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Innovating physiotherapy practice

for patients admitted to the Intensive Care Unit and their relatives

Karin Marie Felten-Barentsz

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geboren op 30 juni 1983
in Grave

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according to the decision of the Doctorate Board
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Friday, June 20, 2025
at 12:30 pm

by

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Chapter 1

General introduction

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Physiotherapists have a role to play in substantiating and demonstrating the quality of physiotherapy care.[1] In this professional profile, the practice of the physiotherapist is outlined through seven roles, derived from the Canadian Medical Education Directives for Specialists (CanMEDS) 2015 model.[2] Each role comprises specific competencies, categorized into interconnected components of 'knowledge', 'skills', and 'attitude'. Every physiotherapist is required to master all competencies associated with these roles to enable their application in professional practice. Moreover, adaptability is crucial, as physiotherapists must assume these roles in diverse combinations, tailored to the practical context. The identified roles include: 1) Care Provider, 2) Health Promoter, 3) Collaborator, 4) Organizer, 5) Reflective Professional, 6) Innovative Professional, and 7) Communicator.[1]

During my daily work as a physiotherapist and physiotherapy scientist working at the Intensive Care Unit (ICU) of an academic hospital, I assume these seven roles in diverse combinations, dependent on the practical context. But the emphasis lies on my role as an innovative professional. In this role, the physiotherapist contributes to innovation in healthcare in general and specifically within the field of physiotherapy. The physiotherapist identifies, analyses, and interprets organizational, professional, and scientific developments in healthcare, with a special focus on physiotherapy, and shares these with colleagues. Actively participating in initiatives for innovation and/or improvement of (physiotherapy) care is a key aspect of this role. It is the responsibility of the physiotherapists to apply and implement relevant innovations in their own practice. The competencies for an innovative professional, in line with the CanMEDS, encompass:[1,2]

1. The physiotherapist identifies (opportunities for) innovation based on the evolution of the profession, field needs, and personal professional development, aiming to identify, formulate, and substantiate improvement suggestions.
2. The physiotherapist applies innovations, alone or in collaboration with partners, as relevant and meaningful, with the goal of enhancing (physiotherapy) care in both short and long terms, addressing both content and organizational aspects.
3. The physiotherapist reads and interprets professional and scientific information, applying it where relevant to ensure that physiotherapy care is as current, efficient, and effective as possible.
4. The physiotherapist analyses the innovation and its application possibilities, considering the patient and environment, to implement the innovation in an efficient and safe manner.
5. The physiotherapist participates in scientific research and applies findings from research to enhance the quality of physiotherapy care and position the field of physiotherapy in society.

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As a physiotherapy scientist I realize that there is a constant need for new knowledge, now and in the future, to ensure the provision of high-quality care. Therefore, I aim to go one step further than the role as innovative professional, by proactively initiating, researching, and implementing initiatives for innovation and/or improvement of (physiotherapy) care. In this combined role as practitioner and scientist, which I coin as the innovative physiotherapy scientist, I hope to generate meaningful scientific knowledge and contribute to evidence based practice that aligns with the practical needs of physiotherapists and other healthcare professionals at the ICU.

QUALITY OF CARE

Not just in the field of physiotherapy, but throughout the whole healthcare field there is a growing need for substantiation and transparency of quality of care. Quality of care is determined by safety, timeliness, efficiency, effectiveness, equality, and patient-centeredness.[3] The importance of substantiating and demonstrating the quality of care, is also relevant for the physiotherapy profession, as it becomes imperative for its inclusion in the broader continuum of care.[1] Within the realm of physiotherapy, evidence-based practice has played an important role to guarantee the quality of care by weighing scientific evidence, clinical expertise, and patient preferences.[4-6] In this evidence-based practice process, also factors related to (practical) applicability and cost-effectiveness,[7] as well as the context of the patient, physiotherapist, and environment[8] are considered. From this perspective, scientific evidence serves in every decisional process as the starting point;[1] also at the intensive care unit (ICU).

PHYSIOTHERAPY AT THE ICU

Improvements in medical care have increased the survival rates of patients admitted to ICUs. Consequently, there is a growing population of patients experiencing long-term physical, cognitive, and/or mental impairments, also known as “post-intensive care syndrome” (PICS).[9] Up to 40% of patients admitted to the ICU develop severe muscle weakness and reduced exercise tolerance.[10] This can lead to major physical impairments, usually denominated as intensive care unit-acquired weakness (ICU-AW). ICU-AW 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*”.[11] ICU-AW is caused by disfunction or damage of the muscles (critical illness myopathy), nerves (critical illness neuropathy), or both (critical illness neuromyopathy) and affects skeletal, trunk and respiratory muscles.[12] It hinders patients’ capacity to preform functional activities and weaning from mechanical ventilation.[13,14] Presently, there is no effective treatment for ICU-AW. However, preventive measures have been outlined, including the avoidance of hyperglycaemia and exposure to parenteral nutrition, minimizing sedation, and providing early mobilization.[12,14]

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The abovementioned interventions are typically addressed by the multidisciplinary team at the ICU with the goal to optimize care for the ICU patient. Physiotherapists play a role in these multidisciplinary teams. The objective of ICU physiotherapy care is to assess, rule out, and, where possible, prevent, monitor, and treat functional impairments and limitations related to the physical and respiratory functioning of patients admitted to an ICU.[15,16] Additionally, physiotherapists frequently guide patients and their relatives through the unfamiliar and often stressful ICU environment. Relatives may also experience mental health symptoms, defined as PICS-family (PICS-F), possibly impacting their life for years.[17] Enabling relatives to participate in essential care activities may decrease relatives' stress and anxiety and might prepare them for their role as informal caregivers after ICU discharge.[18,19]

Physiotherapy interventions, recognized as feasible, safe, and broadly considered beneficial, are widely implemented in the ICU aiming to prevent patients from deconditioning during ICU stay.[20-23] Physiotherapists play an important role in the early progressive mobilisation practice for mechanically ventilated patients, by preventing movement disorders and physical complications in critically ill patients. Even though the benefits of physiotherapy at the ICU have been reported in systematic reviews,[23-26] discussion about the effectiveness of early mobilization interventions remains. For example, recently, two large trials (TEAM trial, STAND trail) did not demonstrate that early mobilization interventions improved overall mobility among mechanically ventilated patients.[27,28]

Physiotherapists in the ICU prioritize clinical care, but a culture of ongoing innovation and optimization prevails. At Radboudumc, physiotherapists collaborate closely with academic healthcare professionals, necessitating an understanding of the complex ICU context for innovation and evaluation. Challenges include a heterogeneous patient population with multimorbidity and various influencing factors, making randomized controlled trials (RCTs) challenging due to high risk of bias. To conduct an RCT, rigorous analysis involving blinding, contamination control, and randomization are all essential.[29] Most of the (R)CTs of early mobilization at the ICU had methodological shortcomings, such as small sample sizes,[30-32] single-centre designs,[32,33] and use of historical controls.[33] These limitations may lead to inaccurate assessments about the value of early mobilisation and rehabilitation on the ICU.[29] In other words, the evidence-based practice paradigm, informed through RCTs, may not be the optimal approach to inform clinical decision making in the complex ICU environment.[34]

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CONTEXT BASED INNOVATIONS

Another approach than evidence-based practice to generate and disseminate knowledge, is the more learning-based approach of context-based practice.[8] Because of the importance of the specific context, the patient, and the setting where the various sources of knowledge are used as the basis for the decisions that are taken.[8] To implement healthcare innovations, for instance at the ICU, context-based feasibility studies with sound qualitative or mixed-methods research approaches are recommended.[8] In these types of studies there should be a close collaboration with direct and indirect stakeholders. Ideally, stakeholders would also need to be involved in study ideation and conceptualisation. Through my role as an innovative physiotherapy scientist, I have derived the following four specific areas for context-based innovations from discussions with healthcare professionals, patients, and their relatives:

1. *Hydrotherapy* (as a mode to stimulate early physical activity for people who are too weak to walk);
2. *Family participation* (as a strategy to optimize rehabilitation by involving close relatives in therapy);
3. *Upper Extremity Rehabilitation* (as a strategy to increase upper body strength as this is frequently overlooked during the rehabilitation process), and;
4. Recommendations and guidance for physiotherapy care *during a pandemic* (as a means to optimize the clinical care routines by physiotherapists at the ICU dealing with patients with COVID-19).

In this thesis, I primarily focus on developing and/or exploring the feasibility, safety, applicability, and merit of these four innovations using methodologically sound experiments as a basis for learning and deriving insights.

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AIM AND OUTLINE OF THIS THESIS

The overarching aim for this PhD-thesis is to investigate several aspects of innovating ICU physiotherapy care. To realize this aim, we conducted eight studies using various scientific research methods in four potential fields.

Chapter 2 and 3: Innovating ICU physiotherapy care through hydrotherapy
In December 2012 the Radboudumc was the first hospital worldwide that opened a specially designed swimming pool for the early mobilisation of critically ill ventilated patients. The idea was simple: in case patients are unable to walk due to ICU-AW, the upward force of the water may help these patients to stand and walk in the pool. In **Chapter 2**, we aim to describe the safety- and feasibility of hydrotherapy in critically ill ventilated patients. In this study we present our experiences with this novel and innovative early mobilisation intervention.

In **Chapter 3** we describe a qualitative study to investigate patient experiences, using a generic phenomenological approach, to understand the impact of hydrotherapy in critically ill ventilated patients.

Chapter 4, 5 and 6: Innovating ICU physiotherapy care through family participation
During physiotherapy interventions, patients' relatives play an essential role. They often want to participate not only during physiotherapy interventions such as hydrotherapy and early mobilization, but also during essential care activities. Both patients and relatives may benefit from family participation in essential care activities. In this thesis, we want to learn from the experiences of patients, relatives and the wide variety of professionals that are involved in family participation at the ICU.

In **Chapter 4** we aim to identify the needs and perceptions regarding family participation in essential care in ICUs from the patients', relatives' and ICU healthcare providers' perspective using an integrative review design. Findings of this review should be addressed in the development of an intervention that enables family participation in essential care.

In **Chapter 5**, we aim to systematically review interventions and outcomes regarding family participation in essential care in the ICU. The review contributes to further insight into interventions aiming at family participation in essential care activities in the ICU and their outcomes. To gain a comprehensive understanding of existing interventions and outcomes when relatives participate during essential care activities, this study is performed from a multi professional perspective.

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In **Chapter 6**, we focus more specifically on family participation during physiotherapy related activities such as massage, passive limb exercises and assisting with mobilisation. Using a grounded theory approach, we aim to gain insight into the needs, beliefs, feelings and behaviour over time of closest-relatives of ICU-patients regarding participation in physical activity promotion during ICU stay. This study could give healthcare providers tools to adapt their own attitude towards the needs of relatives during participation in physical activities.

Chapter 7: Innovating ICU physiotherapy care through implementing an Exercise Box for Upper Extremity Rehabilitation

Hydrotherapy, early mobilisation and family participation during physical activities, usually target the lower extremities. The prevention of further functional decline of the upper extremity during ICU admission could be limited by active exercise therapy as well. We developed a patient-related exercise box with exercise material to allow patients to practice their upper extremities during ICU-stay. In **Chapter 7**, we aim to investigate the feasibility of implementing this exercise box in daily ICU practice. Using a mixed-methods feasibility study, we focus on three key areas of feasibility in terms of demand, acceptability, and limited efficacy testing.

Chapter 8a and 8b: Recommendations and guidance for physiotherapy care during a pandemic

During the COVID-19 pandemic, there was an enormous need for guidance for the (physiotherapy) treatment of patients with COVID-19. Physiotherapists have a crucial role in supporting hospitalized patients with COVID-19 and need to be aware of the challenges when treating these patients. In **Chapter 8a**, using a pragmatic guideline development approach, we aim to provide guidance and detailed recommendations for physiotherapists managing patients hospitalized with COVID-19 through a national approach in the Netherlands. The development of this guideline was given priority because combing the latest scientific insights with expert opinions could provide clarity and guidance and increase safety in uncertain times. We have updated this guideline in **Chapter 8b**, to provide physiotherapists with up-to-date recommendations based on the latest clinical insights, scientific literature and best practices in the Netherlands that are feasible and acceptable in daily practice.

Chapter 9: Evaluating implementations in ICU physiotherapy care

This thesis concludes with a general discussion in **Chapter 9** which summarizes the main findings and describes the methodological considerations of this thesis. I also discuss what evidence is needed to change/optimize ICU physiotherapy care and provide recommendations for clinical practice.

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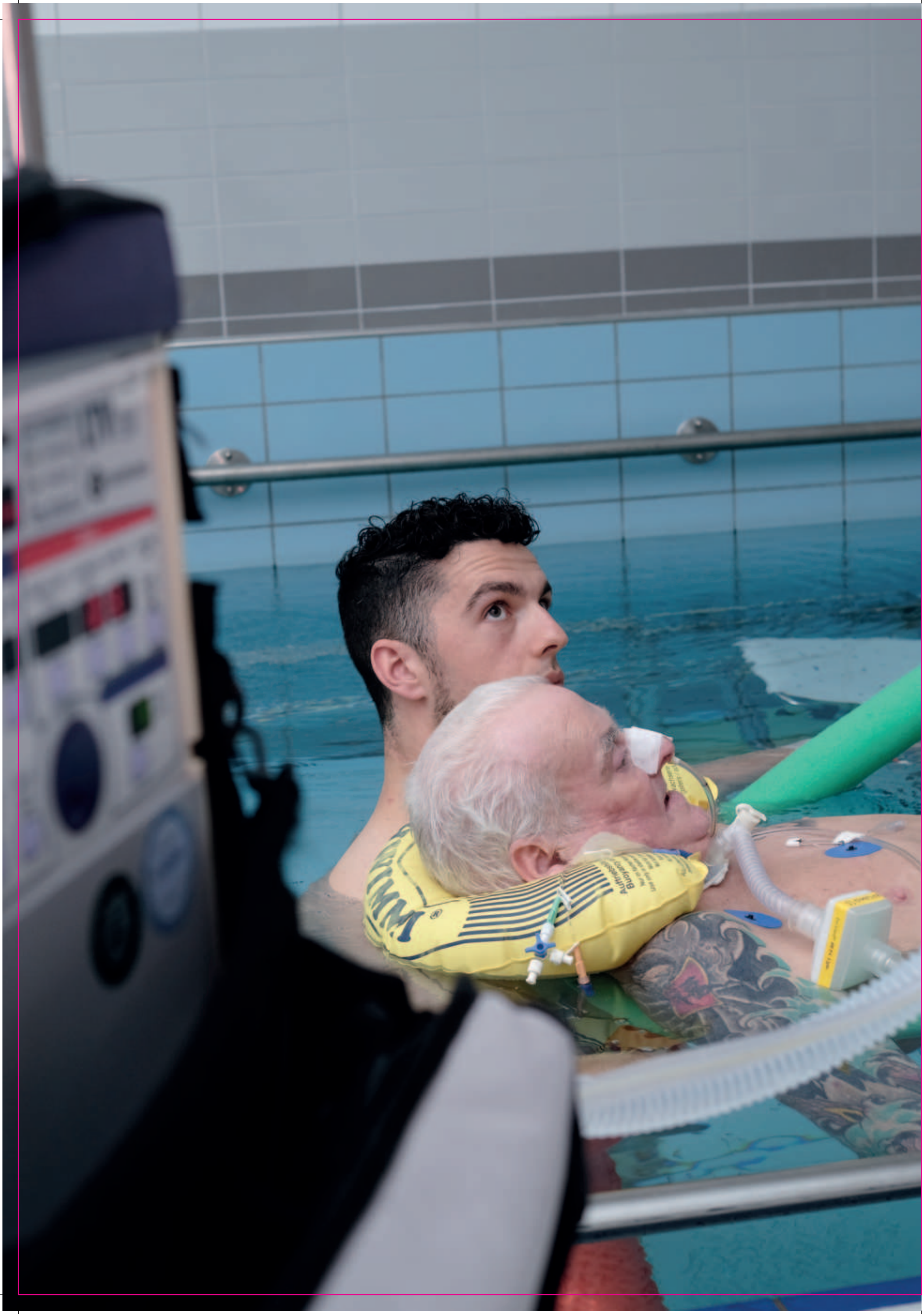

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Chapter 2

Feasibility and safety of hydrotherapy in critically ill ventilated patients

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INTRODUCTION

Early mobilization can improve outcomes in critically ill ventilated patients.[1] Although preliminary data suggest that mobilization in a swimming pool (hydrotherapy) may enhance rehabilitation in very weak patients (e.g., congestive heart failure[2] and multiple sclerosis[3]) because of the reduced gravitational forces, there are challenges and potential safety issues when applied to ventilated patients. In this study, we report feasibility and safety of hydrotherapy in critically ill, ventilated patients.

MATERIALS AND METHODS

Setting

In 2010, the 35-bed adult intensive care unit (ICU) of the Radboudumc hospital implemented a slightly modified Morris early mobilization program.[4] In 2012, a dedicated pool (maximum depth, 1.35 m; total volume, 30 m^3) with a movable floor became available.

Participants and recruitment

Ventilated patients admitted to the medical, surgical, or thoracic ICU were eligible for hydrotherapy if they were severely weak (inability to stand upright despite support by physiotherapist) and were able to respond to verbal commands. Exclusion criteria included high ventilator support (fractional inspired oxygen > 0.6; positive end expiratory pressure > 10 cm H_2O; inspiratory support > 15 cm H_2O), vasopressors, large wounds, severe agitation, and colonization with multiresistant bacteria. Patients and primary decision makers were informed about the novelty of the therapy and potential complications. Formal informed consent was waived by the Radboudumc ethics committee. Patients were screened prospectively for eligibility.

Hydrotherapy session

Before hydrotherapy, any central venous catheters (internal jugular vein) and arterial catheters (radial artery) were disconnected and covered with transparent dressing (Tegaderm; 3M, St. Paul, MN) and secured with elastic bandage (Elastomul,Hamburg,Germany). During transfer and hydrotherapy, patients were ventilated with a portable ventilator (LTV 1000; Carefusion, San Diego, CA), using pressure support mode. Pulse oximetry and heart rate were monitored using a handheld device with finger clip during transport, and during hydrotherapy the pulse oximeter was used only as needed, based on clinical judgment. An individualized program for hydrotherapy was designed for each patient and could include standing, walking, moving upper extremities, and back stroke swimming. The mobility team included two ICU nurses, a physical therapist, and a physician.

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Registration of complications and water quality

The following adverse events were reported prospectively: tachycardia (>100 bpm), bradycardia (<60 bpm), peripheral oxygen saturation lower than 90% while on ventilator, and accidental removal of arterial catheters, central venous catheters, or artificial airway. To assess water quality, samples were obtained twice daily for biochemical analysis (chloride and pH) and at least once per month for cultures, according to Dutch law.[5]

RESULTS

Between July 2012 and October 2013, a total of 3,686 patients were admitted to our ICU. After excluding patients admitted after elective uncomplicated surgery and all patients admitted to the neuro-ICU, 259 patients were evaluated for hydrotherapy. Twenty-five patients received at least one hydrotherapy session in addition to the regular early mobilization program. Reasons for not receiving hydrotherapy

Table 1 Patient characteristics at ICU admission and during first hydrotherapy session

N	25
Male	72 %
Age, years	61 ± 16
BMI, kg/m^2	26 ± 5
Cardiovascular failure	16 %
Sepsis	16 %
Neurological disorders	8 %
Mean APACHE-2	19 ± 5
ICU mortality	20 %
First hydrotherapy session	
Days on ICU	34.8 (3-99)
Days on ventilator	33 ± 25
Tracheostomy	76 %
PEEP, cmH$_2$O	6.7 ± 1.7
Fio$_2$	0.40 ± 0.03
Spo$_2$, %	97.8 ± 1.9 *
Pao$_2$/Fio$_2$ ratio, mmHg	260 ± 72 **
Radial arterial catheter	80 %
Central venous catheter (jugular)	16 %
Foley catheter	100 %

*Abbreviations: Variables are mean ± SD or (range), PEEP; Positive End Expiratory Pressure, Fio2; Fractional inspired Oxygen, Spo2; Pulse Oximeter Oxygen Saturation, Pao2; Partial pressure of oxygen in arterial blood. * Missing value: 1, ** Missing value: 6*

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were failure to meet inclusion criteria (mostly not being severely weak) or meeting exclusion criteria and limited availability and logistical reasons.

Total duration of one hydrotherapy session was approximately 60 minutes, including briefing, transportation to the pool, patient preparation at poolside, hydrotherapy, showering, and transportation back to the ICU. The movie shows a representative patient during hydrotherapy (see Movie E1 in the online supplement). Reasons for ICU admission and other patient characteristics are given in Table 1.

Five patients died while in the ICU. In four patients, active treatment was withdrawn on the patient's request. In one patient, further treatment was deemed futile because of metastatic carcinoma not responding to chemotherapy. No complications as defined here were reported during transport or hydrotherapy. In the study period, microbiological analysis was performed 17 times. Biochemical and microbiological analysis of pool water demonstrated that water quality met standards as dictated by the Dutch law at all times (Table 2).[5]

Table 2 Characteristics of the hydrotherapy sessions and water quality

Duration per session, mean (range), minutes	**29.6 (15-40)**
Type of exercises*	
Moving extremities in supine position	72 %
Swimming back stroke	12 %
Sitting	36 %
Standing	64 %
Walking	56 %
Rate of complications (95% confidence interval)	0 % (0-4.1 %)
Number of sessions during intensive care unit stay	88
Median (IQR)	2 (1-3)
Mean (range)	3.5 (1-20)
Microbiological screening of pool water (17 samples in 15 months)	
Coagulase negative staphylococcus	2 (1 and 2 cfu)
Gram negative rods, not pseudomonas	2 (43 and 27 cfu)
Nonfermative gram negative rods	3 (51, 22 and 55 cfu)

* Exercises could be combined during one session.

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The duration of each hydrotherapy session was determined by the physiotherapist, based on the development of fatigue. None of the sessions was discontinued because of safety issues or adverse events. Although not systematically analyzed, patients and their loved ones highly appreciated the hydrotherapy sessions. None of the patients refused subsequent hydrotherapy sessions.

DISUSSION

This is the first report describing the feasibility and safety of hydrotherapy in critically ill mechanically ventilated patients. The most important finding is that hydrotherapy appears to be safe in a selected group of ventilated ICU patients. It should be acknowledged that hydrotherapy was performed in a university hospital with extensive experience with early mobilization in ICU patients. No patient reported discomfort or exhibited severe oxygen desaturation or hemodynamic instability. No interventions were needed to improve hemodynamics.

In addition to immediate complications, transmission of infections through contaminated water was an initial concern. However, microbiological screening of pool water did not reveal any relevant contamination.

CONCLUSION

In conclusion, hydrotherapy appears to be a feasible and safe intervention in selected critically ill ventilated patients. Future studies are needed to evaluate potential clinical benefits and cost-effectiveness.

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Chapter 3

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

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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]

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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 in order 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

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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 physical therapists who specialise in the field of intensive care medicine. Bracketing was trained during three test-interviews in order to ensure transcendental subjectivity.[30]

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?
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?

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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.

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.

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.

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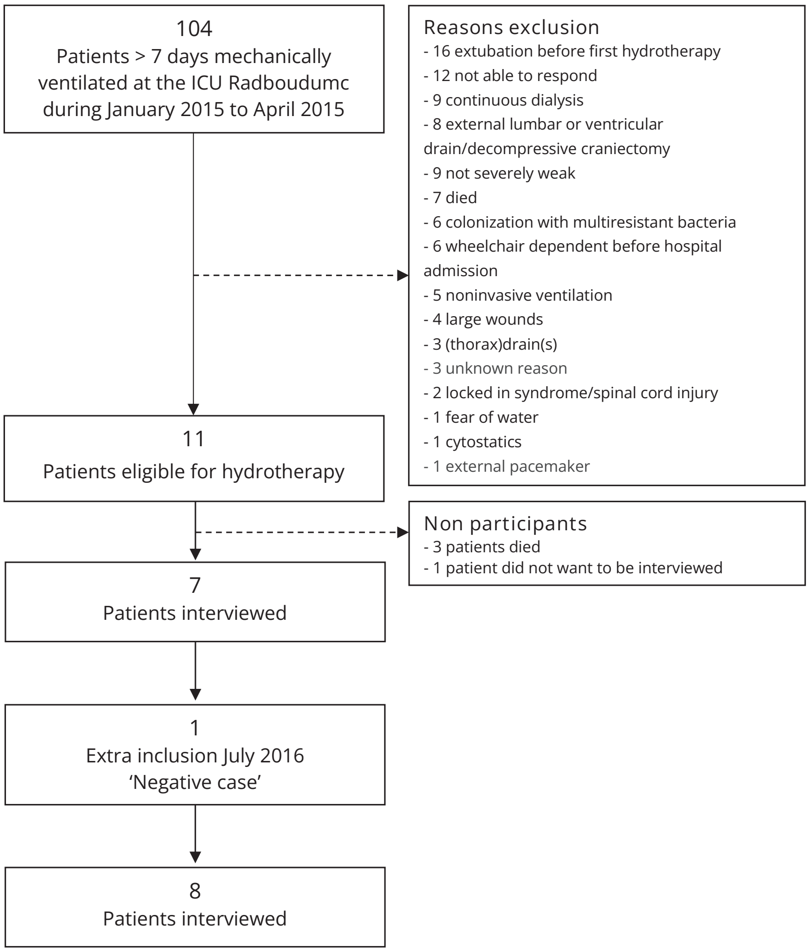

Figure 1 Flowchart patient inclusion and selection

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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)	Hospital length of stay (in days)	Number of HT- sessions	Interview
1*	M	80	30	19	Coronary artery bypass grafting	42	42	75	8	-
2	M	70	28	24	Ventricular septal defect repair	29	29	44	2	+
3	F	44	30	17	Respiratory failure in alveolar lung pattern	20	20	49	3	+
4*	M	75	17	18	Complicated esophageal resection with gastric tube reconstruction	22	22	22	4	-
5	M	72	29	24	Surgery for Gastrointestinal rupture	38	38	49	3	+
6	F	33	23	9	Exacerbation asthma	40	36	56	3	+
7	F	49	30	28	Pneumonia in a patient with COPD GOLD 4	22	22	28	1	+
8	M	63	28	16	Chest/extremity trauma, surgery for HET with external fixation lower leg	33	32	74	11	+
9*	M	69	20	21	Out of hospital cardiac arrest, complicated with ARDS and lung fibrosis	85	69	85	9	-
10	F	70	22	28	Stem cell transplant in non-Hodgkin Lymphoma Complicated with pneumonia	39	32	34	3	-
11	M	65	25	26	Respiratory failure after cardiac surgery	53	29	72	8	+
12	F	73	25	#	Chest/extremity trauma, surgery for HET. Recovery complicated with ARDS, delirium, and severe ICUAW	98	17	119	8	+
Totals **Mean (SD)**	7 males 5 females	64 (14)	26 (4)	21 (6)	3 Cardiac surgery 3 Pulmonary disease 2 High energetic trauma 2 Gastro-intestinal surgery 1 Out of hospital cardiac arrest 1 Complicated stem cell transplant	38 (29)	27 (18)	59 (27)	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; COPD=Chronic Obstructive Pulmonary Disease; GOLD=Global initiative for chronic Obstructive Lung Disease; HET=High Energetic Trauma ARDS=Acute Respiratory Distress Syndrome; ICUAW=Intensive Care Unit Acquired Weakness; # = missing; * = Patient died during hospital-stay;*

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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.

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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 lying 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 liters 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 physical therapists 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)

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Table 3 Themes and exemplifying patient quotes (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 relating 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)

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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

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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

Physical therapist	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

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Supplement 2 Patient descriptions

Patient no. 1 was treated after coronary artery bypass grafting (CABG) complicated by pulmonary oedema. 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 oesophageal 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 physical therapist 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.

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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 physical therapist 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 physical therapist two times a week for physical training. He felt very tired compared to prehospital 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.

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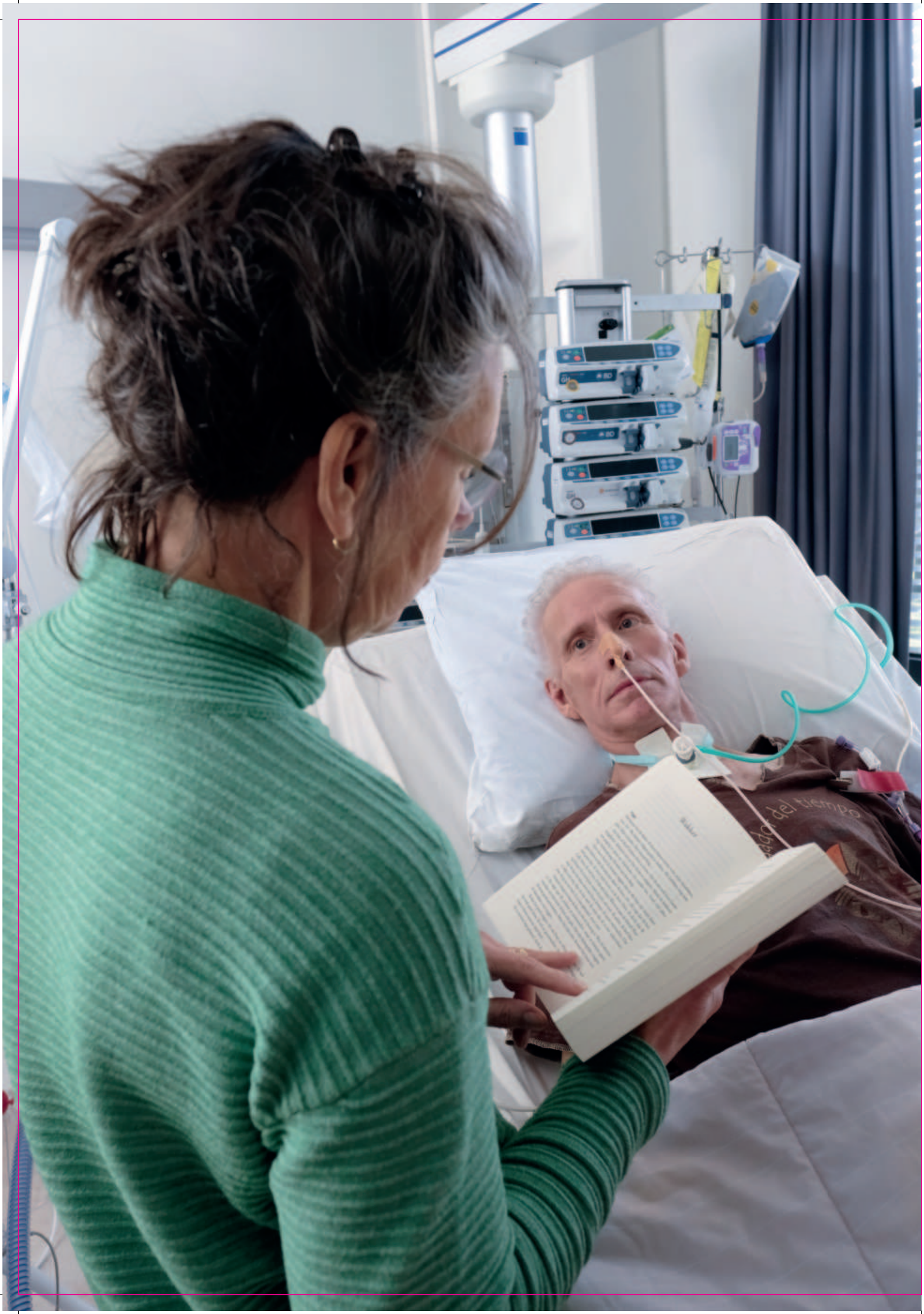

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Chapter 4

Family participation in essential care activities: Needs, perceptions, preferences, and capacities of intensive care unit patients, relatives and healthcare providers

An integrative review

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ABSTRACT

Background

Family participation in essential care activities may benefit both patients and relatives.

Objectives

In this integrative review, we aimed to identify needs, perceptions, preferences and capacities regarding family participation in essential care in intensive care units from the patient's, relatives' and ICU healthcare providers' perspective.

Methods

We searched PubMed, CINAHL, EMBASE, MEDLINE, Cochrane, Web of Science, and reference lists of included articles, from inception to January 25, 2021. We included studies on family participation in essential care activities during ICU stay which reported associated needs, perceptions, preferences and capacities. Quality assessment was performed with the Kmet Standard Quality Assessment Criteria developed for evaluating primary research papers in a variety of fields, and an extensive qualitative thematic analysis was performed on the results.

Results

Twenty-seven studies were included. Quality scores varied from 0.45 to 0.95 (range: 0-1). Patient's needs, perceptions, preferences and capacities, are largely unknown. Identified themes on needs and perceptions: relatives' desire to help the patient, a mostly positive attitude among all involved, stress regarding patient safety, perceived beneficial effects, relatives feeling in control - ICU healthcare providers' concerns about loss of control. Preferences for potential essential care activities vary. Relatives want an invitation and support from ICU healthcare providers. Themes regarding capacities: knowledge, skills, education and training, and organisational conditions.

Conclusions

Implementation of family participation in essential care requires education and training of relatives and ICU healthcare providers, to address safety and quality of care concerns, though most studies lack further specification.

Keywords

Intensive care unit, essential care, family participation, family centred care, relatives

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INTRODUCTION

A stay in the Intensive Care Unit (ICU) is stressful for patients. It has been estimated that 50% of ICU survivors suffer from post-intensive care syndrome (PICS), which includes impairments of physical, cognitive or mental nature. Physical problems include neuromuscular, physical and pulmonary function and ICU-acquired weakness; cognitive problems include attention, memory, planning, processing, problem solving, and visual-spatial awareness; and psychologic problems include anxiety, symptoms of depression, sleep disturbances and symptoms of posttraumatic stress disorder (PTSD).[1,2] An ICU stay is also stressful for the patient's relatives[3] and can lead to feelings of anxiety and powerlessness.[4,5] In 13-56% of relatives, symptoms such as anxiety, depression and PTSD were reported in this population in the first months after the patient's ICU discharge. These symptoms are known as post-intensive care syndrome-family (PICS-F) and have a negative impact on quality of life, resumption of work, and healthcare costs.[6,7] This implies a large impact on both patients and relatives.

Family participation in essential care activities has been suggested to decrease stress during an ICU stay as it increases the patient's feeling of safety.[8] For relatives the opportunity to actively participate in ICU may diminish feelings of powerlessness and decrease the chance of developing PICS-F after discharge.[6] Furthermore, family participation may support relatives in other ways. However, knowledge on the effect of family participation on relatives is still scarce. Olding et al.[9] have described family involvement in ICU as a continuum, ranging from relatively passive ('presence') to active forms ('contribution to care'). They define 'contribution to care' as family participation in essential patient care activities.[9] Relatives may participate in, for example, communication, application of lotion, bed bathing or mobilization, referred to as essential care activities.[10] Family participation in essential care is, however, a complex intervention, as it requires a change in behaviour in both ICU healthcare providers and relatives and needs to be tailored to individual needs.[11] Therefore, a first step in the development of this intervention is to determine the needs and perceptions and the preferences and capacities of patients, relatives and ICU healthcare providers regarding family participation in essential care.[12] Needs and perceptions address why relatives may need family participation and how they experience it; preferences and capacities address the suggested solution: which activities and which conditions.

While guidelines for family centred care (FCC)[13] and several reviews have been published,[9,14-18] implying an increased focus on patient, family centred care (PFCC),[19] none of these reviews addressed needs, perceptions, preferences and capacities with regard to family participation from the perspectives of all involved. Therefore, the aim of this integrative review was to identify needs, perceptions, preferences and capacities related to family participation in essential ICU patient care, from the patient's, relatives' and ICU healthcare providers' perspective.

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METHODS

An integrative review of the literature was conducted, allowing the inclusion of qualitative and quantitative studies,[20] in accordance with the Cochrane Handbook for Systematic Reviews of Interventions.[21] This integrative review was reported in concordance with the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) statement.[22]

Search strategy

A search was performed in PubMed, CINAHL plus (EBSCO), EMBASE (OVID), MEDLINE (EBSCO), Cochrane and Web of Science from inception to January 25, 2021 for relevant articles. Key search terms included 'family', 'relatives', 'intensive care', 'critical care', 'critical care nursing', 'family nursing', 'family/patient centred care', 'family participation' and 'family involvement'. Full search strategies are presented in Appendix 1.

