and awakened.

- Physiotherapists should be aware of their own embodiment and movement when promoting movement quality [13, 14, 88]. Therapists’ interactions with patients occur at the bodily level, involve strongly corporeal aspects, and can be linked to empathy and intercorporeality as described in phenomenological literature [14].

- Physiotherapists should be persistent in their efforts to communicate with their patients. They have to maintain a close and supportive presence with patients at all times, doing things only when they have asked first, and tell what they will do and why they will do it, regardless of the patient’s level of consciousness [89]. Not only as a matter of respect to patients and their integrity but also because it has the potential to empower patients by promoting their agency as much as possible.

- Physiotherapists should be aware of the mediating role of ICU technology. ICU technology can make people experience restriction or powerlessness and mediates patients’ ‘I can’. Patients are aware of the lifesaving functions of ICU technology and may be fearful of potentially disconnecting when mobilising. It is therefore crucial that physiotherapists show that they have prepared sufficient workspace and that they verbalise their understanding of these considerations.

- Physiotherapists should be aware that the (ICU) environment has meaning to patients. When entering the room one must bear in mind that it is a place where physical recovery, personal development and transformation of the body takes place [90]. Physiotherapists should explore this meaning and should sense when to express empathy, respect, care and when to express encouragement, challenge and humour.

- Physiotherapists should support patients in regaining a sense of normalcy [47]. Knowing that patients' lived body in the long-term can be changed for life, physiotherapists should be cautious not to give false hope. Moreover, physiotherapists should speak with patients about their experiences as it may have therapeutic potential for both patients and healthcare professionals [90]. During ICU follow-up clinics, patients should be offered 'to feel the room', giving them the opportunity 'to comprehend lived life in a new way' [91].

Educational

- Teachers should create awareness towards lifeworld dimensions. The lifeworld is not a common topic for physiotherapists to talk and write about. Traditionally in physiotherapy much attention has been given to the (bio)mechanical effects of therapy. However, physiotherapy is a relational profession where people work with people. The fact that these people are embodied and meet in a certain spatial and temporal context should not be overlooked. The lifeworld dimensions are of influence on every physiotherapy consultation. Teaching students phenomenological insights concerning illness and the body might increase their awareness towards these dimensions and might also be helpful in avoiding mind-body dualism, as they complicate the understanding of patients' problems. For instance, when treating patients with medically unexplained symptoms.

- Teachers should promote and support the process of perspective-taking. Written accounts of patients' experiences, as we provided here, might be used as a fundamental basis for teaching healthcare professionals. Additional to textual descriptions, perspective-taking has also been stimulated through experiential learning. In experiential learning laboratories, materials are used to mimic patient experiences such as limited mobility or sight [92]. These methods offer opportunities to increase awareness of the uniqueness of every single patient in clinical practice [93]. In addition, graphical accounts, such as the graphic novel 'Coma' (Slattery Z. Coma. Myriad Editions; 2021), or video accounts of patient perspectives, such as provided by Johns Hopkins (https://www.hopkinsmedicine.org/pulmonary/research/outcomes-after-critical-illness/

oacis-videos-news.html) might also contribute to a better understanding of the patient perspective.

- Teachers should create awareness concerning the positive and negative effects of empathy. Empathising abilities are often seen as an important quality of healthcare professionals because they benefit the communication and the relation between patient and healthcare professional. Empathising can however also be harmful. The theory of mirror neurons indicates that if we see someone suffer, we feel the suffering ourselves [94, 95]. Therefore, healthcare professionals should learn to regulate their emotions and to ethically reflect on their clinical experiences to avoid negative effects of empathy [57, 96].

- Teachers should facilitate the acquiring of practical and bodily knowledge [14]. In the contact between a physiotherapist and a patient, on an implicit level, a dialogue is occurring between the expressions of the body of the therapist and the body of the patient [31]. Several authors have compared this bodily dialogue with a dance [14, 15, 58]. Therefore, physiotherapy education should contain the training of students' body awareness, movement awareness and bodily knowledge [97]. Physiotherapists working with severely weak patients could benefit from training in Kinaesthetic mobilisation techniques, which awakens patients' movement abilities and which also has dance-like aspects [98].

Research

- Researchers should study critically ill patients' experiences in the post-discharge stage. There is already a large body of qualitative research studying patient experiences during their stay in the ICU [48, 52, 53, 99, 100] and the experiences during transfer from the ICU to the nursing ward [101-107]. Therefore, we think that patient experiences in these stages have been sufficiently studied. In contrast, more qualitative research is needed concerning patient experiences after hospital discharge to give guidance to physiotherapists working with patients recovering from critical illness in rehabilitation facilities or at home.

- Researchers should make use of different research traditions to improve their understanding of both qualitative and quantitative perspectives. The lifeworld dimensions as found in this thesis provide a picture of the setting in which early mobilisation and ICU rehabilitation take place. As the phenomenological descriptions are rich in context, they form an important addition to the body of quantitative literature on this topic. We suggest combining both research traditions in a mixed-methods study, for instance in a triangulation design, explanatory design, exploratory design or embedded design [108].

- Researchers should use qualitative research in the development of person-centred interventions for the ICU population. Including the first-person perspective in research projects seems crucial to providing person-centred care. Our findings can be used to gain insight into which aspects are deemed important by patients. Person-centred care is nowadays often confused with personalised care, for instance using prediction models or DNA tailored interventions. However, when we really want to be person-centred, we have to understand patients' experiences and address each individuals' unique personhood.

