

Patients' experiences with early rehabilitation in intensive care units: A qualitative study about aspects that influence their participation

Karina Knutsen¹   | Rita Solbakken¹   | Shaun Gallagher^{2,3}  |
Ranveig Trondsen Müller⁴  | Britt Normann^{1,5} 

¹Faculty of Nursing and Health Science, Nord University, Bodø, Norway

²Department of Philosophy, University of Memphis, Memphis, Tennessee, USA

³Faculties of Law, School of Liberal Arts, University of Wollongong, Wollongong, New South Wales, Australia

⁴Intensive Care Unit, Nordland Hospital, Bodø, Norway

⁵Department of Physiotherapy, Nordland Hospital, Bodø, Norway

Correspondence

Karina Knutsen, Faculty of Nursing and Health Science, Nord University, Mailbox 1490, 8049 Bodø, Norway.
Email: karina.knutsen@nord.no

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Abstract

Aim: To explore patients' experiences with early rehabilitation in the intensive care unit and what they perceive to influence their participation.

Design: A qualitative design anchored in phenomenological and hermeneutical traditions utilizing in-depth interviews.

Methods: Thirteen patients were interviewed from 5 to 29 weeks following discharge from three units, in January–December 2022. Analysed using systematic text condensation and the pattern theory of self. Reporting adhered to consolidated criteria for reporting qualitative research.

Results: Interviews described four main categories: (1) A foreign body, how the participants experienced their dysfunctional and different looking bodies. (2) From crisis to reorientation, the transformation the participants experienced from a state of crisis to acceptance and the ability to look forwards, indicating how bodily dysfunctions are interlinked to breakdowns of the patients' selves and the reorganization process. (3) Diverse expectations regarding activity: ambiguous expectations communicated by the nurses. (4) Nurse–patient: a powerful interaction, highlighting the essential significance of positive expectations and tailored bodily and verbal interaction for rebuilding the patient's outwards orientation.

Conclusion: Outwards orientation and reorganization of the self through a reduction in bodily dysfunctions, strengthening the patients' acceptance of the situation, providing tailored expectations and hands-on and verbal interaction appear to be fundamental aspects of patient participation in early rehabilitation.

Implications: Insights into patients' perceptions show how dysfunctional bodies cloud individuals' perceptual fields, causing inwards orientation and negative thoughts concerning themselves, their capabilities, environment and future. This knowledge can improve nurses' ability to tailor care to promote optimal recovery for patients.

Patient or Public Contribution: User representative contributed to the design of the study.

KEYWORDS

early rehabilitation, ICU, intensive care unit, participation, patient, phenomenology, qualitative

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1 | INTRODUCTION

Advancements in medical treatment and the management of critical illness in intensive care units (ICUs) have increased the number of patients who survive and later require a prolonged period of intensive care treatment (Minton et al., 2021). Recent research emphasizes the long-term impact of these life-saving strategies and focuses on early rehabilitation (Doiron et al., 2018), a multidisciplinary process in which critical care nurses play an essential role (Sosnowski et al., 2015).

The ways in which critically ill persons perceive participation in early rehabilitation are sparsely examined (Egerod et al., 2020). This topic includes the question of how the more existential aspects associated with critical illness influence such participation. Relevant knowledge may improve critical care nurses' ability to tailor care to the individual patient, which is a key principle associated with successful early rehabilitation in ICUs (Sosnowski et al., 2015).

2 | BACKGROUND

For critically ill patients, deconditioning takes place as early as 4 days after entering the ICU and can result in up to 25% peripheral muscle weakness during the first 4 days on a ventilator and a loss of 18% body weight by the time the patient is discharged (Zomorodi et al., 2012). Short- and long-term complications occur, which are often referred to as post intensive care syndrome. This term refers to physical, cognitive and mental impairments that may occur during and after ICU and hospital stays, including intensive care unit-acquired weakness (Inoue et al., 2019), which indicates generalized muscle loss that affects both distal and more proximal muscles, such as the respiratory muscles. This complication is associated with high rates of morbidity and mortality among critically ill patients (Hermans & Van Den Berghe, 2015). Other consequences of prolonged bed rest include decreased circulation leading to blood clots and the risk of pulmonary emboli (Castro et al., 2015), pneumonia and lung damage resulting from prolonged periods on a ventilator (Gilson, 2019). Early rehabilitation can potentially reduce complications that might lead to adverse outcomes, improve functional recovery and decrease the length of high-cost stays in the ICU (Zang et al., 2020).

Early rehabilitation usually includes activities such as bed mobility exercises, transfer training, ambulation and active movements, which can be performed independently by the patient or with assistance from a therapist or nurse. It can also involve equipment, such as an in-bed cycle or ergometer cycle. Moreover, this approach can consist of active participation in functional tasks, such as eating, bathing, dressing and elimination (Doiron et al., 2018). The timing for starting early rehabilitation is individual and can commence during or after mechanical ventilation (Doiron et al., 2018). It depends on the level of sedation or presence of delirium (Sosnowski et al., 2015), and if the patient is haemodynamically stable and receives acceptable levels of oxygen (Dang, 2013). Active patient participation may, however, be challenging or impossible due to coma, sedation or life-threatening illnesses (Schandl et al., 2017). Although

early rehabilitation in the ICU involves a multidisciplinary approach, critical care nurses are at patients' bedsides 24/7, which offers significant opportunities to practice evidence-based rehabilitation as an integrated part of routine care (Sosnowski et al., 2015) before the initiation of regular mobility programs (Dang, 2013).