Study selection procedure

Studies were included when reporting family participation in essential patient care during ICU stay, and needs, perceptions, preferences and capacities from the patient's, relatives' and ICU healthcare providers' perspective. Studies were eligible when published in English or Dutch.

Studies concerning neonatal or paediatric (age <18 years) population and studies that focused on family presence and/or participation in rounds, end-of-life care (EOLC), resuscitation or invasive procedures were excluded. Conference abstracts, narrative reviews, editorials and personal communication were also excluded.

After removal of duplicates, studies were screened on title and abstract by two independent reviewers (BD, LV), disagreements were resolved through discussion. The remaining articles were screened full text by couples of two independent reviewers (BD, KF, MvdV, LV). In addition, reference lists of included articles were screened (BD, KF, MvdV, LV) and potentially relevant publications were selected using similar methods (BD, KF, MvdV, LV).

Quality assessment

To assess the quality of observational studies and qualitative studies a tool developed by Kmet et al.[23] was used. Total quality score for this tool ranged from 0 to 1, with 1 being the highest possible score. The quality assessment was performed by pairs of two independent researchers (BD, KF, MvdV, RE, LV). Disagreement was resolved through discussion, if needed with a third reviewer.

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Data extraction

Data were extracted by three independent researchers (BD, KF, MvdV) and verified by four other researchers (HvdH, LS, RE, LV).

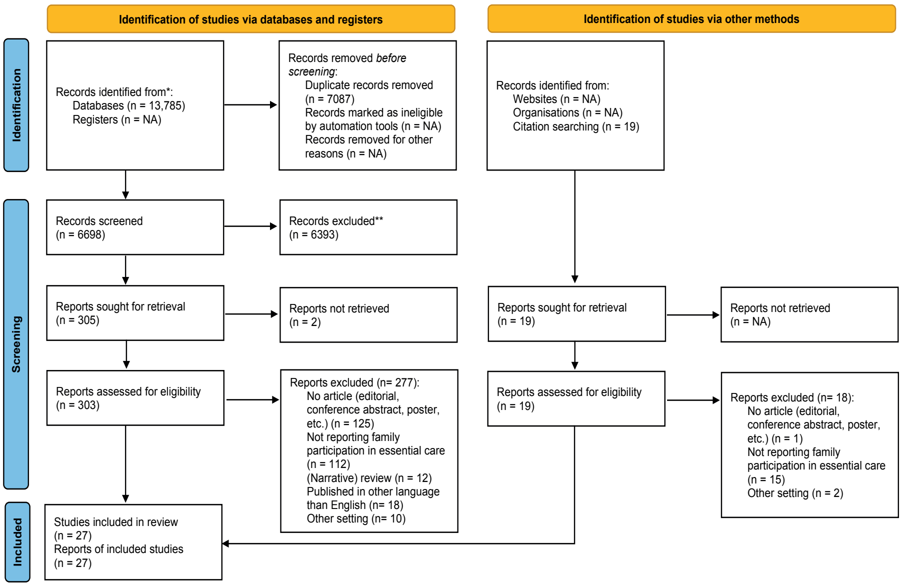
Data analysis

Due to the amount of non-randomised and qualitative designs, a meta-analysis of the included studies was not possible. Instead, after coding the results sections of included studies, an extensive qualitative thematic analysis was performed on the extracted data by two researchers (BD, KF), following Braun & Clark.[24] All data within each theme were examined and agreed to by all researchers.

RESULTS

Review statistics

After duplicate removal 6,698 records were screened. A total of 324 full-text articles were assessed, 305 from database searching and 19 from reference lists, and 27 studies were included (see Figure 1). A list of excluded articles (n=297) is provided in Appendix 2.



*Consider, if feasible to do so, reporting the number of records identified from each database or register searched (rather than the total number across all databases/registers).
**If automation tools were used, indicate how many records were excluded by a human and how many were excluded by automation tools.

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71. For more information, visit: http://www.prisma-statement.org/

Figure 1 PRISMA 2020 flow diagram

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Study characteristics

Study characteristics, including design, country and population are presented in Table 1.1 and 1.2. The included studies consisted of eleven quantitative studies: five prospective/observational,[25-29] three pretest-posttest,[30-32] two pilot/feasibility,[33,34] and one cross-sectional study,[35] six mixed methods studies,[36-41] and twelve qualitative designs.[5, 8, 39, 41-49]

The studies were conducted in Australia (n=9), the USA (n=9), Europe (n=8; Sweden (n=3), France (n=2), Denmark (n=1), UK (n=2)), Argentina (n=1) and Saudi Arabia (n=1), in tertiary ICUs mainly. Most quantitative and qualitative studies addressed relatives (n=20) and/or ICU nurses (n=16).

Quality assessment

The quality of the quantitative and mixed method designs was mostly moderate with a Kmet-score ranging from 0.50 to 0.95 (see Table 2.1). The qualitative study scores ranged from 0.45 to 0.90, also mostly moderate (see Table 2.2).

Themes

Five themes representing needs and perceptions of patients, relatives and ICU healthcare providers regarding family participation in essential care were identified: desire to help the patient and feel useful; (positive) attitude; stress; perceived effects; feeling in control-loss of control. Another five themes representing preferences and capacities were identified: potential essential care activities; invitation and support; an individualized approach; knowledge, skills, education and training; patient's and relatives' characteristics and organisational conditions.

For each theme, results are summarised separately for each of the three populations (patients, relatives and ICU healthcare providers), also see Tables 3.1, 3.2 and 3.3. If a certain population is not listed within a specific theme, then no studies were found for that population related to that theme.

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Table 1.1 Characteristics of quantitative and mixed methods studies (n=17)

1st Author (Year) Country	Aim	Design	Setting (n)	Population (n)	Method	Total quality score (Kmet 0-1)
Ågård (2009) Denmark	To describe how Danish ICU nurses perceive personal knowledge and skills (self-efficacy), outcome expectations to interacting with relatives, and the possible consequences of involving relatives in caring activities.	Cross-sectional	Medical-surgical adult ICU at a university hospital (1)	ICU nurses (68)	Survey	0.86
Al-Mutair (2014) Saudi Arabia	To describe healthcare providers' attitudes to family involvement during routine care and family presence during resuscitation or other invasive procedures in adult intensive care units in Saudi Arabia.	Descriptive	Mixed-surgical adult ICUs at eight different hospitals (8)	ICU healthcare providers (468; nurses, physicians, and respiratory therapists)	Survey	0.70
Azoulay (2003) France	To investigate the opinions and experience of ICU caregivers and family members about involvement of families in the care of ICU patients, irrespective of their prognosis.	Prospective, observational	48% medical-surgical, 40% medical and 12% surgical ICUs 61.6% at university hospitals (78)	ICU healthcare providers (2,754; nurses, nursing assistants, physical therapists, and physicians) Relatives (544) Patients (357)	Survey, interviews	0.75

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Table 1.1 Characteristics of quantitative and mixed methods studies (n=17) (Continued)

1st Author (Year) Country	Aim	Design	Setting (n)	Population (n)	Method	Total quality score (Kmet 0-1)
Davidson (2010) **USA**	To evaluate the feasibility of an intervention for support for families of mechanically ventilated adults, grounded in a new midrange nursing theory titled “Facilitated Sense making”.	Pilot study, feasibility	Mixed use ICU of a trauma center (1)	Relatives (22)	Survey	0.50
Eldredge (2004) **USA**	To describe spouses’ helping behaviours at the ICU bedside and explore how well preferences for closeness and helpfulness explain variation in spouses’ emotional outcomes during their partners’ illness.	Mixed methods	Medical ICU/CCU in a tertiary care community hospital (1)	Relatives (88)	Survey, structured interviews	0.75
Garrouste-Orgeas (2010) **France**	To assess opinions of caregivers, families, and patients about involvement of families in the care of ICU patients; to evaluate the prevalence of symptoms of anxiety and depression in family members; and to measure family satisfaction with care.	Mixed methods	Medical-surgical ICU of a tertiary care hospital (1)	Patient-family pairs (101) ICU healthcare providers (nurses (21), nursing assistants (7), physicians (17))	Survey, structured interviews	0.89

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Table 1.1 Characteristics of quantitative and mixed methods studies (n=17) (Continued)

1st Author (Year) Country	Aim	Design	Setting (n)	Population (n)	Method	Total quality score (Kmet 0-1)
Hammond (1995) Australia	To describe the positive and negative attitudes of intensive care nurses and the relatives of critically ill patients towards the involvement of relatives in giving physical care to their loved ones in the ICU, and also to elicit areas of care that would be appropriate for relatives to become involved in and to determine any perceived benefits of lay participation in care.	Mixed methods	General district hospital ICU (1)	ICU nurses (27) Relatives (20)	Survey, checklist, open and biographical questions	0.70
Hetland (2017) USA	To (1) report patient care activities nurses commonly offer to family caregivers to perform; (2) explore the impact of nurse and organizational characteristics on barriers and facilitators to family engagement in care; and (3) examine the relationships among ICU environment, patient acuity, nurse workflow, and attitudes toward family engagement in the care of the critically ill.	Prospective, observational	American Association of Critical Care Nurses, 30% worked in an academic setting (not described)	ICU nurses (433)	Survey	0.95

Table 1.1 Characteristics of quantitative and mixed methods studies (n=17) (Continued)

1st Author (Year) Country	Aim	Design	Setting (n)	Population (n)	Method	Total quality score (Kmet 0-1)
Kean* (2014) Australia	To describe families' and nurses' experiences of having a family member provide physical care to the ICU patient and to compare how ICU nurses in Australia and the UK perceive families in ICUs.	Mixed methods, quasi-experimental	Metropolitan tertiary adult ICUs (2)	ICU nurses (52)	Survey	0.50
Loudet (2017) Argentina	To determine the effectiveness of a quality management program in reducing the incidence and severity of pressure ulcers in critical care patients.	Pretest-posttest	Medical-surgical ICU within a university-affiliated hospital (1)	Patients (124)	Patient care reports	0.86
McConnell (2015) Australia	To uncover the barriers and enablers that critical care nurses experience to involving relatives in ICU patient care.	Mixed methods	Tertiary adult ICU of a private hospital (1)	ICU nurses (questionnaire: 70, interviews: 6)	Survey, semi-structured interviews	0.55
Mitchell (2009) Australia	To evaluate the effects on family-centred care of having critical care nurses partner with patients' families to provide essential care to patients.	Pretest-posttest	Medical and surgical ICUs in two metropolitan teaching hospitals (2)	Relatives (174)	Survey	0.71

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Table 1.1 Characteristics of quantitative and mixed methods studies (n=17) (Continued)

1st Author (Year) Country	Aim	Design	Setting (n)	Population (n)	Method	Total quality score (Kmet 0-1)
Mitchell (2017) Australia	To determine: the feasibility of recruiting participants; the retention of family members through the study; the feasibility of delivering the intervention as assessed by data collection slips; nurses' perceived acceptability of a family intervention within ICU; an effect size to inform a cautious estimate for future sample size calculations.	Pilot study, feasibility	ICU in a tertiary referral teaching hospital (1)	Patients (91) Relatives (61) ICU nurses (11)	Data slip, semi-structured interviews	0.73
Skoog (2016) USA	To increase engagement of patients' family members by implementing FSM in cardiothoracic ICU and to measure the effect of FSM on family members anxiety levels during the ICU stay.	Pretest-posttest	Cardiothoracic ICU in a large regional heart center (1)	Relatives (64)	Survey	0.77

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Table 1.1 Characteristics of quantitative and mixed methods studies (n=17) (Continued)

1st Author (Year) Country	Aim	Design	Setting (n)	Population (n)	Method	Total quality score (Kmet 0-1)
Smithburger (2017a) USA	To determine opinions and willingness of healthcare providers to involve patients' relatives in non-pharmacologic delirium-prevention activities in the ICU, and of patients' relatives to be involved.	Prospective, observational	Medical ICU from academic medical center (1)	Relatives (60) ICU nurses (60) Physicians (58)	Survey	0.75
Wong* (2021) Australia	To understand families' preferences and observed participation in patient care in an adult ICU.	Mixed methods	ICUs in public hospital (2)	Relatives (30)	Survey	0.67
Wyskiel (2015) USA	To assess family and provider openness to expanding the care team to include family participation and introduce the Family Involvement Menu as a tool to facilitate family engagement.	Prospective, observational	Surgical and medical ICU and an inpatient unit from two academic medical centers (2)	Relatives (37) ICU healthcare providers (37, 95% nurses)	Survey	0.70

*Abbreviations: ICU: intensive care unit, FSM: facilitated sense making; *study divided into a quantitative and qualitative part*

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Table 1.2 Characteristics of qualitative studies (n=12)

1st Author (Year) Country	Aim	Design	Setting (n)	Population (n)	Method	Total quality score (Kmet 0-1)
Blom (2013) Sweden	To explore participation and support as experienced by close relatives of patients at an ICU.	Phenomenological	ICU at a moderately large hospital (1)	Relatives (7)	Semi-structured interviews	0.55
Engström (2011) Sweden	To describe critical care nurses' experiences of relatives' involvement in the nursing care of patients in an ICU.	Qualitative content analysis	An ICU (1)	ICU nurses (8)	Semi-structured interviews	0.65
Hupcey (1999) USA	To investigate how families and nurses interact to increase or decrease the family's involvement in the ICU.	Grounded theory	Large, tertiary ICU (1)	Patients (30) Relatives (11) ICU nurses (10)	Unstructured interviews	0.45
Kean* (2014) UK	To examine families' experiences with critical illness in ICU and nurses' perceptions of families and to compare how ICU nurses in the UK and Australia perceive families in ICUs.	Grounded theory	Tertiary ICU (1)	ICU nurses (20)	Focus groups	0.60
Kydonaki (2020) UK	To understand the different factors that impact on the involvement of relatives in ICU patient care from the perspective of patients, relatives and ICU nurses, to inform the enactment of a PFCC intervention to support the patient–relative–nurse partnership in care involvement.	Thematic analysis	ICUs in tertiary university hospitals (2)	Patients (19) Relatives (21) ICU nurses (15)	Semi-structured interviews and focus groups	0.65

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Table 1.2 Characteristics of qualitative studies (n=12) (continued)

1st Author (Year) Country	Aim	Design	Setting (n)	Population (n)	Method	Total quality score (Kmet 0-1)
McAdam (2008) USA	To describe the contributions to care that family members perform while their loved one is at high risk of dying in the ICU.	Exploratory, descriptive analysis	Tertiary ICUs (2)	Relatives (25)	Interviews	0.45
Mitchell (2010) Australia	To describe families' experiences of providing physical care to their critically ill relatives with bed-side nurses' support.	Content analysis	Large, tertiary ICU (1)	Relatives (10)	Semi-structured interviews	0.85
Smithburger (2017b) USA	To gain insight into opinions of patients' relatives regarding active participation in delirium prevention activities to inform specific recommendations for involving patients' relatives in such activities.	Thematic analysis	Medical ICU at an academic medical center (1)	Relatives (10)	Interviews	0.55
Wåhlin (2009) Sweden	To compare intensive care patients' experiences of empowerment with relatives' and staff beliefs.	Content analysis	General ICUs (2)	Relatives (10)	Interviews	0.70
Wong (2019) Australia	To explore relatives' experiences of their interactions in an ICU to develop a grounded theory that can be used by critical care nurses to improve PFCC.	Grounded theory	Large, tertiary ICU (1)	Relatives (25)	Interviews	0.90

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Table 1.2 Characteristics of qualitative studies (n=12) (continued)

1st Author (Year) Country	Aim	Design	Setting (n)	Population (n)	Method	Total quality score (Kmet 0-1)
Wong (2020) Australia	To describe relatives' perspectives of participation in patient care in adult ICU.	Thematic analysis	Tertiary ICUs (2)	Relatives (30)	Naturalistic observations and semi-structured interviews	0.80
Wong* (2021) Australia	To understand families' preferences and observed participation in patient care in an adult ICU.	Naturalistic observation	ICUs in public hospital (2)	Relatives (30)	Naturalistic observation	0.55

Abbreviations: ICU: Intensive Care Unit; PFCC: patient- and family- centred care; **study divided into a quantitative and qualitative part*

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Table 2.1 Quality of quantitative and mixed methods studies (n=17)

1st Author (Year) Country	1. Question/ objective sufficiently described?	2. Study design evident and appropriate?	3. Method of subject/ comparison group selection or source of information/ input variables described and appropriate?	4. Subject (and comparison group, if applicable) characteristics sufficiently described?	5. If interventional and random allocation was possible, was it described?	6. If interventional and blinding of investigators was possible, was it reported?
Ågård (2009) Denmark	⊕	⊕	⊕	±	N/A	⊕
Al-Mutair (2014) Saudi Arabia	⊕	⊕	±	⊕	N/A	N/A
Azoulay (2003) France	⊕	⊕	⊕	⊕	N/A	N/A
Davidson (2010) USA	±	±	±	±	N/A	N/A
Eldredge (2004) USA	±	⊕	±	±	N/A	N/A
Garrouste-Orgeas (2010) France	⊕	⊕	±	⊕	N/A	N/A
Hammond (1995) Australia	⊕	⊕	±	±	N/A	N/A
Hetland (2017) USA	⊕	⊕	±	⊕	N/A	N/A
Kean* (2014) Australia	⊕	⊕	⊕	⊖	N/A	N/A
Loudet (2017) Argentina	⊕	⊕	⊕	±	N/A	N/A
McConnell (2014) Australia	⊕	⊕	±	±	N/A	N/A
Mitchell (2009) Australia	⊕	⊕	⊕	⊕	⊖	⊖
Mitchell (2017) Australia	⊕	⊕	⊕	⊕	⊕	⊖
Skoog (2016) USA	⊕	±	±	⊕	N/A	N/A
Smithburger (2017a) USA	⊕	±	±	±	N/A	N/A
Wong# (2021) Australia	⊕	±	±	±	N/A	N/A
Wyskiel (2015) USA	⊕	±	±	±	N/A	N/A

⊕ Yes ± Partial ⊖ No

Abbreviations: N/A: not applicable; * This study was assessed on quality twice: results from the quantitative study conducted in Australia are shown in table 2.1, results from the qualitative study conducted in the UK are shown in table 2.2; # This study was assessed on quality twice: results from the quantitative study are shown in table 2.1, results from the qualitative study are shown in table 2.2

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7. If interventional and blinding of subjects was possible, was it reported?	8. Outcome and (if applicable) exposure measure(s) well defined and robust to measurement / misclassification bias? means of assessment reported?	9. Sample size appropriate?	10. Analytic methods described/ justified and appropriate?	11. Some estimate of variance is reported for the main results?	12. Controlled for confounding?	13. Results reported in sufficient detail?	14. Conclusions supported by the results?	Total score (Kmet, 0-1)
N/A	⊕	⊕	⊕	⊖	N/A	⊕	⊕	0.86
N/A	±	⊕	±	±	N/A	±	±	0.70
N/A	±	⊕	⊕	⊕	N/A	±	±	0.75
N/A	±	⊕	±	⊖	N/A	±	±	0.50
N/A	±	⊕	⊕	⊕	N/A	⊕	±	0.75
N/A	⊕	N/A	⊕	⊕	N/A	±	⊕	0.89
N/A	⊖	N/A	±	N/A	N/A	±	⊕	0.70
N/A	⊕	⊕	⊕	⊕	N/A	⊕	⊕	0.95
N/A	±	N/A	⊖	N/A	N/A	±	⊖	0.50
N/A	⊕	⊕	⊕	⊕	⊖	⊕	⊕	0.86
N/A	⊕	±	⊖	⊖	N/A	⊕	⊖	0.55
⊖	±	⊕	⊕	⊕	±	⊕	⊕	0.71
⊖	±	N/A	⊕	⊕	⊕	±	±	0.73
N/A	⊕	⊕	⊕	⊕	N/A	⊕	±	0.77
N/A	⊕	⊕	±	⊕	N/A	⊕	±	0.75
N/A	⊕	N/A	⊕	±	N/A	±	±	0.67
N/A	±	⊕	±	⊖	N/A	⊕	±	0.70

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Table 2.2 Quality of qualitative studies (n=12)

1st Author (Year) Country [ref]	1. Question / objective sufficiently described?	2. Study design evident and appropriate?	3. Context for the study clear?	4. Connection to a theoretical framework / wider body of knowledge?	5. Sampling strategy described, relevant and justified?
Blom (2013) Sweden	⊕	⊕	⊕	±	±
Engström (2011) Sweden	⊕	⊕	⊕	±	±
Hupcey (1999) USA	±	⊕	±	±	±
Kean* (2014) UK	⊕	⊕	±	⊕	⊖
Kydonaki (2020) UK	±	±	⊕	±	⊕
McAdam (2008) USA	⊕	±	⊕	±	±
Mitchell (2010) Australia	⊕	⊕	±	±	⊕
Smithburger (2017b) USA	⊕	±	⊕	±	±
Wåhlin (2009) Sweden	⊕	⊕	±	⊕	⊕
Wong (2019) Australia	⊕	⊕	⊕	⊕	⊕
Wong (2020) Australia	⊕	⊕	⊕	±	⊕
Wong [#] (2021) Australia	⊕	±	⊕	±	±

⊕ Yes ± Partial ⊖ No

* This study was assessed on quality twice: results from the quantitative study conducted in Australia are shown in table 2.1, results from the qualitative study conducted in the UK are shown in table 2.2;

[#] This study was assessed on quality twice: results from the quantitative study are shown in table 2.1, results from the qualitative study are shown in table 2.2

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	6. Data collection methods clearly described and systematic?	7. Data analysis clearly described and systematic?	8. Use of verification procedure(s) to establish credibility?	9. Conclusions supported by the results?	10. Reflexivity of the account?	Total score (Kmet 0-1)
	±	±	⊖	±	⊖	0.55
	⊕	±	⊖	⊕	⊖	0.65
	±	±	⊖	±	⊖	0.45
	⊕	⊕	⊖	±	⊖	0.60
	⊕	±	⊕	±	⊖	0.65
	⊖	±	⊖	±	⊖	0.45
	⊕	⊕	⊕	⊕	±	0.85
	⊕	±	⊖	±	⊖	0.55
	±	⊕	⊖	⊕	⊖	0.70
	⊕	⊕	⊕	⊕	⊖	0.90
	⊕	⊕	⊕	±	⊖	0.80
	⊕	±	⊖	±	⊖	0.55

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Table 3.1 Needs, perceptions, preferences and capacities with regard to family participation in essential care from the patient's perspective

1st Author (Year) Country	Population (n)	Needs	Perceptions	Preferences	Capacities
Garrouste-Orgeas (2010) France	Patients (101)	-	• 77.2% was favourable to FP • 22.8% did not want relatives to participate in care because: o desire to preserve image o unwillingness to be assisted o unwillingness to cause embarrassment o nurses are better skilled o **safety** o physical modesty	-	-
Hupcey (1999) USA	Patients (30)	-	• Felt **safe and protected** when relatives were there	-	-
Kydonaki (2020) UK	Patients (19)	-	• Perceived themselves as receivers of care, with a passive role reflecting that they lacked mental capacity and felt vulnerable at times • Some patients were pragmatic about possible FP, since they felt unwell or simply in need of care	-	-
	Patients and/or relatives and/or ICU nurses	-	• ICU environment: unknown, intimidating and scary to relatives and patients, due to ventilators and monitors, complexity of care and/or risk of infection for patient, causing them to feel overwhelmed and apprehensive • Patients, relatives and nurses agreed that 'ICU nurses have control of care in ICU' and 'there is a fine line as to what can be expected from relatives to do'	• All involved were comfortable with: combing hair, oral care, massaging with cream, bed bathing upper body, washing hair, assist with mobilisation when extubated • Most were less comfortable with: • bed bathing (intimate care), technical care	Time and frequent communication between relatives and ICU nurses to develop a relationship

Abbreviations: FP: family participation in essential care, ICU: Intensive Care Unit

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Table 3.2 Needs, perceptions, preferences and capacities with regard to family participation in essential care from the relatives' perspective

1st Author (Year) Country	Population (n)	Needs	Perceptions	Preferences	Capacities
Azoulay (2003) France	Relatives (544)	• 33.4% wanted to participate, most common reasons: feeling that relationship with patient made care natural (70.2%), a **desire to help the patient** (84%), and a desire to help ICU HCPs (58.3%)	• The most common reason for not wanting to participate was that ICU HCPs did their job perfectly (85.4%) • FP may provide relatives with a feeling of closeness to the patient, and **alleviate stress** and generate a feeling of **usefulness**	-	• Lack of adequate **information** about what FP actually entails • **Education** of **relatives**, who are not healthcare providers, to address patient **safety** and **quality of care** concerns • Independent predictors of the wish for FP were: patient-related (**less severe status** at admission and **longer ICU stay**); family-related (younger age, non-European descent, and **previous ICU admission**), and factors related to emotional burden and to effectiveness of information (symptoms of depression in relatives and more time wanted for information) • FP requires extended **visiting hours**
Blom (2013) Sweden	Relatives (7)	• Being allowed to participate (variation in need to participate)	• Feeling discouraged to participate due to differences in **approach** between ICU HCPs	-	• Inviting atmosphere, created by ICU HCPs (especially ICU nurses) • **Open and flexible attitude** from ICU HCPs • Good **communication** • **Information** and **support** from ICU nurse

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Table 3.2 Needs, perceptions, preferences and capacities with regard to family participation in essential care from the relatives' perspective

1st Author (Year) Country	Population (n)	Needs	Perceptions	Preferences	Capacities
Davidson (2010) USA	Relatives (22)	-	• **Personal care supplies** were helpful	• Different aspects of the Family Support Program were welcomed	• Most engaged when receiving **information** about how to participate at the bedside
Eldredge (2004) USA	Relatives (88)	• 55% wanted to take an **active role** to help or comfort patient	• 80% reported that care activities helped them to **feel positive or productive** • 13% reported that patients did not want them to do anything • 11% reported that helping at the bedside made them feel **apprehensive, useless or helpless** • 21% did not meet their caregiving goals: o 33% felt **incapable** of helping o 53% felt they were not needed	-	• ICU nurses can help relatives **clarify and achieve goals** for helpfulness
Garrouste-Orgeas (2010) France	Relatives (101	• 97% was willing to participate in care, 3.9% refused to participate	• The family satisfaction score was high (11.0 ± 1.2)	-	• 13.8% of the relatives provided care spontaneously or asked to participate • 50% felt that 24-**hour visitation policy** facilitated FP • **Previous ICU experience** and age (55 to 59 range) were associated with a desire to participate in care

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Table 3.2 Needs, perceptions, preferences and capacities with regard to family participation in essential care from the relatives' perspective

1st Author (Year) Country	Population (n)	Needs	Perceptions	Preferences	Capacities
Hammond (1995) Australia	Relatives (20)	• 85% would like to participate in physical care	• 85% would like to participate in physical care • **Adapting to the demanding ICU environment**	• 25% did not want to participate in '**personal care'** (eg. incontinence or vomit) • 10% indicated that participation depended upon their **relationship** with the patient and the patient's severity of illness	• Identifying parameters of **new caring role** • **Personal choice** for individual lay involvement • Adequate **information** for relatives to become involved
Hupcey (1999) USA	Relatives (11)	-	• Participated in order not to feel **helpless** • Considered protecting or looking out for the patient their role	-	-

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Table 3.2 Needs, perceptions, preferences and capacities with regard to family participation in essential care from the relatives' perspective

1st Author (Year) Country	Population (n)	Needs	Perceptions	Preferences	Capacities
Kydonaki (2020) UK	Relatives (21)	-	• Most relatives considered care in ICU complex, lacking expertise and FP was unsafe • Personal and family attributes, such as age, gender, type of relationship, sense of dignity and level of intimacy could explain the different perceptions of the level of FP	-	• Most relatives believed ICU nurses should invite them to participate, two initiated FP themselves
	Patients and/or relatives and/or ICU nurses	-	• ICU environment: unknown, intimidating and scary to relatives and patients, due to ventilators and monitors, complexity of care and/or risk of infection for patient, causing them to feel overwhelmed and apprehensive • Patients, relatives and nurses agreed that 'ICU nurses have control of care in ICU' and 'there is a fine line as to what can be expected from relatives to do'	• All involved were comfortable with: combing hair, oral care, massaging with cream, bed bathing upper body, washing hair, assist with mobilisation when extubated • Most were less comfortable with: • bed bathing (intimate care), technical care	• Time and frequent communication between relatives and ICU nurses to develop a relationship

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Table 3.2 Needs, perceptions, preferences and capacities with regard to family participation in essential care from the relatives' perspective

1st Author (Year) Country	Population (n)	Needs	Perceptions	Preferences	Capacities
McAdam (2008) USA	Relatives (25)	-	• More **support** and **appreciation** of FP may provide relatives opportunities for **intimacy** and promote a sense of belonging in the technical environment of an ICU	-	• Additional work for ICU HCPs due to frequent interactions with relatives
Mitchell (2009) Australia	Relatives (174)	-	-	-	• **Good communication**, **collaboration** and **support** between relatives, patient and the ICU nurse to enable relatives to decide what care activities to participate in
Mitchell (2010) Australia	Relatives (10)	• To **be involved** • To **feel useful**	-	-	• **Communication** is an essential element in meeting family's needs • **Cooperation, enthusiasm and support** of the ICU nurse is essential (partnership between relatives and ICU nurses) • ICU nurses allowed relatives to select the level and complexity of care provided: **individualized FP** to the patient's and relatives' situation (offering opportunity, not putting any pressure, using a **flexible approach**)

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Table 3.2 Needs, perceptions, preferences and capacities with regard to family participation in essential care from the relatives' perspective

1st Author (Year) Country	Population (n)	Needs	Perceptions	Preferences	Capacities
Mitchell (2017) Australia	Relatives (61)	-	• The components of the intervention were not difficult or onerous	-	• FP should occur at a level/ frequency **best suited** to the relatives
Skoog (2016) USA	Relatives (64)	-	• Education on FP (applying lip balm and hand moisturizer) made relatives **feel comfortable** and **less anxious** • Some relatives were **afraid to touch** the patient (receiving mechanical ventilation and connected to various catheters, monitors and intravenous medications) because they **feared they could cause harm**	-	-
Smithburger (2017a) USA	Relatives (60)	-	• A minority was concerned that ICU HCPs may **get angry** or **annoyed** • A minority was **afraid to** pull out an intravenous catheter or tube	-	• A minority **did not know how to help** • **One-on-one discussion** with ICU HCPs on delirium and possible delirium-prevention activities

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Table 3.2 Needs, perceptions, preferences and capacities with regard to family participation in essential care from the relatives' perspective

1st Author (Year) Country	Population (n)	Needs	Perceptions	Preferences	Capacities
Smithburger (2017b) USA	Relatives (10)	• Wanted patient to know **they were there** and **patient's needs were addresse**d throughout the day (specifically: calming and reorienting the patient when agitated or confused)	-	-	• **Invitation to participate** and direction in care from the ICU nurse would aid in their level of comfort • One-on-one discussion and reminder with healthcare providers on delirium and possible activities to **prevent confusion**, coupled with reminders, video could serve as follow-up • Clear **communication** about rules and expectations
Wåhlin (2009) Sweden	Relatives (10)	-	• FP was **empowering** for some relatives	-	-
Wong (2019) Australia	Relatives (25)	-	• Contributing towards the recovery and well-being of the patient, allowed relatives to **regain control** and **resilience of their situation** and made them **feel useful**	-	-

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Table 3.2 Needs, perceptions, preferences and capacities with regard to family participation in essential care from the relatives' perspective

1st Author (Year) Country	Population (n)	Needs	Perceptions	Preferences	Capacities
Wong (2020) Australia	Relatives (30)	• Close proximity to the patient for opportunities to participate in physical care activities • Many relatives wanted to participate in care as a strategy to help themselves **cope with their ICU experience**	• Many relatives reported that it made them '**feel better**', **reduced their feelings of helplessness and negativity**, and they felt **reassured**	-	-
Wong (2021) Australia	Relatives (30)	-	• Family participation in physical care was observed to occur more frequently by a partner or parent (18; 16) than offspring or siblings (8; 2)	• One-third of the relatives (n = 10; 33%) preferred shared participation in physical patient care with ICU HCPs, one relative (3%) preferred to participate with limited involvement of ICU HCPs, the majority of relatives (n = 18; 60%) preferred a passive level of participation • Type of family participation: Physical care: mouth care, eye care, pressure care, hygiene care, range of movement exercises, moisturising hands/feet, feeding, suctioning, brushing teeth Psychosocial care: sitting at bedside, holding patient's hand, talking, reading, watching TV together Communication: conversations about treatments, conversations with other family members, interpreting/explaining care and treatments to patient; conversations about activities outside the hospital	-

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Table 3.2 Needs, perceptions, preferences and capacities with regard to family participation in essential care from the relatives' perspective

1st Author (Year) Country	Population (n)	Needs	Perceptions	Preferences	Capacities
Wyskiel (2015) USA	Relatives (37)	-	• 95% was **interested** in FP • 92% felt **comfortable** with FP • 89% felt **included in the health care team**	-	-

Abbreviations: FP: family participation in essential care, ICU: Intensive Care Unit; ICU HCP: ICU healthcare provider

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Table 3.3 Needs, perceptions, preferences and capacities with regard to family participation in essential care from the ICU healthcare providers' perspective

1st Author (Year) Country	Population (n)	Needs	Perceptions	Preferences	Capacities
Ågård (2009) Denmark	ICU nurses (68)	-	• General belief that FP can **benefit** both patient and relatives	• Less willing to involve relatives in **more direct and comprehensive care activities**	• Based **assessments** for FP on a number of complex, individual, and situational aspects (patient, relative, ICU nurse and other staff) • Proficient interactions with relatives in ICU require competences based on **knowledge and skills** as well as **attitude and values**
Al-Mutair (2014) Saudi Arabia	ICU nurses Physicians Respiratory therapists (468)	-	• 44.9% agreed that relatives should be allowed to participate on request • ICU HCPs who did not support FP perceived the **presence of relatives as stressful**	-	• 64.5% had had sufficient **training** to involve relatives • 63.3% had sufficient **time** to be able to involve relatives in care • Lack of **resources** • Lack of **hospital policies** and **guidelines** • Lack of **staff and public education** • ->Development of written **guidelines and policies**, and **education**al programmes
Azoulay (2003) France	ICU HCPs (2,754)	-	• 88.2% felt that relatives should participate ICU HCPs who were not in favour believed that FP might: • add to the suffering of relatives (65.8%) • cause accidental extubation (65.5%) • negatively affect the **quality of care** (51.2%) • lead to relatives to take too prominent a place (50%)	• 60.7% had actually involved relatives in care (87.4% (feeding), 38.4% (bathing), 24% (tracheal suctioning)) • 61.5% believed all family members could participate, 23.5% family members and friends and 15% spouses	-

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Table 3.3 Needs, perceptions, preferences and capacities with regard to family participation in essential care from the ICU healthcare providers' perspective

1st Author (Year) Country	Population (n)	Needs	Perceptions	Preferences	Capacities
Davidson (2010) USA	ICU nurses	-	-	-	• **Educational** programs providing **ICU nurses** with instructions for FP
Engström (2011) Sweden	ICU nurses (8)	-	• Appreciation of relatives' involvement and seen as **resource** for both patients and ICU nurses (relatives' calming effect on patients, helping patients orientate themselves) • **ICU environment** (unpleasant and **frightening** for relatives as a result of equipment, alarms, patients' changed appearance (due to swelling, tube, sedation))	• Protecting the patients' autonomy and **integrity** (also depending on relationship between patient and relative) • Protecting the patients' **rest** (balance between involvement and rest)	• **Lack of time** • Open **communication** to align needs of relatives (**variation in desire to participate**; balance between involvement and rest) with needs of patient (autonomy and integrity (also depending on **relationship** between patient and relative), rest) and work situation of ICU nurses
Garrouste-Orgeas (2010) France	ICU HCPs (45)	-	• Most ICU HCPs were favourable to FP in at least one care activity: 90% of the nurses, 94% of the nursing assistants, and 100% of the physicians o 10% of the ICU nurses unfavourable to FP expressed concerns about **interacting with relatives** during care activities and **possible occurrence of adverse events**	-	-
Hammond (1995) Australia	ICU nurses (27)	-	• 96.3% agreed with the concept of FP • FP may provide ICU nurses with the opportunity **to build a relationship with relatives**	• 44.4% indicated that relatives should not be involved in **'embarrassing' nursing care** (such as incontinence and catheter care), for maintaining privacy and dignity of the patient	• FP requires a **role adaptation for ICU nurses**