CONCLUSIONS

Critical care, early mobilisation and ICU rehabilitation are often studied using quantitative research methods picturing an objective measurable technological world. In contrast, in this thesis we have explored these settings phenomenologically presenting a qualitative meaningful lifeworld. Through the collection of first-person experiences, we created a better understanding of patients' and healthcare professionals' experiences in critical care, early mobilisation and ICU rehabilitation. By uncovering lifeworld dimensions, making use of the existentials as described by Van Manen, physiotherapists may now 'see' things they earlier took for granted. Through rich thematic descriptions of the illness perspective, we facilitated perspective-taking for healthcare professionals which may lead to person-centred rehabilitation care and improved patient experiences. We found that, in close cooperation with the other ICU professionals, physiotherapists have an important role in the humanisation, liberation and empowerment of patients in early mobilisation and ICU rehabilitation. We argued that patients and physiotherapists could benefit from an embodiment lens and an enriched, relational view on the body to promote embodied recovery in the ICU and beyond.

Box 3. Clinical example: testing strength including new perspective

Physiotherapists working in the ICU will regularly test skeletal muscle strength using the Medical Research Council Sum Score (0-60) to gain insight into patients' muscle strength and to diagnose intensive care unit acquired weakness (MRC-SS < 48). Often, when the patient appears weak this testing takes place with them in their bed. Many times, I have formally tested a patient in bed and the patient scores low, for instance strength 2 (out of 5) on knee extension on both sides (which means that he or she can extend the knee, but not against gravity). The odd thing is that when I then help the patient to a sitting position, on some occasions patient is able to stand up, and even stand in a stable manner, for which you need more strength in your knee extensors than strength 2. I cannot explain this from either a biological or biomechanical perspective.

We found that critically ill patients experience their lived body as unable. When the lived body is unable, 'simple mechanical' commands are often misplaced. In a way you could say it is unfair to ask these patients rationally to help and cooperate with the mobilisation actions. Instead one should empower patients through body experiences and by bringing the patient in the position that they experience 'I can' and bodily knowledge is evoked and awakened. This may explain why the patient cannot extend the knee on request, but is able to stand up.

Box 4. Clinical example: quick recovery including new perspective

Physiotherapists working in the ICU will all know examples of patients who were mechanically ventilated and bedridden for weeks and subsequently developed severe muscle weakness. Intensive care unit acquired weakness is described as a combination of polyneuropathy, critical illness polymyopathy or critical illness neuromyopathy, and is typically combined with muscle atrophy. I have seen many patients being incapable of performing any movement or showing any strength on day 1, but with the help of rehabilitation training, on day 14 he or she can walk around the department. I cannot explain this progression from a physiological or biomechanical perspective because muscle and nerve recovery do not progress this quickly.

We found that critically ill patients can experience a turning point. Small changes in posture and movement can make a huge difference to patients. Patients can feel liberated, empowered and gain a new perspective on life, daring to look forward. These experiences can have a transformative character coming with a lot of energy, increase of willpower and a sense of agency. This may explain why some patients show quick progression.

Box 5. Clinical example: limiting technology including new perspective

Physiotherapists working in the ICU or at a hospital ward will recognise that patients can have all sorts of lines, cables, drains, catheters attached to their bodies. I have had many experiences when a patient is convinced that these lines are a reason to not mobilise, yet I am convinced that it is actually possible. In many cases it is not enough to just 'tell' them how this can be accomplished. When I 'show' them how it is done and how they can manage the lines while mobilising, then they 'see' the possibilities as well. When we arrive back at the patient's room, typically patients say that they didn't expect this to be possible.

We found that (ICU) technology is restrictive in nature. Moreover, we saw that technologies actively mediate how the world becomes present to us. Patients feel intuitively and pre-reflectively that they cannot leave their location, and they may also have been instructed so. When the patients are shown how it can be done, then they experience increased space and new mobilisation opportunities. This may exemplify that experiential knowledge is often more powerful than cognitive knowledge.