A recent meta-synthesis reported that patients receiving mechanical ventilation suffer from severe physical dysfunction and exhibit hopelessness, anxiety, frustration, stress and vulnerability (Danielis et al., 2020). This finding concurs with other qualitative studies indicating that patients in ICUs exhibit disturbances with regard to their perceptions of their bodies, which involve a component of human suffering and a decreased ability to retain their existential will to continue living (Egerod et al., 2015; Haugdahl et al., 2017). The relationship between bodily and mental functions is at stake in cases of critical illness (Berntzen et al., 2020), a situation that demands focus during early rehabilitation. Furthermore, nurses' experiences with patient participation in the ICU in general were investigated by Schandl et al. (2017). In summary, research on the patient perspective in this context is sparse, especially with regard to how patients' experiences of critical illness affect their ability to participate in early rehabilitation. In such investigations, the role of their bodily perceptions and thoughts may indicate a direction that can inform nurses' clinical practice. The study's findings may offer valuable insights for critical care nurses, guiding personalized rehabilitation approaches for patients in the ICU.

3 | THE STUDY

3.1 | Aim

This study aimed to explore how patients experienced early rehabilitation, including how aspects such as physical condition and social interactions influenced their active participation.

We posed the following research question:

What do patients perceive as important influencers in their participation in early rehabilitation in the ICU?

4 | METHODS

4.1 | Design

Guided by the research question, we applied an exploratory, qualitative design anchored in the phenomenological tradition, as this position provides the possibility of generating new knowledge from lived experiences (Creswell et al., 2018). We used individual, in-depth interviews which allowed for the exploration of individuals' reflections pertaining to a particular phenomenon (Brinkmann & Kvale, 2015). Analysis of the interviews was based on a hermeneutical (interpretive) method of identifying patterns of meaning by a back-and-forth consideration of whole interviews and parts, explicitly informed by a particular approach to the concept of self. Because critically ill

patients have severe bodily dysfunction and participation in early rehabilitation requires self-related bodily and mental capacities, the pattern theory of self (PTS) (Gallagher, 2013), provided the most useful approach. This approach, based on the phenomenology of the body (Merleau-Ponty, 2013), considers multiple self-related factors that allowed us to obtain an extended understanding of bodily dysfunction and experiences from early rehabilitation among critically ill patients.

Reporting is in adherence to the consolidated criteria for reporting qualitative research (COREQ) (Tong et al., 2012), see File S1.

4.2 | Theoretical framework

Essential to the phenomenology of the body is the concept of the body as the centre of experience and expression (body-as-subject), which operates concurrently with a view of the body as a biological organism (body-as-object). An important characteristic of everyday experience known as outwards directedness or intentionality is constituted by the entity's movement, sensation and perception (Merleau-Ponty, 2013) which are bodily functions that may be impaired in critically ill patients.

The notion of a self-pattern (as developed in PTS) includes a variety of dynamic processes or factors that constitute the self. In the following, some of these factors that are relevant to our study are highlighted. Prereflective factors involve the *body schema* (BS), which is described as a system of sensory-motor capacities that function without awareness or the necessity of perceptual monitoring (Gallagher, 2005). Body schematic processes, which include proprioception and kinaesthesia, generate (1) a *sense of agency* for action (SA), which is based on a strong motor component and described as the experience of the initiation and control of one's movement, and (2), alongside interoceptive sensations, a *sense of body ownership* (SO), which is described as the feeling that it is my body that is moving, even in the case of passive or involuntary movement. These notions are described as the minimal self, a prereflective self-awareness of one's embodied experience (Gallagher, 2005). As the bodily functions involved in the minimal self are often impaired in critically ill patients, these prereflective aspects of self may serve to deepen our understanding of their body experiences. Importantly, the minimal self shapes the more reflective aspects of self-consciousness. These aspects can manifest as a body image, i.e., a system of perceptions, attitudes and beliefs pertaining to one's own body (Gallagher, 2005) as well as the specific affordances that may be available to the patient. Affordances, i.e., the action possibilities perceived by an agent, which are essential in early rehabilitation, depend on the person's bodily capacities or what the person 'can do' (Gibson, 2015). The various bodily capacities and their relation to prereflective aspects of self-experience (such as the BS, SA and SO) also inform intersubjective processes in the self-pattern. In turn, social/intersubjective processes, such as those that take place between the patient and the nurse in the ICU, shape the narrative processes involved in self-understanding. The self-pattern also includes ecological factors

or aspects of the environment, including artefacts and technologies that support self-related processes. Affective processes ranging from very basic processes, such as hunger and fatigue, to more typical patterns of emotion and mood are additional aspects of the self-pattern (Gallagher, 2013, 2024; Gallagher & Daly, 2018). (See Table 1 for the full set of processes that constitute the self-pattern.)