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Table 3.3 Needs, perceptions, preferences and capacities with regard to family participation in essential care from the ICU healthcare providers' perspective

1st Author (Year) Country	Population (n)	Needs	Perceptions	Preferences	Capacities
Hetland (2017) USA	ICU nurses (433)	-	• Had a **positive attitude** towards FP and did not view it as a hindrance to their clinical performance • Agreed that allowing relatives to participate in patient care could improve patient **safety**, decision-making, and overall **quality of care** as well as **improve relatives' levels of stress, anxiety, and fear** • Had mixed feelings about the extent to which relatives should be involved in light of **high patient acuity**	• Were most likely to ask relatives to participate in **less complex daily care activities** (such as: applying lotion, feeding the patient, washing the patient's hands and communicating with the patient); and less likely in more **intimate or invasive care activities** (such as: toileting, perineal care, symptom assessment, tracheostomy care, and endotracheal tube suctioning) • Expressed concern about **appropriateness** of some care activities	• Expressed concern about **safety** of some care activities • 66% reported having a **unit culture** that valued FP • Most participants '(strongly) disagreed' when asked if their unit had **policies and procedures** to support FP • **Higher age, higher degree earned, more ICU experience**, hospital location (rural), unit type (paediatric) and **staffing ratios (lower)** had higher QFIFE scores: characteristics that positively influenced ICU nurses' attitudes towards FP • ->A close examination of ICU family culture, staffing decisions, patient acuity, and other work environmental factors to develop solutions to alleviate time constraints and promote a milieu that supports family engagement in ICU • ->**Evidence-driven policies and procedures**, supported by current practice guidelines, to help standardize patient care and support nurses' decisions on how to involve family members • Additional **education and training** may be needed for nurses to understand their role in **communicating opportunities and safely** guiding FP in the ICU

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Table 3.3 Needs, perceptions, preferences and capacities with regard to family participation in essential care from the ICU healthcare providers' perspective

1st Author (Year) Country	Population (n)	Needs	Perceptions	Preferences	Capacities
Hupcey (1999) USA	ICU nurses (10)	-	• **Decrease in confusion or agitation in patients** through relatives	-	• **Maintaining control** over both their ability to provide **patient care and the relatives** • Make relatives feel comfortable and **encourage their involvement** • FP depended on **individual ICU nurses' perception of the patient's physiological and psychological responses to FP and acuity (instability or numerous lines and machines)** • **Longer term patients** (and **developing a relationship with relatives**) • **Lack of time and ability** to care for relatives

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Table 3.3 Needs, perceptions, preferences and capacities with regard to family participation in essential care from the ICU healthcare providers' perspective

1st Author (Year) Country	Population (n)	Needs	Perceptions	Preferences	Capacities
Kean (2014) UK/ Australia	ICU nurses (52 / 20)	-	• 98% considered the concept of **FP should be part of 'usual care'** in ICU • Open visitation policies **impact ICU nurses' working conditions**, with a constant flow of visitors inhibiting and delaying patient care (attending (information) needs of relatives and allowing relatives to be with the patient or protecting the patient's privacy) • Difference of opinion between bedside ICU nurses more often considering '**the patient' remaining the focus of care,** while nurses with managerial responsibility defining relatives and the patient as the unit of care	-	• The **patient's condition** and **receptiveness and coping ability of relatives** influence the decision to involve relatives • Some limit FP to **long-term patients**, others comment that it depends on the **individual situation** and the amount of involvement the **relatives want** • 81% considered FP had **minimal effect on their workload** • To **control their working time and space** • The i**nvitation** to participate should be initiated by ICU nurses (allowing them to **remain in control over their work environment**, and evidence suggests that when relatives would like to participate, they do not ask to) • 'Vision' that the **integration of relatives in today's healthcare system** (including ICUs) is mandatory as relatives will become caregivers during an often prolonged recovery trajectory • **Specific strategies** to support ICU nurses in the integration of relatives into the ICU

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Table 3.3 Needs, perceptions, preferences and capacities with regard to family participation in essential care from the ICU healthcare providers' perspective

1st Author (Year) Country	Population (n)	Needs	Perceptions	Preferences	Capacities
Kydonaki (2020) UK	ICU nurses (15)	-	• Felt accountable for patient and family care and some were hesitant involving FM in care for two main reasons: 1) to avoid the risk of slips and errors, and 2) to protect relatives from the burden of caring • Many viewed themselves as their patient's advocates with the objective of providing care without interruptions, reflected in their need of controlling to some extent when a relative can be present and involved in care • Some felt exposed and frustrated at times when some relatives were constantly present	• For FP in physical care activities, all felt more comfortable inviting relatives after the acute phase, the level of involvement being determined by the relative • Spent time observing family dynamics and levels of intimacy, previous experience with patient care (patients with long-term conditions), as well as the type of relationship with the patient before inviting a relative to participate	-
	Patients and/or relatives and/or ICU nurses	-	• ICU environment: unknown, intimidating and scary to relatives and patients, due to ventilators and monitors, complexity of care and/or risk of infection for patient, causing them to feel overwhelmed and apprehensive • Patients, relatives and nurses agreed that 'ICU nurses have control of care in ICU' and 'there is a fine line as to what can be expected from relatives to do'	• All involved were comfortable with: combing hair, oral care, massaging with cream, bed bathing upper body, washing hair, assist with mobilisation when extubated • Most were less comfortable with: • bed bathing (intimate care), technical care	• Time and frequent communication between relatives and ICU nurses to develop a relationship
Loudet (2017) Argentina	ICU HCPs	-	• **Reduction of burden on limited nursing staff**	-	-

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Table 3.3 Needs, perceptions, preferences and capacities with regard to family participation in essential care from the ICU healthcare providers' perspective

1st Author (Year) Country	Population (n)	Needs	Perceptions	Preferences	Capacities
McConnell (2015) Australia	ICU nurses (70/6)	-	Relatives' perspective: • Perceived **fragility** and **vulnerability** • Fear of **increasing their stress levels** • **Loudness** and **obnoxiousness** (causing stress for ICU nurse and patient) ICU nurses' perspective: • **Personal attitudes** towards FP (personal values) • **Negative past experiences** with FP • Felt **uncomfortable** performing activities in front of relatives	Patient's perspective: • **Privacy** (linked to relative-patient relationship)	Patient's perspective: • Safety • Short term length of ICU stay Relatives' perspective: • **Fear** of relatives injuring themselves when participating and possible **legal consequences** ICU nurses' perspective: • Less ICU **nursing experience** • **Education** of ICU nurses on (understanding possible benefits of) FP ICU environment factors: • Compact **sized rooms** • **Work interruption** by relatives in a busy environment • **Lack of time** to explain care activities to relatives • Lack of hospital **policy/guidelines** • Development of directed strategies to reduce barriers
Mitchell (2017) Australia	ICU nurses (11)	-	• Were **supportive** of all aspects of the intervention • Relatives were seen as important **care partners**, and their involvement afforded positive outcomes for the patient and themselves • **Relatives' fear** or discomfort with FP • Negative ICU nurses' **attitudes**	-	• Physical **ICU environment** (patient treatment (turns, doctors' review, assessments, examinations))

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Table 3.3 Needs, perceptions, preferences and capacities with regard to family participation in essential care from the ICU healthcare providers' perspective

1st Author (Year) Country	Population (n)	Needs	Perceptions	Preferences	Capacities
Smithburger (2017a) USA	ICU nurses (60)	-	• A majority believed FP in delirium prevention would benefit the patient through a **reduced incidence of ICU delirium** because of increased time devoted to delirium prevention Belief that relatives: • **Fear** the setting, including machines, catheters, and ICU sounds • Are apprehensive about **getting in the way** of ICU HCPs • Experience **stress** or **anxiety** associated with preventative care	-	• **Lack of time** to explain delirium or delirium prevention Belief that relatives: • **Lack knowledge** about delirium and prevention strategies and **need education** • Do not understand about delirium and prevention • **Could harm** the patient
	Physicians (58)	-	• A majority believed FP in delirium prevention would benefit the patient through a **reduced incidence of ICU delirium** because of increased time devoted to delirium prevention	-	• **Lack of time** to explain delirium or delirium prevention • Belief that **relatives lack knowledge** about delirium and prevention strategies and need education

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Table 3.3 Needs, perceptions, preferences and capacities with regard to family participation in essential care from the ICU healthcare providers' perspective

1st Author (Year) Country	Population (n)	Needs	Perceptions	Preferences	Capacities
Wyskiel (2015) USA	ICU HCPs (37)	-	• 78% **comfortable** with inviting relatives to participate • 70% routinely invited relatives to participate some of the time, 16% did so consistently • **More time** for other nursing tasks (35%) • Some relatives were not invited to participate for being perceived **scared** (19%), **uncomfortable** (19%), and **unwilling** (14%)	• Relatives were least likely to be involved in **physiotherapy** (32%), **bathing** (27%), and **mouth care** (19%) due to reasons such as 'anxiety about patient falling', 'bathing because they may be uncomfortable with their families in that state', and 'not wanting to hurt them'	• Opportunity to **educate** family members in patient care (16%), better preparing them for transition of care and discharge • The Family Involvement Menu could help engage relatives as part of the healthcare team • Opportunities for relationship building (19%) • **Lack of time** (14%)

Abbreviations: FP: family participation in essential care, ICU: Intensive Care Unit; ICU HCP: ICU healthcare provider; QFIFE scores: Questionnaire on Factors That Influence Family Engagement

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Needs and perceptions

Desire to help the patient and feel useful

The first theme, the desire to help the patient and feel useful, was described in ten studies. Relatives wanted or were willing, when invited, to help the patient, feel useful and be allowed to participate.[5,26,36-38,42,44,46,48,49]

(Positive) attitude

The second theme, (positive) attitude, among patients, relatives and ICU healthcare providers was described in twelve studies.

One study reported a majority of the patients (77.2%) being in favour of family participation in essential care. The other 22.8% did not want relatives to participate for one or more of the following reasons: desire to preserve image, embarrassment, physical modesty, safety, and the notion that ICU nurses are better skilled.[37] Another study described some patients as being pragmatic about family participation, since they felt unwell or in need of care,[45] implying a positive attitude.

The number of relatives with a positive attitude towards family participation varied between studies from 33.4-95%.[26,29,36-38] A minority (3.9-15%) indicated they did not wish to participate in care.[37,38] Possible reasons were: ICU healthcare providers did their job perfectly, concerns about patient safety and quality of care, lack of adequate information about what family participation actually entails,[26] the patient's condition,[38] and differences in approach between ICU healthcare providers (discouraging relatives to participate).[42]

The number of ICU healthcare providers with a positive attitude towards family participation also varied: 44.9-98% felt that relatives should participate (on their request).[25-27,29,37-39] Individual ICU nurses' characteristics such as higher age, higher degree, and more critical care experience, positively influenced attitudes towards family participation.[27]

In one study a majority of ICU healthcare providers had a negative attitude,[25] other studies described some individuals' negative attitudes, sometimes related to past negative experiences.[34,37,40]

Stress

The third theme, stress, among relatives and ICU healthcare providers was described in fourteen studies. Several conditions were described, that are (potentially) stressful for relatives and ICU healthcare providers.

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Some relatives were afraid to touch the patient, in fear of causing harm; others had concerns about annoying or creating additional work for ICU healthcare providers due to frequent interactions with relatives.[8,32,46]

ICU healthcare providers considered the ICU environment stressful for relatives.[28,43,45] Some ICU healthcare providers had concerns about adding to the suffering of relatives, patient safety (accidental extubation or adverse events), and quality of care.[26,27,29,34,37,40,44,45] Some ICU healthcare providers perceived the presence of and interaction with (loud and obnoxious) relatives as stressful.[25,37,40,45]

Perceived effects
The fourth theme, perceived effects, was described in 11 studies. Family participation was perceived to be beneficial in several ways, by patients, relatives and ICU healthcare providers.

One study reported that patients felt safe and protected when relatives were present.[44]

Most relatives reported that participating made them feel positive, some felt apprehensive, useless or helpless,[32,36] other relatives participated in order not to feel helpless.[44]

ICU healthcare providers generally believed that family participation could benefit patients,[28,43,44] both patients and relatives,[34,35] and might alleviate stress among relatives.[27,36] According to Hetland et al. family participation could benefit patient safety and quality of care.[27] Furthermore, family participation allowed ICU healthcare providers to build a relationship with relatives.[29,34,38]

Feeling in control - loss of control
The fifth theme, feeling in control - loss of control, was described in nine studies. Family participation enabled relatives to feel in control and led to some ICU healthcare providers experiencing loss of control.

Family participation allowed relatives to cope with and regain control over their situation, and build resilience[48,49] and adapt to the ICU environment.[38] Some perceived family participation as empowering.[47]

Some ICU healthcare providers had concerns about relatives taking too prominent a place,[26] open visitation policies impacting working conditions, differing opinions between bedside and managing nurses on the patient or both patient and relatives being the focus of care,[39] and controlling their working time and space.[39, 40, 44, 45]

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Preferences and capacities

Potential essential care activities
The sixth theme, potential essential care activities, was described in eighteen studies. Preferences for essential care activities varied between and among relatives and ICU healthcare providers.

More than 70% of the patients were comfortable with eye care, hydrating lips, moistening of the oral cavity, and applying body lotion being performed by relatives,[37] see Table 4.

Twelve studies elicited possible essential care activities from the relatives' perspective,[5,8,28,31,37,38,41,44-46,48,49] studies providing sufficient detail on descriptive statistics are presented in Table 4. Preferences for essential care activities varied between relatives, making identification of a uniform list impossible.

ICU healthcare providers favoured several essential care activities, again preferences varied. [5,28,31,33,35,37,38,43,44] In the studies of Azoulay et al. and Hetland et al. ICU healthcare providers actually invited relatives to perform specific activities,[26,27] see Table 4. There is no agreement on essential care activities that can be performed by relatives.

The majority of patients, relatives and ICU healthcare providers endorsed participation in eye care, moistening of the oral cavity and applying lip balm and body lotion; however, there was no agreement on participation in bathing and hair washing.[37,38,45]

Few relatives did not wish to participate in 'private care' (eg, incontinence or vomit), and some stated that participation depended upon their relationship with the patient.[38,45] In the study of Wong et al. one-third of the relatives preferred shared participation in physical patient care with ICU healthcare providers, one (3%) preferred an active level and the majority (60%) preferred a passive level of participation.[41]

Some ICU healthcare providers experienced difficulties maintaining the patients' privacy, dignity, autonomy and integrity when relatives provided care, and expressed concerns about appropriateness of some care activities,[27,29,35,38,45] again dependent on the relationship between patient and relative.[38,40,43,45]

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Table 4 Possible essential care activities from the patient's, relatives' and ICU healthcare providers' perspective[a]

		Patient **Garrouste (29)** **% in favour[b]**	**Relative** **Garrouste (29)/** **Hammond (30)** **% in favour[b]**	**ICU HCP** **Garrouste (29)/** **Hammond (30)** **% in favour[b]**	**Azoulay (22)/** **Hetland (33)** **% invited[c]**
Care	Nail care	61.3	63.3	58.4-**79.2**	
	Eye care	70.4	73.2-**100**	**79.2-92.0**	>50
	Hydrating lips/ applying lip balm	72.7	**84.1**	**76.2-83.1**	
	Moistening of the oral cavity	**75**	**86.1-100**	**85.1-93.0**	
	Aspirating secretions from mouth	*40.9*	*25.7*	*26.7*-53.4	>50
	Mouth care	68.1	53.4-**76.5**	65.3-**81.5**	**>75**
	Cleaning nose	*46.5*	60.3	*49.5*-72.2	
	Hair care (shampoo)	68.3	65.9-**88.2**	*43.5*-**96.3**	>70
	Washing hands				**>80**
	Bed bathing	65.9	*40.5*-**76.5**	*35.6*-**88.8**	38.4->70
	Toileting				*48*
	Applying body lotion	**75.2**	70.4	74.2-**87.1**	**>80**
Breathing	Tracheostomy care				*21.7*
	Tracheal suctioning				*3.9-24*
Movement/ mobilization	Passive limb exercises		**88.2**	**88.8**	
	Assisting with turning		70.6	55.5	>50
	Assisting with repositioning	65.9	70.6-**77.2**	51.4-**80.1**	
	Assisting with transfer	65.9	**77.2**	51.4-**80.1**	
	Assisting with mobilization				*>30*
Feeding	Offering help with eating				**>80-87.4**
	Nasogastric feeding		*41.2*	*40.7*	
Communication	Communicating with the patient				**>80**
Comfort	Reposition pillow				**>75**
	Massage				>70

[a] Azoulay et al. (2003) (22), Garrouste-Orgeas et al. (2010) (29), Hammond (1995) (30), and Hetland et al. (2017) (33) provided quantitative data in sufficient detail for this table.

[b] Garrouste-Orgeas et al. (2010) (29) and Hammond (1995) (30) described essential care activities that were in favour, from the patient's, relatives' and ICU healthcare providers' perspective.

[c] Azoulay et al. (2003) (22) and Hetland et al. (2017) (33) described essential care activities that ICU healthcare providers' actually invited relatives to participate in **>75% (bold)** *<50% (italic).*

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Invitation and support, individualized approach
The seventh theme, invitation and support, individualized approach, was described in ten studies. Relatives require an invitation and support, individualized to their situation.

Relatives wanted to be invited, encouraged and supported to participate in essential care by ICU healthcare providers. These ICU healthcare providers need to do this with an open and flexible attitude,[5,8,28,31,42] requiring good communication and information,[5,28,38,42,45] individualized to the patient's and relatives' situation, allowing relatives to select the level, frequency and complexity of care provided.[5,34,35,38,39]

Knowledge, skills, education and training
The eighth theme, knowledge, skills, education and training, was described in twelve studies. Relatives and ICU healthcare providers require knowledge, skills, education and training to enable safe family participation in essential care.

Family participation requires information for and education of relatives to address patient safety and quality of care concerns.[26,28,33,38,42,46].

Interactions with relatives in ICU require competences based on knowledge and skills as well as attitude and values, and open communication to align patient's and relatives' needs with the ICU healthcare providers' work situation.[35,43]

Several studies addressed the need for education, training and guidelines for ICU healthcare providers to deliver family participation in essential care safely.[25, 27,28,33,39,40,46]

Characteristics of patients and relatives
The ninth theme, characteristics of patients and relatives, was described in three studies. ICU healthcare providers were negatively influenced to enable family participation by high patient acuity or relatives lacking receptiveness.

High patient acuity decreased ICU healthcare providers willingness to allow family participation.[27,39, 44]

Occasionally individual relative's receptiveness and coping ability influenced ICU healthcare providers decision to allow family participation.[39]

Organisational conditions
The tenth theme, organisational conditions, was described in eleven studies. Several organisational characteristics and factors had either a positive or negative influence on family participation, according to ICU healthcare providers.

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Organisational characteristics such as nursing management identifying relatives as care recipients[39], a unit culture that valued family engagement and lower staffing ratios[27] were considered supportive of family participation. Furthermore, family participation was perceived to reduce burden on limited nursing staff,[30] and provide nurses with more time for other tasks.[29] In addition, family participation requires an open visitation policy.[26,37,39]

The following organisational factors were perceived to have a negative influence on family participation: lack of time,[25,29,40,43,44] the ICU treatment (turns, doctors' review, assessments, examinations),[34] a lack of resources or compact sized rooms,[25,40] and a lack of hospital policies and guidelines.[25,27,40]

DISCUSSION

Our review yielded the following themes, using the addition of Bleijenberg et al.[12] to the Medical Research Council (MRC) framework,[11] on needs and perceptions regarding family participation in essential care activities. The themes were: desire to help the patient and feel useful; (positive) attitude; stress; perceived effects; feeling in control-loss of control. Regarding preferences and capacities, the following themes were identified: potential essential care activities; invitation and support; an individualized approach; knowledge, skills, education and training; characteristics of patients and relatives and organisational conditions. These themes should be addressed in the development of an intervention that enables family participation in essential care. No single theme was present in a majority of the reviewed studies.

Family participation in essential care activities in the ICU is possible, but several aspects should be taken into account. The desire to help the patient and feel useful, expressed by relatives, has been endorsed in several reviews.[14,50,51] However, research on relatives actively participating in essential care is limited, as Olding et al. have established as well.[9] In our integrative review we have tried to distinguish between the concept of family involvement in care, including both passive forms such as presence and support, and active forms such as reading to the patient, and family participation in essential care activities implying active forms only. Furthermore, how family participation should be performed is unknown and requires further research.

Most patients had a positive attitude towards family participation in essential care, though only one study addressed this explicitly.[37] In only two other studies patients' perceptions were described,[44,45] reflecting difficulties studying the patients' perspective. Limited knowledge about patients' needs and perceptions, with regard to family participation in essential care, can be explained by the altered states of consciousness that many ICU patients experience due to sedatives or illness, reducing their ability to express their needs. Relatives usually appear quite capable to act as a spokesperson, though not all relatives know what the patient's needs are. A recent review of ICU patients' needs across the recovery trajectory, considered informational, emotional, instrumental, appraisal and spiritual support needs evident;[52] some of these needs could be addressed through family participation. Future research should aim to gain more insight in the patients' needs, perceptions, preferences and capacities regarding family participation.

Not only relatives' needs, with regard to family participation should be taken into account; concerns about stress among relatives, possibly related to patient acuity, warrants attention for relatives' circumstances, specifically physical and mental strength and possible development of PICS-F. In their review Zante et al. advised to direct future research at individualized prevention of PICS-F, based on risk factors of relatives, a psychologic assessment and right timing of interventions.[53] Xyrichis et al. described similar concerns about relatives' preparedness for involvement.[18] This theme should be addressed when family participation is implemented.

Preferences for potential essential care activities, appropriate for family participation, vary. This was also found in recent studies by Liput et al. and Kydonaki et al.[16,45] Therefore, identification of a uniform list of essential care activities that relatives can participate in is impossible. To find a middle ground that facilitates the provision of standardized patient and family care on the one hand and allows an individualized approach on the other, requires a thorough consideration of preferences of all involved, which have to be taken into account prior to the implementation of family participation in essential care. Most studies focused on physical care activities, only Hetland et al. and Wong et al. described communication and psychosocial care as well.[27,41] This may be explained by a movement in recent studies to a broader approach of essential care activities, including both physical and psychosocial care.

Most relatives want to receive an invitation and support of ICU healthcare providers, individualized to their situation, requiring adequate communication and information. Further research to identify the most effective ways to improve communication with relatives is recommended;[13,54] as is an individualized approach.[18,55,56]

According to several survey studies education and training were deemed necessary, to address safety and quality of care concerns,[27,40] though no further specifications were presented; specific safety concerns relate to accidental removal of tubes, catheters or intravenous lines.[26,32] Both review and guidelines described family education, but they did not include studies addressing education of relatives on family participation.[13,17] Smithburger et al. propose the use of one-on-one discussions between ICU healthcare providers and relatives to educate and train

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relatives.[28] Depending on the activities that are deemed appropriate, other educational strategies, such as brochures, 'training-on-the-job' and videos may also be useful, and require further research.

An intervention aiming at family participation in essential care will need to provide an accurate and detailed description of family participation and corresponding actions and interventions.[26, 42] This was confirmed by several studies,[9,16,57] warranting further specification of an intervention aiming at family participation in essential care. Also, concerns about loss of control over the work situation of ICU healthcare providers needs to be addressed. Aligning the needs of everyone involved requires adequate communicative skills and a flexible attitude.[16,35,39] Furthermore, recent studies showed that involvement of stakeholders is essential to promote adherence to an intervention.[58-60]

Hetland et al.[27] did not present an explanation for the lower staffing ratios positively influencing ICU healthcare providers' attitudes towards family participation. Correspondingly, family participation to address personnel shortage or enable ICU nurses to carry out other tasks,[29,30,61] in our opinion, do not match with PFCC and participation in essential care should be free of obligation and left to the relatives' discretion.

Organisational conditions such as staffing ratios, time and resources, a culture endorsing family participation, visitation policies, and hospital policies should be analysed and where possible addressed before implementing family participation in essential care.

Most studies were conducted in Australia (n=9), the USA (n=9) and Europe (n=8), in which western norms and values will have played a role. In the Saudi study, local healthcare providers supported family involvement during routine care more than did expatriate healthcare providers. The authors attributed this to a better understanding of the needs of relatives related to sharing the same culture, norms and values.[25] Some detail on ethnic background of patients and/or relatives was provided in seven studies,[8,26,32,36,37,45,49] though none of these authors addressed possible cultural influences. Olding et al. established a lack of attention to ways in which gender, ethnicity, age and socio-economic status may influence practices and preferences around patient or family involvement as well.[9]

ICU care has gone through some substantial developments in the past decades, in terms of patient acuity, ICU treatment, visiting policies and family engagement opportunities. Eleven studies were published before 2011 (four before 2006), changes in ICU care may influence the interpretation of results; however in terms

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of needs, perceptions, preferences and capacities regarding family participation in essential care, older studies have provided valuable content.

Limitations
The quality of most included studies was moderate. Therefore, the interpretation of the results needs cautious interpretation.

The use of different study designs, populations and perspectives made synthesis of data impossible.

CONCLUSION

Knowledge on the patient's needs and perceptions regarding family participation in essential care is scarce. For relatives the opportunity to actively participate in ICU care, met their need to help the patient and feel useful. Further, family participation potentially reduces stress and the chance of developing PICS-F after discharge. Generally, most relatives and ICU healthcare providers favoured family participation in essential care, with variation in favourable care activities. Most relatives prefer to be invited and supported, individualized to their situation. Education and training of both relatives and ICU healthcare providers are necessary, to address safety and quality of care concerns, though most studies lack further specification. These themes should be addressed in the development of an intervention that enables family participation in essential care.

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Appendix 1 Search string

Appendix 2 List of excluded articles

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Chapter 5

Family participation in essential care activities in adult intensive care units: An integrative review of interventions and outcomes

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ABSTRACT

Aims & objectives

To systematically review interventions and outcomes regarding family participation in essential care in adult intensive care units.

Background

Patients and relatives may benefit from family participation in essential care activities.

Design

An integrative literature review.

Methods

The following databases were systematically searched from inception to January 25, 2021: PubMed, CINAHL, EMBASE, MEDLINE, Cochrane, Web of Science and reference lists of included articles. Studies were included when reporting on family participation in essential care activities in intensive care including interventions and outcomes. Quality of the studies was assessed with the Kmet Standard Quality Assessment Criteria. Interventions were assessed, using the TIDieR framework. Data were extracted and synthesised narratively.

Results

A total of 6,698 records were screened, 322 full-text studies were assessed. Seven studies were included, describing an intervention to support family participation. Four studies had a pretest-post-test design, two were pilot feasibility studies and one was observational. Quality of the studies was poor to good, with Kmet-scores: 0.50-0.86 (possible score: 0-1, 1 being the highest). Five studies offered various essential care activities. One study provided sufficient intervention detail. Outcome measures among relatives varied from mental health symptoms to satisfaction, supportiveness, comfort level and experience. Two studies measured patient outcomes: delirium and pressure ulcers. Among ICU healthcare providers, perception, comfort level and experience were assessed. Since outcome measures varied, only narrative synthesis was possible. Family participation is associated with a reduction of anxiety and PTSD symptoms.

Conclusion

Intervention descriptions of family participation in essential care activities are generally inadequate and do not allow comparison and replication. Participation of relatives was associated with a significant reduction in mental health symptoms. Other outcome measures varied, therefore, the use of additional outcome measures with validated measurement instruments should be considered.

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Keywords
Intensive care unit, essential nursing care, family centred care, family participation, intervention, relatives

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INTRODUCTION

Intensive care unit (ICU) stay and treatment is stressful for both adult patients and relatives.[1] Long-term consequences of physical, cognitive or mental nature, are reported in half of former ICU patients, referred to as post-intensive care syndrome (PICS).[2-4] Relatives are at risk to develop post-intensive care syndrome-family (PICS-F) after ICU discharge, with symptoms such as anxiety, depression and posttraumatic stress.[5] Family participation in essential care activities may benefit both patients and relatives.[5-7]

Family participation in adult ICU patient care is receiving increasing attention from both researchers and healthcare providers, though terms, concepts and approaches differ.[8-14] Previous reviews have focused on the broader concepts of family involvement,[15] possible barriers for Patient and Family Centered Care (PFCC)[16] and the effect of PFCC interventions, including ethics, diary, or information/ educational interventions.[17] Olding et al. consider family involvement in ICU to be a continuum, ranging from more passive forms, such as 'presence' to more active forms as 'communication and receiving information' and 'decision making'.[14] These components are positioned in the middle of their continuum, relating to eg. family involvement in rounds, invasive procedures and decision making, implying a less passive role for relatives. Olding et al.'s most active form 'contribution to care' corresponds to family participation in essential patient care activities.[14] Relatives may participate in activities, including communication, amusement/distraction, comfort, personal care, breathing, mobilization and nutrition. Examples of these activities are communicating with the patient, combing hair or helping with changing the patient's position in bed, referred to as essential care activities.[18-21]

Family participation may be considered as a complex intervention, since a change in behaviour in both ICU healthcare providers and relatives is needed and tailoring to individual needs of all involved is required. This warrants a systematic identification of evidence, determination of needs, perceptions, preferences and capacities and examination of current practice and identification of possible barriers and facilitators.[22] Recent guidelines for Family-Centred Care (FCC)[9] do not provide details of family participation nor how to implement this. In a previous review we identified the following needs and perceptions, regarding family participation in essential ICU patient care: relatives' desire to help the patient; a generally positive attitude among patients, relatives and ICU healthcare providers; stress concerning patient safety; relatives feeling in control as opposed to ICU healthcare providers having concerns about loss of control over their work situation. Preferences for potential essential care activities vary, based on the comfort of all involved and individual appropriateness for relatives. Relatives want to be invited and supported by ICU healthcare providers, individualized to their situation.[20]

In this study, we aimed to identify interventions and related outcomes, with regard to family participation in essential care activities in the ICU.

METHODS

We performed an integrative review to allow inclusion of both quantitative and qualitative studies.[23] This review was conducted in compliance with the Cochrane Handbook for Systematic Reviews of Interventions,[24] and reported in concordance with the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) statement[25] (Supplementary file 1: Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist;). A description of design, search strategy, study selection procedure, quality assessment, data extraction and data synthesis have been published in an earlier review.[20]

Search strategy

The following databases were searched for relevant articles: PubMed, CINAHL plus (EBSCO), EMBASE (OVID), MEDLINE (EBSCO), Cochrane and Web of Science, from inception to January 25, 2021. Key search terms were 'family', 'relatives', 'intensive care', 'critical care', 'critical care nursing', 'family nursing', 'family/patient centred care', 'family participation' and 'family involvement'. Search strategies are presented in Appendix 1.

Study selection procedure

Studies were included when reporting in English on interventions and outcomes regarding family participation in essential patient care during ICU stay. Exclusion criteria were: neonatal or paediatric (age <18 years) population, focus on family presence and/or participation in rounds, end-of-life care (EOLC), resuscitation or invasive procedures. Also no conference abstracts, narrative reviews and editorials were included.

Studies were screened independently on title and abstract by two reviewers (BD, LV), resolving disagreements through discussion. The remaining full-text articles were screened by pairs of independent reviewers (BD, KF, MV, LV). Reference lists of included articles were screened for potentially relevant publications.

Quality assessment

The quality of studies was assessed with a tool developed by Kmet et al.[26] The tool enables the assessment of the quality of both quantitative and qualitative studies, with a scoring system for each design. In our study we used the tool for quantitative studies consisting of 14 items: 1) Question/ objective, 2) Study design, 3) Method of subject/comparison group selection or source of information/input variables, 4)

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Subject (and comparison group) characteristics, 5) Random allocation, 6) Blinding of investigators, 7) Blinding of subjects, 8) Outcome and exposure measure(s), 9) Sample size, 10) Analytic methods, 11) Some estimate of variance, 12) Controlled for confounding, 13) Results, and 14) Conclusions. For each item a study could score 'yes' (2 points), 'partial' (1 point),'no' (0 points) or not applicable (possible score for 9 items). Calculation of the summary score led to a total quality score ranging from 0 to 1, with 1 being the highest possible score. Pairs of independent reviewers performed the quality assessment (BD, KF, MvdV, RE, LV), again resolving disagreement through discussion.

Data extraction and analysis

The following data were extracted: first author (year and country), aim, design, setting, population and method. Furthermore, data on interventions and outcomes related to family participation in essential ICU patient care, were extracted. Interventions were assessed using the TIDieR framework[27] by two researchers (BD, LV).

The checklist contains 12 items to describe an intervention in order to improve reporting and replicability: a brief name of the intervention, its rationale/theory or goal, used materials, used procedures, its provider(s), modes of delivery, its location, the number of times the intervention is delivered and over what period of time, whether the intervention is tailored or personalised, modified, and how well the intervention was performed and possible strategies to maintain or improve adherence.[27]

Outcomes were assessed from the three perspectives involved: relatives, patients and ICU healthcare providers, again by two researchers (BD, LV). Furthermore, measurement instruments, questionnaires, tools or the way outcomes were operationalised and results were assessed.

Interventions and outcome measures varied substantially and therefore a formal meta-analysis was not allowed, only narrative synthesis. The developed tables for interventions and outcomes were used to compare and synthesise the findings and identification of similarities and differences between studies.

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Results

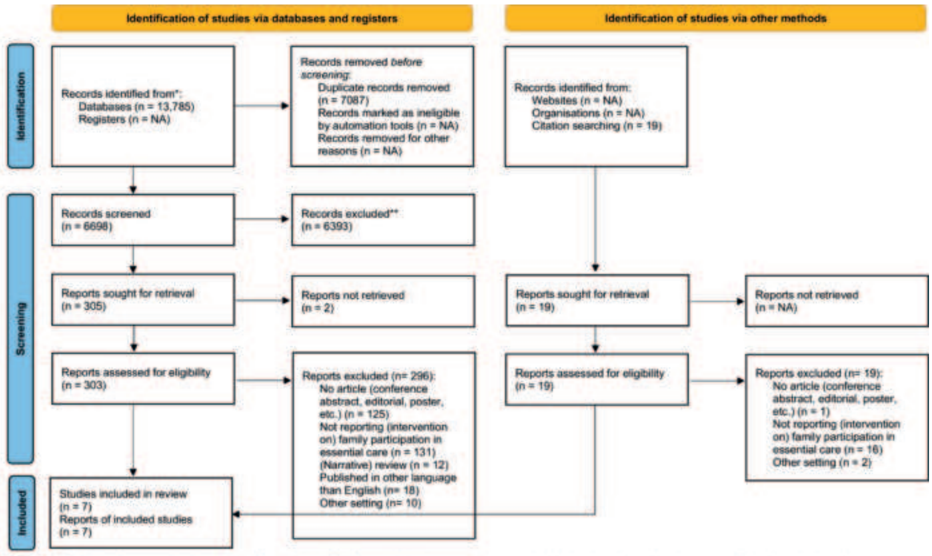
Review statistics

After removal of duplicates 6,698 records were screened. A total of 322 full-text studies were assessed, and seven studies were included (see Figure 1). Screening of the studies on title and abstract by two reviewers (BD, LV), resolving disagreements on 67 studies through discussion. The remaining full-text articles were screened by pairs of independent reviewers (BD, KF, MvdV, LV), resolving disagreements on one study through discussion.

An overview of excluded studies (n=315) is provided in Appendix 2.

Study characteristics

Study characteristics, including aim, design, country, setting, population and method are presented in Table 1. The studies were conducted in the USA (n=4),[28-31] Australia (n=2),[32,33] Argentina (n=1)[34] and Italy (n=1; this study was conducted in both Italy and the USA).[28] Most studies addressed relatives (n=6),[28-33] some included patients (n=3)[28,33,34] and/or ICU nurses or ICU healthcare providers (n=2).[31,33] Four studies had a pretest-posttest design,[28,30,32,34] two were pilot feasibility studies[29,33] and one was a prospective observational study.[31] Three studies were multicenter studies,[28,31,32] four were monocenter studies.[29,30,33,34]



*Consider, if feasible to do so, reporting the number of records identified from each database or register searched (rather than the total number across all databases/registers).
**If automation tools were used, indicate how many records were excluded by a human and how many were excluded by automation tools.