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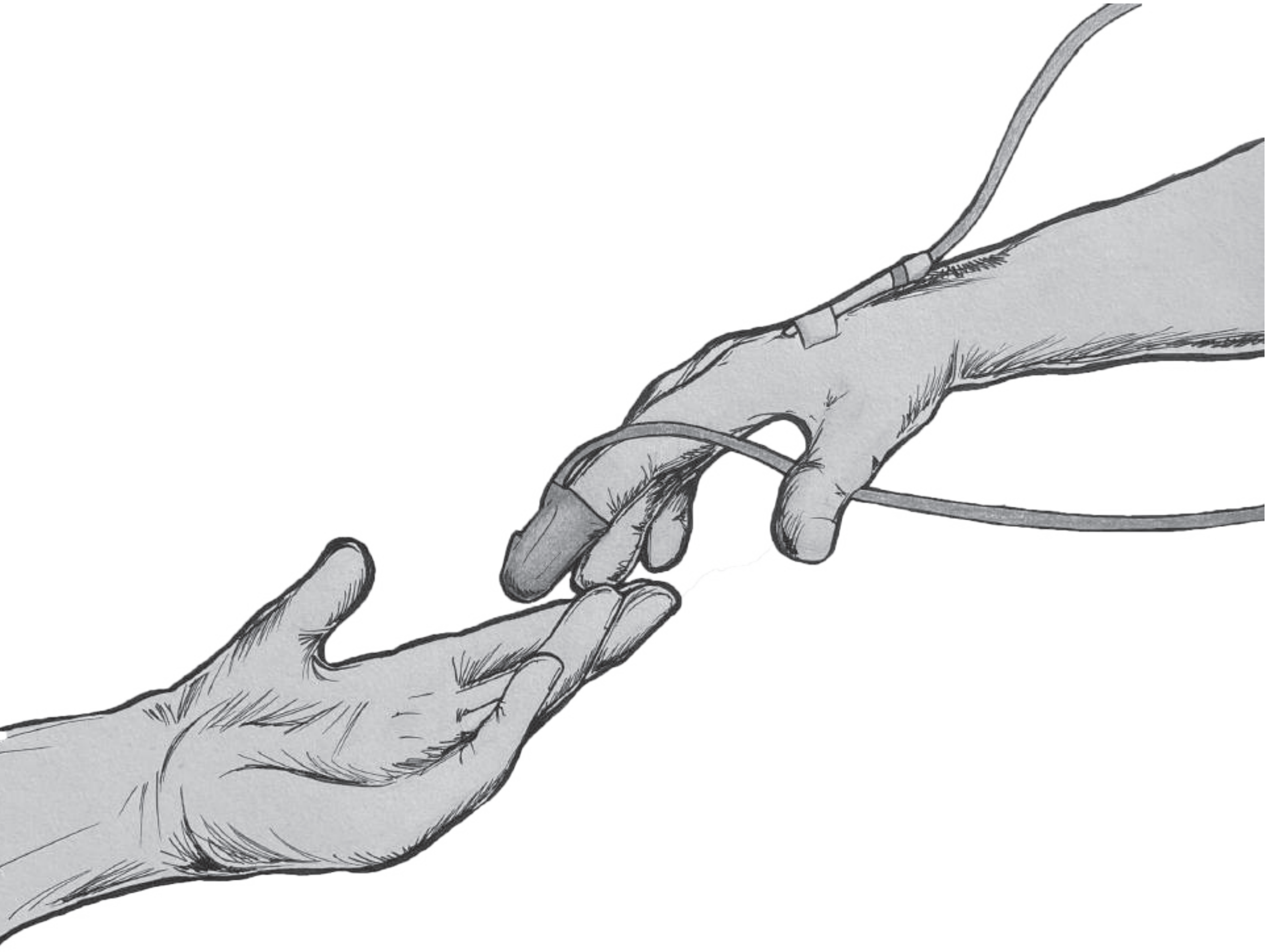

APPENDICES

Summary

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SUMMARY

Patients who are critically ill and admitted to an intensive care unit (ICU) are at risk of deconditioning. They can develop impairments in the cognitive, psychological and physical domain, which can remain long after discharge from the ICU. Physiotherapists aim to prevent and decrease this deconditioning by early mobilisation and treating prolonged physical impairments in ICU rehabilitation. During last decade, a large body of scientific literature has been released studying the safety, feasibility and potential effectiveness of early mobilisation and ICU rehabilitation. In these predominantly quantitative studies, the objective, third-person disease perspective is investigated. In order to gain a richer understanding of the value of physiotherapy and to enable person-centred care, we need to gain insight in the subjective, first-person illness perspective. This perspective can be explored using qualitative research and specifically by adopting a phenomenological approach. Phenomenology goes back to the things as they appear to us and turns away from theories, interpretations and constructions. It reveals our lifeworld through the study of lived experiences. The overall aim of this PhD trajectory was to uncover lifeworld dimensions in early mobilisation and ICU recovery through first-person experiences collected from patients and physiotherapists and other healthcare professionals using multiple different phenomenology approaches.

In **Chapter 2** we explored the impact of hydrotherapy in critically ill ventilated patients from a patient perspective, using a generic phenomenological approach. A total of twelve patients were enrolled in the study, of which eight patients could be interviewed. The in-depth, face-to-face, semi-structured interviews took place six to twelve weeks after hospital discharge. Thematic analysis of the interview data resulted in five main themes: experiencing consequences of critical illness, feeling safe in the water, being able to move, positive experiences relating to hydrotherapy and experiencing a turning point. Hydrotherapy seemed to help patients regain control and belief in their recovery. The finding that patients experienced a turning point when being able to move in the water, raised the idea that self-efficacy and a sense of agency were powerful experiences in early mobilisation, and laid a foundation for the rest of this thesis.

In **Chapter 3** we gained insight in how patients experience their body in the ICU and in recovery from critical illness. Taking a meta-ethnographic approach, we extracted and synthesised data from 45 phenomenological studies that included patient experiences in the ICU or beyond. This led to rich descriptions of embodied themes. Moreover, an overall explanation of lived body experiences in the ICU and

recovery from critical illness was provided by three lines of arguments: ‘recovery from critical illness starts from a situation in which patients experience the lived body as unable’, ‘patients experience progress in recovery from critical illness when the lived body is empowered’, and ‘recovery from critical illness results in a lived body changed for life’. We argued that healthcare professionals should be aware of the different ways in which patients can experience their body. We discussed that experiential knowledge plays a role in early mobilisation, that the ICU environment and related technology mediate patients’ ability to mobilise, and those patients should be offered support to regain a new sense of normalcy and to comprehend life in a new way.