4.3 | Study setting and recruitment

The participants were recruited from three Norwegian ICUs in one university hospital and two local hospitals. As the project was conducted during the COVID-19 pandemic, we used two approaches to obtain a sufficient sample: (1) The local contact persons, LCPs, (critical care nurses) identified eligible patients in the ICU, and at the end of their stay, the patients were asked for their consent to participate (no data were available regarding how many requests were made; six patients accepted the invitation). (2) Information regarding the study and invitations to participate were sent to former patients fulfilling the inclusion criteria, who had stayed at selected hospital ICUs, limited to the start date of the project. Fifty invitations were sent out and 10 patients made contact to participate. However, three were excluded from the study as they clearly stated that they had no memory of their stay in the ICU. Written consent was obtained, and information regarding the project and the interviewers background was provided to all participants by the first author (KK) prior to the interviews. Characteristics of all participants are visualized in Table 2.

4.4 | Inclusion and exclusion criteria

The inclusion criteria were as follows: adult patients (≥ 18 years old) who (1) had resided in the ICU > 7 days, which is the definition of a long-term intensive care patient (Minton et al., 2021); (2) qualified to register in the Norwegian Intensive Care Registry, which ensured the inclusion of patients with manifest or threatened organ failure who were in need of intensive care treatment from highly trained personnel in adequate facilities (The Norwegian Intensive Care Registry, 2020) and (3) a Clinical Frailty Scale Score (CFS) ≤ 4 when admitted to the ICU, which indicates a patient living with very mild frailty, patients who are not dependent on others for daily help but who have symptoms that can limit their activities (Church et al., 2020). Using this score, we aimed to include patients who could partake in early rehabilitation. Terminal patients were excluded, as the care these patients received was palliative and not rehabilitative. These patients were identified by the LCPs.

4.5 | Data collection

The data collection process lasted from January 2022 to January 2023. The location for interviews was mainly the patient's home

TABLE 1 Elements of the self-pattern (Gallagher, 2024).

Elements of the pattern	Brief description
Bodily processes	Includes core bio-systemic and autopoietic processes related to motoric, autonomic, endocrine, enteric, immune, interoceptive functions, allowing the overall system to maintain homeostasis necessary for survival, and to distinguish between itself and what is not itself.
Prereflective experiential processes	Includes prereflective self-awareness, a structural feature of first-person consciousness constrained by bodily factors; the sense of ownership (mineness) and the sense of agency, which can involve various sensory-motor modalities, such as proprioception, kinaesthesia, touch and vision. These aspects form the experiential core of what is sometimes called the minimal self.
Affective processes	The fact that someone manifests a certain temperament or emotional disposition reflects a particular mix of affective factors that range from very basic and mostly covert or tacit bodily affects (e.g., hunger, fatigue, libido) to what may be a typical emotion pattern, a set of existential feelings, a background mood.
Behavioural/action processes	Behaviours and actions make us who we are – behavioural habits and skills reflect, and perhaps actually constitute, our character. This is a classic view that goes back at least to Aristotle.
Social/intersubjective processes	Humans (possibly some non-human animals) are born with a capacity for attuning to intersubjective existence; at a certain point in social relations a more developed self-conscious recognition of oneself as being distinct from others, a sense of self-for-others, and a sense of being part of a group or community.
Cognitive/psychological processes	These are aspects emphasized in traditional theories of personal identity highlighting psychological continuity and memory, including one's conceptual understanding of oneself, beliefs, cognitive dispositions, as well as personality traits.
Reflective processes	The ability to reflect on one's experiences and actions – closely related to notions of autonomy and moral personhood, including the capacity to reflectively evaluate and form second-order volitions about one's desires.
Narrative processes	Self-interpretation has a narrative structure and recursively reflects (and often reinforces) the self-pattern. On some theories, selves are inherently or constitutively narrative entities.
Ecological processes	We tend to identify ourselves with our stuff – physical pieces of property, clothes, homes, and various things that we own, the technologies we use, the institutions we work in, etc. Our embodied-situated actions engage with (and sometimes incorporate) artefacts, instruments, bits and structures of the environment in ways that define us and scaffold our identities. Situations shape who we are, and affordances define our possibilities.
Normative processes	Our extensive engagement with the environment includes social and cultural practices. These are not just what we do, but involve what we ought to do, and obligations that we keep or not. Constraints (and sometimes well-defined roles) imposed by social, cultural, institutional factors shape our habitual behaviours and our self-conceptions of who we are, and who we think we should be.

(9), according to their choice. Four interviews were completed in convenient and neutral locations. The interview times ranged from 31 to 73 min, with a total time of 573 min and a mean time of 52 min. All interviews were audio-recorded digitally and transcribed verbatim, resulting in a total of 96 A4 pages. All audio and text files were assigned a numerical code at transcription that was used to facilitate further identification, thus ensuring the participants' anonymity.