Figure 1 Study selection procedure

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Table 1 Characteristics of the intervention studies (n=7)

1st Author (Year) Country	Aim	Design	Setting (n)	Population (n)	Method
Amass (2020) Italy/USA	To assess feasibility and efficacy of implementing 'Family Care Rituals' as a means of engaging relatives in ICU patient care, with a high risk of ICU mortality, on outcomes including stress related symptoms in relatives.	Prospective, before-and-after intervention evaluation	Academic medical ICUs (2; USA), and academic medical/surgical ICU (1; Italy)	Relatives (452) Patients (263)	Survey
Davidson (2010) USA	To evaluate the feasibility of an intervention for support for families of mechanically ventilated adults, grounded in a new midrange nursing theory titled 'Facilitated Sense Making' (FSM).	Pilot study, feasibility	Mixed use ICU of a trauma centre (1)	Relatives (22)	Survey
Loudet (2017) Argentina	To determine the effectiveness of a quality management program in reducing the incidence and severity of pressure ulcers in critical care patients.	Pretest-posttest	Medical-surgical ICU within a university-affiliated hospital (1)	Patients (124)	Patient care reports
Mitchell (2009) Australia	To evaluate the effects on family-centred care of having ICU nurses partner with relatives to provide essential care to patients.	Pretest-posttest	Medical and surgical ICUs in two metropolitan teaching hospitals (2)	Relatives (174)	Survey

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Table 1 Characteristics of the intervention studies (n=7)

1st Author (Year) Country	Aim	Design	Setting (n)	Population (n)	Method
Mitchell (2017) Australia	To determine: the feasibility of recruiting participants; the retention of family members through the study; the feasibility of delivering the intervention as assessed by data collection slips; nurses' perceived acceptability of a family intervention within ICU; an effect size to inform a cautious estimate for future sample size calculations.	Pilot study, feasibility	ICU in a tertiary referral teaching hospital (1)	Patients (91) Relatives (61) ICU nurses (11)	Data slip, semi-structured interviews
Skoog (2016) USA	To increase engagement of patients' family members by implementing FSM in a cardiothoracic ICU and to measure the effect of FSM on family members anxiety levels during the ICU stay.	Pretest-posttest	Cardiothoracic ICU in a large regional heart centre (1)	Relatives (56)	Survey
Wyskiel (2015) USA	To assess family and ICU healthcare provider openness to expanding the care team to include family participation and introduce the Family Involvement Menu as a tool to facilitate family engagement.	Prospective, observational	Surgical and medical ICU and an inpatient unit from two academic medical centres (2)	Relatives (37) ICU healthcare providers (37; 95% ICU nurses)	Survey

Abbreviations: ICU: intensive care unit, FSM: facilitated sense making

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Table 2 Quality of the intervention studies (n=7)

1st Author (Year) Country	1. Question/ objective sufficiently described?	2. Study design evident and appropriate?	3. Method of subject/ comparison group selection or source of information/ input variables described and appropriate?	4. Subject (and comparison group, if applicable) characteristics sufficiently described?	5. If interventional and random allocation was possible, was it described?	6. If interventional and blinding of investigators was possible, was it reported?
Amass (2020) Italy/USA	⊕	⊕	⊕	±	N/A	N/A
Davidson (2010) USA	±	±	±	±	N/A	N/A
Loudet (2017) Argentina	⊕	⊕	⊕	±	N/A	N/A
Mitchell (2009) Australia	⊕	⊕	⊕	⊕	⊖	⊖
Mitchell (2017) Australia	⊕	⊕	⊕	⊕	⊕	⊖
Skoog (2016) USA	⊕	±	±	⊕	N/A	N/A
Wyskiel (2015) USA	⊕	±	±	±	N/A	N/A

⊕ Yes ± Partial ⊖ No
Abbreviations: N/A: not applicable

Quality assessment

The quality of the intervention studies was mostly moderate with a Kmet-score ranging from 0.50 to 0.86 (see Table 2). Most studies provided sufficient information on their objective.[28,30,32-35] The majority also provided sufficient information on design and method of subject selection.[28,32-34] Three studies reported sufficiently on subject characteristics.[30,32,33] Outcome measures were well defined in three studies,[28,30,34] the others scored partial on this item.[29,32,33,35] Most studies described appropriate analytic methods,[28,30,32-34] and results in sufficient detail.[28,30,32,34,35] Two studies reported conclusions supported by the results,[32,34] the others scored partial on this item.[28-30,33,35]

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7. If interventional and blinding of subjects was possible, was it reported?	8. Outcome and (if applicable) exposure measure(s) well defined and robust to measurement / misclassification bias? means of assessment reported?	9. Sample size appropriate?	10. Analytic methods described/ justified and appropriate?	11. Some estimate of variance is reported for the main results?	12. Controlled for confounding?	13. Results reported in sufficient detail?	14. Conclusions supported by the results?	Total score (Kmet, 0-1)
N/A	⊕	⊕	⊕	⊕	⊖	⊕	±	0.82
N/A	±	⊕	±	⊖	N/A	±	±	0.50
N/A	⊕	⊕	⊕	⊕	⊖	⊕	⊕	0.86
⊖	±	⊕	⊕	⊕	±	⊕	⊕	0.71
⊖	±	N/A	⊕	⊕	⊕	±	±	0.73
N/A	⊕	⊕	⊕	⊕	N/A	⊕	±	0.77
N/A	±	⊕	±	⊖	N/A	⊕	±	0.70

Interventions

Seven studies described an intervention to support family participation.[28-30,32-35] Five studies offered relatives various possible essential care activities to participate in,[28-30,32,35] such as hair care, passive limb exercises and assisting with repositioning, aiming to support relatives.

Davidson et al.[29] developed a Family Supportive Program utilizing the ‘Facilitated Sense Making model’, providing relatives instructions for participation. Skoog et al.[30] offered a similar intervention in the form of a ‘Facilitated Sense Making intervention card’ for relatives and patients, depending on relatives’ needs, abilities and willingness to engage in discussion and activities.

In the study of Davidson et al.[29] relatives were provided with family visiting kits, containing a family workbook, cognitive recovery tools, personal care items and

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information on relevant websites. They also received a personalized instruction from the investigator, a clinical nurse specialist, with an introduction and explanation of the project, decoding of the ICU environment, instructions on helpful visiting activities (eg, use of visiting kit, passive range of motion, cognitive recovery activities), coaching on how to ask questions of physician, identification of unmet needs, review of available hospital services and debriefing using reflective inquiry. The investigator kept the ICU nurse informed of all activities and responses, strategies used for family participation and family preferences.[29]

In the study of Skoog et al.[30] the 'Facilitated Sense Making intervention card' card was used with information about the ICU environment, care plan, procedures/ terminology; treatment, status and outcome; support services; education and assistance on activities (passive range of motion, hand massage, applying lip balm and nail care) and coaching on asking questions. Facilitated Sense Making interventions were administered by the principal investigator, an advanced practice nurse in the cardiology department, and repeated at least two times.[30]

In the study of Amass et al.[28] a researcher delivered an informational booklet, containing seven domains identified as potentially beneficial for family participation: the five physical senses, personal patient care and spirituality of patient and relatives. The researcher discussed activities/ rituals, that could be performed by relatives, as suggestions that relatives could choose from. Relatives were informed that they were not obliged to perform any of the activities, specifically nursing and hospital duties (eg. providing pillows, bathing, mouth/ ventilator care) that would be performed independent of family participation. After delivery of the booklet and discussion with the relative, there was no further contact between researchers and relatives. The role of ICU nurses is not described, apart from 'several activities requiring assistance and education from the patient's ICU nurse'.[28]

In the study of Mitchell et al. [32] ICU nurses helped relatives to participate in combinations of essential care activities, such as hair combing, hand massage and bathing, after negotiation between ICU nurses and relatives, taking the patients' condition and context into consideration. Use of possible materials is not decribed.[32]

In the study of Wyskiel et al.[35] ICU nurses invited relatives to select items from the 'Family Involvement Menu', with a list of patient care activities to participate in. The Menu was posted in each patient room, without further description.

Both Mitchell et al.[33] and Loudet et al.[34] had a more specific aim: to reduce delirium and the incidence and severity of pressure ulcers in ICU patients.

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In the study of Mitchell et al.[33] a research nurse provided relatives and staff with educational materials for each protocol component, orientation materials near the patient (white-board day planner and family photographs) and hearing aids and/or glasses. The research nurse also provided daily information and ongoing one-on-one education and training for relatives and ICU nurses about the intervention. Two components of the intervention (orientation and therapeutic engagement) were compulsory, the third (sensory) only if applicable. The white-board day planner was updated daily by the ICU nurse with the staff's name and care plan. Relatives were asked to bring family photographs. Relatives were instructed at each visit by the research nurse on: 1) How to orientate patient (where, why, day, date, and time); 2) To speak about current family events and reminisce on events of known interest to the patient; 3) Check that patient had glasses on and hearing aids in (if applicable). Relatives were asked to fill in data collection slips.[33]

In the study of Loudet et al.[34] a paper form for pressure ulcer monitoring and treatment and Whatsapp® smartphone application for ICU staff were developed. Possible materials for relatives were not described. A 'process improvement' team, consisting of 16 ICU nurses, three ICU physicians and one dermatologist, was formed, followed by the design of a multifaceted educational intervention for ICU staff on pressuere ulcer assessment, treatment, monitoring, registration and communication. One component was the 'family prevention bundle' with involvement of relatives, after training from ICU staff. Relatives performed pre-specified, limited activities, including daily skin monitoring for new lesion detection and evolution of older lesions, application of lotions, creams for hydration or silicone sprays for bony prominences and assisting in rotating the patient with the ICU nurse; no further description of the role of ICU nurses is presented.[34]

Assessment of all interventions, using the TIDieR framework[27] (see Table 3) showed several limitations. Only Mitchell et al.[33] provided sufficient detail using the TIDieR framework. Five interventions endorsed FCC, by promoting family involvement and participation.[29,30,32,33,35] One study was grounded in the in new midrange nursing theory 'Facilitated Sensemaking'.[29] Four studies provided insufficient or no detail on procedures, modes of delivery, type(s) of locations, the number of times the intervention was delivered and over what period of time and whether it had been tailored to individual needs.[28,32,34,35] One study did not report on which professional(s) provided the intervention.[35]

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Table 3 Description of intervention according to TIDieR items

1st Author (Year) Country	Item 1 Brief name	Item 2 Why	Item 3 What (materials)	Item 4 What (procedures)
Amass **(2020) Italy/ USA**	⊕ 'Family Care Rituals'	⊕ Participation of relatives in care of patients at high risk of dying in ICU may reduce symptoms of PTSD in relatives 90 days after death or discharge of patient from ICU	⊕ Informational booklet (developed in multidisciplinary, literature-based process; in English, Spanish and Italian), containing seven domains identified as potentially beneficial for family participation: - the five physical senses - personal patient care - spirituality of patient and relatives Booklet intended to act as framework describing activities	± - Researcher delivered booklet, discussing activities/ rituals, that could be performed by relatives, as suggestions that relatives could choose from - Relatives were informed that they were not obliged to perform any of the rituals, specifically, nursing and hospital duties (eg. providing pillows, bathing, mouth/ ventilator care) would be performed whether or not they participated - After delivery of booklet and discussion with relative, there were no further points of contact between researchers and relatives - No description of the role of ICU nurses is presented, apart from 'several activities requiring assistance and education from the patient's ICU nurse'
Davidson **(2010) USA**	⊕ Family Support Program	⊕ - To support relatives of mechanically ventilated adults - Grounded in new midrange nursing theory: "Facilitated Sensemaking"	⊕ Provision of family visiting kits: zip-locked plastic bag with: - family workbook - cognitive recovery tools - personal care items - information on relevant websites	⊕ Personalized instruction: - introduction and explanation of project - decoding of ICU environment - instructions on helpful visiting activities (eg, use of visiting kit, passive range of motion, cognitive recovery activities) - coaching on how to ask questions of physician - identify unmet needs - review of available hospital services - debriefing using reflective inquiry Investigator kept ICU nurse informed of all activities and responses, strategies used for family participation and family preferences
Loudet	⊕	⊕	⊖	±

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Item 5 Who provided	Item 6 How	Item 7 Where	Item 8 When & how much	Item 9 Tailoring	Item 10 Modifications	Item 11 How well (planned)	Item 12 How well (actual)
± Researcher, without further description	± - Face-to-face with relative and researcher - No description of the role of ICU nurses is presented	± - 8-bed medical/ surgical ICU in a level 1 trauma centre (Italy) - 18- bed medical ICU in a level 1 trauma centre; - 23-bed medical ICU in a level 2 trauma centre (USA)	± - ICU nurses observed rituals daily: 57.2 % of the time (495 of 865 patient days) prior to intervention and 72.0% of the time (622 of 864 patient days) during intervention - Significant increase in all categories of care rituals from usual care to intervention phases ($p<0.05$ in all cases) Notable increases in: - personal care (16.9% to 45.2%) - sight (6.1% to 26.9%) - taste (13.3% to 31.7%) - touch (34.7% to 63.7%)	⊖ Not described	N/A No modifications were made during the course of the study	N/A Intervention adherence or fidelity were not assessed	N/A Intervention adherence or fidelity were not assessed
⊕ Clinical nurse specialist (investigator)	⊕ Face-to-face at bed-side with relative	± 32-bed, mixed-use ICU of a 400-bed trauma centre	± Each relative met at least three times with the investigator and more often if desired	± Length of intervention varied depending on: - relative needs - ability - willingness to engage in discussion and activities - Often occurred with ICU nurse in room	N/A No modifications were made during the course of the study	N/A Intervention adherence or fidelity were not assessed	N/A Intervention adherence or fidelity were not assessed
⊕	⊖	±	±	⊖	N/A	N/A	N/A

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Table 3 Description of intervention according to TIDieR items

1st Author (Year) Country	Item 1 Brief name	Item 2 Why	Item 3 What (materials)	Item 4 What (procedures)
(2017) Argentina	Quality-of-care program to reduce incidence and severity of PUs in ICU patients including 'family prevention bundle'	To reduce incidence and severity of PUs in ICU patients with prolonged mechanical ventilation	- Paper form for PU monitoring and treatment and Whatsapp® smartphone application for ICU staff - No description of materials for relatives	- Formation of 'process improvement' team (16 ICU nurses, 3 ICU physicians and 1 dermatologist), and design of multifaceted educational intervention for ICU staff on PU assessment, treatment, monitoring, registration and comunication on a paper form and smartphone application - One component was 'family prevention bundle': involvement of relatives, after training from ICU staff: - performing pre-specified, limited activities, including daily skin monitoring for new lesion detection and evolution of older lesions - application of lotions, creams for hydration or silicone sprays for bony prominences - assisting in rotating patient with ICU nurse
Mitchell	⊕	⊕	⊖	±
(2009) Australia	Family-centred care with ICU nurses partnering with relatives to provide essential ICU patient care	To determine the effect of a family-centred nursing intervention on perceptions of relatives of ICU patients of family-centred care as measured by respect, collaboration, and support	Not described	ICU nurses helped relatives to participate in combinations of essential care activities, such as hair combing, hand massage and bathing, after negotiation between ICU nurses and relatives, taking the patients' condition and context into consideration
Mitchell	⊕	⊕	⊕	⊕

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Item 5 Who provided	Item 6 How	Item 7 Where	Item 8 When & how much	Item 9 Tailoring	Item 10 Modifications	Item 11 How well (planned)	Item 12 How well (actual)
'Family prevention bundle': ICU staff	- 'Family prevention bundle': training from ICU staff - No further description	14-bed medical-surgical ICU within a university-affiliated hospital	'Family prevention bundle': for a minimum of two hours per day, twice a day, seven days a week	Not described	No modifications were made during the course of the study	Intervention adherence or fidelity were not assessed	Intervention adherence or fidelity were not assessed
⊕	±	⊖	±	⊖	N/A	N/A	N/A
ICU nurses, after instruction about the project, and their role to support relatives	ICU nurses helped relatives to participate in essential care	Two medical-surgical ICUs in metropolitan teaching hospitals	- Care was provided a median of 3 times, during 48 hours - Massage, bathing and eye care were most common	Not described	No modifications were made during the course of the study	Intervention adherence or fidelity were not assessed	Intervention adherence or fidelity were not assessed
⊕	⊕	⊕	⊕	⊕	N/A	⊕	⊕

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Table 3 Description of intervention according to TIDieR items

1st Author (Year) Country	Item 1 Brief name	Item 2 Why	Item 3 What (materials)	Item 4 What (procedures)
(2017) Australia	- Orientation - Therapeutic engagement - Sensory checks, all by relatives	- Addressing modifiable patient risk factors for delirium (eg. orientation and sensory stimulation), may assist in the prevention and reduction of delirium incidence and duration in ICU - Multicomponent interventions, mostly delivered by nursing staff, some have demonstrated potential efficacy delivered by relatives - Orientation, therapeutic engagement and sensory checks designed to be delivered by the relative who has intimate knowledge of the patient	- Educational materials for relatives and staff for each protocol component - Orientation materials near patient: white-board day planner and family photographs - Hearing aids and/ or glasses	- Daily information and ongoing one-on-one education and training by research nurse for relatives and ICU nurses about intervention. - Two components (orientation and therapeutic engagement) were compulsory, the third (sensory) if applicable. 1) White-board day planner updated daily by ICU nurse with staff's name and care plan 2) Relatives were asked to bring family photographs. - Relatives were instructed at each visit by the research nurse on: 1) How to orientate patient (where, why, day, date, and time); 2) To speak about current family events and reminisce on events of known interest to the patient; 3) Check that patient had glasses on and hearing aids in (if applicable). - Data collection slips for relatives
Skoog	⊕	⊕	⊕	⊕
(2016) USA	FSM intervention card for relatives and patients	- To increase relative engagement by implementing FSM - To decrease relatives' anxiety levels	FSM card with information about: - ICU environment, care plan, procedures/ terminology - treatment, status and outcome - support services - education and assistance on activities (passive range of motion, hand massage, applying lip balm and nail care) - coaching on asking questions	- FSM interventions were administered by principal investigator - Repeated at least two times
Wyskiel	⊕	⊕	±	⊖

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Item 5 Who provided	Item 6 How	Item 7 Where	Item 8 When & how much	Item 9 Tailoring	Item 10 Modifications	Item 11 How well (planned)	Item 12 How well (actual)
Research nurse (bachelor degree and post graduate qualification in critical care nursing)	Face-to-face at bed-side with relative when visiting patient	- Near patient in public 25-bed adult tertiary referral teaching hospital, with a one-to-one nurse/patient ratio - Patient rooms varied from single room to 'havens' with walls and curtains	- The intervention was designed to be delivered by the relative each day they visited, if they stayed for longer periods, they could select when they wanted to deliver the intervention components, guided by the ICU nurse to choose the most appropriate time	Each patient had the intervention delivered by their own relative, thus completely individualised	No modifications were made during the course of the study	- Intervention fidelity was assessed by examination of completed data slips - Individual education sessions were provided to relatives to improve intervention fidelity	Relatives in intervention group (76%) and non-intervention group (87%) completed at least one data slip
⊕	⊕	±	±	⊖	N/A	N/A	N/A
Advanced practice nurse in cardiology department	Face-to-face at bed-side with relative	Cardiothoracic ICU in a large regional heart centre, treating a large nonwhite, culturally mixed population	Principal investigator met with each patients' relatives at least two times	Not described	No modifications were made during the course of the study	Intervention adherence or fidelity were not assessed	Intervention adherence or fidelity were not assessed
⊖	⊖	⊖	⊖	⊖	N/A	N/A	N/A

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Table 3 Description of intervention according to TIDieR items

1st Author (Year) Country	Item 1 Brief name	Item 2 Why	Item 3 What (materials)	Item 4 What (procedures)
(2015) USA	FIM: document with a list of patient care activities relatives could participate in	To support active participation in ICU patient care to address senses of lack of information, uncertainty, vulnerability and anxiety among relatives	FIM, posted in each patient room	ICU nurses invited relatives to select items from the FIM to participate in, no further description

⊕ Yes ± Partial ⊖ No
Abbreviations: N/A: not applicable; FIM: family involvement menu; FSM: facilitated sense making; PTSD: Post-Traumatic Stress Disc

OUTCOMES

Five studies offered relatives to participate in various essential care activities,[28-30,32,35] aiming to support relatives.

Two studies, both with a pretest-posttest design, and Kmet-scores between .77 and .82, measured mental health symptoms among relatives varying from anxiety,[28,30] depression and PTSD,[28] to satisfaction.[28] Family participation was associated with a significant reduction in (situational) anxiety scores,[28,30] and PTSD symptoms in relatives.[28] Family satisfaction showed a trend towards a positive relationship between family participation and satisfaction (see Table 4).[28]

Three studies, a pilot feasibility study, one with a pretest-posttest design and one prospective observational study, and Kmet-scores between .50 and .71, measured relatives' perceptions, e.g. helpfulness and supportiveness,[29] perceived respect, collaboration and support,[32] and perception, comfort level, experience and interest in implementation of family participation among relatives.[35] Relatives perceived various intervention items as useful and helpful, personal care supplies were considered most helpful.[29] In the study of Mitchell et al.[32] relatives in the intervention group perceived more respect, collaboration and support. According to Wyskiel et al.[35] most relatives were interested and felt comfortable participating in care.

Four studies, of which three with a pretest-posttest design and one pilot feasibility study, and Kmet-scores between .71 and .86, operationalised family participation in number and type of activities,[28,32,33] or number of relatives participating.[34] Amass et al.[28] found a significant increase in all care activities in the intervention group.

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Item 5 Who provided	Item 6 How	Item 7 Where	Item 8 When & how much	Item 9 Tailoring	Item 10 Modifications	Item 11 How well (planned)	Item 12 How well (actual)
ICU nurses, no further description of their background, expertise or specific training	Invitation from ICU nurses, no further description	Surgical and medical ICU and an inpatient unit from two academic medical centres	Not described	Not described	No modifications were made during the course of the study	Intervention adherence or fidelity were not assessed	Intervention adherence or fidelity were not assessed

rder; PU: pressure ulcer

In both studies of Mitchell et al. most relatives participated in care activities,[32,33] individualized to their situation, with help from the bedside ICU nurse.[32] Relatives did not consider these care activities difficult or onerous, though recording of these activities was low.[33] The number of relatives participating increased significantly in the post-intervention group.[34]

Two studies included patient outcomes: pressure ulcers and delirium,[33,34] with the intervention resulting in a significant reduction in incidence and severity of pressure ulcers[34] but not in the prevalence of delirium.[33]

Three studies measured perceptions from the ICU healthcare providers perspective, acceptability[33] and perception,[28,35] appropriateness of specific care activities, comfort level, experience and interest in implementation of family participation were assessed.[35] ICU nurses generally favoured family participation.[33] They agreed with the statements ‘the intervention did not interfere with their care of the patient’ and ‘the intervention improved their communication with the relatives’.[28] Most ICU healthcare providers supported family participation, and several activities were considered appropriate, however few actually invited relatives to participate all the time.[35]

Two of the intervention studies were assessed for feasibility and considered feasible, however issues hindering recruitment and barriers concerning relatives’ fear and discomfort and need for information occurred.[29,33]

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Table 4 Outcomes, measurement instruments/ questionnaires/ tools/ operationalisation, results

1st Author (Year) Country	Outcomes (population/ level)	Measurement instruments/ questionnaires/ tools/ operationalisation	Results
Amass (2020) Italy/USA	Primary: 1) PTSD at 90 day follow-up post-death/ discharge of patient (relatives) Secondary: 2) Symptoms of depression and anxiety (at enrolment and at 90 day follow-up) (relatives) 3) Family satisfaction at 90 day follow-up (relatives) Other data collected: 4) Rituals employed by relatives during both phases (ICU nurses) 5) Survey evaluating perception on workflow during intervention phase (ICU nurses)	1) IES-r (22-item) 2) HADS (14-item) 3) FS-ICU24 (24-item) 4) Recording daily observations of prespecified rituals during each shift 5) Survey (7-item)	1) IES-r scores ≥ 30 at follow-up: Usual care group (N=130): 39.2% (CI 30.7–47.4); FCR group (N=129): 27.1% (CI 19.2–35.1); a significant reduction in relatives with symptoms of PTSD (adjusted OR: 0.54 (CI 0.30–0.98, p=0.041)) 2) Depression at follow-up: Usual care group (N=131): 26.5% (CI 18.8–34.3); FCR group (N=129): 25.2% (CI 17.4–33.1); no difference in symptoms of depression (adjusted OR: 0.92 (CI 0.51–1.66, p=0.787)). Usual care group: −14.5% (CI −23.7- −5.4); FCR group: −26.7% (CI −35.9- −17.5); a non-significant decrease in depression scores (p=0.068). Anxiety score ≥8 at follow-up: Usual care group: 41.0% (CI 32.3–49.6); FCR group: 45.5% (CI 36.5–54.4); a non-significant difference (adjusted OR: 1.19 (CI 0.70–2.02, p=0.519). Usual care group: −19.3% (CI −29.2- −9.4); FCR group: −35.7% (CI −45.1- −26.3); a significant decrease in anxiety scores (p=0.019). 3) Mean FS-ICU24 at follow-up: Usual care group (N=126): 85.1 (CI 82.4–87.8); FCR group (128): 89.0 (CI 86.2–91.8); not statistically different (adjusted difference 2.96, CI −0.67–6.58, p=0.110). Three selected questions likely to be impacted by FCR: for 'included in the decision making', the mean adjusted response was significantly higher post-intervention (0.25, CI 0.04–0.47, p=0.021); for 'satisfied with care question', the mean response was not significantly different (adjusted difference −0.08, CI −0.36–0.21, p=0.606) and for 'had control over the care', the mean adjusted response change was not significant (0.22, CI −0.6–0.51, p=0.124). 4) Rituals observed: Prior to intervention: 57.2 % of the time (495 of 865 patient days) During intervention: 72.0% of the time (622 of 864 patient days) ignificant increase in all categories of care rituals from usual care to intervention

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Table 4 Outcomes, measurement instruments/ questionnaires/ tools/ operationalisation, results

1st Author (Year) Country	Outcomes (population/ level)	Measurement instruments/ questionnaires/ tools/ operationalisation	Results
			phases (p<0.05 in all cases): - personal care (16.9% to 45.2%) - sight (6.1% to 26.9%) - taste (13.3% to 31.7%) - touch (34.7% to 63.7%) 5) ICU nurses (N=524) completed surveys; three statements had mean responses ~4, indicating agreement: 'the quality of the care they delivered was improved' was 3.98 (CI 3.9–4.06), 'the intervention did not interfere with their care of the patient' was 4.42 (CI 4.34–4.49) and 'the intervention improved their communication with the relatives' was 4.0 (3.92–4.08).
Davidson (2010) USA	1-2) Helpfulness and supportiveness (relatives) 3) Feasibility (intervention)	1) aCCFNI (45-item; importance scale and needs-met scale (4-point Likert scale: 1= not important to 4= very important)) 2) Family Support Program evaluation (11 questions) 3) Investigator log	1) Internal consistency reliability of the aCCFNI was high (α = .96). All 45 needs were considered of some importance. Ranking items in order of importance, further validated the relatives' informational needs. A weighted analysis of needs-met to importance identified unit-specific improvement opportunities (mean importance scores: 3.30-3.89; mean needs-met scores: 2.60-3.37). 2) Each of the intervention items (eg. suggestions for bedside activities, cognitive recovery activities) was used and considered helpful by some relatives, also depending on the patient's condition and personal preference. The journal was considered least useful; personal care items were considered most helpful. 3) Various observations, comments from ICU HCPs and relatives, barriers and relevant occurrences are described, mostly concerning relatives' informational needs.

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Table 4 Outcomes, measurement instruments/ questionnaires/ tools/ operationalisation, results

1st Author (Year) Country	Outcomes (population/ level)	Measurement instruments/ questionnaires/ tools/ operationalisation	Results
Loudet (2017) Argentina	1) PUs (patient) 2) Rate of family participation (relatives)	1) Daily monitoring of incidence, location and evolution of PUs 2) Number of relatives participating in 'family prevention bundle'	1) Number of patients included: Pre-intervention group: 55; Post-intervention group: 69. Incidence of PUs: Pre-intervention group: 41 (75%), of which advanced PUs: 27 (49%); Post-intervention group: 37 (54%), of which advanced PUs: 7 (10%); a significant decrease in both ($p< 0.05$). A logistic regression model showed that the intervention program acted as a protective factor for the development of PUs ($p=0.000$). 2) Number of relatives participating was: Pre-intervention group: 5 (9%); Post-intervention group: 39 (57%); a significant increase in number of relatives participating ($p < 0.05$).
Mitchell (2009) Australia	1) Family participation (relatives) 2) Effect of the intervention on relatives' perceptions of family-centred care, measured by respect, collaboration and support (at enrolment and at approximately 48 hours follow-up) (relatives)	1) Type and number of episodes of care that relatives provided, recorded by the bedside ICU nurse. 2) Adapted Family-Centred Care Survey, a 20-item tool, developed for paediatric settings, adjusted to the adult ICU context, to measure respect, collaboration and support (4-point Likert scale: 1= never to 4= always).	1) Care was provided by 82% of the relatives in the intervention group and a median of 3 times (IQR, 3; range, 1-14). Most common care activities were massage (29%), bathing (23%), and eye care (17%). 2) Total median survey scores at baseline were: Control: 3.2 Intervention: 3.2 Total median survey scores at follow-up were: Control: 3.2 Intervention: 3.5 After adjustments in the multivariate ordinal logistic regression model, the intervention was the strongest predictor of higher total family-centred care scores at follow-up (OR= 1.66; $p<.001$). Other independent predictors included relatives with previous ICU experience (OR=1.27; $p=.006$) and being partner of the patient (OR=1.33; $p=.002$).

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Table 4 Outcomes, measurement instruments/ questionnaires/ tools/ operationalisation, results

1st Author (Year) Country	Outcomes (population/ level)	Measurement instruments/ questionnaires/ tools/ operationalisation	Results
Mitchell (2017) Australia	1) Family participation (relatives) 2) Patient delirium (patients) 3) Acceptability (ICU nurses) 4) Feasibility (research nurse)	1) Data slip at bedside for each visit, with tick box for each of the three intervention components, and free text space for additional comments (intervention group); free text space for activities (non-intervention group). 2) CAM-ICU 3) Acceptability was assessed via semi-structured, digitally recorded interviews. 4) Study notes provided general reflections on study feasibility; retention of relatives; completed data slips.	1) Recorded data slips were low for therapeutic activities (35%), orientation (30%), and sensory checks (20%). 2) No statistical difference was found in prevalence of delirium in the groups: non-intervention (56%) and intervention (59%) (p = 0.87). 3) ICU nurses generally favoured relatives' involvement, however taking set boundaries and possible overburdening of relatives into account. Barriers from the relatives perspective were: fear, discomfort or being overwhelmed, and from the ICU nurses perspective: some perceived relatives as an impediment to deliver care and some the ICU environment (assessment, examinations and treatment). 4) Five issues hindered recruitment: 1) infrequent visits of relatives (15); 2) complex relatives/social situations (9); 3) relatives' perceptions that the study would add to stress and detract attention from the patient (6); 4) patient delirium symptoms, likely due to pre-existing conditions (5); and 5) working hours of research nurse hours limiting enrolment opportunities (14). The requirement to complete data slips was 'too much' for some relatives according to the field notes. Relatives considered the intervention components not difficult or onerous.
Skoog (2016) USA	1) Anxiety levels (state and trait) (relatives)	1) STAI	1) Mean levels of **state** anxiety: Before: 53.64 (SD 12.29); After: 40.61 (SD 10.72); a significant decrease after FSM (p=.001). Mean levels of **trait** anxiety: Before: 36.40 (9.99); After: 35.92 (10.16); non-significant difference (p=.46).

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Table 4 Outcomes, measurement instruments/ questionnaires/ tools/ operationalisation, results

1st Author (Year) Country	Outcomes (population/ level)	Measurement instruments/ questionnaires/ tools/ operationalisation	Results
Wyskiel (2015) USA	1) Perceived importance of relatives' needs (ICU HCPs) 2) Perception, comfort level, experience and interest in implementation of FIM (ICU HCPs) 3) Perception, comfort level, experience and interest in implementation of FIM (relatives)	1) CCFNI (nine out of 45 items, covering needs for information, support, comfort, proximity, and assurance; 4-point Likert scale: 1= not important to 4= very important) 2) FIM Clinician Survey (14 items), including a list of 14 care activities to evaluate for appropriateness, and open-ended questions on least likely activities, rationale, encountered barriers and opportunities 3) FIM Family Survey (7 items), completed in an interview	1) None of the nine items address needs related to family participation and are therefore not described 2) Most ICU HCPs considered relatives as part of the healthcare team (n=34; 92%); 29 (78%) reported being comfortable inviting relatives to participate in care (78%), 26 (70%) actually did so some of the time and 6 (16%) all of the time. Several activities were considered appropriate by the majority of ICU HCPs: entertainment (music, reading, and TV) (37; 100%), eating/feeding (36; 97%), mouth care and pillow repositioning 35 (35; 95%), hand and leg care (34; 92%), breathing exercises/exercises in bed (33; 89%), bathing (32; 86%), , shampoo/shave (30; 81%), sitting up & walking (26; 70%). ICU HCPs also reported that relatives were least likely to be involved in physiotherapy (32%), bathing (27%), and mouth care (19%). Some ICU HCPs identified some barriers among relatives: anxiety, discomfort (19%), and unwillingness (14%), and lack of time for ICU HCPs (14%). Value in family participation was perceived in providing ICU nurses with more time for other tasks (35%), opportunities for relationship building (19%), and educating relatives in care activities (16%). 3) Most relatives were interested in family participation (n=35; 95%), felt comfortable participating (n=34; 92%) and felt part of the healthcare team (n=33; 89%).

Abbreviations: (a)CCFNI: (adapted) Critical Care Family Needs Inventory; CAM-ICU: Confusion Assessment Method for the Intensive Care Unit; FCR: Family Care Rituals; FS-ICU24: Family Satisfaction in the ICU-24 questionnaire; FSM: facilitated sense making; HADS: Hospital Anxiety and Depression Scale; HCP: healthcare provider; ICU: intensive care unit; FIM: family involvement menu; IES-r: Impact of Events Scale-revised; OR: odds ratio; PU: pressure ulcer; STAI: State-Trait Anxiety Inventory

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DISCUSSION

In this review we identified seven studies describing interventions and outcomes, with regard to family participation in essential care activities in the ICU. Quality of the included studies varied considerably and often insufficient details were provided to weigh the importance of the intervention or the outcome.

The need for a detailed description of an intervention aiming at family participation in essential care has been mentioned in several studies,[12,14,36-39] however the number of studies we identified and the level of detail provided by the authors were limited.

Participation of relatives in care activities was associated with a significant reduction in mental health symptoms as anxiety[28,30] and PTSD.[28] Zante et al.[40] also studied interventions aimed at prevention, reduction or treatment of anxiety, depression, PTSD, and complicated grief in relatives. The studies they found included interventions that improved information through brochures and family conferences, and optimization of communication between ICU healthcare providers and relatives, both being effective. They propose the use of multifaceted interventions to reduce the burden experienced by relatives during the patient's ICU stay and to influence mental health outcomes of relatives.[40] A recent study advised critical care nurses to encourage relatives to participate in care.[41] This implies the use of interventions that go beyond information and communication, and may include family participation. Two other reviews aimed to provide an overview of relatives and ICU HCPs perceptions and current understandings of family participation in essential care activities, they suggest more research to ascertain the effect on patients and relatives.[11,12]

Outcome measures were highly variable, measured with both validated and unvalidated scales, some including somewhat outdated content. Several outcome measures, such as anxiety, depression and PTSD were investigated with validated scales.[28,30] Other studies measured helpfulness and supportiveness,[29] perceived respect, collaboration, and support,[32] and perception, comfort level, experience and interest in family participation,[35] however with unvalidated scales. Furthermore, both Davidson et al.[29] and Wyskiel et al.[35] used an adapted or shortened version of the Critical Care Family Needs Inventory (CCFNI),[42] focusing on need for information, proximity, comfort, assurance and support. According to Olding et al.[14] family needs are almost exclusively assessed with the CCFNI, however surveys alone cannot clarify relatives' personal experiences and contextual factors that shape their needs. This was endorsed in a previous review identifying needs and perceptions, regarding family participation in essential ICU patient care among relatives.[20] Amass et al.[28] used three questions from the FS-ICU:[43] 'included in the decision making', 'satisfied with care', 'had control over the care', that were considered likely to impact

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relatives' satisfaction by family participation. One may question to what extent these questions reflect relatives' satisfaction with family participation in essential care activities. Two recently developed scales to assess family needs and satisfaction include family participation in essential care activities.[44,45] These scales illustrate that relatives' needs may have developed over time, and focus may have moved towards less passive or more active strategies among relatives to cope with a patient being in ICU and reflect the need for other suitable outcome measures.