In **Chapter 4** we explored lived experiences of patients recovering from COVID-19-associated intensive care unit acquired weakness (ICUAW). For this study we took a hermeneutic phenomenological approach based on the writings of Van Manen. Semi-structured, in-depth, video-call interviews were performed four to eight months after hospital discharge with a total of thirteen participants. Hermeneutic phenomenological 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. Recovery from COVID-19-associated ICUAW starts from a situation in which patients experience a strong sense of alienation, which is applicable to all five ‘existentials’ (lived body, lived time, lived human relations, lived space and lived materials). Patients want to return to the familiar situation, back to the old, balanced, bodily self. They want to feel homelike again. The provided phenomenological descriptions reflect a recovery process that does not follow a linear improvement, but comes with moments of success, setbacks, trying new steps and breakthrough moments of achieving mobilising milestones. We discussed that when healthcare professionals are more conscious towards patients’ experience, the healthcare professionals will start to act and communicate differently. Moreover, we found that bodily knowledge plays an important role in early mobility and ICU recovery.

In **Chapter 5** we explored lived experiences of rehabilitation professionals working in hospitals during the COVID-19 pandemic, including the ethical issues and moral distress these professionals encountered. For this study we adopted an interpretative phenomenological approach based on the writings of Smith. We included a total of 39 hospital-based rehabilitation professionals, including dieticians, occupational therapists, physiotherapists, and speech-language therapists, based in four different hospitals across different regions in the Netherlands. In semi-structured, in-depth, video-call interviews, participants were asked to share their experiences.

Four themes emerged from the interpretative phenomenological analysis: a disease with great impact, personal health and safety, staying human in chaotic times, and solidarity and changing professional roles. Thorough descriptions of the themes were provided, including the ethical issues as experienced by the participants. We concluded that hospital-based rehabilitation professionals faced a wide range of situations that were morally complex and led to moral distress. In order to diminish the long-lasting negative impact of the COVID-19 pandemic we urged employers to empathise with the experiences of hospital-based rehabilitation professionals and to create conditions for ethical reflection.

In **Chapter 6** we provided detailed recommendations and guidance for hospital-based physiotherapists managing patients hospitalised with COVID-19. This study was rapidly set up and carried out in March and April 2020, during the first wave of COVID-19 in the Netherlands, when there was only limited understanding of the symptomatology, clinical course, recovery and transmissibility. As there was an urgent need for guidance to hospital-based physiotherapists we used a pragmatic approach. Forming a working group, we conducted a purposive scan of the literature and drafted initial recommendations based on the knowledge of symptoms in patients with COVID-19 and current practice for physiotherapists' management of patients hospitalised with lung disease and patients admitted to the intensive care unit. An expert group of hospital-based physiotherapists in the Netherlands provided feedback on the recommendations, which were finalised when consensus was reached among the members of the working group. The results included safety recommendations, treatment recommendations, discharge recommendations, and staffing recommendations. Our recommendations were endorsed by the Royal Dutch Society for Physiotherapy (KNGF) and the World Health Organization.

In **Chapter 7** the main findings were discussed. We found that, in close cooperation with the other ICU professionals, physiotherapists have an important role in the humanisation, liberation and empowerment of patients in early mobilisation and ICU rehabilitation. By uncovering lifeworld dimensions, making use of the existentials as described by Van Manen, physiotherapists may now 'see' things they earlier took for granted. Through rich thematic descriptions of the illness perspective, we facilitated perspective-taking for healthcare professionals which may lead to person-centred rehabilitation care and improved patient experiences. Based on these findings we formulated implications for physiotherapy clinicians, teachers and researchers. We argued that patients and physiotherapists could benefit from an 'embodiment lens' and an enriched, relational view on the body to promote embodied recovery in the ICU and beyond.

SAMENVATTING

Patiënten die kritiek ziek zijn en opgenomen op een Intensive Care (IC) lopen het risico op deconditionering. Ze kunnen cognitieve, psychische en fysieke beperkingen ontwikkelen die vaak tot lang na ontslag van de IC blijven bestaan. Fysiotherapeuten streven ernaar deze deconditionering te voorkomen en te verminderen door vroegmobilisatie en behandeling van langdurige fysieke beperkingen in IC-revalidatie. Het afgelopen decennium is er veel wetenschappelijke onderzoek gedaan naar de veiligheid, haalbaarheid en potentiële effectiviteit van vroegmobilisatie en IC-revalidatie. In deze voornamelijk kwantitatieve studies is de setting vanuit het objectieve, derdepersoons perspectief onderzocht. Om de waarde van fysiotherapie voor deze patiënten beter te begrijpen en om persoonsgerichte zorg mogelijk te maken, bestuderen we de setting in deze thesis vanuit het subjectieve, eerstepersoons perspectief. Dit perspectief kan worden verkend met kwalitatief onderzoek en specifiek middels een fenomenologische benadering. Fenomenologie richt zich op de zaken zoals ze aan ons verschijnen door het bestuderen van geleefde ervaringen en het opschorten van heersende opvattingen, theorieën en constructies. Het overkoepelende doel van dit promotietraject was om leefwereld dimensies in vroegmobilisatie en IC-herstel zichtbaar te maken door eerstepersoons ervaringen van zowel patiënten als zorgprofessionals te bestuderen, gebruik makende van verschillende fenomenologische benaderingen.

In **Hoofdstuk 2** hebben we onderzoek gedaan naar de impact van hydrotherapie bij kritiek zieke beademde patiënten. Voor deze generiek fenomenologische studie werden in totaal twaalf patiënten geïncludeerd, waarvan acht patiënten werden geïnterviewd. De face-to-face, semigestructureerde diepte-interviews vonden plaats zes tot twaalf weken na ontslag uit het ziekenhuis. Thematische analyse resulteerde in vijf hoofdthema's: het ervaren van gevolgen van kritieke ziekte, zich veilig voelen in het water, in staat zijn om te bewegen, positieve ervaringen met betrekking tot hydrotherapie en het ervaren van een omslagpunt. Hydrotherapie leek patiënten te helpen weer controle te krijgen en vertrouwen te hebben in hun herstel. De bevinding dat patiënten een omslagpunt ervaren wanneer zij in staat zijn om zich in het water te bewegen, bracht ons op het idee dat zelfeffectiviteit en 'agency', krachtige ervaringen zijn in vroegmobilisatie en vormden de basis voor de rest van deze thesis.