During the interviews, the first author (KK) remained observant of whether the participants were suffering any kind of distress. In some cases, it was obvious that participants' memories of their ICU stays were emotional. In such cases, participants were given a short break before the interview continued. Some patients who were still undergoing the rehabilitation process became visibly tired, which made it necessary to end the interview earlier than planned; however, the main themes had already been covered. The majority of participants had family members in the same house while the interviews were conducted, although those family members were not in close proximity and did not participate in the interviews.

A theme-based interview guide featuring open-ended questions was used, which allowed for rich and detailed data to emerge. An example of an open-ended question was "Can you tell me about situations where you were active in bed or out of bed?" Follow-up questions could include "can you describe how this happened?" or "how did you feel then?" The researcher questioned previously provided data throughout the interview for the purpose of validation and took field notes. The guide was developed by the first and fifth authors based on previous research, clinical experience and input from a user representative, a previous intensive care patient. In this process, preconceptions were identified. The guide (File S2) covered themes such as descriptions of situations in which participants were active, their interaction with the nurses and their experiences and reflections regarding their body, themes that aimed to highlight their narratives and experiences with early rehabilitation.

After the interviews, data regarding diagnosis, clinical frailty score, days in the ICU, days on the ventilator, and admission/discharge date were collected from local contact at the ICU with the patient's consent.

TABLE 2 Characteristics of participants at the time of the interview.

Age	Range	22–81
	Mean	61
	Median	67
Gender	Male	10
	Female	3
ICU admission diagnosis	Surgical (elective and acute)	6
	Sepsis	4
	Covid+	1
	Neurological	1
CFS (1–4)	Cardiac	1
	1	1
	2	3
	3	5
LOS, days	4	4
	Range	7–27
	Mean	16
	Median	14
LOVT, days	Range	0–24
	Mean	10
	Median	10
Weeks since discharge	Range	5–29
	Mean	18
	Median	16
Rehabilitation program	Usual care ^a	13

Abbreviations: CFS, Clinical Frailty Scale; LOS, length of stay; LOVT, length of ventilator treatment.

^aRoutine nursing care combined with individually customized physiotherapy 1–2 times a day.

Following the predefined inclusion criteria and within the designated timeframe, a total of 11 interviews were conducted consecutively. Throughout this process, the first, second and fifth authors continuously evaluated the informative strength provided by the various interviewees. An additional two interviews were carried out; however, they yielded limited new insights. Consequently, the sampling procedure concluded with a total of 13 participants. We employed convenience sampling, also referred to as availability sampling, which encompassed all individuals who met the inclusion criteria and willingly participated. To gauge the information richness inherent in the sample, we adhered to the recommendations of Malterud (2016). We determined our sample to possess a high degree of information power, attributable to the study's focused objective, the concentrated specificity represented within the sample and the application of theoretical frameworks during the analysis and the findings.

4.6 | Data analysis

The data were transcribed and systematized using NVivo software by QSR international, version 12, and were analysed using

systematic text condensation, a thorough four-step process of decontextualization and recontextualization inspired by phenomenology (Malterud, 2012). Step 1: To obtain an overview of the data, the first author read all the interviews multiple times. The second and fifth authors read most of the interviews, which led to a discussion and ultimately an agreement regarding possible preliminary themes. Step 2: The first author identified meaning units, i.e., pieces of fragmented text that were relevant to the research question. These meaning units were then sorted into preliminary themes, which were subsequently given names that described their content; these themes became the codes used in further analyses. Step 3: Based on the meaning units associated with each code, a condensate, i.e., a short artificial summary in first-person format, was written. These condensates were important and served as the foundation for the final step of the analysis. Step 4: The final step was a recontextualization, which involved putting the pieces back together again. An analytical text was produced, and a great deal of consideration was invested into the task of ensuring that all common features were highlighted while simultaneously allowing all stories to be heard. The text was validated by reviewing the transcriptions to ensure that no important themes were omitted. Specific quotations that illustrated the content were identified and included in the presentation of the results. Through discussions and workshops including the first, second and fifth authors, the final categories were given new names that described the content of the codes. Table 3 shows an example of the analysis of one category, and the progression of the analysis is visualized in File S3. The theoretical analysis (Malterud, 2016) was informed by concepts drawn from PTS and is elaborated in the discussion section.

4.7 | Ethical considerations

The study was conducted in accordance with the Declaration of Helsinki and was assessed by the Regional Committee on Health Research Ethics on 4 November 2020, where approval was deemed unnecessary according to national legislation (#179247). The study was further assessed and approved by the National Agency for Shared Services in Education and Research, and data privacy officers and department heads of each participating hospital.

4.8 | Rigour and reflexivity

In this qualitative study, rigour and reflexivity were obtained by our clear descriptions of all steps involved in the research process. Additionally, the use of theoretical concepts contributed to the preservation of methodological rigour and reflexivity (Jamie & Rathbone, 2022; Malterud, 2016) due to a theoretical generalization that may contribute to new knowledge.