Feasibility of the intervention study was established in two studies,[29,33] however difficulties in recruitment and attrition among relatives may indicate that relatives are inclined to participate in essential care activities, but require good information and support to participate in research.

Strengths and limitations

A thorough systematic search was performed for studies reporting on interventions and outcomes regarding family participation in essential care activities in ICU. The included studies were assessed for quality; followed by a critical appraisal of interventions and outcomes and a narrative synthesis.

Only seven studies of poor to good quality were included. Due to heterogeneity of populations, interventions and outcome measures, a meta-analysis was not possible. Furthermore, most studies provided insufficient details to weigh the importance of the intervention or the outcome, warranting cautious interpretation of the results.

CONCLUSION

Relatively few studies, of poor to good quality, investigated family participation in essential care activities in the ICU. Overall, family participation is associated with a reduction of symptoms of anxiety and PTSD among relatives. Intervention descriptions were brief and should be addressed in future research to facilitate comparison and replication. Other outcome measures varied considerably warranting the use of possible additional and updated outcome measures with validated measurement instruments. Furthermore, the use of mixed methods should be considere

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Appendix 1 and 2 Search string and list of excluded articles

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Chapter 6

Family participation during physical activity in the intensive care unit: A longitudinal qualitative study

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ABSTRACT

Purpose

Family-centered care has been implemented in the ICU to meet relatives' needs concerning information, support, participation and shared decision making. This study explores the needs, beliefs, feelings and behaviors of relatives of patients admitted to the ICU regarding participation during physical activity.

Methods

Longitudinal qualitative study design following a grounded theory approach. Relatives were interviewed at 4, 8 and 12 days after the patient's ICU-admission. Data were analyzed using constant comparison.

Results

Twenty-five interviews were conducted in ten relatives. Relatives believed that physical activity in the ICU improves recovery. Participating in physical activity decreased their feelings of powerlessness and uselessness. Relatives mentioned that they would be stimulated to participate if they were invited, guided and informed by healthcare providers. The perceived reticence of healthcare providers, patient's health-changing capacity and the inability to communicate led to a more passive attitude towards participation.

Conclusions

The conceptual model shows how family participation during physical activity changes from a passive role, with negative beliefs and feelings of uselessness and powerlessness, to a more proactive participatory role. Relatives felt more useful and like they were part of the team. Providing relatives with additional information might be a viable strategy to help and stimulate participation.

Keywords

Physical activity, family participation, family-centered care, intensive care unit, qualitative research

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INTRODUCTION

The environment in the ICU is not only stressful for patients, but also for their relatives.[1,2] Findings from several studies suggest that symptoms of anxiety, depression and post-traumatic stress symptoms may persist for three months or longer.[3,4] These symptoms are known as Post Intensive Care Syndrome-Family (PICS-F) and have a negative impact on quality of life.[4,5]

Family-centered care (FCC) is an approach to healthcare that is respectful of and responsive to individual families' needs and values.[6] Family education programs have demonstrated beneficial effects for family members in the ICU by reducing anxiety, depression, post-traumatic stress, and generalized stress, while improving family satisfaction with care.[7] One component of FCC is family participation in patient care activities.[8-10] This participation might help to decrease PICS-F and feelings of powerlessness,[11] while the presence of relatives is known to increase patients' feelings of safety.[12] Most relatives prefer being present during the daily bedside rounds and partaking in tasks such as massaging, oral care and bathing (of) their loved ones in the ICU.[13,14]

In a scoping review, Davidson et al.,[6] highlighted the importance of additional research to identify effective interventions to improve participation during physical activity by relatives in the ICU.[6] Current patient physical activity levels in the ICU are low, for a variety of reasons, including the severity of illness, the presence of an endotracheal tube, delirium, the availability of equipment and human resources and/or a lack of knowledge in healthcare providers.[15,16] All of these factors might contribute to patients being unable to return to premorbid physical functioning.[3,17] Physical therapists play an important role in encouraging physical activity, although involving relatives in physical activity may not be usual practice.[18-20] The engagement of relatives might increase the frequency of physical activities and could be a positive contribution to patient recovery. To date, only one study has investigated relatives' beliefs and needs to be actively involved in stimulating physical activity within the ICU. Most relatives were open to helping the ICU-staff to change the patients' positions in bed or transfer them to the chair.[21]

Our qualitative study focuses on new topics like: 1) how do relatives feel about participating during physical activities, 2) what are relatives' needs, beliefs, feelings and behaviors immediately after ICU admission, and 3) over time, at what level do relatives participate? Therefore, this study aims to explore the needs, beliefs, feelings and behavior of relatives of adult patients in the ICU while participating in physical activity.

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MATERIALS AND METHODS

Study design

A longitudinal qualitative study with an inductive, interpretative approach was conducted according to the grounded theory method by Corbin et al.[22-24] Three semi-structured interviews were scheduled with each relative on days 4, 8 and 12 after the patient was admitted to the ICU.[25,26] This study follows an inductive approach to develop a conceptual model. The study protocol was approved by the ethics committee of the Radboudumc (CMO: 2017-3635).

Setting

The study was conducted at the ICU of Radboud university medical center (Radboudumc) in Nijmegen, the Netherlands, between January and June 2018. The ICU consists of five units with eight single rooms in each. There is a 24-hour open visiting policy and separate family rooms. The ICU at the Radboudumc adopted FCC as part of the clinical care, and family participation was implemented into multidisciplinary practice in 2017. At these units, early mobilization is usual practice, while hydrotherapy is used to activate and rehabilitate critically ill ventilated patients.[27,28]

Quality procedures

Two authors (KF and VvdW) work at the neurological ICU. To prevent observer bias, we excluded this unit. To improve trustworthiness, a third independent expert (NK) performed a peer review to check the open codes. Differences in codes were resolved by discussing them. Member validation was carried out by verifying a summary of the first and second transcribed interviews prior to the second and third interview.[29] The Consolidated Criteria for Reporting Qualitative research (COREQ) checklist was used for reporting.[30]

Participants and recruitment

Participants were sampled conveniently (through availability). Inclusion criteria were: relative of a patient admitted to the ICU for at least 48 hours, age >18 years, related by blood or a close relationship with the patient, have visited at least once and able to speak Dutch. They were approached by telephone or in person and received additional information by e-mail or letter. Informed consent was signed prior to the first interview. Sampling and data collection were continued until no new conceptual insights were generated and theoretical saturation was reached.[12,31]

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Data collection

Semi-structured interviews were held face-to-face in a family room or by telephone. The interviews were performed by VvdW. She was not related to any of the patients or their relatives.

The interviewer had no prior interviewing experience. Bracketing and reflexivity skills were developed through four pre-study practice interviews.[29] Observational memos were made to catch relevant impressions and thoughts during the interviews. An interview guide including open questions based on literature and best practice was used to ensure that relevant topics were covered during the interview (see Appendix 1).[21,32]

The baseline characteristics of relatives were obtained prior to the first interview. Baseline characteristics of patients were collected from the Electronic Patient Database (EPD), including the number of physiotherapy treatments and Functional Status Score for the Intensive Care Unit (FSS-ICU) during ICU admission. The FSS-ICU is a measure of physical function for ICU patients.[33] It describes the level of patient independency in activities of daily living.

Data analysis

Data analysis was conducted in accordance with the grounded theory methodology by Glaser and Strauss (see Table 1).[23,29] All interviews were audio-recorded and transcribed verbatim (VvdW). Transcripts were entered in the qualitative software ATLAS.ti (Scientific Software Development GmbH. Version 7, 2012). To identify meaningful codes, line-by-line examination was carried out independently by two researchers (KF and VvdW). The results of the first interview identified codes for the subsequent interviews.[34] Axial coding was performed to identify the relationships between codes to formulate themes. In a reflective meeting, themes were discussed with KF, VvdW, NK, AO and TH until consensus was reached. Key themes were integrated into a conceptual model with the consensus of all authors.[24] The use of memos supported the analytical interpretation regarding relatives' expression.

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Table 1 Analytical process

Data analysis:

- **Transcribed verbatim:** all of the interviews to gain insight into the overall impression of the separate cases and the change in every case over time (VvdW).
- **Reading transcriptions:** to gain insight into the overall impression of the separate cases and the change in every case over time (KF). Six interviews (24%) were controlled to correct typing errors (KF).
- **Summarizing** all interviews to compare the time-changing beliefs, needs, feelings and behavior of the participants (VvdW).
- **Open coding:** two members independently identified text segments that contained meaningful codes for each of the 25 interviews (KF and VvdW).
- **Axial coding:** the two members compared the codes and discussed them to reach agreement. Matching codes were combined. A hierarchy of categories was formulated to show various relationships between themes which can be discussed during selective coding (KF and VvdW).
- **Longitudinal comparison** within cases and between categories. Quotations and codes were ordered chronologically to detect whether there was a time-dependent change in the family's beliefs, needs, feelings and behaviors regarding physical activity promotion (KF and VvdW).
- **Investigator triangulation:** to increase reliability and detect inappropriate subjectivity, an independent expert performed a peer review to check the open codes (NK). Themes were identified and discussed until consensus in interpretation was reached (KF, VvdW, NK, AO and TH) and the final conceptual model was created (KF, VvdW, NK, RN and TH).
- **Selective coding:** a theoretical framework within final themes were developed that give a deeper understanding of the changes over time and differences in the beliefs, needs and behaviors of relatives (KF, VvdW, NK, AO and TH).

Observational memos to enhance the transparency of the analytical process and to reflect on the process of the interviews by catching relevant impressions and thoughts (VvdW). The memos were written out in the transcriptions and linked to the codes to explain interpretations and conclusions.

Based on Strauss & Corbin 2007

The method used for data analysis is informed by the constant comparative method.[22,35] Each separate case (all longitudinal data of one participant) was analyzed, followed by an analysis across all cases and finally a synthesis of the findings.[25,26] Baseline characteristics were analyzed descriptively.

RESULTS

Participants

All approached participants were willing to participate. Ten relatives of ten patients represented a heterogeneous sample in terms of relationship to the patient, age, gender and educational level (see Table 2). The relationship to the patient was classified as parent, child (in law), sibling or spouse. Nearly

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all relatives visited the patient daily for one or more hours. The mean age of critically ill patients was 57.5 years (SD=20.4) and the mean (SD) length of ICU stay in days was 18 (11) (see Table 2). Seven patients were completely immobile following ICU admission and needed help in all physical activities (FSS-ICU ≤2). Two patients were able to transfer out of bed with minimal assistance (FSS-ICU 19 and 23), and one patient was ambulating and able to walk while ventilated (FSS-ICU 30). **Table 2** Baseline characteristics

Interviews

A total of 25 interviews were conducted with a duration varying from 5-25 minutes. On average, the first, second and third interviews were conducted 4 days (n=10), 9 days (n=9) and 14 days (n=6) after ICU admission (see table 2). All interviews were conducted while the patient was still in the ICU. Data were incomplete for some cases as two patients died and two patients transferred to the low-care nursing department after the second interview (see table 2). Theoretical saturation was reached after interviewing the eighth participant. To confirm data saturation, two additional interviews were conducted that generated no new conceptual insights.

Nine out of ten relatives were willing to participate, except for participant 4. In her role as sister, she wanted *'to be there'* for her brother, but not participate during physical activities. The other nine relatives participated in the following activities: massage of extremities, changing bed positions, transfer from supine to sit; supporting head and torso in upright position; sitting next to the patient at the edge of the bed; guiding the intravenous lines; assisting in breathing exercises and coughing; and giving verbal stimulation. Relatives believed physical activity had a positive effect on the recovery of the patient.

Four key themes were identified as a final theoretical framework. They described whether relatives wanted to participate during physical activities and what they needed for participation:

Relatives' expectations toward healthcare providers

There was a lack of knowledge among all relatives about the type of physical activity provided in the ICU. This led to a need for information, explanations and guidance to learn how to participate in the activities. Relatives needed a clear invitation to participate. Sometimes they found it difficult to participate, because there were no fixed times scheduled.

Two relatives mentioned a discrepancy in healthcare providers' attitude towards encouraging participation. Some healthcare providers were more reluctant to invite relatives and told them *'No, it's bad timing'*. One participant said:

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Table 2 Baseline characteristics

Relatives **No.**	**Sex (M/F)**	**Age (years)**	**Relationship to patient**	**Highest education level**	**How many times did you visit your relative (hours/ week) at first interview**
1	M	53	Father	HBO/4-years degree	Continuously
2	M	66	Spouse	MBO/2-years degree	28 hours/week on daily basis (every day 4 hours)
3	F	41	Sister	Academic graduation	7 hours/week (every day 1 hour)
4	F	60	Sister	MBO/2-years degree	7 hours/week (every day 1 hour)
5	F	54	Mother	MBO/2-years degree	Continuously
6	M	52	Son	Academic graduation	6 hours/week (three days a week, 2 hours per visit)
7	F	64	Mother	HBO/4-years degree	Continuously
8	M	69	Spouse	MBO/2-years degree	28 hours/week on daily basis (every day 4 hours)
9	F	37	Daughter	MBO/2-years degree	28 hours/week on daily basis (every day 4 hours)
10	F	41	Daughter in law	MBO/2-years degree	Continuously

Abbreviations: No.=number, M=male, F=female, ICU=Intensive Care Unit, FSS-ICU=Functional Status Score for the ICU, OOHCA=O
*This score has a range of 0–35 with higher score, indicating better functional status.

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Patients					Interviews		
Sex (M/F)	**Age (years)**	**Reason for ICU admission**	**Length of ICU stay (days)**	**FSS-ICU score* at ICU admission**	**T0 First interview (days after ICU admission)**	**T1 Second interview (days after ICU admission)**	**T2 Third interview (days after ICU admission)**
M	19	OOHCA after caffeine intoxication	24	0	3	8	13
F	65	Bilateral pneumonia (had two kidney transplantations and pacemaker because of atrium fibrillation)	11	0	2	6	11
F	39	Respiratory failure by pneumonia (already known with mitochondrial myopathy)	30	30	6	10	17
M	69	Exacerbation COPD by pneumonia	18	23	5	10	14
M	22	High energetic injury after a motor cross accident	3	19	2	6	X Nursing department
M	78	Respiratory failure by pneumonia	17	0	3	9	15
M	41	Suicide attempt by intoxication an unknown drug	35	2	4	9	16
F	63	Cholangitis by pancreatic cancer	8	0	2	X Died	X
M	67	Respiratory failure by pneumonia	16	0	9	16	X Died
F	52	OOHCA by ventricular fibrillation and ventricular tachycardia	5	0	3	12	X Nursing department

ut Of Hospital Cardiac Arrest, COPD Chronic Obstructive Pulmonary Disease.

"Yes uhm...to be honest, I participate less.., as I no longer feel free to participate. Because the healthcare providers' views differ too much" (participant 7, interview 3).

Others were more open and willing to invite relatives to participate. Relatives often felt redundant, because there were already two healthcare providers helping the patient.

Benefits of participation for relatives

The need to *'being a part of the treatment'* instead of *'standing on the side'* was expressed by almost all relatives. The possibility to participate during physical activities made relatives *'feel useful'*. One relative even felt guilty if he chose not to participate. Another expressed it in the following way:

> *"To say in soccer terms: Otherwise it's a game of others and you are standing at the side, only watching. At least now you can make yourself useful...even if you are the ball boy. Now you at least have some influence on the game." (participant 1, interview 2).*

Some relatives believed that participating improves emotional coping. Others only experienced making a contribution to the functional recovery of the patient. A father said:

> *"He was surrendered by the white coats and by touching him, it feels like he becomes more connected to us, his loved ones." (participant 1, interview 3).*

The feeling of powerlessness is expressed by several relatives:

> *"I've been sitting here for two days now and I see a lot of people doing things, but I have had no influence. Now I have the feeling that I can do something, even if it is a little bit." (participant 1, interview 1).*

Impact of patient status

Relatives felt insecure about the patient's health-changing capacity, which made them hold back because they found it hard to estimate this. Patients' inability to express wishes and needs led to difficulties in communication and made relatives reluctant to ask permission to participate. They often tried to take into account and minimize the patients' embarrassments. A daughter said:

> *"I don't know if she wants me to help her. She is not quite awake yet and she is intubated." (participant 8, interview 1).*

One mother said:

> *"I don't know what's the right or the wrong thing to do for him...*
> *Well, now I think it's difficult to, for example, change the position of the pillow.*
> *Because I'm not sure if he can handle it." (participant 7, interview 1).*

Impact of fear and the relationship to the patient

A lot of relatives felt a strong fear *'of doing something wrong', while* participating in physical activities fear that they '*might harm*' the patient or breaking some intravenous lines or tubes. The bronchial toilet was a frightening moment for relatives. Furthermore, they were afraid to stand in the way of the healthcare providers. A few relatives felt that healthcare providers had expert knowledge, so they decided to *"leave it to the specialist"*. Although one relative said:

> *"Patients have a better understanding when surrounded by people they are familiar with."*

One relative decided not to participate because of her own limited capacity. Participant 4 made a conscious choice to stand back and look over the shoulder of healthcare providers during physical activities. She said:

> *"You know, when I am visiting my brother, I would be completely down if I'm sitting there and have to do something...I would rather be happy to make some jokes when I'm sitting next to his bed...yeah, pass the time together." (participant 4, interview 1).*

Relatives 'relationship to the patient was a determining factor in that relatives wanted to be included during physical activities. Parents and spouses were closely involved and easily started to participate. However, a son, a sister and a daughter-in-law felt more distance between themselves and the patient. One sister said:

> *"Of course, I love my brother, but I think it is different... yeah, that I, as his sister, have to do that with him. It's my brother, not my spouse." (participant 4, interview 2).*

Level of participation over time

The change in needs, beliefs, feelings and behavior over time is an ongoing process. Relatives experienced that it took time to get used to the situation in an ICU. During the first interviews, most relatives had a wait-and-see attitude because of fears and a lack of knowledge. A participant said:

> *"For healthcare providers it's a piece of cake, but I had to find out in which order things are done and how to act in the ICU environment." (participant 2, interview 2).*

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While analyzing the data and comparing the data over time, we found that relatives' behaviors and needs to participate during physical activities changes over time into a more proactive participating behavior. Actual participation in physical activity decreased feelings of powerlessness and uselessness. Participants confirmed this:

"I can imagine there are people who are in the ICU for 1-2 days. But if you are admitted for a long time, like my wife… she has been there for 11 days … and then … yes, surely you can help." (participant 2, interview 3).

Finally, the impact of the four key themes and their inter-relationship was visualized in a conceptual model (see Figure 1).

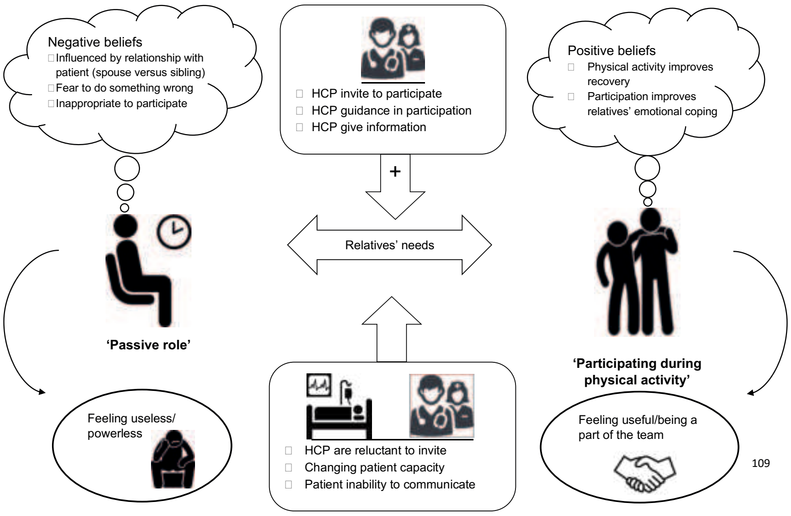

Figure 1 Conceptual model of how family participation during physical activity in the intensive care unit changes from a passive role to more proactive participatory behavior. *Abbreviations: HCP; healthcare provider*

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DISCUSSION

This study shows relatives' needs for information, explanation and guidance from healthcare providers when participating in physical activities to reduce fear and gain insight to in the patient's health-changing capacity. According to relatives, participation could be facilitated if relatives were presented fixed time schedules, and all healthcare providers would display an unambiguous positive attitude regarding family participation. Barriers to participate include the believing that healthcare providers are more skilled in providing physical activity, and the impossibility to communicate with and ask permission from the patient to participate. Relatives' behavior and needs in participating during physical activities changes over time from a wait-and-see attitude in the first days after ICU admission, to a more proactive participatory behavior.

Other research specifically focused on family participation in daily care activities instead of physical activities at the ICU.[14,32] According to both relatives and healthcare providers, participation of relatives during transfers and respiratory training are the most unpleasant active care tasks.[14] Findings in this study are a positive attitude of relatives towards participating in physical activities such as changing the position in bed or keeping the trunk or head upright. Earlier research described that being able to move during ICU admission appeared to help patients regain control and belief in their recovery and therefore involving family in physical activities could be an extra motivator.[28] Our study also sanctions the need for explanation that relatives have about safe participation during physical activities.[36] Mistraletti et al. try to answer this need by using an information brochure and dedicated website.[10] However, as already suggested by those authors, our findings confirm that besides information there is a need for explanation by human interaction and guidance during participation.[37]

Strengths and weaknesses of the study

Longitudinal data collection is a strong point in this study as it contributes to understanding the dynamic process relatives are going through and how they respond to the ICU environment. This provided insight into the needs that were most relevant when relatives were participating during physical activity. Another benefit of serial interviewing is the development of a relationship between researcher and participant. Reflecting on earlier findings enables more depth in the following interviews.

A first limitation of this study is that, at the start of their first interview, relatives were provided with information about early mobilization and physical activity in the ICU as a part of their usual care. This culture may have influenced the interview outcomes, because it provided them with information on the effect and benefits

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of physical activity. Moreover, as mentioned by the relatives themselves, providing additional information seems to be a viable intervention to help and motivate relatives to participate during physical activities of their loved ones.

A second limitation is that the interviewer (VvdW) had limited interview experience, but she has five years of working experience as a physical therapist, of which three years in ICU-care. The literature shows that professional experience makes interviewers more sensitive to patients' beliefs and experiences.[38] To improve the interview experience, we performed four pilot interviews,[29] and VvdW followed education in qualitative research.

A third limitation is that this is a single center study in an academic setting in the Netherlands with a positive attitude towards early physical activity. The transferability of the outcomes to other settings might, therefore, be limited. Moreover, we included a low number of relatives with different relationships to the patients. Other ethnical or religious backgrounds or other cultural attitudes towards physical activity, family participation and/or FCC can influence the needs, beliefs, feelings and behaviors of relatives regarding participation during physical activity. In this study, we included a convenience sample, whereby we first checked the eligibility of the patients admitted to the ICU and afterwards approached their relatives after checking the inclusion criteria. This resulted in a non-homogeneous sample with a wide variation of relatives concerning sex, age, educational level and relationship to the patient. Moreover, there was considerable variability in the characteristics and health status of the patients. We noticed that the relationship between relative and patient influenced the level of participation. For a more in-depth interpretation of these data, we should have asked more detailed how well relatives knew their relative. However, in this study we reached data-saturation, so although, the variation in answers can be larger, it seems that the themes will be comparable. Regardless, future studies with a larger and more homogeneous population in different settings will still be necessary to fully understand all beliefs, needs, feelings and behaviors of relatives with loved ones admitted to the ICU.

Implications for clinical practice

This study could give healthcare providers tools to adapt their own attitude towards the needs of relatives during participation in physical activities. However, the differences in the individual approach implicate the need for a clear vision and agreement of the department about family participation and a uniform attitude and approach to relatives. The results of this study could contribute to the development of a program that will coach healthcare providers how to improve the participation by relatives in ICU-care. This program should provide general information on the way of working in the ICU for relatives of patients: an open invitation. Healthcare providers need to communicate with relatives whether or not physical activity can

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be fitted to the agenda of relatives. Shared decision-making could enhance the motivation of relatives. In addition, healthcare providers should receive training how to: 1) start personal communication and information to relatives, 2) invite relatives participate safely in physical activities, and 3) stimulate, instruct, and guide relatives during physical activities. We believe that there is no one-size-fits-all solution to include relatives, in part because of the changing needs of the relatives. Healthcare providers should take into account these (changing) needs of each individual relative. Above all: family participation is always voluntarily. It is allowed, if it is safe and it contributes to the needs and possibilities of relatives and patients.

CONCLUSIONS

Our interpretations of the interview data suggest that, at ICU admission, relatives can feel powerless, useless and frightened of harming the patient. Relatives reported that these feelings can decrease if they are invited, guided and informed to participate during therapeutic sessions and the promotion of physical activity. The grounded theory suggests that family participation during the ICU admission is an evolving process, starting from a 'passive role' towards 'proactive participation'; however, this theory needs to be confirmed in future research.

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Chapter 7

Introducing an exercise box for upper extremity rehabilitation in the intensive care unit: Results from a real-world, mixed-methods feasibility study

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In preparation

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ABSTRACT

Purpose

Interventions specifically targeting the upper extremities of people admitted to the intensive care unit (ICU) are scarce, even though it is conceivable that active exercises of the upper extremities might also contribute to the prevention of muscle loss and functional decline. We aim to investigate the feasibility of implementing an exercise box in daily ICU practice.

Methods

This mixed-methods feasibility study focused on three key areas of feasibility in terms of demand, acceptability, and limited-efficacy, using qualitative and quantitative data.

Results

Demand: Out of 660 patients, only 11 (1.6%) met eligibility criteria for using the exercise box in the ICU. Six patients used it multiple times during their stay.

Acceptability: Facilitators and barriers were identified and organized within a conceptual framework through semi-structured interviews involving six patients and four physiotherapists. Facilitators included simple and clear exercises, patient contribution to their own recovery, high patient satisfaction, and involvement of relatives and/or occupational therapists. Barriers identified encompassed fatigue, conflicting exercise goals, and a lack of motivation or supervision.

Limited efficacy: Individual patient curves were only generated for two patients, describing functional improvement and progressive muscle strength over time.

Conclusions

Despite the use of an extensive implementation strategy for adoption, demand proved to be insufficient. Patient acceptability varied, and therapists' willingness to use the exercise box was limited. Assessment of limited efficacy was not possible. However, the exercise box was found to be feasible for a very small patient population.

Keywords

Exercise Box, Rehabilitation, Intensive Care Unit, Upper Extremity, Feasibility

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INTRODUCTION

Early mobilization is feasible and safe in patients in the intensive care unit (ICU) and has a positive effect on the length of the ICU stay and functional outcomes.[1-4] There is a growing body of evidence suggesting that early mobilization might also prevent further functional decline and muscle loss in patients with ICU-acquired weakness.[5-8] In general, early mobilization interventions focus on the lower extremities,[9] including bed cycling,[10] transfer out of bed, walking with walking aids or more innovative treatments such as walking on a bedside body weight-supported treadmill[11] or hydrotherapy.[12]

Interestingly, interventions specifically targeting the upper extremities of people admitted to the ICU are scarce, even though it is conceivable that active exercises of the upper extremities might also contribute to the prevention of muscle loss and functional decline. One might even reason that exercise of the upper extremities is of crucial importance because proper ability of the upper extremities is essential to perform (instrumental) activities in daily life, such as using a telephone or eating meals independently. In other words, exercise of the upper extremities might benefit patients' recovery process and improve their autonomy.

To our knowledge, no interventions have been described in the scientific literature with the specific focus to improve muscle strength of the upper extremities of people admitted to the ICU. We codesigned an exercise box to facilitate training of the upper extremities for patients admitted to the ICU. In this study, we aim to investigate the feasibility of implementing this exercise box in daily ICU practice, in terms of demand, acceptability and limited efficacy.

METHODS

Design and participants

This mixed-methods feasibility study was conducted in the adult ICU of the Radboudumc, Nijmegen, the Netherlands, between November 2021 and March 2022. In this ICU, early mobilization is standard of care and there is a 24-hours visiting policy. Patients were eligible for the exercise box if they met the following inclusion criteria: having a cooperative Standardized 5 Questions (S5Q) score of ≥3, being ≥18 years of age, being admitted for ≥72 hours at the ICU, Medical Research Council (MRC) shoulder abduction, elbow flexion or wrist extension strength ≥2 or <4+. Patients were excluded if they did not meet the safety criteria described in the Evidence statement Physiotherapy in the ICU.[13] Informed consent was given verbally and, in case of an interview, also audio recorded at enrollment. The study was approved by the ethics committee of the Radboudumc (number: 2019-5627). Baseline characteristics of patients were collected from the Electronic Patient Database (EPD) and analyzed descriptively.

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Description and implementation strategies of the exercise box

The exercise box is developed by experienced physiotherapists in the field of intensive care medicine and aimed to train the upper extremities of patients admitted to the ICU. The exercise box is a plastic, transparent box with a colorful lid and two handles. It contains exercise materials such as a sensory ball (10 cm), four different resistance bands, two 0.5-kilogram dumbbells, two hand therapy eggs with different resistance, two balloons and a small soft-over ball (18 cm). A cleaning plan was developed in collaboration with the Hygiene and Infection Prevention (HIP) department of our hospital. The exercise box incurred a cost of 55 euros per patient, covered by an in-hospital subsidy. Photos, material details and cleaning plan of the exercise box are described in supplementary materials (Appendix 1).

Implementation strategies for using the exercise box included instruction and training of the responsible physiotherapists, providing information to ICU-nurses, organizing group discussions in general meetings, having conversations with HIP, monitoring eligibility, making announcements on intern ICU-website and consultation of occupational therapists.

Feasibility assessment

To understand the feasibility of implementing an exercise box aimed at training the upper extremities of patients admitted to the ICU, we focused on the following three key areas of feasibility:[14]

1. *Demand*: We aimed to ascertain the percentage of critically ill patients admitted to the ICU who were eligible for and utilized the exercise box, along with identifying the specific characteristics associated with this utilization.
2. *Acceptability:* We aimed to gain insight into patients' and therapists' experiences with the exercise box and to identify facilitators and barriers for its use in daily practice. To do so, we used qualitative data from semi-structured interviews with patients and physiotherapists. When the exercise box was distributed to a patient, this patient was approached, after hospital discharge, for a semi-structured interview to ask about their user experiences. In addition, we also approached physiotherapists working at the ICU because they also played an important role in terms of the feasibility of implementing the exercise box. The interviews were performed by KF. She is an experienced physiotherapist in the field of intensive care medicine. Bracketing and reflexivity skills were developed through previous experiences in her role of interviewer. An interview guide including open questions based on literature and best practice was used to ensure that relevant topics were covered during the interview (see Appendix 2). The interviews were conducted over the phone or face-to-face, and audio recorded. Member check was performed by providing a summary after the interview. If this summary was incorrect or incomplete, the patient had the opportunity for revision. A summary of the interview was transcribed, and

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quotes from attendees were collected. Facilitators and barriers were clustered and presented in the result section.

3. *Limited efficacy*: We aimed to gain insight into the potential impact of the exercise box on key intermediate variables. To do so, we aimed to create individual patient curves that describe functional mobility, physical function, and muscle strength over time. Physiotherapists who were part of the usual care at the ICU were instructed to perform these physical assessments on a weekly basis. ICU Mobility Scale (IMS) score and Functional Status Score for the ICU (FSS-ICU) were used to evaluate physical functions. IMS is a scale of mobilization capabilities ranging from 0 (lying in bed) to 10 (walking independently).[15-17] FSS-ICU, consists of five functional tasks, including rolling, transfer from spine to sit, sitting at the edge of the bed, transfer from sitting to standing position, and walking.[18] Scores range from 0 (unable to attempt or complete task due to weakness) to 7 (complete independence). Muscle strength of the upper extremities was evaluated using the Medical Research Council (MRC) score, testing the strength of shoulder abductors, elbow flexors and wrist extensors.[19]

RESULTS

Between November 2021 and March 2022, 660 patients were admitted at the ICU. Eleven patients were eligible for using the exercise box (see Figure 1). Out of these 11 patients, the exercise box was distributed to nine patients, with a mean of 20.2 days after ICU admission (SD=11.5).

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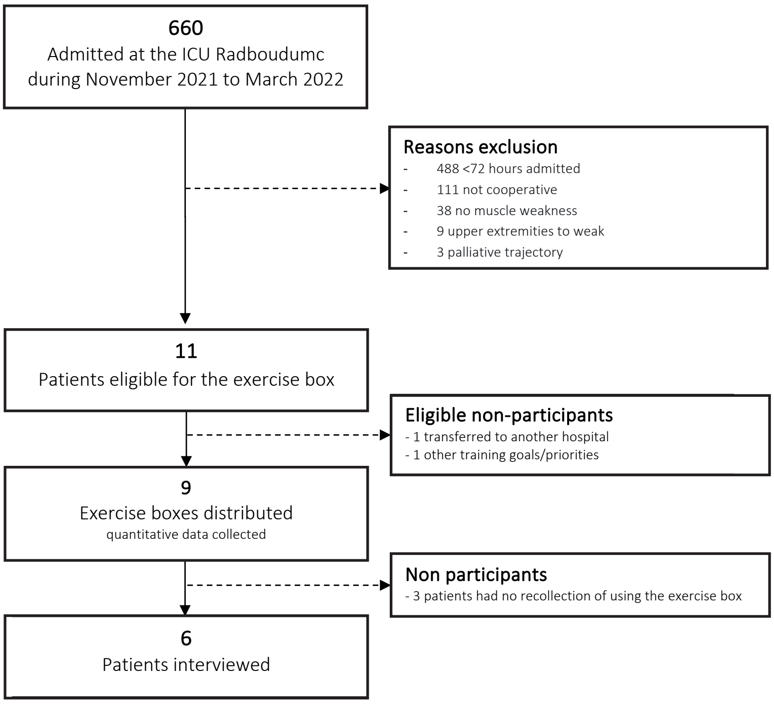

Figure 1 Flowchart patient inclusion and selection

Table 1 shows the patient characteristics at baseline (n=9). The mean age of critically ill patients was 56 years (SD=11) and two (22%) of the patients were female. Five patients (57%) were admitted to the ICU due to a COVID-19 infection. The mean Acute Physiology and Chronic Health Evaluation (APACHE II) score was 17.6 (SD=4.7) and the mean length of ICU stay was 28 days (SD=13.6). Of these nine patients, six were available and provided informed consent for an interview after ICU discharge. Finally, four physiotherapists were interviewed to describe their experiences with the exercise box.

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Table 1 Baseline characteristics of patients to which the exercise box was distributed.

Pt No	Sex	Age (rage)	BMI	Reason for ICU admission	APACHE II score	ICU LOS (in days)	Start box after ICU admission (in days)	Interviewed	Discharge destination
1	M	36-40	29.1	Para-influenza infection	23	39	35	Yes	home
2	M	51-55	31.9	COVID-19	23	22	16	Yes	home
3	F	46-50	34.7	Capillary leak syndrome	16	15	13	Yes	rehab clinic
4	M	61-65	21.8	Septic shock	23	39	25	Yes	home
5	M	41-45	41.4	COVID-19	13	28	21	Yes	rehab clinic
6	F	51-55	26.0	COVID-19	18	48	38	No	rehab clinic
7	M	71-75	24.8	COVID-19	10	17	9	No	rehab clinic
8	M	66-70	37.0	COVID-19	17	37	22	No	other hospital
9	M	61-65	21.3	Guillain Barré Syndrome	15	7	3	Yes	other hospital

Abbreviations: Pt No=Patient Number; M=Male; F=Female; BMI=Body Mass Index; ICU=Intensive Care Unit; COVID-19= Coronavirus disease; APACHE II=Acute Physiology and Chronic Health Evaluation (range 0-71); LOS=Length of Stay; rehab=rehabilitation

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Demand

As depicted in Figure 1, 11 (<2%) out of the 660 patients at the ICU were eligible for the exercise box. Out of the 11 eligible patients a total of 9 patients (82%) had the exercise box prescribed. One eligible non-participants transferred to another hospital and one patient had other training goals. Out of the 9 patients, 3 patients had no recollection of using the exercise box. A review of the electronic patient database confirmed that the physiotherapist did not continue practicing with the exercise box after distribution. Finally, 6 patients (55%) used the exercise box more than once during their stay at the ICU.