In **Hoofdstuk 3** hebben we inzicht gekregen in de lichaamservaringen van patiënten op de IC en tijdens IC-herstel. Middels een meta-etnografie hebben we gegevens uit 45 fenomenologische studies geëxtraheerd en gesynthetiseerd, die patiëntervaringen op de IC of in IC-herstel bevatten. Dit leidde tot thematische beschrijvingen van lichaamservaringen. Een overkoepelend beeld van het onderzochte fenomeen werd gegeven aan de hand van drie argumentatielijnen: ‘herstel van kritieke ziekte begint vanuit een situatie waarin patiënten hun geleefde lichaam als onbekwaam ervaren’, ‘patiënten ervaren vooruitgang bij het herstel van kritieke ziekte wanneer hun geleefde lichaam wordt bekrachtigd’, en ‘herstel van kritieke ziekte resulteert in een geleefd lichaam dat blijvend is veranderd’. We betoogden dat zorgverleners zich meer bewust zouden moeten zijn van de verschillende manieren waarop patiënten hun lichaam kunnen ervaren. We bespraken dat ervaringskennis een rol speelt bij vroegmobilisatie, dat de IC-omgeving en gebruikte technologie de mobiliteit van patiënten beïnvloeden en dat patiënten ondersteuning moeten krijgen om een nieuwe vorm van normaliteit te hervinden en het leven op een nieuwe manier in te kunnen vullen.

In **Hoofdstuk 4** hebben we de geleefde ervaringen onderzocht van patiënten die herstellende waren van COVID-19-gerelateerde intensive-care-verworven spierzwakte (ICUAW). Voor deze studie volgden we een hermeneutisch fenomenologische benadering zoals beschreven door Van Manen. Er werden semigestructureerde diepte-interviews uitgevoerd middels video-bellen, vier tot acht maanden na ontslag uit het ziekenhuis, met in totaal dertien deelnemers. Hermeneutisch fenomenologische analyse leverde vijf thema’s op: wakker worden in vervreemding, menselijk contact waarderen in isolatie, vooruitgang boeken door uitgedaagd te worden, thuiskomen maar nog steeds herstellende zijn, en een nieuwe balans vinden. Herstel van COVID-19-gerelateerde ICUAW begint vanuit een situatie waarin patiënten een sterk gevoel van vervreemding ervaren, welke van toepassing is op alle ‘existentials’ (geleefd lichaam, geleefde tijd, geleefde menselijke relaties, geleefde ruimte en geleefde materialen). Patiënten willen terugkeren naar de vertrouwde situatie, terug naar hun oude, evenwichtige, lichamelijke zelf. Ze willen zich weer thuis voelen. De fenomenologische beschrijvingen weerspiegelen een herstelproces dat niet lineair is opgebouwd, maar komt met momenten van succes, tegenslagen, het uitproberen van nieuwe stappen en doorbraakmomenten en het bereiken van mobilisatie mijlpalen. We bespraken dat wanneer zorgverleners zich bewust zijn van de ervaringen van patiënten, zij anders zullen handelen en communiceren. Bovendien zagen we dat een lichamelijk weten een belangrijke rol speelt in vroegmobilisatie en IC-herstel.

In **Hoofdstuk 5** hebben we de geleefde ervaringen van revalidatieprofessionals onderzocht die werkten in ziekenhuizen tijdens de COVID-19 pandemie, inclusief de ethische kwesties en morele stress die zij ondervonden. Voor dit onderzoek volgden we een interpretatieve fenomenologische benadering zoals beschreven door Smith. We includeerden 39 revalidatieprofessionals, waaronder diëtisten, ergotherapeuten, fysiotherapeuten en logopedisten, werkzaam in vier verschillende ziekenhuizen in verschillende regio's in Nederland. In semigestructureerde diepte-interviews, afgenomen middels video-bellen, werden deelnemers gevraagd om hun ervaringen te delen. Interpretatieve fenomenologische analyse resulteerde in vier thema's: een ziekte met grote impact, persoonlijke gezondheid en veiligheid, menselijk blijven in chaotische tijden, en solidariteit en veranderende professionele rollen. Grondige beschrijvingen van de thema's werden gegeven, inclusief de ethische kwesties zoals ervaren door de deelnemers. We concludeerden dat revalidatieprofessionals werkzaam in het ziekenhuis te maken hadden met een breed scala aan situaties die moreel complex waren en leidden tot morele stress. Om de langdurige negatieve impact van de COVID-19 pandemie te verminderen, adviseerden we werkgevers oog te hebben voor de ervaringen van de revalidatieprofessionals en om voorwaarden te scheppen voor ethische reflectie.