Researcher triangulation based on various backgrounds represented in the author group (i.e., critical care nurses, physiotherapists, nurse managers and phenomenologists), allowed us to be open and

TABLE 3 Example of analysis – The category “from crises to reorientation”.

Overall impression: from disorder to preliminary themes	Meaning units: coding and sorting preliminary themes		Condensation: from codes to abstracted content		Synthesis: from condensation to descriptions, conceptions and results	
	Meaning units	Code	Subgroup	Condensation in the first person	Analytical text	Category
Preliminary theme						
Motivation	<p>“I have my life here waiting for me; I wanted to get back to it as fast as possible”</p> <p>“I want to get well, I want to walk again, I want to be able to get around”</p> <p>“I wanted to get back in shape... so that I could take care of myself”.</p> <p>“I did not want to be stuck in a bed. I thought about my grandkid, my kids and my husband”</p>	<p>Personal motivation and drive</p>	<p>Looking forwards</p>	<p>The most important thing was for me to get well so that I could take care of myself and return to my life at home and my family. I hoped for a worthy life because I had so much I wanted to do, and it wasn't an option to be confined to the bed. It was the little things that made me look ahead, like getting up and feeling my body functioning.</p> <p>Quotation: “It was liberating to get up. It made me start to feel that things were working and that things were getting into place in a way so that I could proceed to the next level (P9)”.</p>	<p>At a point in the course of their illness, it became clear to the participants that it was possible to look towards the future. Each of the participants described how getting back home and being able to take care of themselves was a tremendous motivation due to their ability to return to their house, family, friends and everyday life. One participant stated clearly that she had more to do in her life, that she had more to accomplish.</p>	<p>From crises to reorientation</p>
Decontextualization						
Recontextualization						

ask different questions regarding the interpretation of the material and understand the findings from different perspectives. Discussion about reflexivity was oriented towards personal, interpersonal, methodological and contextualized issues that arose during the research process (Olmos-Vega et al., 2023).

5 | FINDINGS

The analyses generated four main categories that described the patients' experiences, supported by direct participant quotes to highlight meaning and context.

- A foreign body
- From crises to reorientation
- Diverse expectations regarding activity
- Nurse–patient: A powerful interaction

5.1 | A foreign body

The interviews disclosed how the participants experienced the malfunctioning of their own bodies and the elements on which they reflected when looking at their bodies. They described a body that to some degree did not work, and one patient had the following example:

It is like a frozen computer. You press the button, but nothing happens. You can see that it is processing, but nothing happens (ID11).

A main feature of the interview material was the descriptions of the terrible feelings experienced when the participants looked at their arms and feet, urging them to move, but with no results. The patients frequently described how they felt by making reference to their phones; they were not able to use their phones for weeks because they could not hold them due to their weight, or they had forgotten how to use them.

The participants' feelings of weakness and tiredness arose instantly and were perceived as frightening; in addition, the decline of bodily energy was described as worrisome. One patient recounted the experience of exhaustion as follows:

I remember looking at the clock on the wall and following the second hand, but I was so exhausted that I couldn't follow it for 60 seconds. I just had to close my eyes and breathe (ID1).

Thoughts and descriptions regarding the appearance of their bodies emerged, and expressed astonishment about what they saw. They described seeing a skinny version of themselves and pointed out that they could see that their muscles had disappeared. One participant

recounted how the skin on his calves looked like an accordion. The visual difference was obvious to the participants, and it caused them to be concerned about the future, making them wonder whether they ever could return to their previous state.

I could almost see the difference from one day to the next day. I saw the muscles were gone, and I felt it too. You could see that the body kind of curled together... Normally, the body is connected, but at the end, it wasn't... That was tough for me (ID10).

Simultaneously, some participants expressed satisfaction with their weight loss, as overweight had been an issue for them in the past.

5.2 | From crises to reorientation

After waking up in the ICU and realizing their grave situation, the participants described emotional reactions such as fright and anger and a sense of failure. They recounted how they made a conscious choice to focus on staying in the present because worrying and thinking about what might happen in the future was either too difficult for them or felt useless.

A key aspect expressed by the participants was the acceptance of their situation during this early stage. They indicated acceptance of their non-functioning bodies, as well as the help on which they were dependent. Furthermore, they reported how they contained unwanted and negative thoughts concerning the difficult situation they were in. They accepted whatever was necessary, did as much as they possibly could and acknowledged that the process of returning to their previous condition would take time. One participant described this situation as follows:

If you are ill, you must accept the help you need and adapt to the situation... If I hadn't told myself that this was a temporary situation, I don't know how well I would have done that (ID6).

At a certain point in the course of their illness, it became clear to the participants that it was possible to look towards the future.

It was liberating to get up. It made me start to feel that things were working and that things were falling into place in a way so that I could proceed to the next level (ID9).

A common perception was the great motivation in the prospect of returning to their homes and regaining the ability to take care of themselves. Their house, family, friends and everyday life were considered important. One participant clearly noted that she had more to do in her life, more to accomplish. Another participant described his thoughts about the future as follows:

I wasn't going to let this rock in the road destroy the rest of my life. I was told my condition could last up to a year and I thought that one year out of maybe 80 years was nothing (ID11).