Acceptability

In semi-structured interviews with patients and physiotherapists, facilitators and barriers were identified and organized within a conceptual framework utilizing the Consolidated Framework for Implementation Research (CFIR),[20] see Figure 2.

Patients' experiences

To gain insight into patients' experiences with the exercise box, a total of six interviews were conducted (patient no 1, 2, 3, 4, 5, 8). Patients described several facilitators for the use of the exercise box in daily practice. First, using the exercise box made patients feel empowered, thereby wanting to use the box more frequently. After all, exercising with the box gave them the feeling of working actively on their own recovery:

> *"It could speed up your recovery, so to speak. And you had control over it yourself: so, if you had the energy, you would engage with it. I always had the idea: the more I could do with it, so to speak, the faster I would get better" (patient no 1).*

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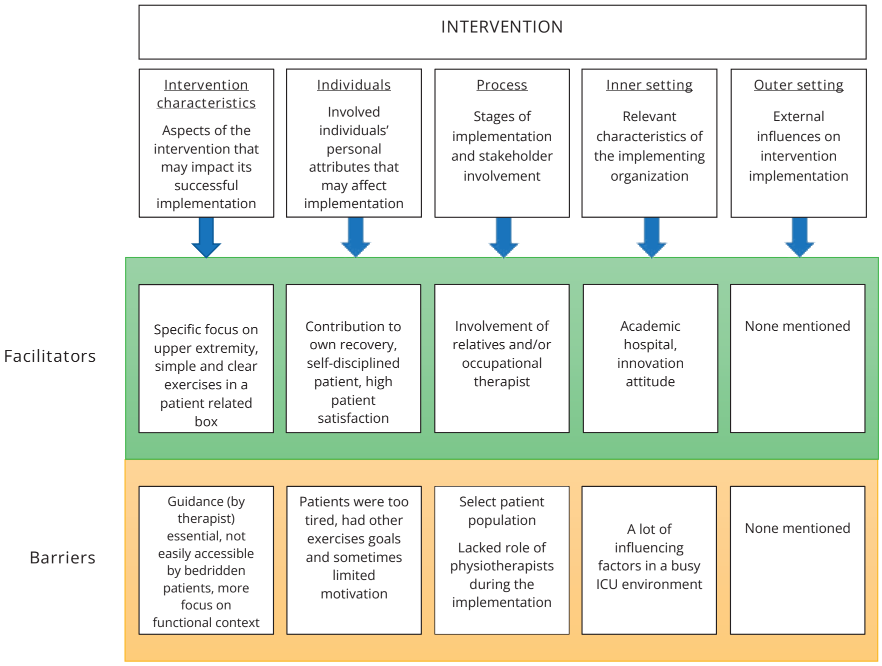

Figure 2 Overview of Consolidated Framework for implementation Research (CFIR) domains and examples of barriers and facilitators from patients' and therapists' perspectives.

Second, some patients found that especially practicing with their relatives was helpful to use the exercise box. For example, one patient stated: "[…] *when my wife was there, I would do some exercises with her. Initially, I couldn't get out of bed, so when she was there, I would often ask if she could hand them* [dumbbells] *to me*" (patient no 2).

Patients also discovered that practicing with the exercise box outside formal therapy sessions, such as on the weekends when they had more energy, was the most effective. The practice with the exercise box was more effective when the patient was in control. Patients found the exercises easy to understand and were satisfied with the exercise materials provided. They appreciated the ability to practice several times a day. For some patients, it was helpful to integrate their practice sessions into their daily program. It was motivating for them when their relatives or healthcare professionals provided the exercise box. Some patients mentioned that occupational therapists encouraged the use of the exercise box to stimulate movements in the upper extremities.

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Considering barriers, patients told that the box was clearly visible (mostly standing on the hospital bedside cabinet) but not easily accessible because they were immobile. Although the exercises were easy to perform, some patients preferred that the exercises could have been supported by instructions on paper. Sometimes patients could not practice with the exercise box because they were too tired, or their health condition did not allow. Some patients mentioned that they had other exercise goals (e.g., walking) that they preferred over exercising with the box. One patient said: "[...] *after fatigue, and certainly at a certain point when I started to become more mobile, then the box was somewhat neglected"* (patient no 5).

Limited motivation of the patient and a lack of supervision during practicing were also mentioned as barriers. This was confirmed by one patient: *"The motivation to train alone was far from present in my case"* (patient no 8).

Physiotherapists' experiences

To gain insight into the expressed interest and intent to use the exercise box, we gathered feedback from four dedicated ICU physiotherapists with experience in the field to share their experiences. They indicated that the rationale for using the exercise box was clear, and the initiative to initiate practice should be led by physiotherapists. They suggested that prolonged mechanically ventilated patients might be the most suitable patient population for exercise box utilization. However, this patient group may have insufficient physical capacity, and they may have other priorities that limit their engagement with these upper extremity exercises, as exemplified by a therapist who stated, *"I must say that I have given priority to mobilization and weaning from ventilation* [...]" (therapist no 4). Consequently, physiotherapists did not frequently distribute the exercise box.

Most of the therapists found the exercise materials and routines to be clear and adequate. Some therapists expressed regret that the exercises were not more functionally oriented and would have preferred to include exercises using everyday items: "[...] *in it there are no materials, that you could use more in a functional context. Such as a comb, a brush or a toothbrush, you don't have anything like that"* (therapist no 4).

Physiotherapists also discussed the potential role of relatives in assisting patients with the exercises and suggested that occupational therapists could play a part in encouraging and assessing upper extremity exercise practice.

Limited efficacy

Table 2 shows the IMS, FSS-ICU and MRC-scores of the upper extremity, per patient, at inclusion (T0), one week (T1) and two weeks after inclusion (T2). The aim was to create individual patient curves that describe functional mobility, physical function

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and muscle strength in order to clarify the expected effects of the exercise box on key intermediate variables at the aforementioned endpoints. Due to missing data, this was only possible for patient no 4 and patient no 6. These patients showed functional improvement and progressive muscle strength over time (see Appendix 3). In patients no 7 and 8 we could only show the functional improvement over time using the IMS and FSS-ICU scores.

Table 2 Physical assessments of patients to which the exercise box was distributed

	ICU Mobility Scale (range 0-10)			Functional Status Score for the ICU (range 0-35)			MRC Shoulder Abduction left/right (range 0-5)		MRC Elbow Flexion left/right (range 0-5)		MRC Wrist Extension left/right (range 0-5)	
Pt No	**T0**	**T1**	**T2**	**T0**	**T1**	**T2**	**T0**	**T1**	**T0**	**T1**	**T0**	**T1**
1	3	-	4	6	-	18	3/3	-	4/4	-	4/4	-
2	5	5	-	31.25	31.25	-	4/4	4/4	4/4	4/4	4/4	4/4
3	3	3	-	6	10	-	1/1	2/2	3/2	4/4	2/2	4/4
4	3	3	3	3	6	11	1/1	1/1	2/2	4/2	2/2	4/3
5	1	4	-	1	9	-	1/1	2/2	3/3	4/4	3/3	5/5
6	3	3	6	4	12	17	2/2	2/2	2/2	4/4	2/2	4/4
7	3	5	8	3	9	26	2/2	3/3	3/3	3/3	2/2	4/4
8	3	3	3	5	7	10	1/1	3/3	3/3	4/4	3/3	4/4
9	3	3	9	4	5	-	2/2	-	4/4	-	4/2	-

Abbreviations: ICU=Intensive Care Unit; MRC=Medical Research Council; Pt No=Patient Number; T0=baseline; T1=one weeks after inclusion; T2=two weeks after inclusion; -=missing data

DISCUSSION

In this study, we examined the feasibility of implementing an exercise box into daily ICU practice, with a focus on assessing its acceptability, demand, and limited efficacy testing. In this section, we discuss whether the exercise box represents either a beautiful failure or an example of highly specific care.

First, regarding the topic of demand, it is important to realize that during the implementation of the exercise box, the COVID-19 pandemic was ongoing. Patients admitted to the ICU were critically ill and frequently deeply sedated, rendering them unable to respond. Furthermore, due to a high turnover rate of patients to other wards or hospitals upon awakening, we were unable to include them in this study. Despite the challenges posed by the deep sedation and immobilization of

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the COVID-19 patient population, a subset of patients did not experience significant muscle loss and thus did not meet our inclusion criteria. Additionally, the pandemic led to a reduced number of post-surgical patients being admitted to the ICU, while acute care patients, often presenting with neurological disorders, continued to be admitted. However, this latter group was frequently uncooperative or exhibited upper extremity weakness, such as in cases of spinal cord injury. The reasons mentioned above resulted in a limited participation rate. Overall, out of the 660 patients admitted to the ICU, only 11 patients (1.6%) met the eligibility criteria for engaging with the exercise box. Nevertheless, among patients there was a high interest for the exercise box, considering that 9 out of the 11 patients actually used the box.

Second, in terms acceptability of the exercise box in patients, we aimed to understand patients' experiences through six interviews. Patients found empowerment in using the box, considering it encouraging to actively participate in their recovery. Some highlighted the benefits of practicing with relatives and engaging outside formal therapy sessions. Patients preferred control, easy-to-understand exercises, and the flexibility to integrate practice into their daily routines. Barriers included the box's limited accessibility for immobile patients. While exercises were perceived as easy, some desired paper instructions. Fatigue, competing exercise goals, and lack of motivation or supervision were identified barriers.

Regarding the topic of acceptability, the expressed interest and intention to use the box among therapists was limited. Throughout the implementation and data collection phases, the role of the physiotherapist emerged to be a significant factor. Feedback from four ICU physiotherapists revealed a clear rationale for the exercise box, but priority was given to alternative training objectives, such as improving standing, transferring, walking, or breathing exercises.[13] The suitability of the exercise box for prolonged mechanically ventilated patients was acknowledged, but challenges related to patients' physical capacity and priorities were noted. Therapists suggested more functionally oriented exercises and involvement of relatives and occupational therapists in supporting and assessing upper extremity exercises.

Occupational therapists may serve as training coaches and evaluators for upper extremity exercises, a point highlighted during interviews with therapists and patients. However, occupational therapy services in the intensive care setting are limited and variable.[21] Therefore, it could be advantageous to extend the role of occupational therapists within the ICU. Occupational therapists can utilize the exercise box to enhance upper extremity performance, thereby improving (instrumental) activities of daily living.

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Third, regarding the topic of limited efficacy, we cannot draw any conclusions due to the presence of missing data, particularly of the MRC muscle strength scores at T2. This deficiency is likely to be due to the involvement of physiotherapists, whose standard practice typically includes physical assessments without specific use of outcome measures. In particular, researchers were not engaged in the assessments of these measurements, as we anticipated strong endorsement from physiotherapists. However, this suggests limited acceptability among physiotherapists.

Considering the aspects of demand, acceptability, and limited efficacy, the question arises whether the exercise box at the ICU is a beautiful failure or a form of highly specialized care. From the perspective of highly specialized care, patient no 4 likely epitomizes the ideal candidate for the use of the exercise box. This cooperative and self-disciplined patient diligently engaged with the exercise box daily throughout his ICU stay, expressed a high level of satisfaction with the materials and exercises provided. In this case, demand and acceptability were high. However, from a critical standpoint, it may be questioned whether the extensive efforts invested are justified. Realistically, one may question the value of establishing a system with the exercise box for such a small and specific patient group.

CONCLUSION

We aimed to assess the feasibility of integrating an upper extremity exercise box into daily ICU practice, considering demand, acceptability, and limited efficacy. Despite employing implementation strategies for its adoption, demand proved to be insufficient. Patient acceptability varied, and therapists' willingness to use it was limited due to other training priorities. Assessment of limited efficacy was not possible. However, the exercise box was found to be feasible for a very small patient population. While training the upper extremities seems to be important, introducing exercise boxes in the ICU appears impractical due to the limited size of the target population. Based on these results, the implementation of an exercise box to train activities of the upper extremities in the ICU appears to be a beautiful failure.

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APPENDICES

Appendix 1. Images, material details and cleaning plan of the exercise box.

Article/Item	Image	Cleaning Instructions	Cleaning Time
Bumpy Ball 1x blue 10cm		Manually clean with cleaning wipes (Bacillol 30 Tissues), ensuring thorough cleaning between the bumps.	At discharge (preferably after each use as well)
Exercise Band Approximately 120cm 1x XX-light: Beige 1x Extra-Light: Yellow (2-3 kg) 1x Light: Red (4-5 kg) 1x Medium: Green (5-6 kg)		Disposable: discard or give to the patient.	At discharge
Exercise Egg 1x pink (extra soft) 1x purple (soft)	 	Manually clean with cleaning wipes (Bacillol 30 Tissues), ensuring thorough cleaning between the folds. Replace if material starts tearing.	At discharge (preferably after each use as well)
Weights 2x 0,5 kg		Manually clean with cleaning wipes (Bacillol 30 Tissues) Soak in Teralin and let dry.	At discharge (preferably after each use except for Teralin)
Balloons		Disposable: discard or give to the patient.	At discharge
Green Yoga ball 18 cm 1x green		Manually clean with cleaning wipes (Bacillol 30 Tissues).	At discharge (preferably after each use as well)
Exercise Elastic Band 1x red		Washing machine at 60 degrees.	At discharge
Exercise Box With lid and handles		Wash lid and handles in the dishwasher at 60 degrees. Manually clean the exercise box itself with cleaning wipes (Bacillol 30 Tissues), ensuring cleaning in all corners!	When transferring to another department, only clean the outside of the box, lid, and handles with a Bacillol wipe.

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Appendix 2. Topic list for the semi-structured interviews.

Topics	Questions
General	Do you know what the exercise box contained during your ICU admission? Familiarity Memories Still in your possession?
Offering	Who offered the exercise box? When? Was the purpose clear? Evaluation Information Guidance
Visibility	What did you think of the visibility of the exercise box? Colour Placement Easy to access (by patient/family) Presence Image
Content	What did you think of the content of the exercise box? Choice of materials What did you use a lot/little? What do you miss? Quantity Cleaning
Exercises	What did you think of the exercises? Understandable Clear Feasibility Expandable Logical Challenging Quantity Customized
Exercise timing	Patient’s endurance level? Daily program Load When did you exercise? Suitable time With or without help What helps When did you not exercise? Why not Obstacles What doesn’t work/what works well?

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Appendix 2. Topic list for the semi-structured interviews.

Topics	Questions
Useability	What did you think of the user-friendliness of the exercise box? Opening method Size Weight
Role of caregivers	Which caregivers were involved in using the exercise box? Role of physiotherapist Role of nurse Other caregivers
Role of family	What was the role of relatives in using the exercise box?
Added Value	What was the added value of exercising with the exercise box for you? Recovery Rehabilitation Purpose Do you still occasionally exercise with the exercise box? Hospital ward At home
Dairy	Was the exercise diary used? Recording exercise sessions Clear layout
Other	Are there any other points that have not been addressed?

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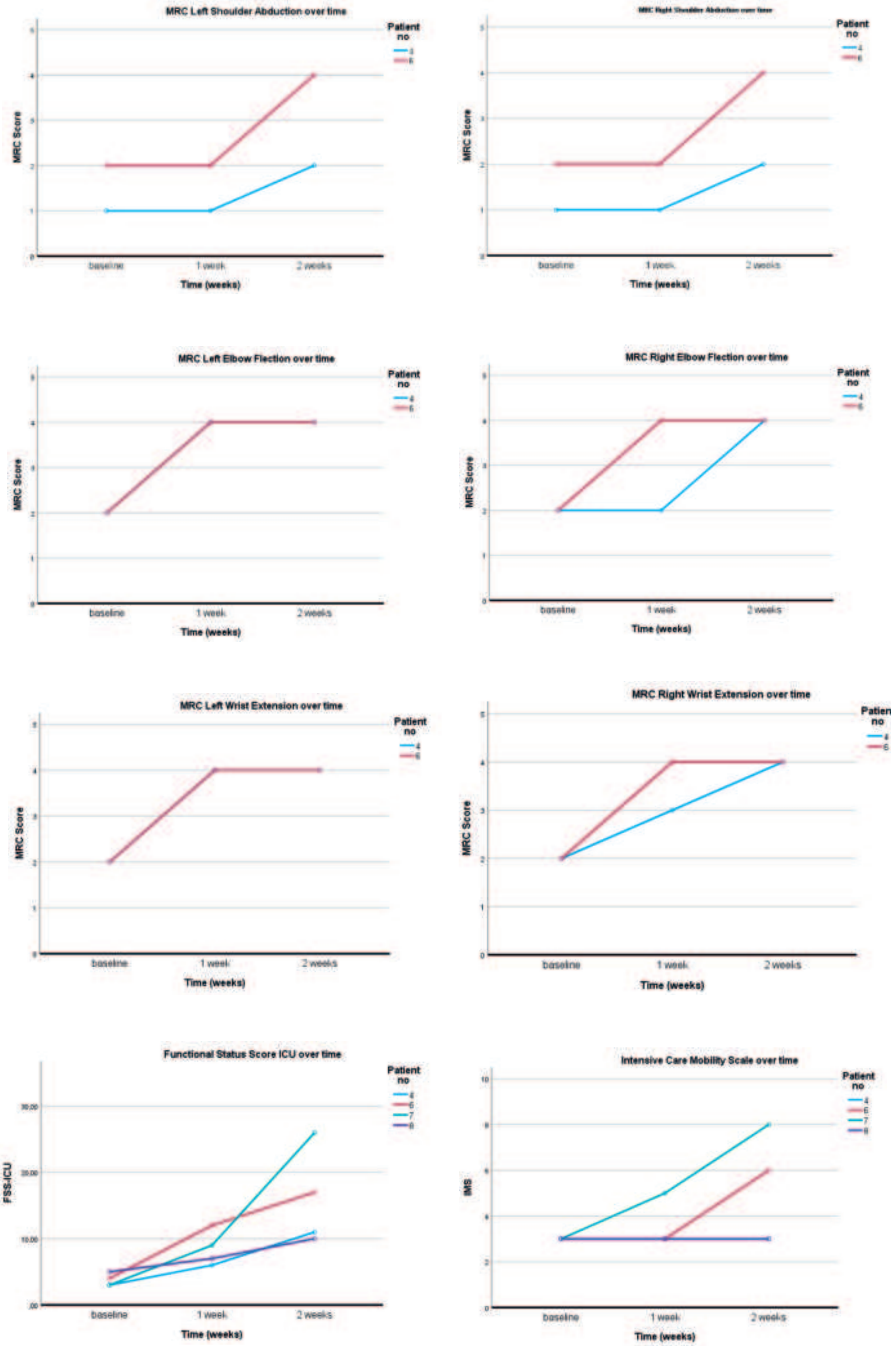

Appendix 3. Selection of individual patient curves that describe muscle strength, physical function and functional mobility.

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Chapter 8a

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

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ABSTRACT

Objective

The COVID-19 pandemic is rapidly evolving, leading to increased numbers of hospitalizations worldwide. Hospitalized 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. Physical therapists have an important role in supporting hospitalized patients with COVID-19, but also need to be aware of challenges when treating these patients. In line with international initiatives we aim to provide guidance and detailed recommendations for hospital-based physical therapists managing patients hospitalized with COVID-19 through a national approach in the Netherlands.

Methods

We utilized a pragmatic approach. 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 physical therapy management in patients hospitalized with lung disease and in patients admitted to the Intensive Care Unit (ICU). An expert group of hospital-based physical therapists in the Netherlands provided feedback on the recommendations, which were finalized 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 two phases of hospitalization: when patients are critically ill and admitted to the ICU, and when patients are severely ill and admitted to the COVID-ward. Physical therapy management for patients hospitalized with COVID-19 comprises elements of respiratory support and active mobilization. Respiratory support includes breathing control, thoracic expansion exercises, airway clearance techniques and respiratory muscle strength training. Recommendations towards active mobilization include bed mobility activities, active range-of-motion exercises, active(-assisted) limb exercises, ADL training, transfer training, cycle ergometer, pre-gait exercises, and ambulation.

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INTRODUCTION

Currently, 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] SARS-CoV-2 RNA can also be detected in stool and blood.[4] Chest CT images from patients with COVID-19 typically demonstrate bilateral, peripheral ground glass opacities. Unfortunately, this pattern is non-specific and overlaps with other infections, the diagnostic value of chest CT imaging for COVID-19 may be low.[4,5]

Recent data from China and Italy indicate that in 80 percent of cases COVID-19 infection causes ‘mild and moderate illness’, approximately 15 percent of cases develop ‘severe illness’ leading to hospitalization, and 5 percent develop ‘critical illness’ requiring Intensive Care Unit (ICU) treatment.[2,4-6] Hospitalized 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] Physical therapists have an important role in supporting hospitalized patients through respiratory support and active mobilization. Physical therapy 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, >70 years of age, obesity, comorbidity and other complications.[10,11] Yet, physical therapists need to be aware of potential challenges when treating patients with COVID-19. In a recent study, an international group of authors described the physical therapy management for COVID-19 in the acute hospital setting, including workforce planning, screening, delivery of physical therapy interventions and personal protection equipment.[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 physical therapists managing patients hospitalized with COVID-19 through a national approach in the Netherlands.

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SCOPE

This study focuses on adult patients admitted to the (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) like 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, critically ill patients, 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]

Healthcare professionals should be aware that the clinical progression of symptoms might occur one 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 designed 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 physical therapy goals during hospital stay.[10-13,17]

Our recommendations focus on the physical therapy management for adult patients with COVID-19 admitted to the (acute) hospital setting. Recommendations contain specific physical therapy goals concerning respiratory problems and deconditioning including ICU-AW and PICS. The recommendations are outlined in two sections:

- SECTION 1: Critically ill patients with COVID-19 admitted to the ICU.
- SECTION 2: Severely ill patients with COVID-19 admitted to the COVID-ward.

We used existing international recommendations[12,13] as basis for further specification and contextualization. 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

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following order: safety recommendations, treatment recommendations (specified for different phases of hospitalization), 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 physical therapy management, either based on evidence or best-practices, are crucial to support the recovery of patients and safety of healthcare 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 utilized a pragmatic approach, rather than a formal approach (such as GRADE),[18] to formulate our recommendations. First a working group was installed comprising experts on content (KF, RO, EK, NK, MS, EH) and experts on guideline methodology (FD, TH, PW). 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 physical therapy management in patients hospitalized with lung diseases and in patients admitted to the ICU. Simultaneously, an expert group of hospital-based physical therapists 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 finalized when consensus, in terms of no opposing votes, was reached among the members of the working group.

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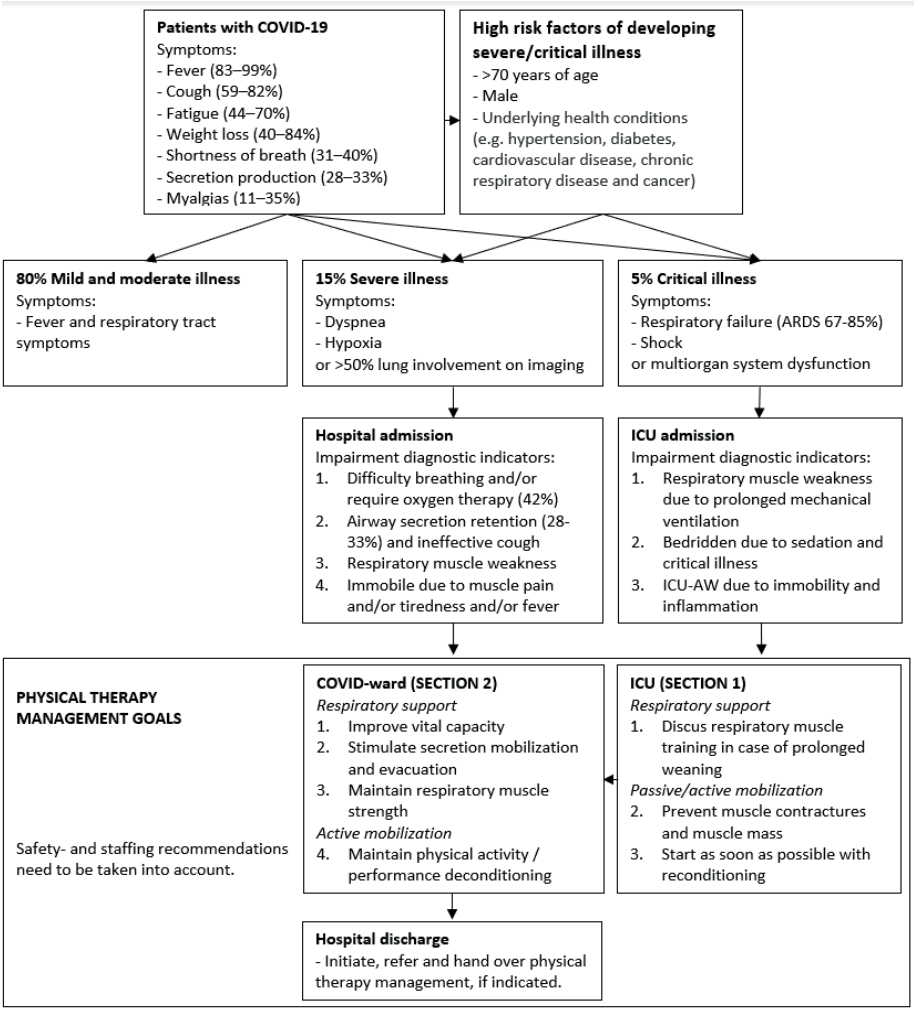

Figure 1 The flow of patients with COVID-19 with their signs and symptoms before[4,6,7] and during hospital admission;[4,5,7,8,13,16] the severity classification[2,4-6] and the physical therapy goals during hospital stay.[10-13,17]

The final recommendations are summarized in Table 1. We sought and received endorsements for our recommendations from 40 hospital-based physical therapists from over 20 Dutch hospitals, the Royal Dutch Society for Physical Therapy (KNGF), the Dutch Association for Hospital-Based Physical therapists (NVZF), Association for Cardiovascular and Respiratory Physical Therapists (VHVL) and the Dutch Society for Intensive Care Medicine (NVIC). The authors and consulted experts were all based in the Netherlands, therefore generalizability to hospital-based physical therapy settings in other countries, with different healthcare organisations, different task profiles and different scope of practice, could be limited.

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Table 1 Summary of recommendations of hospital-based physical therapist managing patients with COVID-19

Safety recommendations
Minimize contact with patients with COVID-19, always consider the benefits of hands-on physical therapy 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
A. **Patient is unconscious**
Physical therapy management for respiratory support and active mobilization 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 physical therapists for advice on passive movements, limb positioning or splinting.
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 mobilization including bed mobility activities. In case safety recommendations for physical therapy management cannot be met, instruct nurses to combine active mobilization with their daily care activities.
Monitor patients' respiratory and hemodynamic functions continuously, when performing active mobilization.
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 mobilization and evacuation.
Use inspiratory and expiratory respiratory muscle training in patients recovering from critical illness with suspected respiratory muscle weakness.
Active mobilization
Use bed mobility activities to improve physical functioning and respiratory functioning.
Stimulate active mobilization as much as possible based on patients' needs, preferences and physical functioning.
Discharge recommendations
Initiate, refer, and hand over patients to physical therapists in primary care practices, rehabilitation clinics, nursing homes or recovery centers in order to continue physical therapy management, if required.
Staffing recommendations
Deploy physical therapists 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 physical therapists.

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SAFETY RECOMMENDATIONS

Respiratory droplets and aerosols may be released from patients during physical therapy interventions and may cause further spreading of the virus. Therefore, direct contact between physical therapists and patients with COVID-19 should be minimized to avoid risk of virus transmission and reduce usage of scarce personal protection equipment. Therefore, we recommend physical therapists to make optimal use of telecommunication and written information material. If direct (face-to-face) contact with patients with COVID-19 is required, physical therapists should use personal protective equipment (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 physical therapists 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]

- Non-invasive assisted ventilation or high flow nasal oxygen therapy;
- Manual techniques for respiratory support - including compression - which may lead to coughing and secretion mobilization;
- Secretion mobilization devices e.g., Positive expiratory pressure (PEP) , Flutter, Acapella, High Frequency Chest Wall Oscillation (HFCWO);
- Endotracheal suctioning;
- Active mobilization, which may lead to coughing and secretion mobilization or disconnection of the mechanical ventilation.

If one of the above procedures is performed, physical therapists are recommended to wear a facemask that filters at least 95% of airborne particles (i.e. FFP2 mask, N95 facemasks). Physical therapists 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 physical therapy management. Benefits of hands-on physical therapy management should always be weighed against the potential risks of virus transmission.

→ **Recommendation:** Minimize contact with patients with COVID-19, always consider the benefits of hands-on physical therapy treatment versus the risks of virus transmission and the use of scarce personal protective equipment.

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

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TREATMENT RECOMMENDATIONS

Physical therapy management for patients hospitalized with COVID-19 comprises elements of respiratory support and active mobilization.[20,21] Recommendations towards 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 towards active mobilization 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 mobilization are bed mobility activities (e.g. bridging, rolling, lying to sitting), active range-of-motion exercises, active(-assisted) limb exercises, ADL training, transfer training, cycle ergometer, pre-gait exercises, and ambulation.[23]

SECTION 1: Patient is critically ill and admitted to the ICU

Recommendations for physical therapy during mechanical ventilation at the ICU depend on the level of consciousness and cooperation of the patient.[17] Therefore, the recommendations for physical therapy 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 Score ≥ -2 and S5Q ≥ 3.[17]

Phase A Patient is unconscious: respiratory support

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

Phase A Patient is unconscious: active mobilization

Deeply sedated patients cannot actively participate in mobilization. Physical therapy management in this phase focuses on maintaining joint mobility and preventing (soft tissue) contractures. However, the administering of neuromuscular blocking agents reduces the risk of contractures.[27] Additionally, the evidence base for

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preventive stretching is limited.[28] Based on these considerations, we think that the risk of transmission of the virus and the limited availability of personal protective equipment do not outweigh the benefits of regular joint mobility screening by physical therapists. When neuromuscular blocking agents are discontinued, the risk for developing contractures increases. If contractures are suspected, nurses can consult physical therapists for advice on passive movements, limb positioning or splinting.[17]

→ **Recommendation:** Physical therapy management for respiratory support and active mobilization 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.

→ **Recommendation:** If contractures are suspected, nurses can consult physical therapists 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 mobilization 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 physical therapists 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 to not detach 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 three weaning attempts or require more than seven 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 (EMT) 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, non-invasive handheld manometers, to assess Maximal Static Inspiratory Pressure (MIP), can help quantify respiratory muscle strength and initiate training.[34,35] Usually, scores <30 cmH$_2$O may indicate a degree of inspiratory muscle weakness which could impact on weaning and recovery.[36] However, the use of these devices is not recommended in patients

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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 based on clinical presence, experienced dyspnea and BORG score for perceived exhaustion.[37]

For respiratory muscle strengthening, a combination of both IMT and EMT 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 mobilization

When patients become conscious and cooperative, active mobilization can be considered. Active mobilization should aim to prevent ICU-AW and deconditioning from immobilization and illness. The Medical Research Council Sum-Score (MRC-SS) is widely used to diagnose ICU-AW, which is defined as an MRC-SS <48.[38] It is assumed that patients diagnosed with ICU-AW may benefit from active mobilization also following their ICU admission.[39] These physical activities for critically ill patients should be planned and targeted following the evidence based statement for physical therapy management at the ICU as much as possible.[17] Patient safety criteria according to Sommers et al.[17] for active mobilization that always need to be considered at the ICU, are presented in Figure 2.

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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 mobilizations 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 mobilization/physical activities.

Red Flags (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 (level 3 and 4*)
- Clinical View
  - Decreased level of awareness/consciousness
  - Sweating
  - Abnormal face color
  - Pain
  - Fatigue
- Unstable fractures
- Presence of lines that make mobilization unsafe.
- Neurological instability: Intra Cranial Pressure (ICP) ≥ 20 cmH_2O

Figure 2 Criteria for safety of treatment according to Sommers et al.[17]

** Level of evidence of the literature and the 'clinical expertise: level 1 = recommendation based on evidence of research of level A1 or at least two independent studies from level A2; level 2 = recommendation based on one Level A2 study or at least two independent Level B studies; level 3 = recommendation based one study from Level B or C; level 4 = recommendation based on experts' opinion.*

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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 (e.g. a bed cycle) might be used to support active mobilization. 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 (ACSM) guidelines for exercise testing and prescription,[40] BORG score[37] and/or the evidence based statement of Sommers et al.[17] can be used. Box 1 shows our expert opinion suggestions for active mobilization sessions in patients with COVID-19 at the ICU.

Box 1 Expert opinion suggestions for active mobilization sessions in critically ill patients with COVID-19 at the ICU, Phase B

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 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.

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Ideally, the physical therapist is the leading healthcare professional to guide active mobilization. However, safety recommendations can also be decisive in initiating physical therapy management. If safety recommendations for healthcare providers do not warrant direct physical therapy contact, we recommend to instruct nurses to combine active mobilization with daily care activities. In this case the physical therapist has a coaching role.

- → **Recommendation**: Stimulate active mobilization including bed mobility activities. In case safety recommendations for physical therapy management cannot be met, instruct nurses to combine active mobilization with their daily care activities.
- → **Recommendation:** Monitor patients' respiratory and hemodynamic functions continuously, when performing active mobilization.

SECTION 2: Patient is severely ill and admitted to the COVID ward

Severely ill patients with COVID-19 who require hospitalization 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 hospitalization including secondary bacterial infections.[4] Because the consequences of the infection impact the respiratory system, one of the goals of physical therapy management is to optimize respiratory function. Therefore, respiratory support aims to improve breathing control, thoracic expansion and mobilization/evacuation of secretion. Active mobilization aims to increase (or maintain) physical functioning and independence in activities of daily living (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, namely improve vital capacity, evacuation of secretion and respiratory muscle strengthening. Each of these techniques and their goals will be briefly introduced in the following paragraphs.

- *Improve vital capacity*

To relax the airways and relieve the symptoms of wheezing and tightness which 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, 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

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breathing control may vary depending on how breathless patients feel.[41] Evaluated the difficulty of breathing 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 etc.) 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 mobilization or evacuation. When using these techniques, please keep the safety recommendations in mind. The Active Cycle of Breathing Techniques (ACBT) is the preferred procedure. It 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 healthcare 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 physical therapist can be considered.

- *Respiratory muscle strengthening*

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.B. Training protocols typically use resistive loads ranging between 30-80% of MIP.[46] However, the use of non-invasive handheld manometers is not recommended in patients hospitalized 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 (< 10 cmH2O), and can be increased based on clinical presence, experienced dyspnea and BORG

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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/day). 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 in need of airway clearance to stimulate secretion mobilization and evacuation.
→ **Recommendation**: Use inspiratory and expiratory respiratory muscle training in patients recovering from critical illness with suspected respiratory muscle weakness.

Active mobilization

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 mobilization as much as possible through the hospitalization period. Physical therapists 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 mobilization 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 (ACSM) guidelines for exercise testing and prescription,[40] BORG score[37] and/or the evidence based statement of Sommers et al.[17] can be used. Box 2 shows our expert opinion suggestions for active mobilization sessions in patients with COVID-19 at 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 physical therapists cannot be met, it is recommended to instruct nurses how

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to support active mobilization. It is a decision of the interprofessional team of healthcare professionals to assess benefits of support by a physical therapist versus 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 mobilization as much as possible based on patients' needs, preferences and physical functioning.

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Box 2 Expert opinion suggestions for active mobilization sessions in severely ill patients with

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, ankle pumps.
  - Start with 5 repetitions in 1 set, with progression to 8–10 repetitions in 3 sets.
  - Use criteria of the American College of Sports Medicine (ACSM) for moderate intensity:
    - Patients should be able to talk but not sing
    - Perceived exertion: 3–4 out of 10, Metabolic Equivalent Tasks (MET) 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 or > 130 beats/min, blood pressure (MAP) < 65 or > 110 mmHg, respiratory frequency > 40 breaths/minute, oxygen saturation < 85%, cardiac arrhythmia, clinical symptoms (e.g. 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, going from sit to stand
  - Start with 5 repetitions in 1 set, progressing to 8–10 repetitions in 3 sets.
  - Use ACSM moderate intensity criteria:
    - Patients should be able to talk but not sing
    - Perceived exertion: 3–4 out of 10, MET 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 again be considered with the same relative contra-indications as in Step 2.