In **Hoofdstuk 6** hebben we richtlijnen en gedetailleerde aanbevelingen opgesteld voor ziekenhuisfysiotherapeuten aangaande de behandeling van patiënten opgenomen in het ziekenhuis met COVID-19. Dit onderzoek werd binnen korte tijd opgezet en uitgevoerd tijdens de eerste golf van COVID-19 in Nederland, toen er nog weinig bekend was over de symptomen, het klinische beloop, het herstel en de overdraagbaarheid van het virus. Vanwege de dringende behoefte aan richtlijnen voor de behandeling van deze doelgroep gebruikten we een pragmatische aanpak. Na een doelgerichte scan van de literatuur en op basis van kennis van symptomen bij patiënten met COVID-19 en de huidige praktijk voor fysiotherapeutische behandeling bij soortgelijke patiënten werden initiële aanbevelingen opgesteld. Een expertgroep gaf feedback op de aanbevelingen in meerdere rondes, totdat consensus werd bereikt. De resultaten omvatten aanbevelingen op gebied van veiligheid, behandeling, ontslag en personele bezetting. Deze aanbevelingen zijn onderschreven en overgenomen door het Koninklijk Nederlands Genootschap voor Fysiotherapie (KNGF) en de Wereldgezondheidsorganisatie (WHO).

In **Hoofdstuk 7** werden de belangrijkste bevindingen bediscussieerd. We vonden dat fysiotherapeuten, samen met de andere IC-professionals, een belangrijke rol hebben in het menselijk maken, het bevrijden en het aansterken van patiënten in vroegmobilisatie en IC-revalidatie. Door het zichtbaar maken van leefwerelddimensies, gebruik makende van de vijf 'existentials' zoals beschreven door Van Manen, zou het kunnen dat fysiotherapeuten nu zaken 'zien' waar ze eerder geen aandacht voor hadden. Wanneer zorgprofessionals de beschrijvingen van het patiënten-perspectief lezen, kunnen ze zich wellicht beter inleven, wat kan leiden tot persoonsgerichte revalidatiezorg en betere patiëntervaringen. Op basis van deze bevindingen hebben we implicaties geformuleerd voor fysiotherapeuten werkzaam in de kliniek, als docent en als onderzoeker. We betoogden dat patiënten en fysiotherapeuten baat kunnen hebben bij een 'embodiment lens' en een rijkere, relationele kijk op het lichaam om belichaamd herstel op de IC en daarna te bevorderen.

RESEARCH DATA MANAGEMENT

Ethics and privacy

This thesis is based on the results of medical-scientific research. All studies in this thesis were performed in accordance with the Good Clinical Practice principles and the Netherlands Code of Conduct for Research Integrity. The studies described in **Chapter 2, 4 and 5** involved human participants. The Medical Ethics Committee for Research Involving Human Subjects Region Arnhem and Nijmegen, judged that these studied studies did not fall within the scope of the Dutch Medical Research Involving Human Subjects Act (WMO): **Chapter 2** (2015-1552), **Chapter 4 (**2020-6708) and **Chapter 5** (2020-6520). Informed consent was obtained from all research participants. No ethical approval was required for the meta-ethnographic synthesis in **Chapter 3** and the clinical practice guideline in **Chapter 6**.

Data collection and storage

The data obtained during my PhD at the Radboud university medical center have been stored on the secured disk “Reval_onderzoek/fysiotherapie/Roel”. Paper (hardcopy) data, including informed consent forms, are stored in cabinets in the department. Technical and organisational measures were followed to safeguard the availability, integrity and confidentiality of the data (these measures include the use of pseudonymisation, access authorisation and secure data storage). Only members of the research group had access to the data. The personal data of study participants (i.e. research identifiers, names, birthdates) are stored separately from the pseudonymized data.

Availability of data

Data were analysed using Atlas.ti. The data will be archived for 15 years after termination of the particular study. Reusing the data for future research is only possible after a renewed permission from the participants. The anonymous datasets that were used for analysis are available from the corresponding author upon reasonable request.

ABOUT THE AUTHOR

Roel van Oorsouw was born in Beek-Ubbergen, the Netherlands on the 14th of May, 1987. He grew up in Heythuysen together with his parents, his sister and two brothers.

After secondary school he started studying Physiotherapy at Fontys University of Applied Sciences in Eindhoven. A successful final internship at the Anna ziekenhuis in Geldrop, meant his graduation (BSc. 2008) and the start of a professional career as hospital-based physiotherapist.

While working in the hospital, Roel specialised towards physiotherapy for patients with cardiovascular and pulmonary conditions. He received internal mentoring from Peter van Heesch, Marlène Koolen and Sanne Linders and followed multiple relevant NPI-courses. He was delivering physiotherapy care to patients admitted to a variety of clinical departments and to patients coming to the hospital for outpatient cardiac and pulmonary rehabilitation. Moreover, Roel became one of the dedicated therapists providing the physiotherapy care for patients admitted to the six-bed Intensive Care Unit.

In 2012 Roel started the pre-master Clinical Health Sciences in Utrecht, directly followed by the master study Physiotherapy Science, which he completed in 2015. For his master thesis he studied the experiences of patients who received hydrotherapy while being mechanically ventilated in the ICU of the Radboudumc. Attracted by the highly specialized working environment and the academic possibilities Roel left the Anna ziekenhuis and started working as a physiotherapist in the Radboudumc in 2016.

In close cooperation with Karin Felten-Barentsz, and under supervision of Prof dr. Ria Nijhuis-van der Sanden, the master thesis was further developed and ultimately published in an international scientific journal. From then on Roel participated in a diversity of research projects and supervised several master students. With help of internal funding raised by Dr. Amy Sman, alongside his clinical work, in 2019 Roel started a PhD trajectory supervised by Prof. dr. Philip van der Wees. The individual projects, with the overall goal to increase quality of physiotherapy care for critically ill patients, ultimately led to the current thesis.