The experiences of small improvements and changes in both their environment and their functions were of great importance during this process. One example of improvements was getting rid of medical equipment, such as removing tracheostomies and catheters and requiring less monitoring. However, thoughts regarding their quality of life in the future also emerged. Concerns regarding whether their future lives would be worthy and acceptable lives were mentioned.

5.3 | Diverse expectations regarding activity

This category contains two opposing subgroups; on the one hand, patients recounted experiences of passivity, while on the contrary, multiple patients described their participation and cooperation between themselves and the nurse.

A common experience among participants pertained to the fact that they spent a great deal of time in bed. They described becoming dull, bored and ultimately restless while lying in bed. They were washed by others even though they might have been able to wash themselves. One participant made the following statement:

You're just lying there; there is nothing you need to keep up with. No one wants you to do anything (ID2).

Another procedure recounted by the participants pertained to situations in which they were lifted from the bed and placed into a chair. This process was easy and comfortable because they did not have to do anything themselves; it was also perceived as less work for the nurses.

You got very used to the routines. You got used to being lifted into the chair. I didn't react to it. I saw that getting up myself would be a lot of work, and I am a bit indolent. So I thought it was fine to avoid that... (ID2).

In contrast, there were descriptions of situations that involved participation and cooperation. The participants described how the nurses clearly communicated the expectations of the patients. Examples included requests for the patients to lift their heads, provide help while turning in the bed, use their hands to grab a hold and facilitate the movements as much as possible. The fact that the nurses clearly explained what was supposed to happen and how they could participate was important to the participants. One participant recounted the following:

Many times, they gave me the washcloth and asked me to wash myself. They explained that it was good exercise to do this myself (ID10).

Another prominent feature was descriptions of the cooperation that took place between the participants and the nurses in situations in which the patients were unable to perform tasks independently. Such situations could include shifts to an upright sitting position and grounding their feet, support while sitting on the bed, transfer training and ambulation. Nurses always had a hand on the participants to give them an adequate amount of support.

I needed help to sit up; there were two of them. They held me until I had grounded my feet on the floor, and I was ready to stand up. It was necessary (ID4).

5.4 | Nurse-patient: A powerful interaction

The interaction between the patients and the nurses emerged as a crucial part of the patients' experiences in the ICU. This interaction appeared to be important because it caused the participants to feel seen, made them feel safe and provided them with motivation.

It emerged as highly important for the participants to spend time with the nurses and become familiar with them. Being able to have a conversation with someone nearby helped the participants manage their thoughts and worries regarding the situation. Some participants also noted that this close interaction with the nurses caused them to want to work more diligently and put more effort into their training.

I felt like.... It was almost embarrassing not to be able to do it when you're around friends (ID4).

The participants experienced being closer to some nurses, particularly nurses who took an interest in the participants' lives by asking about their work, family or hobbies while simultaneously sharing some of their own everyday stories. There were accounts about how some of the nurses did things that were perceived as extra, i.e., as outside the scope of ordinary care. Examples of such actions were putting out a flag on birthdays, wrapping participants' feet the way they preferred at night and searching for suitable podcasts and helping participants listen to them. One participant showed his appreciation of the fact that the nurses followed him all the way to his new floor upon transfer and noted that this action made him feel that he received excellent care. Another interviewee made the following statement:

They wanted me to sit on the side of the bed, but I was terribly tired. The male nurse offered in a humorous way to sit shoulder-to-shoulder with me while he wrapped his arm around me. So in the end, I sat up for a while. I just had to laugh at the whole thing, but it was things like this that made a big difference for me (ID9).

Another experience mentioned was the atmosphere in the ICU, which was described as a relaxed atmosphere, despite participants'

grave situation. The nurse's calm appearance, laughter and jokes were perceived as positive.

Nurses who were positive, encouraging and motivated were also highlighted. There were plentiful descriptions of nurses who exhibited positive attitudes when the patients did not, nurses who cheered the patients on when they made progress, no matter how small. In addition, nurses who motivated the patients when the patients could not find their own motivation were appreciated, as described by one patient:

I didn't have the guts, so they transferred it to me.
I didn't have it... They just didn't give up; they were
dead set on what they believed in (ID10).

The feeling of safety that the nurses contributed was a common experience. The nurses were always around, and they were very attentive to what the participants might need. Even other personnel who were not involved with the participant on a given day could stop by, which was meaningful for the participants. One participant noted that he felt helpless but simultaneously received excellent care:

I felt that they were there all the time, that they were
there to take care of me (ID6).

Although the participants generally had positive experiences when interacting with the nurses, there was one notable instance of negative feedback: the participants frequently expressed a strong need for water. This thirst was either not recognized by the nurses or the nurses did not fully grasp its importance for the patients. This was a significant concern for the participants.