- **Exercises while standing** such as: hip flexion, knee flexion, shoulder anteflexion, shoulder abduction, stepping in place
  - Start with 5 repetitions in 1 set, progressing to 8–10 repetitions in 3 sets.
  - Use ACSM moderate intensity criteria:
    - Patients should be able to talk but not sing
    - Perceived exertion: 3–4 out of 10, MET level: 3–6

- Additional active mobilisation interventions that need to be considered: Activities of Daily Living (ADL) training, e.g.: eating, washing, ambulation, cycle ergometer

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DISCHARGE RECOMMENDATIONS

The hospital-based physical therapist should screen patients with severe illness due to COVID-19 on whether physical therapy management should be continued after hospital discharge.[48] Patients may experience loss of function and independence due to hospitalization and in severe cases develop a Post Intensive Care Syndrome (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 healthcare need for patients with COVID-19. Continuing care based on patients' needs after hospital discharge is important. The hospital-based physical therapist has an important role in warranting continuity of physical therapy management. When hospital discharge is forthcoming, sufficient hand over of patient information to physical therapists working in primary care practices, rehabilitation clinics, nursing homes, or recovery centres 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 physical therapy and recovery process, current limitations in functioning and daily life activities, and other involved healthcare professionals.[49-51]

→ **Recommendation**: Initiate, refer, and hand over patients to physical therapists in primary care practices, rehabilitation clinics, nursing homes or recovery centers in order to continue physical therapy management, if required.

STAFFING RECOMMENDATIONS

Professional expertise

Careful planning is required when physical therapists are deployed in departments where they are not used to work, such as the ICU. Hospital-based physical therapists 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 physical therapists in a COVID-19 ward or ICU with sufficient skills, knowledge and attitude (self-confidence) and experience in critical care, should be optimized.[19] Hospital-based physical therapists 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 physical therapy **management** of patients with COVID-19.

→ **Recommendation**: Deploy physical therapists with sufficient skills, knowledge and self-confidence in care for severely ill patients at a COVID-19 ward or at the Intensive Care unit.

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Psychosocial support

The COVID-19 outbreak presents new challenges for healthcare professionals. Physical therapists will work intensively with severely ill patients, which can lead to mental health distress. It is recommended for managers to plan sufficient recovery time between work shifts of physical therapists 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 physical therapists.

REFLECTIONS

In this manuscript we provide detailed recommendations and intervention descriptions for hospital-based physical therapists managing patients hospitalized 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 physical therapy management interventions:

- We do not recommend neuromuscular electrical stimulation (NMES) 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 severely/critically ill patients.
- 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 physical therapists.

In our recommendations we focus on physical therapist managing hospitalized patients with COVID-19. However, it is important that recommendations will be provided for the multidisciplinary care after the 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 are still emerging. Thus, treatment paradigms need to be evaluated and updated as new information becomes available.

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Chapter 8b

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

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With the surge of COVID-19 in China and seasonal fluctuations across the globe, it seems appropriate to share with PTJ's readership the latest update of the 2020 Dutch recommendations published in PTJ[1] regarding the management of patients hospitalized with COVID-19. This update was necessary due to an improved understanding of the disease, an increase in clinical expertise, and a growing body of scientific literature. To update the initial recommendations, we followed a pragmatic approach. First, we installed a working group comprising experts on content and guideline methodology. Subsequently, we consulted a group of 71 Dutch hospital-based physical therapists working with patients with COVID-19 to determine which recommendations should be updated and which topics should be added. For the highest 10 rated recommendations and topics, our working group conducted a pragmatic literature search. Finally, new and updated recommendations were formulated by merging the literature findings and the practical experiences. Below we address some of the salient updates.

SAFETY RECOMMENDATIONS

Regarding the safety recommendations, we deem it no longer necessary to minimize contact with patients with COVID-19 because personal protective equipment (PPE) is sufficiently available in the Netherlands. If hospital-based physical therapists use the recommended PPE, as indicated by hospital policy, it is safe to work "hands on" with patients with COVID-19.

RESPIRATORY SUPPORT

We still recommend starting with inspiratory muscle training (IMT) in patients with evident clinical signs of inspiratory muscle weakness, perceived dyspnea, or both. Physical therapists should be aware that patients are suspected to be at risk for respiratory muscle weakness in the case of (prolonged) mechanical ventilation. This recommendation is supported by one study that evaluated the effects of IMT (pulmonary functions, dyspnea, functional performance, and quality of life) after weaning from mechanical ventilation in patients who recovered from COVID-19.[2] No studies were found that evaluated the effects of expiratory muscle training, so this recommendation was removed due to a lack of evidence and clinical rationale. Finally, we recommend that physical therapists should consider the FITT-principles (Frequency, Intensity, Time, and Type) when prescribing breathing exercises to patients with COVID-19, to ensure the exercise is explicit and measurable.

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ACTIVE MOBILIZATION WHILE PATIENT IS UNCONSCIOUS

We recommend that physical therapists should monitor and support passive range of motion when patients are sedated in the intensive care unit (ICU). When patients are lying in prone position, plexopathy is a high-risk complication caused by tension and compression of the brachial plexus. Contralateral head rotation and shoulder abduction beyond 90 degrees should be prevented when patients are lying in a swimmer's position.[3]

→ **Recommendation:** We recommend that physical therapists need to be alert for the development of heterogenic ossifications.

During the first wave of the pandemic, it was noted that patients with prolonged ICU stay due to COVID-19 developed heterogenic ossifications in their elbows, shoulders, knees and hips.[4] A stiff, painful, and warm joint should alert physical therapists to consider the diagnosis of (being at risk of) heterogenic ossification. A radiograph or computed tomography scan might inform clinicians about relevant calcifications of the muscles. For the treatment of heterogenic ossifications, a rehabilitation physician should be consulted. If a heterogenic ossification is diagnosed, it is recommended that the patient exercise within a comfortable range of motion.

In the previous report of our recommendations, we were hesitant to recommend neuromuscular electrical stimulation (NMES) in sedated patients with COVID-19 in the ICU because of the lack of evidence of effectiveness, the hygienic challenges, 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. Recently, more scientific literature has become available supporting NMES as a potential treatment modality for patients with COVID-19 who are sedated and lying in a supine position.[5] If electrical muscle contraction is possible, NMES might be helpful to reduce muscle atrophy in these patients.

ACTIVE MOBILIZATION WHILE PATIENT IS CONSCIOUS AND ABLE TO COOPERATE

We recommend that physical therapists should have an active role in mobilizing and activating patients on both the hospital ward and in cooperative patients in the ICU. Physical therapists should be aware that patients with COVID-19 are at risk to develop ICU-acquired weakness, even when they have no prior physical comorbidities. Experts in the field reported that patients with COVID-19 had disproportional rises in heart rate and strong deoxygenation during low-intensity active mobilization sessions. Patients experienced this low-intensity physical activity as extremely exhausting. As a result, physical therapists need to be aware of an increased risk of overload and exhaustion in this population. We still recommend

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that physical therapists should strictly follow safety criteria during their treatment.[1] While performing active mobilization, we still recommend monitoring peripheral oxygen saturation, heart rate, and Borg Rating of Perceived Exertion score for perceived exhaustion in rest and during and after active mobilization.[1] Ideally, active mobilization should be offered progressively based on the exercise response, with a maximum of 4 on the Borg scale.[1] Finally, we recommend that physical therapists should advise nurses about mobilization principles in patients with COVID-19 (eg, using an expert-based flow chart (Figure 1).

In summary, our goal was to develop up-to-date recommendations based on new clinical insights, scientific literature, and best practices in the Netherlands that were feasible and acceptable in daily practice, facilitating their adoption and implementation. Although our recommendations overlap with other comprehensive, international acute care physical therapy guidelines for COVID-19,[6] we believe that this letter offers practical tips and reminders at a time when COVID-19 is having a seasonal surge. We invite readers who are interested in receiving more detailed information about how we have applied and adapted our recommendations to contact the corresponding author.

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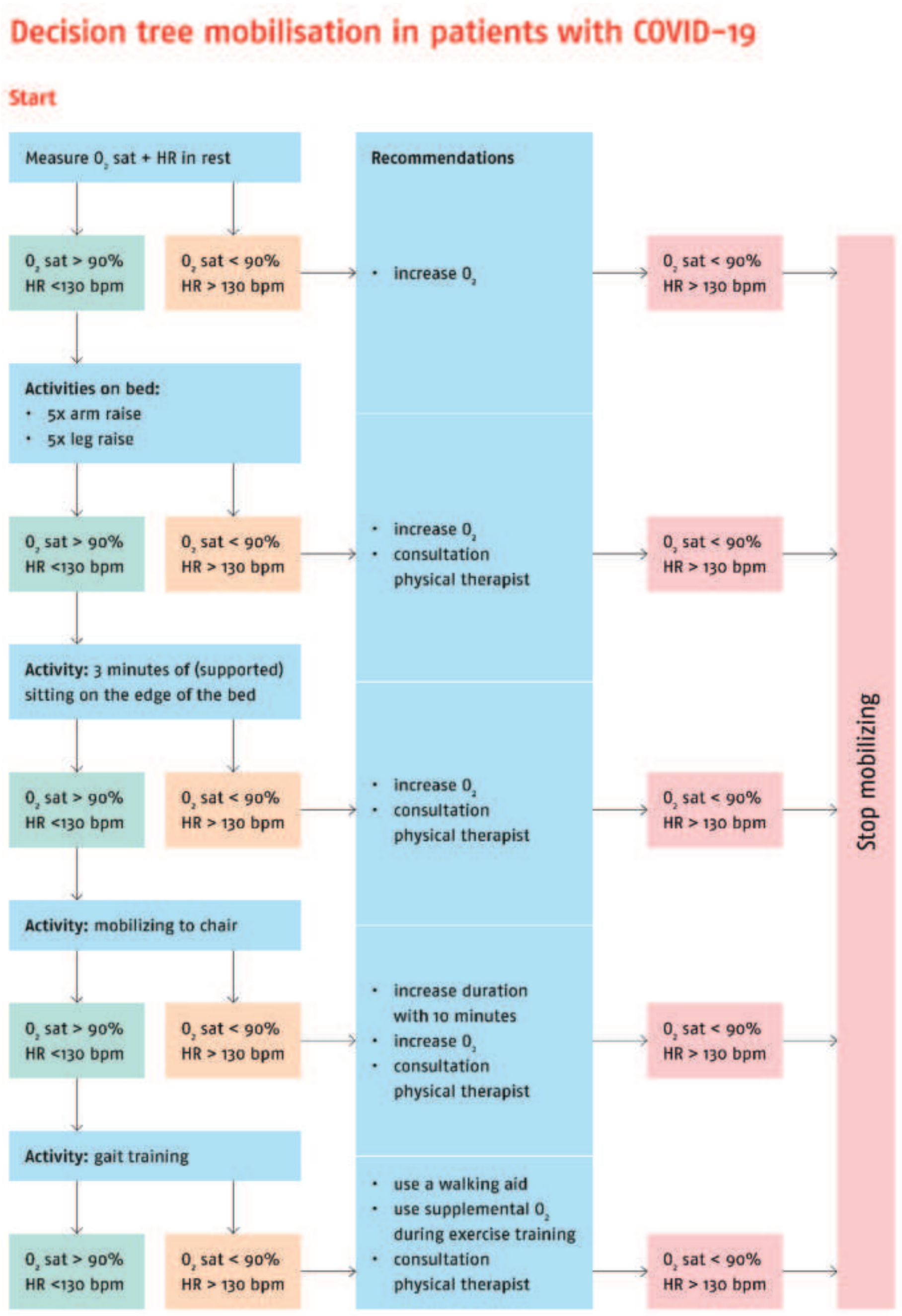

Figure 1. Flow chart for mobilization in patients with COVID-19.

Abbreviations: HR, heartrate; bpm, beats per minute; O2 sat, oxygen saturation; O2, oxygen

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Chapter 9

Summary and General discussion

In this thesis, I shared our findings related to the four physiotherapy innovations that we studied in the context of the Intensive Care Unit (ICU) of a university hospital; namely hydrotherapy, family participation, upper extremity rehabilitation and standardized physiotherapy during a pandemic; aiming at optimizing care for patients and their relatives. In this chapter, I will present a brief and a detailed summary of the findings of this thesis. Afterwards, I will discuss the methodological considerations and potential limitations of our work from a scientific and clinical perspective. Additionally, I will discuss the challenges in demonstrating the efficacy of physiotherapy interventions in the ICU and my role as an embedded scientist. Finally, I will pose several clinical implications and recommendations for further scientific research that came forth from our work.

BRIEF SUMMARY

What did we already know?

Physiotherapists, as members of the multidisciplinary team, play an important role in early mobilisation of patients at the ICU. Early mobilisation has been shown to be safe and feasible, with potential benefits including improved physical function outcomes and reduced hospital and ICU stays.[1,2] However, the effects of early mobilisation on mortality, duration of mechanical ventilation, and quality of life remain unclear due to mixed research results from systematic reviews and meta-analyses.[3] Despite these uncertainties, there is continued emphasis on early mobilisation based on its safety, potential to improve physical function outcomes,[4-6] and its potential cost-effectiveness.[7] Thereby, family participation during early rehabilitation interventions might be beneficial for both patients and their relatives. Early mobilisation and family participation have been incorporated in care bundles and guidelines by major critical care societies, with evidence suggesting their effectiveness in improving outcomes for patients and their relatives and reducing long-term physical, cognitive or mental impairments after ICU admission.[8]

What this thesis adds

The research presented in this PhD thesis shows that:

- Hydrotherapy appears to be a feasible and safe early rehabilitation intervention in selected critically ill ventilated patients (**Chapter 2**).
- Hydrotherapy seems to help critically ill ventilated patients regain control and belief in their recovery. Patients experienced exercising in water as a turning point in their recovery process (**Chapter 3**).
- Implementation of family participation in essential care requires education and training of relatives and ICU healthcare providers, to address safety and quality of care concerns (**Chapter 4**).

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- Family participation of relatives is associated with a significant reduction in mental health symptoms, potentially reduces stress and the chance of developing PICS-F (**Chapter 4 and 5**).
- Intervention descriptions of family participation in essential care activities in the ICU are generally inadequate and do not allow comparison and replication (**Chapter 5**).
- Family participation during physical activity in the ICU can shift relatives from a passive role, with negative beliefs and feelings of uselessness and powerlessness, to a more proactive participatory role. Relatives felt more useful and like they were part of the team. Providing relatives with additional information might be a viable strategy to help and stimulate participation (**Chapter 6**).
- Upper extremity exercise may be beneficial for patients admitted to the ICU; however, the implementation of exercise boxes in this setting appears impractical due to the limited size of the target population, variability in patient acceptability, and limited therapist adherence (**Chapter 7**).
- During a pandemic, it is important to offer guidance and detailed recommendations for hospital-based physiotherapists in the Netherlands on managing COVID-19 patients through a national approach (**Chapter 8a/b**).

DETAILED SUMMARY

In this section, we offer additional insights into the individual chapters of this thesis.

In **Chapter 1**, we introduce the background of this thesis and outline the overarching aim: to investigate various aspects of innovating ICU physiotherapy care. To achieve this, we aimed to answer eight research questions using diverse scientific research methods across four key areas: hydrotherapy, family participation, upper extremity rehabilitation, and recommendations and guidance for physiotherapy care during a pandemic.

In **Chapter 2**, we examine the feasibility and safety of hydrotherapy for critically ill ventilated patients. We describe patient eligibility criteria, hydrotherapy session specifics, complications, and water quality assessments. Twenty-five patients participated in at least one hydrotherapy session in addition to the standard early mobilization program. None reported discomfort, severe oxygen desaturation, or hemodynamic instability during the sessions. Microbiological analysis of pool water indicated no significant contamination. Our findings suggest that hydrotherapy is safe for a selected group of ventilated ICU patients.

Chapter 3 explores the impact of hydrotherapy on critically ill ventilated patients using a generic phenomenological methodology. We included twelve patients, with eight participating in in-depth, face-to-face, semi-structured interviews six to

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twelve weeks post-hospital discharge. Thematic analysis identified five main themes: experiencing consequences of critical illness, feeling safe in the water, being able to move, positive experiences related to hydrotherapy, and experiencing a turning point. Hydrotherapy appeared to help patients regain control and confidence in their recovery.

In **Chapter 4**, we conducted an integrative review to identify needs, perceptions, preferences, and capacities regarding family participation in essential care in ICUs from the patients', relatives' and ICU healthcare providers' perspective. Twenty-seven studies were reviewed, with quality scores ranging from 0.45 to 0.95 (on a scale of 0-1). Despite a gap in understanding patients' needs, perceptions, preferences, and capacities, several themes emerged. Identified needs and perceptions are: relatives' desire to help the patient, a mostly positive attitude among all involved, stress regarding patient safety, perceived beneficial effects, relatives feeling in control, and ICU healthcare providers' concerns about loss of control. Preferences for potential essential care activities vary. Relatives want an invitation and support from ICU healthcare providers to participate. Themes regarding capacities are: knowledge, skills, education and training and organisational conditions. We concluded that effectively implementing family participation in essential care necessitates educating and training both relatives and ICU healthcare providers to address safety and quality of care concerns, though many studies lacked detailed specifications.

In **Chapter 5**, we employed the same search strategy and integrative review approach as in chapter 4, to systematically analyse interventions and outcomes related to family participation in essential care within adult ICUs. A total of seven studies were included, with quality scores ranging from 0.50 to 0.86 (on a scale of 0 to 1). Outcome measures among relatives encompassed mental health symptoms to satisfaction, supportiveness, comfort level and experience. Two studies assessed patient outcomes, focusing on delirium and pressure ulcers. Among ICU healthcare providers, perception, comfort level and experience were assessed. Since outcome measures varied, only narrative synthesis was possible. We concluded that intervention descriptions of family participation in essential care activities are generally inadequate and do not allow comparison and replication. Participation of relatives was associated with a significant reduction in mental health symptoms. Other outcome measures varied, therefore, the use of additional outcome measures with validated measurement instruments should be considered.

Chapter 6 explores the needs, beliefs, feelings, and behaviours of relatives of patients admitted to the ICU regarding participation during physical activity. We used a longitudinal qualitative study design following a grounded theory approach. Relatives were interviewed at 4, 8 and 12 days after the patient's ICU-admission.

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Twenty-five interviews were conducted in ten relatives. Relatives believed that physical activity in the ICU improves recovery. Participating in physical activity decreased their feelings of powerlessness and uselessness. Relatives mentioned that they would be stimulated to participate if they were invited, guided, and informed by healthcare providers. The perceived reticence of healthcare providers, patient's health-changing capacity, and the inability to communicate led to a more passive attitude towards participation. Our conceptual model shows how family participation during physical activity changes from a passive role, with negative beliefs and feelings of uselessness and powerlessness, to a more proactive participatory role. Relatives felt more useful and felt like they were part of the team. Providing relatives with additional information might be a viable strategy to help and stimulate participation.

Chapter 7 describes the feasibility of implementing an exercise box in daily ICU practice. In this mixed-methods feasibility study we assessed demand, acceptability, and limited efficacy using both qualitative and quantitative data. Despite an extensive implementation strategy, demand was found to be inadequate, with only 11 patients (<2%) meeting eligibility criteria for using the exercise box in the ICU. Patients' acceptability varied, and therapists demonstrated limited willingness to utilize the exercise box. Assessment of limited efficacy was not feasible.

In **Chapter 8a** we provided detailed recommendations and guidance for hospital-based physiotherapists tasked with managing patients hospitalized due to COVID-19. This study was rapidly conducted in March and April 2020, during the initial wave of the pandemic in the Netherlands, when understanding of the virus was limited. Given the urgent need for guidance, we adopted a pragmatic approach. A working group was formed to conduct a targeted review of the literature and develop initial recommendations based on available knowledge of COVID-19 symptoms and existing physiotherapy interventions for patients with lung disease or in ICU settings. Feedback from an expert panel of hospital-based physiotherapists in the Netherlands was sought, and final recommendations were established through consensus within the working group. The recommendations covered safety, treatment, discharge, and staffing considerations. They were subsequently endorsed by the Royal Dutch Society for Physiotherapy and the World Health Organization.

In **Chapter 8b**, we provide an updated set of recommendations for managing hospitalized COVID-19 patients, building on the recommendations outlined in Chapter 8a. This revision was motivated by advancements in understanding of the disease, improved clinical expertise, and an expanding body of scientific evidence. To revise the initial recommendations, we adopted a pragmatic approach. First, we installed a working group comprising experts on content and guideline methodology. Then, we consulted with 71 Dutch hospital-based physiotherapists who actively

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work with COVID-19 patients to identify recommendations needing updates and additional topics. We conducted a pragmatic literature search on the top 10 rated recommendations and topics identified by the therapists. Finally, we formulated new and updated recommendations by integrating literature findings with practical experiences. Summarising the updated recommendations: physiotherapists should be aware that COVID-19 patients in the ICU may be at risk of ICU-acquired weakness, heterotopic ossifications, and brachial plexus plexopathy, with an increased risk of overload and exhaustion.

METHODOLOGICAL CONSIDERATIONS

This thesis includes two feasibility studies (**Chapters 2 and 7**), two qualitative studies (**Chapters 3 and 6**), two integrative reviews (**Chapters 4 and 5**), and one (updated) clinical practice guideline (**Chapters 8a/b**). Here, we reflect on the usefulness of these approaches in the field of ICU physiotherapy and acknowledge several potential limitations.

For most new physiotherapy interventions, we started with a comprehensive literature search, either systematically (**Chapters 4 and 5**) or pragmatically (**Chapters 8a/b**). Synthesizing the available evidence allows for an assessment of similar interventions in comparable patient populations within the complex ICU context. Gaining insights into daily practice and patients' needs (**Chapter 4**) and considering the feasibility and safety of the new intervention (**Chapters 2 and 7**) are essential steps. Finally, understanding how these new interventions are implemented in real-world practice through user perspectives (**Chapters 3 and 7**) is imperative for ensuring their adoptability and relevance in clinical practice. Our approach aligns largely with the recommendations of the Medical Research Council (MRC) on the development and evaluation of complex interventions.[9] The MRC developed a new framework that divides complex intervention research into four stages: development or identification of the intervention, feasibility, evaluation, and implementation.[9]

In line with the MRC-framework,[9] we employed a feasibility study design to outline novel interventions in **Chapters 2 and 7**: hydrotherapy and an exercise box for critically ill ventilated patients in the ICU. For hydrotherapy in **Chapter 2**, we detailed the intervention, the eligible patient population, and the practical procedure, with a specific focus on safety during implementation. In **Chapter 7**, our focus shifted towards key feasibility areas, describing the implementation trajectory of a patient-related exercise box to promote upper extremity rehabilitation during ICU stays. Both studies encompassed small study populations, which is common in feasibility studies. This small and selectively chosen study population limits the generalizability of our findings. Feasibility studies assess the suitability of an

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intervention for further testing and enable researchers to refine ideas and findings for practical and sustainable application.[10] In our feasibility studies, we focused on a few key areas, but we should have emphasized the key area of "practicality"—the extent to which an idea, program, process, or measure can be implemented with intended participants using existing means, resources, and circumstances without outside intervention.[10] For example, we did not conduct a cost-benefit analysis of the hydrotherapy intervention, which would have been helpful for considering further implementation. In addition, we could have more thoroughly investigated the need for the innovations and identified potential barriers in advance. For the exercise box, this approach may have yielded different insights.

The research topics in **Chapters 3 and 6** focused on novel approaches to physiotherapy in the ICU context: hydrotherapy with mechanically ventilated patients (**Chapter 3**) and family participation during physical activity promotion (**Chapter 6**). The exploratory nature of these topics justified the use of a qualitative research approach. **Chapter 3** employed a phenomenological approach to explore the subjective experiences of patients undergoing the new hydrotherapy intervention. **Chapter 6** used a grounded theory approach to develop a model explaining the evolving needs, beliefs, feelings, and behaviours of relatives over time. While this emphasis on qualitative data over quantitative data may limit the generalizability of our conclusions, qualitative research provides deep insights into the "why" behind findings. It prioritizes understanding human behaviour, motivations, and emotions through text-based information, offering a "thick description" that enhances external validity. By detailing field experiences and contextualizing patterns of cultural and social relationships, qualitative research allows for the evaluation of the transferability of conclusions to other times, settings, situations, and populations. [11,12] Quantitative data are also needed to investigate the implementation and added value of the innovations. Therefore, qualitative and quantitative approaches are complementary.

A systematic literature review was not suitable for gaining insight into family participation in essential care activities in the ICU due to the diversity of study designs, populations, and perspectives, which made data synthesis impossible. To address this, we utilized an integrative review approach in **Chapters 4 and 5**. This method was chosen for its ability to incorporate various study types with differing quality assessments, allowing for a comprehensive synthesis of evidence. Integrative reviews transcend simple analysis and synthesis of primary research, offering novel insights and a holistic understanding of a specific topic by synthesizing both qualitative and quantitative data.[13] The strength of the integrative review lies in its capacity to evaluate research literature, assess the quality of evidence, identify knowledge gaps, and amalgamate research from different designs, facilitating the generation of theories and classification of key constructs.[14] By synthesizing

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all available evidence, healthcare professionals can apply this knowledge more effectively in clinical practice.[15] The integrative review can serve as a powerful tool to advance knowledge in the field of physiotherapy.

In **Chapters 8a/b**, we employed a pragmatic approach for guideline development due to time constraints during the COVID-19 pandemic, with the goal of expanding the guideline from a national to an international scope. While the recommendations are based on the Dutch context, the international publication enabled us to share insights and experiences globally. The guideline is designed for continuous evaluation, adaptation, and updates based on emerging evidence. However, due to time limitations, we adopted a pragmatic rather than a systematic approach, which may have impacted the comprehensiveness and rigor of the methodology. The challenge of keeping up with scientific developments during COVID-19, coupled with the uncertainty surrounding the novel virus and the influx of non-peer-reviewed research, made rapid reviews necessary.[16] These reviews, though useful, lacked the thoroughness of systematic reviews and required regular updates to remain relevant as the evidence base quickly evolved.[16]

CHALLENGES IN DEMONSTRATING THE EFFICACY OF PHYSIOTHERAPY IN THE ICU

This thesis contributes to the advancement of evidence for physiotherapy in the ICU. Despite varying levels of evidence regarding early mobilization and family participation in the ICU, uncertainties persist regarding optimal dosage, timing, methods, intervention descriptions, and patient selection.[17] The latter underscores the necessity for further research in this domain. As a physiotherapy scientist, I acknowledge the perpetual demand for new knowledge to ensure the delivery of high-quality care in the ICU. In addition, as an innovative professional, I have a role in identifying and initiating opportunities for innovation and improvement. Embracing context-based practice, according to the report "No evidence without context: About the illusion of evidence-based practice in healthcare" by the Council for Public Health and Society in the Netherlands (RVS)),[18] aligns with my vision to innovate and initiate pilot programs in physiotherapy clinical practice. Especially in the ICU, where the context is highly complex and multifactorial, it is difficult to test and evaluate innovations in a highly controlled setting.

Therefore, the question arises: what constitutes meaningful evidence for instigating healthcare change? Whether a multicentre randomised controlled trial (RCT), conducted in a different context and healthcare system, or qualitative analysis of a new intervention in the relevant context holds greater value is not a straightforward question. An RCT "strips" context, while in the ICU, the complex context must be considered. As highlighted in 'No evidence without context', evidence devoid of contextual relevance risks being detached from the intricacies of practice, overlooking critical variables such as local workflows, cultural factors, and stakeholder perspectives.[18] The rigid evidence hierarchy should be reconsidered, allowing more space and appreciation for study designs better suited to capturing the complexities of real-life healthcare settings.[19]

For me, as an embedded physiotherapy scientist in the ICU, comprehending the intricacies of the ICU environment in both practical and scientific contexts is crucial to produce clinically relevant insights. Critically ill ventilated patients present a challenging study population due to their heterogeneity, multimorbidity, and numerous influencing factors. The largest RCT (TEAM trial) on early mobilization versus usual care in 750 patients demonstrated that early mobilization might lead to an increased probability of adverse events and mortality, without clear clinical benefits.[20] In response, Paton et al.[21] conducted a systematic review and meta-analysis assessing the association of active mobilization variables with adverse events and mortality in ICU patients requiring mechanical ventilation. They found that mobilization in the ICU was associated with less than a 3% chance of adverse events and did not increase overall adverse events or mortality, reassuring clinicians about the intervention's safety. Furthermore, subgroup analyses did not clearly identify any specific variable of mobilization implementation that increased harm. Nevertheless, physiotherapists need to closely monitor safety. Recently, Woodbridge et al.[21] developed an adverse event tool to ensure uniform measurement of safety for studies of physiotherapy rehabilitation to inform clinical practice when risk-assessing rehabilitation initiation in patients receiving vasoactive drugs. Moreover, physiotherapists need to shift from a one-size-fits-all approach for the mobilization of the highly diverse ICU population, towards a right dosage for the right patient approach.[17] An example of such an approach was detailed in the feasibility study of Fuest et al.,[23] who used artificial intelligence to explore personalized mobilization approaches by identifying predictors of discharge to home. Early mobilization was particularly beneficial for young trauma and middle-aged patient clusters, supporting an individualized, patient-centred approach. In other words, when considering physiotherapy interventions like early-mobilization, or in our case, hydrotherapy, family participation, developing a toolbox, or drafting recommendations during a pandemic, it is essential to understand the ICU context and employ appropriate approaches to describe and assess these interventions. Often, only a small subset of patients will be eligible for such interventions, necessitating a thorough understanding of this population and their specific needs. Conducting RCTs for new interventions in the ICU is often impractical and premature, warranting a more cautious approach.

In other words, the current body of literature struggles to conclusively demonstrate the benefits of physiotherapy in the ICU due to several inherent challenges. Patient

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heterogeneity is a major challenge, as ICU populations include a wide range of conditions, severities, and comorbidities, making it difficult to generalize findings. Variability in intervention dosage—the frequency, intensity, and duration of physiotherapy—further complicates the ability to define optimal treatments, particularly when patients' conditions fluctuate rapidly. Moreover, inconsistent outcome measures often focus on short-term metrics (e.g., ICU length of stay, muscle strength) that may not fully capture the long-term functional and quality-of-life benefits of physiotherapy.

ROLE OF THE EMBEDDED SCIENTIST IN THE ICU

As an embedded scientist, I have applied alternative research methodologies better suited to the ICU context. These include mixed methods designs, real-time data collection, and the integration of qualitative methods to explore patient and family experiences. By combining clinical insights with scientific inquiry, I have contributed to generating more context-based evidence that complements traditional RCTs. This approach acknowledges the limitations of RCTs in highly variable environments such as the ICU and encourages a multi-method strategy where both mixed-methods designs and controlled methodologies inform each other.

Regarding the innovative hydrotherapy intervention, our feasibility study demonstrates its safety and feasibility in ventilated ICU patients. Moreover, qualitative findings indicated that patients and their relatives perceived considerable value of hydrotherapy; some describing it as a pivotal moment in their rehabilitation journey. These preliminary data, subsequently led to the integration of hydrotherapy into standard physiotherapy care at ICU of the Radboudumc. Currently, this intervention is offered daily to severely weak ICU patients. On the one hand, some might say that we implemented this intervention without solid scientific evidence and extensive efficacy studies. On the other hand, the pool was already built, everyone (i.e., patients, their relatives, nurses, physiotherapists, and physicians) was enthusiastic, and it seemed feasible and safe. This is a good example of context-based practice, where a RCT is not always essential to move good clinical practice forward. Nevertheless, we must remain critical of whether we should continue this innovation. Therefore, during current practice we still collect data of patients using hydrotherapy to monitor the safety of the approach and in time to investigate the cost-effectiveness of this intervention.

However, not all innovative developments yield success and can be seamlessly incorporated into routine physiotherapy care for ICU patients. This was evident in the implementation of an exercise box for upper extremity rehabilitation, which despite well-substantiated hypotheses and motivation, appeared unfeasible in daily physiotherapy care. During the implementation of the exercise box,

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challenges arose due to the ongoing COVID-19 pandemic, particularly with a subset of patients failing to meet the study's inclusion criteria. Additionally, hygienic concerns hindered the implementation of the exercise box. Furthermore, feedback from ICU physiotherapists highlighted competing priorities, favouring alternative training objectives such as standing, transferring, walking, or breathing exercises.[24] Physiotherapists recommended the involvement of relatives and occupational therapists in supporting and assessing upper extremity exercises, which is in line with the latest scientific evidence.[25] Despite the outcomes of our feasibility study, the exercise box remains accessible in our hospital, prompting further investigation into its utility as part of occupational therapy care.

Finally, in some cases time pressure can result in the decision to choose for a more pragmatic than rigorous approach to science. A good example of are our recommendations for hospital-based physiotherapists working with patients with COVID-19. During the start of the pandemic, much was uncertain. Consequently, there was a significant demand from the clinical setting for treatment advice or recommendations for physiotherapy in this new and unfamiliar disease. From clinical practice, the following question arose: How do we ensure continuity of physiotherapy during the COVID-19 pandemic? We had to act swiftly, adopting a pragmatic approach with input from numerous field physiotherapists. Our pragmatic, yet consensus-based approach, resulted in the quickly developed recommendations for physiotherapy management for patients hospitalized with COVID-19. Initially, we shared these recommendations nationally[26] and then internationally (**Chapter 8a**). Our recommendations had a significant global impact, with over 140 citations (Google Scholar), over 42,000 views, and an Altmetric score of 50 (ranking this publication in the top 5% of all research outputs scored by Altmetric).

Moving forward, I believe the future lies in combining traditional RCTs with mixed-methods designs and context-driven methods. Both strategies are complementary in providing a deeper understanding of the value of physiotherapy interventions in the ICU. My role will be to continue bridging the gap between clinical practice and scientific research, ensuring that innovative physiotherapy interventions are not only tested rigorously but also adopted in real-world settings. My position as embedded scientist allows me to identify emerging questions in practice and seek evidence-based solutions that improve patient outcomes.

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CLINICAL IMPLICATIONS AND FUTURE RESEARCH

This thesis, “Innovating Physical Therapy Practice for Patients Admitted to the Intensive Care Unit and Their Relatives”, has significant implications for clinical practice. It highlights the need to contextualize evidence and emphasizes the physiotherapist’s role as an effective communicator. Following the development of international guidelines and the demonstration of innovative interventions, the focus must shift to implementation and valorisation. Successful implementation requires addressing knowledge, attitude, and culture through education. After publishing the “Recommendations for Hospital-Based Physical Therapists Managing Patients with COVID-19” (**Chapter 8a**), online education (CME-Online) and a Dutch manual were introduced to support practice integration.[26] Sharing knowledge about the COVID recommendations consisted of giving national webinars and promoting adherence to the COVID-recommendations to enhance competence and patient outcomes. Additionally, it is crucial in my role as a communicator and innovator not only to introduce treatment recommendations into the field but also to maintain and update them as expert in the domain (**Chapter 8b**).

Future research in ICU physiotherapy should prioritize person-centred care, better content control, context-based approaches, and integration into a learning health system. Learning health systems provide a pathway towards continuous improvement and innovation in healthcare through the routine collection, analysis, and more timely use of data in a context-based approach.[26] Over the past decade, the focus has shifted from mere survival to improving functionality and quality of life post-ICU. Early mobilisation has shown benefits, but the optimal approach remains unclear, particularly given the diverse patient profiles in the ICU. Future studies should focus on personalizing mobilisation protocols, considering patient-specific factors to optimize outcomes. Additionally, research should standardize adverse event monitoring and reporting to enhance the safety and effectiveness of these interventions.

CONCLUSION

The aim of this PhD thesis was to investigate various aspects of innovating ICU physiotherapy care. Despite limitations, including small study populations and methodological constraints, this research contributes to our understanding of physiotherapy in critical care. It emphasizes the importance of diverse interventions and the role of the embedded scientist in driving innovation. This thesis describes healthcare innovations within physiotherapy, aiming to improve care, predominantly investigated through ICU-related questions. We primarily considered the perspectives of patients and their relatives in the complex ICU context, providing recommendations for ICU physiotherapists to implement new interventions. As an embedded scientist I aimed to address, investigate, and re-implement context-

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driven issues in practice. Despite often small research populations, heterogeneous groups, and single-center studies, various studies in this thesis have significantly benefited the quality of physiotherapy at the ICU of the Radboudumc. We debated whether larger-scale studies are always necessary or if we should focus more on context-based evidence and personalized care. Moving forward, further research is needed to develop feasible and effective physiotherapy interventions in the ICU, with the hope that this thesis serves as a step towards that goal.