After completing his PhD, Roel will continue to work as hospital-based physiotherapist. As an embedded scientist, he will aim to translate clinically relevant questions into meaningful research projects. He will combine this with educational activities, among others as a lecturer in the basic course qualitative research, which he provides together with his direct colleague Dr. Niek Koenders. In addition, Roel will remain active as member of the ethics committee of the Radboudumc and the ethics committee of the Royal Dutch Society for Physical Therapy (KNGF).

LIST OF PUBLICATIONS

International scientific publications – PhD thesis

Roel van Oorsouw, Anke J. M. Oerlemans, Gijs van Oorsouw, Mark van den Boogaard, Philip J. van der Wees and Niek Koenders. *Patients' lived body experiences in the intensive care unit and beyond: a meta-ethnographic synthesis.* Physiotherapy Theory and Practice, 2023. https://dx.doi.org/10.1080/09593985.2023.2239903

Roel van Oorsouw, Emily Klooster, Niek Koenders, Philip J. van der Wees, Mark van den Boogaard and Anke J. M. Oerlemans. *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, 2022, 78, 3358-3370. https://doi.org/10.1111/jan.15338

Roel van Oorsouw, Anke Oerlemans, Emily Klooster, Manon van den Berg, Johanna Kalf, Hester Vermeulen, Maud Graff, Philip van der Wees and Niek Koenders. *A sense of being needed: an interpretative phenomenological analysis of hospital-based allied health professionals' experiences during the COVID-19 pandemic.* Physical Therapy and Rehabilitation Journal, 2022, 3;102(6), 1-10. https://doi.org/10.1093/ptj/pzac052

Roel van Oorsouw, Karin Felten-Barentsz, Emily Klooster, Niek Koenders, Femke Driehuis, Erik Hulzebos, Marike van der Schaaf, Thomas Hoogeboom and Philip van der Wees. *Recommendations for hospital-based physical therapists managing patients with COVID-19.* Physical Therapy and Rehabilitation Journal, 2020, 100(9), 1444-1457. https://doi.org/10.1093/ptj/pzaa114

Roel van Oorsouw, Karin M. Felten-Barentsz, Antonius J. Haans, J. Bart Staal, Johannes G. van der Hoeven and Maria W.G. Nijhuis-van der Sanden. *Patient views regarding the impact of hydrotherapy on critically ill ventilated patients: a qualitative exploration study.* Journal of Critical Care, 2018, 48, 321-327. https://doi.org/10.1016/j.jcrc.2018.09.021

International scientific publications - other

Kathrin Scholz, **Roel van Oorsouw**, Sander Hermsen and Thomas Hoogeboom. *Development and pilot-testing of a behavioural intervention to enhance physical activity in patients admitted to the cardiology ward: a proof-of-concept study.* European Journal of Physiotherapy, 2021, published online. https://doi.org/10.1080/21679169.2021.1949038

Roel van Oorsouw, Niek Koenders, Joost Seeger and Thomas Hoogeboom. *Physical activity promotion is lacking in local treatment protocols for patients hospitalized with myocardial infarction: A cross-sectional study.* MedRxiv, 2021, https://doi.org/10.1101/2021.05.05.21256684.

Rudi Steenbruggen, **Roel van Oorsouw**, Marjo Maas, Thomas Hoogeboom, Paul Brand and Philip van der Wees. *Development of quality indicators for departments of hospital-based physiotherapy: a modified Delphi study.* BMJ Open Quality, 2020;9:e000812. http://dx.doi.org/10.1136/bmjoq-2019-000812

Niek Koenders, **Roel van Oorsouw**, Joost Seeger, Ria Nijhuis – van der Sanden, Irene van de Glind and Thomas Hoogeboom. *"I'm not going to walk, just for the sake of walking…": a qualitative, phenomenological study on physical activity during the hospital stay.* Disability and Rehabilitation, January 2020. https://doi.org/10.1080/09638288.2018.1492636

Remko van Lieshout, Elja Reijneveld, Sandra van den Berg, Gijs Haerkens, Niek Koenders, Arina de Leeuw, **Roel van Oorsouw**, Davy Paap, Else Scheef, Stijn Weterings and Mirelle Stukstette. *Reproducibility of the modified star excursion balance test composite and specific reach direction scores.* International Journal of Sports Physical Therapy, June 2016. DOI: 10.1186/s13643-016-0252-2

Congress presentations

Roel van Oorsouw. *Patient experiences in recovery from COVID-19-associated intensive care unit acquired weakness. a study from the perspective of patients and healthcare professionals.* European Society of Intensive Care Medicine Lives 35th annual congress, Paris, October 2022, poster presentation.

Roel van Oorsouw. *A sense of being needed: a phenomenological analysis of hospital-based rehabilitation professionals' experiences during the COVID-19 pandemic.* Dag van de fysiotherapeut, Den Bosch, May 2022, poster presentation.

Roel van Oorsouw. *Hydrotherapy in critically ill ventilated patients: a mixed-methods study.* International Early Mobilization Network, 3rd European Conference on Weaning and Rehabilitation in Critically Ill Patients, Copenhagen, November 2015, poster presentation.

National publications

Roel van Oorsouw. Boekrecensie van "Houterman A. Wij zijn ons lichaam. Wat sport en beweging ons vertellen over menselijk gedrag. Amsterdam: Ambo/Anthos Uitgeverij, 2020. ISBN: 9789026327384". In tijdschrift voor Geneeskunde en Ethiek, jaargang 33, maart 2023.