6 | DISCUSSION

Based on the findings, which are organized into four categories, two main aspects appeared to be important with regard to patients' ability to participate in early rehabilitation: (1) the close relationships among perceived bodily appearance, capacities and thoughts and (2) the embodied interactional and contextual factors.

The inability to move and do things was described by the participants as an obvious barrier to their participation in early rehabilitation, a result which is in line with previous findings (Falk et al., 2019; Schandl et al., 2017). In light of PTS, these experiences indicate changes in patients' sense of agency and sense of ownership, implying that both their bodily processes and prereflective experiential processes (the minimal self) are altered and may influence their thoughts negatively and restrict their orientation towards the environment, other people or participation. Furthermore, we argue that the patients' affordances (Gibson, 2015), i.e., their perceived possibilities for action, which the participants take for granted when healthy, are diminished in the ICU. Examples mentioned by several participants were their lost ability to move or their inability to use their cell phones. Corner et al. (2019) found that unexpected and

rapid deterioration of physical ability blur patients' selves, supporting the descriptions provided by our participants. Interestingly, our findings contained descriptions of a foreign body that indicate that patients adopt an observer-view towards their own bodies, a third-person view of their bodies, which is similar to previous reports of experiences of illness (Normann, 2021). This finding implies that patients' own bodies dominate their perceptual fields and prevent them from being fully oriented to their surroundings, which may to some degree block outwards orientation and attention. Accordingly, bodily dysfunctions are not merely biological dysfunctions (Hermans & Van Den Berghe, 2015; Zomorodi et al., 2012) but rather disturbances in the patients' intentionality and prereflective aspects of self. These processes can be physically strengthened through the activation of sensorimotor body functions, i.e., touch, actions and movements performed by the nurse, or especially in a cooperative process with the nurse, which may enhance the patient's sense of ownership and active participation, leading to increases in the patient's sense of agency and ability to orient outwards.

The participants' narratives revealed a transition in their thoughts and affective feelings from crises to acceptance and future orientation, which is consistent with previous findings regarding a recalibration of the self during recovery in the ICU and an inner will that helps patients reconstruct a desirable future (Alexandersen et al., 2019; Corner et al., 2019; Söderberg et al., 2020). Based on PTS, we can understand this acceptance phase as an activation and reorganization of the reflective and affective aspects that facilitates outwards orientation. The conscious choice to keep their thoughts in the present to avoid experiencing frightening thoughts regarding an unknown and uncertain future points to a pragmatic strategy, thereby highlighting the forementioned reorganization and this choice is thus a valuable illustration of the dynamic relations that are present within the self-pattern (Gallagher, 2013). We interpret the end of the transition described by the participants as returning function (improved body-schematic processes and a gain in the sense of agency) and the removal of medical equipment along the way (reorganizing the immediate environment) as a return of affordances (Gibson, 2015) that were diminished at an earlier stage in the course of illness. Our findings indicate that the nurses play a role in this transition process by providing verbal and physical support in terms of movements, including the example of the nurse sitting shoulder-to-shoulder with an arm wrapped around the patient. The significance for the patients may be a complex sense of the intersubjective relation with the nurse, an experienced success or "I can" in an activity such as sitting on the side of the bed, and a sense of shared agency. The nurse thus contributes to the patient's acceptance of the situation and accordingly supports outwards orientation and an increase in affordances.

The diversity of expectations communicated by the nurses regarding patient participation in activities in bed was interesting. As early rehabilitation contains an extensive line-up of activities (Doiron et al., 2018), there are several opportunities for including patient participation, including in functional tasks. Schandl et al. (2017) found that patient participation was dependent on the

nurse's ability to include patients in various care actions. Our findings illuminate variations in this ability; some patients were asked to wash their face and to try the best they could while the nurse supported them. Others described passivity, such that no expectations of active participation were communicated to them, despite the fact that they were able to participate in such activities. Being able to wash your own face is an example of an affordance that is often diminished due to illness but can easily be restored if the nurse includes the patient and provides the necessary adaptations, as the findings in this study show. The pivotal role of the nurse in the patients' recovery becomes evident based on a tailored amount of expectation, support and cooperation with the patient, i.e., in transfer training. To the best of our knowledge, the curricula designed for the education of critical care nurses covers little to no literature on early rehabilitation. Furthermore, the absence of national guidelines concerning early rehabilitation is evident. Thus, clinical practice may reflect a random variability in regard to patient participation, and may be an explanation for the diversity of expectations and the patients experienced.