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Nederlandse samenvatting
Research data management
About the author
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NEDERLANDSE SAMENVATTING

Inleiding

In **Hoofdstuk 1** introduceren we de achtergrond van dit proefschrift en schetsen we het overkoepelende doel: het onderzoeken van verschillende aspecten van vernieuwing in fysiotherapie op de intensive care (IC). Om dit te bereiken, hebben we acht studies uitgevoerd met diverse wetenschappelijke onderzoeksmethoden, gericht op vier kerngebieden: hydrotherapie, familieparticipatie, revalidatie van de bovenste extremiteiten en aanbevelingen voor fysiotherapeutische zorg tijdens een pandemie.

Hydrotherapie

In **Hoofdstuk 2** onderzoeken we de haalbaarheid en veiligheid van hydrotherapie voor ernstig zieke beademde patiënten. We beschrijven de criteria voor patiëntgeschiktheid, specifieke aspecten van de hydrotherapiesessies, complicaties en de waterkwaliteit. Vijfentwintig patiënten namen deel aan minstens één sessie hydrotherapie, naast het standaard vroege mobilisatieprogramma. Geen van de patiënten ervaarde ongemak, ernstige desaturatie of hemodynamische instabiliteit tijdens de sessies. Het zwembadwater bleef ten alle tijden van goede kwaliteit. We concludeerden dat hydrotherapie veilig is voor een geselecteerde groep beademde IC-patiënten.

Hoofdstuk 3 verkent de impact van hydrotherapie bij ernstig zieke beademde patiënten met behulp van een generieke fenomenologische methodologie. We includeerden twaalf patiënten, waarvan er acht deelnamen aan face-to-face, semigestructureerde diepte-interviews zes tot twaalf weken na ontslag uit het ziekenhuis. Thematische analyse identificeerde vijf hoofdthema’s: de gevolgen ervaren van kritieke ziekte, zich veilig voelen in het water, in staat zijn om te bewegen, positieve ervaringen gerelateerd aan hydrotherapie en het ervaren van een omslagpunt. Hydrotherapie leek patiënten te helpen weer controle te krijgen en vertrouwen te hebben in hun herstel.

Familieparticipatie

In **Hoofdstuk 4** voerden we een integratieve review uit om behoeften, percepties, voorkeuren en capaciteiten met betrekking tot familieparticipatie in essentiële zorg te identificeren vanuit het perspectief van patiënten, naasten en zorgverleners op de IC. Zevenentwintig studies werden beoordeeld, met kwaliteitsscores variërend van 0,45 tot 0,95 (op een schaal van 0-1). Hierbij kwamen verschillende thema’s naar voren. Geïdentificeerde behoeften en percepties omvatten: de wens van naasten om de patiënt te helpen, een overwegend positieve houding onder alle betrokkenen ten opzichte van familieparticipatie, bezorgdheid met betrekking tot de veiligheid van de patiënt, waargenomen gunstige effecten, naasten die het gevoel hebben

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controle te hebben en bezorgdheid van IC-zorgverleners over verlies van controle. Voorkeuren voor potentiële essentiële zorgactiviteiten variëren. Naasten willen een uitnodiging en ondersteuning van IC-zorgverleners om deel te nemen. Thema's met betrekking tot capaciteiten omvatten: kennis, vaardigheden, educatie en training en organisatorische voorwaarden. We concludeerden dat voor een effectieve implementatie van familieparticipatie in essentiële zorg, educatie en training van zowel familieleden als IC-zorgverleners noodzakelijk is om zorgen over veiligheid en kwaliteit van zorg aan te pakken, hoewel in veel studies details hierover ontbraken.

In **Hoofdstuk 5** hebben we dezelfde zoekstrategie en integratieve review-benadering gebruikt om interventies en uitkomsten op het gebied van familieparticipatie te analyseren. In totaal werden zeven studies geïncludeerd, met kwaliteitsscores variërend van 0,50 tot 0,86 (op een schaal van 0-1). Er werden vijf verschillende essentiële zorgactiviteiten in de studies beschreven. De meeste interventies waren echter onvoldoende gedetailleerd beschreven, wat vergelijking en herhaling van studies heeft bemoeilijkt. Familieparticipatie werd geassocieerd met een significante vermindering van mentale gezondheidssymptomen zoals angst en posttraumatische stressstoornissen bij naasten. Verder vonden we aanzienlijke variatie in andere uitkomstmaten.

Hoofdstuk 6 heeft de behoeften, overtuigingen, gevoelens en gedragingen van naasten met betrekking tot participatie tijdens fysieke activiteiten van patiënten op de IC onderzocht. We gebruikten een longitudinaal kwalitatief onderzoeksontwerp volgens een grounded theory-benadering. Naasten werden geïnterviewd op 4, 8 en 12 dagen na de IC-opname van de patiënt. Vijfentwintig interviews zijn afgenomen bij tien naasten. Naasten waren ervan overtuigd dat het aanbieden van fysieke activiteiten op de IC het herstel van de patiënt bevordert. Het mogen helpen tijdens fysieke activiteiten heeft gevoelens van machteloosheid en nutteloosheid verminderd. Familieparticipatie werd bevorderd door uitnodiging, begeleiding en informatieverstrekking van zorgverleners. Terughoudendheid van zorgverleners, de veranderende gezondheidstoestand en het onvermogen van de patiënt om te communiceren leidden tot een passievere houding bij naasten. Ons conceptuele model toont hoe familieparticipatie tijdens fysieke activiteiten verandert van een passieve rol, met negatieve overtuigingen en gevoelens van nutteloosheid en machteloosheid, naar een meer proactieve participerende rol van naasten. Ze voelden zich nuttiger en hadden het gevoel deel uit te maken van het team.

Revalidatie bovenste extremiteiten

Hoofdstuk 7 beschrijft de haalbaarheid van het implementeren van een oefenbox van de bovenste extremiteiten in de dagelijkse IC-praktijk. In deze mixed-methods haalbaarheidsstudie hebben we vraag/behoefte, acceptatie en effectiviteit ten aanzien van deze nieuwe interventie beoordeeld met zowel kwalitatieve als

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kwantitatieve gegevens. Ondanks een uitgebreide implementatiestrategie was er een beperkte vraag/behoefte voor de oefenbox, waarbij slechts 11 patiënten (1,6%) geschikt bleken om de oefenbox daadwerkelijk te gebruiken. De acceptatie onder patiënten varieerde en therapeuten toonden beperkte bereidheid om de oefenbox te gebruiken. Beoordeling van de effectiviteit was niet haalbaar.

Aanbevelingen tijdens COVID-pandemie

In **Hoofdstuk 8a** hebben we gedetailleerde aanbevelingen en leidraad gegeven voor de fysiotherapeutische behandeling tijdens de ziekenhuisopname bij patiënten met COVID-19. Deze studie werd in relatief korte tijd uitgevoerd tijdens de eerste golf van de COVID-pandemie in Nederland. De kennis over het virus en de behandeling was destijds erg beperkt. Gezien de dringende behoefte aan richtlijnen, kozen we voor een pragmatische aanpak. Er werd een werkgroep gevormd om een gerichte literatuurstudie uit te voeren en eerste aanbevelingen te ontwikkelen op basis van beschikbare kennis over COVID-19, in combinatie met bestaande fysiotherapeutische interventies voor patiënten met longaandoeningen en patiënten op de IC. Feedback van een expertpanel van ziekenhuisfysiotherapeuten in Nederland werd gevraagd en de uiteindelijke aanbevelingen werden opgesteld op basis van consensus binnen de werkgroep. De aanbevelingen hadden betrekking op veiligheid, fysiotherapeutische behandeling, ontslag en personeelsbezetting. Ze werden vervolgens onderschreven door het Koninklijk Nederlands Genootschap voor Fysiotherapie en de Wereldgezondheidsorganisatie.

In **Hoofdstuk 8b** bieden we een bijgewerkte reeks aanbevelingen voor de fysiotherapeutische behandeling van patiënten met COVID-19 die in het ziekenhuis zijn opgenomen, voortbouwend op de aanbevelingen beschreven in Hoofdstuk 8a. Deze herziening werd gemotiveerd door een beter begrip over de ziekte, verbeterde klinische expertise en een groeiende hoeveelheid wetenschappelijk bewijs. Om de oorspronkelijke aanbevelingen te herzien, kozen we opnieuw voor een pragmatische aanpak. Eerst stelden we een werkgroep samen met experts op het gebied van inhoud en richtlijnmethodologie. Vervolgens raadpleegden we 71 Nederlandse ziekenhuisfysiotherapeuten die actief werkten met COVID-19-patiënten, om aanbevelingen te identificeren die moesten worden bijgewerkt en aanvullende onderwerpen te formuleren. We voerden een pragmatisch literatuuronderzoek uit naar de top 10 beoordeelde aanbevelingen en onderwerpen die door de therapeuten werden geïdentificeerd. Tot slot formuleerden we nieuwe en bijgewerkte aanbevelingen door de bevindingen uit de literatuur te integreren met ervaringen uit de praktijk. De nieuwe aanbevelingen samenvattend moeten fysiotherapeuten zich ervan bewust zijn dat patiënten met COVID-19-patiënten op de IC het risico kunnen lopen op IC-verworven spierzwakte, heterotope ossificaties en plexopathie van de plexus brachialis en een verhoogd risico hebben op overbelasting en uitputting tijdens het mobiliseren.

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Discussie/conclusie

Hoofdstuk 9 geeft een korte en gedetailleerde samenvatting van de bevindingen van dit proefschrift. Vervolgens bespreken we de methodologische overwegingen en de potentiële beperkingen van ons werk vanuit een wetenschappelijk en klinisch perspectief. Daarnaast bespreek ik de uitdagingen bij het aantonen van de effectiviteit van fysiotherapie op de IC en mijn rol als embedded scientist. Ten slotte stel ik verschillende klinische implicaties en aanbevelingen voor verder wetenschappelijk onderzoek voor die voortkomen uit ons werk.

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RESEARCH DATA MANAGEMENT

General information about the data collection

The presented research followed the applicable laws and ethical guidelines. Research data management was conducted according to the FAIR principles. The paragraphs below specify in detail how this was achieved.

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, 3, 5 and 6 involved human participants. These chapters were conducted according to the principles of the Declaration of Helsinki (version 64th WMA General Assembly, Fortaleza, Brazil, October 2013) and in accordance with the Dutch Medical Research Involving Human Subjects Act (WMO). The principles of Good Clinical Practice were followed throughout.

The institutional ethical review committee CMO Radboudumc, Nijmegen, the Netherlands has given approval to conduct these studies (CMO Radboudumc dossier number: 2015-1552, 2017-3635, 2019-5627). Informed consent was obtained from participants to collect and process their data for this research project. No ethical approval was required for the integrative reviews in Chapter 4a/b and the clinical practice guideline in Chapter 7a and the update of this guideline in Chapter 7b.

Data collection and storage

The data obtained during my PhD at the Radboud university medical center have been stored on the secured departmental network drive. 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). Data for chapter 2, 3, 6 and 7 was extracted from (electronic) health records (EPIC). Only members of the research group had access to the data. The pseudonymization key was stored on a secured network drive that was only accessible to members of the project who needed access to it because of their role within the project. The pseudonymization key was stored separately from the research data.

Availability of data

No consent was obtained for sharing the pseudonymized data after research. Therefore, the pseudonymized data underlying Chapters 2, 3, 6 and 7 are archived on the Radboud Data Repository in a closed access DAC (DOI 10.34973/map6-y575) for at least 15 years after termination of the studies. For the data of the studies in

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Chapters 4 and 5, the first author is responsible to make the data compliant with the F&A of FAIR. Due to the sensitivity of this data, it will also be archived in a DAC in the RDR.

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ABOUT THE AUTHOR

Karin Felten-Barentsz was born on June 30 1983, in Grave, the Netherlands. She grew up in Malden with her parents and two brothers. She completed her secondary education at the Stedelijke Scholengemeenschap Nijmegen (SSgN).

Subsequently, she pursued a degree in Physiotherapy at the HAN University of Applied Sciences in Nijmegen. A successful final internship at the Radboud University Medical Center in Nijmegen led to her graduation (BSc, 2006) and marked the beginning of her professional career as a hospital-based physiotherapist.

She initially worked as a physiotherapist in the Intensive Care Unit (ICU), focusing on patients with traumatic injuries. Over time, her expertise expanded to include patients with neurological disorders, which remains her primary area of interest. In 2012, she completed a Master's degree in Clinical Health Sciences, specializing in Physiotherapy Science, at Utrecht University.

During her tenure as a dedicated ICU physiotherapist in an academic hospital, she was introduced to innovative interventions such as hydrotherapy. In her role as an innovative professional, she implemented these interventions and sought to support them with scientific evidence to facilitate global knowledge dissemination. One such innovation involved increasing family involvement during ICU admissions, particularly during physiotherapy sessions. This initiative aligned with the Research Department of Emergency and Critical Care at the HAN University of Applied Sciences, which, through a RAAK grant, aimed to approach 'family participation in essential care activities' from a multidisciplinary perspective.

During the COVID-19 pandemic, she took on the role of an embedded scientist, striving to provide the field with recommendations based on both literature and practical expertise to optimize physiotherapy treatment for this new patient population. This effort contributed to the development of national and international COVID guidelines for ICU physiotherapy.

To support the implementation of an exercise box for upper extremity rehabilitation in the ICU, she applied for a personal grant from the Rehabilitation Department's foundation. This funding enabled her to conduct studies with limited resources, bridging the gap between science and clinical practice. These endeavours culminated in a PhD trajectory.

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Following the completion of her PhD, Karin will continue her dual role as an academic physiotherapist and researcher in hospital-based physiotherapy care. As an embedded scientist, she aims to translate clinically relevant questions into meaningful research to advance patient care.

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LIST OF PUBLICATIONS

International scientific publications

Dijkstra BM, Schoonhoven L, **Felten-Barentsz KM**, van der Valk MJM, van der Hoeven JG, Vloet LCM. Health care providers' perceptions of family participation in essential care in the intensive care unit: A qualitative study. Nursing Critical Care. 2024 Oct 21.

Dijkstra BM, **Felten-Barentsz KM**, van der Valk MJM, van der Hoeven JG, Schoonhoven L, Vloet LCM. Exploring patients' and relatives' needs and perceptions regarding family participation in essential care in the intensive care unit: A qualitative study. Intensive & critical care nursing. 2023 Dec.

Dijkstra BM, **Felten-Barentsz KM**, van der Valk MJM, Pelgrim T, van der Hoeven JG, Schoonhoven L, Ebben RHA, Vloet LCM. Family participation in essential care activities in adult intensive care units: An integrative review of interventions and outcomes. Journal of clinical nursing. 2023 Sep.

Felten-Barentsz KM, Sommers J, van Oorsouw R, Klooster E, Koenders N, van Heusden-Scholtalbers L, Ormel HL, Werkman MS, Hulzebos EHJ, van der Wees PJ, van der Schaaf M, Hoogeboom TJ.
On "Recommendations for Hospital-Based Physical Therapists Managing Patients with COVID-19."
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Felten-Barentsz KM, van Oorsouw R, Haans AJC, Staal JB, van der Hoeven JG, Nijhuis-van der Sanden MGW. Patient views regarding the impact of hydrotherapy on critically ill ventilated patients: A qualitative exploration study. Journal of Critical Care. 2018 Dec.

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National publications/media

Werkgroeplid: Vertegenwoordiger Nederlandse Vereniging voor Ziekenhuis Fysiotherapie (NVZF). KNGF-standpunt: Fysiotherapie bij COVID-19. Aanbevelingen voor fysiotherapeutisch handelen in de eerste lijn. Koninklijk Nederlands Genootschap voor Fysiotherapie (KNGF). Versie 3.0. Maart 2022.

Harm Ormel, **Karin Felten-Barentsz**, Juultje Sommers, Thomas Hoogeboom. Aanbevelingen voor fysiotherapeutisch handelen tijdens de ziekenhuisopname: KNGF-standpunt Fysiotherapie bij COVID-19. FysioPraxis. Versie 1.0 Maart 2020. Versie 2.0 April 2020. Versie 3.0 Nov 2021.

Fysiotherapeuten krijgen hulp van Radboudumc bij behandeling coronapatiënten

Protocol voor corona-revalidatie van Deventer fysiotherapeuten gaat de wereld over

Fysiotherapeuten Radboudumc maken revalidatieplan voor coronapatiënten

Fysiotherapeuten bereiden zich met spoed voor op intensieve behandeling coronapatiënten

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Awards and grants

Anna Reynvaan Praktijkprijs 2020. HAN Health project 'PICS is niet niks': familieparticipatie op Intensive Care (IC). Mei 2020. (Gesprekskaart helpt bij voorkomen problemen na opname Intensive Care (han.nl))

Nomination RIHS Societal Impact Award 2020. "Recommendations for physiotherapy management of patients hospitalized with COVID-19". Pitch March 2020.

Subsidie innovatieprojecten Revalidatie Radboudumc. Inzet van een patiëntgebonden oefenbox voor oefentherapie van de bovenste extremiteit bij patiënten opgenomen op de Intensive Care (IC). €5000. Dec 2019.

Research profile

oRCiD: 0000-0001-5155-7384
Publons: H-7866-2018

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RIHS PORTFOLIO

Department: Rehabilitation-Physiotherapy
PhD period: 01/09/2017 – 01/09/2024
PhD Supervisor(s): Prof. dr. Philip van der Wees, Prof. dr. Hans van der Hoeven
PhD Co-supervisor(s): Dr. Thomas Hoogeboom, Dr. Lilian Vloet

Training activities	Hours
Courses	15.00
- RIHS - Introduction course for PhD candidates (2018)	8.00
- Course qualitative research HAN (2019)	4.00
- Course Literature Reviews HAN (2019)	8.00
- Informal training to write a practice guideline (2020)	
- Radboudumc - eBROK course (for Radboudumc researchers working with human subjects) (2021)	26.00
- RU - Effective Writing Strategies (2021)	75.00
- Radboudumc - Scientific integrity (2022)	20.00
- Basis course qualitative research (2022)	16.00
Seminars	
- Learning network meetings focus on HAN Health (2017-2020)	18.00
- Radboud Research Rounds (2017-2024)	20.00
- Research meetings physiotherapy scientists (2017-2024)	60.00
- Research meetings LAIZ HAN (2018-2024)	60.00
- Promovendi meetings Paramedical sciences (2017-2024)	15.00
Conferences	
- NExCOB symposium: ‘Globaal en lokaal spierversterken.’. Oral presentation and workshop (2017)	8.00
- Invitational Conference HAN ‘Samenwerken in keten acute zorg’. Oral presentation and workshop (2018)	4.00
- NVZF congres: ‘Ademspiertraining en vroegmobilisatie tijdens weaning: casuïstiekbespreking’. Oral presentation (2018)	8.00
- REZ symposium. ‘Vroegmobilisatie & ademspiertraining’. Oral presentation (2018)	4.00
- Day of the Physiotherapist 2018. Poster presentation (2018)	8.00
- Symposium HAN Health. Oral presentation (2019)	8.00
- Symposium ‘Beweeg mee’ Isala kliniek Zwolle. ‘Vroeg mobilisatie & ademspiertraining’ Oral presentation (2019)	4.00
- 7th European Conference on Weaning and Rehabilitation in Critically ill Patients, Amsterdam. Oral- and poster presentation (2019)	16.00
- PhD retreat 2019. Oral presentation (2019)	16.00
- MONITOR-IC symposium. (2020)	8.00
- 5th European Congress of the ER-WCPT on Physiotherapy Education. Poster presentation (2020)	4.00
- PhD retreat 2021. Oral presentation (2021)	16.00
- WCF-day Scientific College of Physiotherapy. (2018, 2019, 2021, 2024)	24.00
- Day of the Physiotherapist 2022. Oral presentation (2022)	8.00
- WEAN symposium. Oral presentation (2023)	8.00

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Teaching activities	
Lecturing	
- Workshop ‘Hydrotherapy in hospitals’ EWAC Medical (2019)	8.00
- COVID-19 webinar netwerk Nijmegen eo 1e lijn (2020)	3.00
- Webinar Physical Therapists Managing Patients with COVID-19 (2020, 2021)	4.00
- CME online course for Physical Therapists Managing Patients with COVID-19 (2022)	20.00
- Radboud Health Academy, course for ICU nurses (2022-2024)	20.00
Supervision of internships / other	
- Supervision Master student Clinical Health Sciences Utrecht University (2018)	48.00
- Supervision Bachelor HBO-V students: Quality project (2019)	20.00
Total	**612.00**

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DANKWOORD

Mijn promotie heeft een langere looptijd gehad dan gebruikelijk. Dit proefschrift is tot stand gekomen omdat dat ik mijn ervaringen uit de praktijk wil vertalen naar de wetenschap en ik wil deze ervaringen (inter)nationaal met mijn beroepsgroep delen. Het voelt hierdoor ook een beetje als een soort 'levenswerk'. Dat ik dit werk kan bundelen in dit proefschrift, daar ben ik veel mensen dankbaar voor. Een aantal wil ik in het bijzonder noemen.

Frank Hofmans, bij jou startte mijn 'loopbaan' bij het Radboudumc. Jij was mijn stagebegeleider en nam mij mee naar de Intensive Care en de traumatologie afdeling. De complexiteit in een academisch ziekenhuis in de acute zorg spraken mij enorm aan. Mijn plannen om dierfysiotherapeut te worden gooide ik overboord. En ik probeerde ervoor te zorgen dat ik niet meer weg hoefde uit deze setting, door ook mijn afstudeerproject en afstudeerstage bij jou op de traumatologie te lopen. Bedankt dat je mij enthousiast hebt gemaakt voor deze specialistische fysiotherapeutische zorg, die we in het ziekenhuis leveren. Ik heb nog steeds het idee, dat ik mijn eigen droombaan in het Radboudumc kan creëren, onder andere door mijn werk wetenschappelijk te kunnen onderbouwen. Hiervoor wil ik met name **Marlou Essink** bedanken: jij zorgde ervoor dat ik de ruimte kreeg om hier invulling aan te geven. En ik voelde me enorm gesteund om mijn eigen pad te bewandelen.

Prof. Dr. Leo Heunks, onze samenwerking startte in het 'weaningsteam'. Jij wist mij te inspireren en probeerde mij te prikkelen met onderzoeksvragen, die direct betrekking hadden op de praktijk. Als eerste ziekenhuis wereldwijd gingen wij met beademde patiënten 'te water'. Deze unieke vorm van vroeg mobilisatie op de IC moesten wij dan ook wereldkundig maken in de vorm van een haalbaarheidsstudie. Jij nam hierbij het voortouw, maar gaf mij al snel de touwtjes in handen, zodat ik onze praktijkervaringen wetenschappelijk kon onderbouwen. Heel erg bedankt voor deze kans, want dit smaakte naar meer!

Prof. Dr. Ria Nijhuis-van der Sanden, jij was destijds hoogleraar paramedische wetenschappen en regelmatig zat ik met jou aan tafel om te sparren over mijn onderzoeksplannen. Jij omarmde mijn enthousiasme en zette mij aan het denken om mijn plannen in te bedden in een 'voorgenomen promotie'. Samen met jou stelde ik hiervoor een 'promotieteam' op en bedachten we nieuwe onderzoeksvragen, die relevant voor de praktijk waren. Jij maakte maandelijks tijd voor mij vrij om de voortgang te bespreken. Ik merkte echter, dat ons enthousiasme niet voldoende was om daadwerkelijk meters te maken met het wetenschappelijk onderzoek en ik vond het vervelend dat ik je steeds moest teleurstellen: 'Ik wil wel, maar ik kan

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niet'. Gelukkig bleef jij mijn ambities steunen, en vonden we de financiële middelen waarmee we mijn onderzoeksplannen wel voort konden zetten en de 'voorgenomen promotie' een heus promotietraject werd. Bedankt voor jouw steun, je professionele en kritische begeleiding en de vele inspirerende overlegmomenten.

De financiële middelen kwamen onder andere bij het **lectoraat Acute Intensieve Zorg** van de Hogeschool van Arnhem en Nijmegen (HAN) vandaan. **Dr. Lilian Vloet**, bedankt dat jij het project 'familieparticipatie op de IC' multidisciplinair wilde aanvliegen en op zoek was naar een paramedicus die het onderzoeksteam kon versterken. Vanaf de eerste dag dat ik aan dit project mocht werken voelde ik mij erg welkom in jouw team en heb ik veel ervaring mogen opdoen en veel kennis kunnen delen. Fijn dat het ook mogelijkheden bood om familieparticipatie binnen mijn eigen professie te onderzoeken. **Boukje en Margriet**, jullie wil ik specifiek bedanken voor de fijne samenwerking binnen het project familieparticipatie. Het doorspitten en beoordelen van de literatuur, het transcriberen en analyseren van vele interviews, het publiceren van een aantal artikelen, het verzorgen van workshops en het ontwikkelen van de 'praatkaart' zijn werkzaamheden die we toch mooi samen hebben volbracht.

Dr. Thomas Hoogeboom, jij sloot aan bij mijn onderzoeksoverleg bij IQ-Healthcare en benaderde mij met de woorden: 'Jou ken ik nog niet, maar we moeten elkaar zeker leren kennen'. Ik was aan het pionieren op onderzoeksgebied als fysiotherapeut uit de praktijk met een passie voor de IC en jij kon me de juiste ondersteuning bieden op wetenschappelijk gebied. Jouw ervaring, jouw visie op ons vak, jouw uitgebreide kennis op epidemiologisch gebied en jouw enthousiasme werkten erg inspirerend voor mij. Tijdens de 1^e golf van de COVID-19 pandemie schoof jij mij tijdens een online onderzoeksoverleg naar voren: 'We gaan het werkveld ondersteunen met aanbevelingen voor de fysiotherapeutische behandeling van patiënten met COVID-19, die opgenomen zijn in het ziekenhuis en Karin is hierbij in de lead!'. Dit resulteerde uiteindelijk in nationale en internationale richtlijnen, waarbij zelfs de pers om de hoek kwam kijken. Bedankt voor het vertrouwen in mij en jouw ondersteuning tijdens mijn hele promotietraject.

Prof. Dr. Philip van der Wees, jij werd de nieuwe hoogleraar paramedische wetenschappen en nam hiermee het stokje van Ria over. Daarmee werd je ook mijn promotor. Bij jouw inauguratie zette jij jouw onderzoekslijnen uit en vond ik het erg fijn om te horen dat 'mijn onderzoekslijn' daar ook een plekje in had gekregen. Jouw begeleiding tijdens mijn verdere promotietraject heb ik als zeer prettig ervaren: laagdrempelig in contact, altijd een snelle concrete reactie, zeer deskundige begeleiding. Ook 'out-of-the-box' durven denken, de input tijdens jaargesprekken en creatief zijn in het creëren van financiële middelen voor mijn onderzoek, zijn hierbij voor mij waardevol geweest. Dank hiervoor.

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Prof. Dr. Hans van der Hoeven, als toenmalig hoofd van de Intensive Care in het Radboudumc, hebben wij u benaderd om deel uit te maken van mijn promotieteam. Tijdens een van onze eerste gesprekken benoemde u de grote meerwaarde van fysiotherapie op de IC, maar was u ook kritisch: welke patiënt op de IC is het meest gebaat bij intensieve fysiotherapie? En hoe ga je het effect van fysiotherapie aantonen bij deze complexe, heterogene populatie met zeer veel beïnvloedbare factoren? Deze kritische blik van een inhoudelijk deskundig specialist op de IC was precies de begeleiding die ik nodig had. U heeft mij tot het einde scherp gehouden en mij geleerd mijn onderzoeksresultaten te omarmen, te bekritiseren, hier de juiste conclusies uit te trekken en weer te vertalen naar de meerwaarde voor de praktijk. Enorm bedankt dat u als een van mijn promotoren deel heeft uitgemaakt van mijn promotieteam.

Ik herinner me mijn eerste patiënt op de IC als de dag van gisteren. Het was een jonge dame met een septisch beeld bij een ontsteking van haar externe fixateuren. We hadden een gezamenlijk hobby: paardrijden. Ik wilde er alles aan doen om ervoor te zorgen dat ze ooit weer zou kunnen paardrijden. En ik besefte dat haar revalidatie al op de IC startte en dat ik haar daarbij wilde helpen. Hierbij wil ik alle **patiënten op de IC en hun naasten** bedanken dat ik hen mocht begeleiden tijdens het starten van het revalidatietraject. Samen hebben we hele bijzondere, intense en aangrijpende momenten meegemaakt. Daarbij heb ik speciale dank voor degenen die deel wilden nemen aan een van de studies uit dit proefschrift of mijn studies hebben ondersteund met prachtig beeldmateriaal.

Op de IC werk je niet alleen, ik voel mij als een vis in het water in dit multidisciplinaire team. Daarom wil het gehele **multidisciplinaire team op de IC**, van intensivist tot zorghulp, bedanken voor de prettige, professionele, specialistische en menselijke zorg die wij samen leveren. Specifiek waardeer ik de samenwerking op de ‘neuro-IC’, op de ‘ontwenningsunit’ en de extra intensieve samenwerking tijdens de COVID-19 pandemie. Ook de mogelijkheden om samen op te gaan in wetenschappelijk onderzoek, het innoveren en implementeren, bood mij unieke kansen om de (fysiotherapeutische) zorg voor patiënt en naasten op de IC te verbeteren. Dank hiervoor.

Marcel Rekers, bedankt voor de mooie, sprekende en indringende beelden die jij hebt weten vast te leggen vanuit de ogen van zowel IC-verpleegkundige als fotograaf.

Medeauteurs en collega fysiotherapeuten uit den landen, wat is het belangrijk om samen op te gaan in het onderzoek op de IC en in het ziekenhuis. Heel bijzonder dat we elkaar nog beter wisten te vinden in tijden van nood, tijdens de COVID-19 pandemie, waardoor onze samenwerking werd geïntensiveerd. Ideeën en initiatieven werden gedeeld in de ‘Covid19 rehab groep’ groeps-app en zorgden ook voor zeer

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buikbare input bij het (her)schrijven van het ‘KNGF-standpunt Fysiotherapie bij COVID-19’. Bedankt voor het meedenken en meeschrijven bij de studies van dit proefschrift. Heel fijn dat we elkaar nu met vaste regelmaat (online) treffen, om (werk)ervaring uit te wisselen of om te discussiëren over de fysiotherapeutische zorg op de IC.

Team fysiotherapie-revalidatie, samen geven wij invulling aan de fysiotherapie in het Radboudumc. Vanuit de verschillende units met ieder zijn eigen expertise, verzorgen wij ook de fysiotherapie op de IC. Waardevol is, dat we hierin de samenwerking opzoeken, elkaar kunnen aanspreken en maandelijks overleggen over de zorg op de IC. Bedankt voor jullie input in de verschillende onderzoeken uit dit proefschrift. **Roel van Oorsouw**, ik vind het fijn dat jij mijn ‘partner in crime’ bent op het gebied van wetenschappelijk onderzoek bij fysiotherapie op de IC. Samen sparren, onderwijs verzorgen, onderzoek uitvoeren en presenteren werkt voor mij erg stimulerend. Bedankt ook voor jouw hulp bij het verwezenlijken van dit proefschrift.

Collega’s uit unit 4, door jullie ga ik elke keer weer met veel plezier naar mijn werk. De humor, de kritische blik en de loyaliteit in ons team zorgen voor een fijne werksfeer. Maar ook buiten het werk om geniet ik van onze Sinterklaasavondjes, BBQ’s en teamuitjes. Bedankt dat jullie mij al die jaren gesteund hebben, door mij af en toe wat minder vol te plannen in de kliniek, zodat ik mijn onderzoekstaken kon vervullen.

Daphne, we weten natuurlijk dat 1983 een heel mooi bouwjaar is en dat schept al een band. We hebben hierdoor op dezelfde tijd de opleiding fysiotherapie gevolgd in Nijmegen, maar we leerden elkaar pas echt goed kennen als collega’s van de toenmalige afdeling fysiotherapie van het neuro-sensorisch cluster in het Radboudumc. Met jou kan je goed lachen, maar ook serieuze gesprekken voeren. Ik ben gecharmeerd van jouw checklists en jouw manier van doorpakken, die goed van pas zijn gekomen tijdens het organiseren van mijn promotie. Bedankt voor al jouw hulp als paranimf en de tijd die je hiervoor wil vrijmaken.

Veerle, samen gingen we op in het onderzoek over familieparticipatie op de IC tijdens de fysiotherapie. Jouw precieze manier van werken, het vooruitlopen op deadlines en jouw rustige karakter zijn hierbij erg waardevol geweest. Ik vond het wel jammer (maar heel begrijpelijk) dat je het onderzoek op de IC los ging laten, voor een promotietraject op ademhaling bij de ziekte van Parkinson. Heel bijzonder dat je mij hebt gevraagd om jouw paranimf te zijn en vind het heel fijn dat ik jou ook terug kon vragen. Hierdoor heeft onze fijne en succesvolle samenwerking als collega’s en onderzoekers toch nog een vervolg gekregen. Bedankt voor jouw steun tijdens mijn promotie.

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Lieve vriendinnen: **Marloes, Margot, Nancy, Sandra en Suzanne**. Bedankt dat jullie er altijd voor mij zijn. Onze vriendschappen zijn zeer waardevol voor mij en ondanks onze drukke levens proberen we elkaar regelmatig te zien op feestjes, verjaardagen, maar ook om gezellig een kopje thee met elkaar te drinken.

Lieve broertjes **Maarten en Sander**, zwager **Leo** en schoonzussen **Marjolein, Lieke en Hatta**. Fijn dat we elkaar regelmatig zien en leuke dingen met elkaar en de kinderen ondernemen. Ik geniet van deze familiebijeenkomsten en vind het heel leuk om onze kinderen met elkaar te zien opgroeien. Hopelijk komen er nog veel van deze momenten.

Lieve schoonouders, **Leo en Wilma**. Ik kan me geen betere schoonouders wensen dan jullie! Heel fijn dat we altijd voor elkaar klaar staan en dat jullie ons regelmatig helpen met de kinderen, dat waardeer ik enorm. Jullie zijn heel liefdevol en ik voel me altijd welkom. Gezellig dat ik regelmatig langs kan komen voor een kopje koffie als ik de kinderen naar school heb gebracht, dat geeft me even rust. Dat houden we erin!

Lieve **papa en mama**, jullie hebben mij altijd mijn eigen pad laten bewandelen, af en toe een klein beetje bijgestuurd, maar vooral mij het gevoel gegeven dat jullie in mij geloofden. Jullie hebben mij altijd gesteund in mijn plannen, van het (ver)bouwen van huizen, het krijgen van kinderen, tot aan het realiseren van dit promotietraject. Heel erg fijn en waardevol dat jullie op onze kinderen willen en kunnen passen, ook een keertje extra als dat voor mijn promotie noodzakelijk was. Papa, bedankt dat ik regelmatig met jou heb kunnen sparren over mijn onderzoeken, dat jij het taaltechnisch (en stiekem ook inhoudelijk) wilde corrigeren als ik erom vroeg en ik waardeer jouw bewondering voor mij. Ik ben ook heel trots op jullie!

Lieve **Tom** onze technische uitvinder in spe, lieve **Tessa** onze sociale vrolijke meid en lieve **Mark** onze kleine deugniet en tractorliefhebber. Het moederschap is iets waar ik intens van geniet. Heel waardevol dat de mogelijkheid er is dat ik maar twee dagen in de week werk om er zo voor jullie te kunnen zijn. Een druk bestaan, maar met de juiste structuur komen we een heel eind. We genieten van onze uitstapjes naar Vlissingen, heel fijn om daar met z’n allen uit te waaien: intens geluk!

En dan mijn laatste woorden van dank voor mijn lieve man **Thomas**. Samen bouwden wij letterlijk en figuurlijk aan onze toekomst. We zijn hierbij goed op elkaar ingespeeld en vullen elkaar aan. Ik waardeer jouw doorzettingsvermogen, jouw zorgzaamheid en ik vind het ontzettend fijn dat jij mij nog elke dag verteld hoe leuk je mij vindt. Jij hebt mij alles gegeven waar ik van droomde: een mooi huis en een liefdevol gezin. Bedankt dat ik op jou kan bouwen! Ik hou van jou.

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