Niels Gritters, Koen Simons, Marissa Vrolijk, Lena Koers, Rik Endeman, Mark van den Boogaard, **Roel van Oorsouw**, Nicole Hunfeld, Wai-Ping Manubulu-Choo, Marianne Brackel. *Richtlijn, Sedatie en analgesie op de IC*. Federatie voor Medisch Specialisten richtlijnendatabase, december 2022.

Roel van Oorsouw, Mark Loeffen, Mark van den Boogaard en Marieke Zegers. *Post-intensive care syndroom, Deel 2, Preventie en behandeling.* Physios, september 2022.

Roel van Oorsouw, Mark Loeffen, Mark van den Boogaard en Marieke Zegers. *Post-intensive care syndroom, Deel 1, Kenmerken en risicofactoren.* Physios, juni 2022.

Niek Koenders, **Roel van Oorsouw**, Emily Klooster, Anke Oerlemans, Manon van den Berg, Hanneke Kalf, Hester Vermeulen, Maud Graff en Philip van der Wees. *Ervaringen van paramedici tijdens de coronapandemie*. FysioPraxis, December 2020.

Patient interaction

Roel van Oorsouw. *Fysiek herstellen na de IC, hoe doe je dat?* IC café, Nijmegen, 6 oktober 2022, fysieke presentatie.

Spiegelbijeenkomst COVID-19 patiënten, Experience center Radboudumc, 2 november 2021.

Roel van Oorsouw. *Fysiek herstellen na de IC, hoe doe je dat?* Digitaal IC café, 3 december 2020, presentatie via Zoom.

Research profiles

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PORTFOLIO

Department: **Rehabilitation**
PhD period: **01/06/2019 – 01/06/2023**
PhD Supervisor(s): **Prof. dr. P.J. (Philip) van der Wees**
PhD Co-supervisor(s): **Prof. dr. M. (Mark) van den Boogaard**
Dr. N. (Niek) Koenders
Dr. A.J.M. (Anke) Oerlemans

Training activities	**Hours**
Courses	
- Introduction day Radboudumc (2019)	8
- Graduate School specific introductory course (2019)	12
- eBROK course (2019)	20
- Project management for PhD candidates (2019)	40
- Cursus observeren (2020)	16
- Minor medical humanities opleiding geneeskunde, thema lichaam en geest (2020)	16
- Loopbaanmanagement voor Promovendi (2021)	16
- Coaching sessions Radboud Writing Lab (2021)	8
- Scientific Integrity course (2021)	16
Seminars	
- Radboud Research Rounds, various (2019-2023)	20
- Research meeting physiotherapy scientists, every two weeks (2019-2023)	60
- Mirror sessions (2020, 2021, 2022)	10
Conferences	
- PhD retreat (2019)	16
- European Conference on weaning and early rehabilitation of critically ill patients (2019)	16
- NVZF (Dutch hospital physical therapy) congress, including talk (2019	8
- KWALON najaarsconferentie (2019)	8
- Invitational conference NFU – waardegedreven zorg (2020)	4
- NVZF Week van de ziekenhuisfysiotherapie (2020)	4
- VFG Jaarcongres (2020)	4
- WCF dag, Deventer (2021)	8
- Dag van de fysiotherapeut, including poster (2022)	8
- WCF dag, Den Bosch (2022)	8
- European society of intensive care medicine congress, Paris, including poster (2022)	24
Teaching activities	
- Supervising a group of bachelor students in their course writing a grant proposal (2020)	20
- Hydrotherapy course NPI (2021, 2023)	4
- Basis course qualitative research (2021, 2022, 2023)	60
- Radboud Health Academy, course for ICU nurses (2022, 2023)	20
Total	**454**

DANKWOORD

Als ziekenhuisfysiotherapeut, en gelukkig ook als onderzoeker, ben ik dagelijks veel in contact met mensen. De ontmoetingen met patiënten, collega's, vrienden en familie hebben elk op hun eigen wijze bijgedragen aan de totstandkoming van dit proefschrift. Een aantal mensen wil ik in het bijzonder bedanken.

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Simon Rogers, ever since that futsal tournament in Milan you are a dear friend to me. Sweet memories I carry from our shared weekends, mixing hours of study with games of football, squash, FIFA, sauna visits, and eating pizza, making the study a pleasure instead of an annoyance. It laid a base for the rest of the studying that had to be done for this thesis to see the light. It is always a joy to spend time with you and I am grateful for your support!

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In 2016 maakte ik de overstap naar het Radboudumc. Naast de prachtige omgeving, zijn het de mensen die maken dat ik mij thuis voel in het Nijmeegse en in dit boeiende academische ziekenhuis. Ik dank alle collega's van de afdeling Revalidatie, zowel de revalidatieartsen, de ergotherapeuten, de logopedisten als de fysiotherapeuten, voor de prettige samenwerking. In het bijzonder de collega's van unit 2, Maud, Marcel, Niek, Karlijn, Sjoerd, Charlotte, Yvonne, Shanna, en (oud-collega) Hermien wil ik bedanken, omdat we een fijne groep vormen met oog voor elkaar, en omdat we strak georganiseerd zijn maar voldoende flexibel waardoor het mogelijk is om klinische werkzaamheden met onderzoek te combineren. Ook collega fysiotherapeuten Karin

Felten-Barentsz en Emily Klooster wil ik hier specifiek bedanken voor het samen optrekken tijdens de diverse projecten en het delen van eerste auteurschappen.

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