Turning to the last main finding, there were plentiful descriptions of how the engaged interaction between patient and nurse increased the patients' effort and motivation to actively participate. A previous study showed patients' negative experiences in such interactions (Kisorio & Langley, 2019), and others identified the lack of both willingness and resources in the ICU as barriers to developing meaningful relations (Burns et al., 2018; Falk et al., 2019). Our findings contrast with these reports, as the participants highlighted the kindness, availability, engagement and personal contact they experienced while in the ICU. With respect to the intersubjective aspects of the self-pattern, we can interpret the meaning of the interactive relation as a way of strengthening the patient's embodied subject; the patient is encountered as a human being with a history, not merely as a physical body lying in a bed. Both our study and previous research (Falk et al., 2019; Schandl et al., 2017) agree on the importance of nurses' role in such interactions. However, by examining the social and intersubjective processes that are essential for reorganizing a self-pattern, we might deepen our understanding of the patient's role in this interaction. These intersubjective processes may be restricted by the patient's illness, bodily capacities, and medical equipment, thus conveying interactional challenges for the nurses, especially when the patient is unable to talk and move. Another aspect of the interaction that participants remembered and appreciated was when the nurses created a light-hearted environment by using humour. Combined with descriptions of nurses doing something extra, such as finding a suitable podcast or putting out a flag, we consider that in addition to intersubjective processes, ecological processes are also enabling elements for partaking in early rehabilitation. The nurses may strengthen the patients' relations to the environment and shape their narrative about the future by bringing in familiar and meaningful objects or initiating conversations about family and home, resulting in the outwards orientation that is necessary to optimize recovery.

6.1 | Strengths and limitations of the work

Several different authors contributed to the interpretations and discussions throughout all phases of the study, which may be viewed as a strength of this work in regard to the complex issue that subjectivity poses to qualitative research. Transferability might always be a limitation in qualitative research; however, by applying theoretical concepts of a general character, such as PTS, we seek to provide insights that are recognizable and of relevance within the ICU field in general.

We consider the fact that this research included participants who varied in terms of age, gender, Clinical Frailty Scale and various amounts of time spent in the ICU and on the ventilator, including patients who were drawn from three different ICU units, to be a strength of this work. Face-to-face interviews were preferred due to the confidentiality and calmness they provided, which we considered to be important for such vulnerable patients. When dealing with a vulnerable group of patients such as this, a limitation to consider is that there might be an inclusion bias. Patients with illness, little resources and negative experiences in the ICU might not make contact to participate, possibly yielding a sample dominated by positive experiences. Another relevant limitation is that patients might not have a memory of their ICU stays (Chahraoui et al., 2015). During interviews, there were occasionally themes that the participants did not remember well, but overall, it was not perceived as a challenge. The disparity between invited patients and those who actually participated poses a limitation to this study. Including patients immediately after intensive care hospitalization was equally challenging as inviting letters after discharge. It is important to acknowledge the challenges of including critically ill patients in research, as highlighted by Dahlberg et al. (2020). Further investigation into this area is warranted. Returning the interviews for member check was not an option due to a presumed decontextualization from the interview situations and respect for participants who still showed various impairments following their critical illnesses.

Utilizing PTS as a theoretical framework allowed us to produce valuable insights. The findings, however, indicate a complex interaction between patient and nurse, a joint creation that results in something more than either party could achieve individually. We believe that these findings imply a kind of co-construction of meaning that is undeveloped in the context of PTS and requires additional research.

6.2 | Recommendations for future research

In future research, it would be useful to explore *how* nurses can tailor their expectations and to identify necessary considerations for doing so. Furthermore, the importance of interaction suggests further investigations into the precise nature of the interaction between critical care nurses and patients while performing early rehabilitation in the ICU.

7 | CONCLUSION

The aim of this study was to explore patients' experiences with early rehabilitation in ICUs, particularly focusing on aspects that might have influenced their ability to participate in this process. We found that bodily dysfunction influenced patients' perceptual fields and thoughts, causing disturbances in their prereflective processes that restricted their orientation towards the environment and other people, thereby influencing their ability to participate. The described re-orientation from crises to being able to focus in a forward direction is a necessary step in rehabilitation that can be supported by nurses through verbal and hands-on interactions alongside the initiation of shared agency between nurse and patient. Furthermore, nurses should communicate adequate expectations to patients to enhance their participation in early rehabilitation. Finally, we found the interaction between nurses and patients to be very important because it allows nurses to understand and support patients' self-reorganization and outwards orientation during their recovery through means such as personal contact, humour and environmental factors.

By using PTS as an interpretative approach, the analysis revealed that embedded in all four categories, patients' embodied intentionality (especially their sense of agency), their capacities for outwards orientation and engagement with affordances and other persons, appeared as fundamental for patient participation and for the improvement in function that accompanied that participation. Thus, nursing practice in this area should enhance bodily, contextual and interactional aspects that enable the patient to orient themselves to outwards engagement.

AUTHOR CONTRIBUTIONS

All the authors have agreed on the final version and meet at least one of the following criteria (recommended by the ICMJE*): (1) substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data; (2) drafting the article or revising it critically for important intellectual content.

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There are no conflicts of interest.

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DATA AVAILABILITY STATEMENT

Data available on request due to privacy/ethical restrictions.

ETHICS STATEMENT

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ORCID

Karina Knutsen  <https://orcid.org/0000-0003-2338-3844>

Rita Solbakken  <https://orcid.org/0000-0002-3047-7155>

TWITTER

Karina Knutsen  karinaknutsen1

Rita Solbakken  FSHNord

Shaun Gallagher  Norduniversitet

Ranveig Trondsen Müller  RanveigTMuller

Britt Normann  nlsh01

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