



Family participation in physiotherapy-related tasks of critically ill patients: A mixed methods systematic review

L.M.M. van Delft ^{a,*}, K. Valkenet ^a, A.J.C. Slooter ^b, C. Veenhof ^{a,c}

^a Department of Rehabilitation, Physiotherapy Science and Sport, University Medical Center Utrecht Brain Center, Utrecht University, Utrecht, the Netherlands

^b Department of Intensive Care Medicine, University Medical Center Utrecht Brain Center, Utrecht University, Utrecht, the Netherlands

^c Research Group Innovation of Human Movement Care, HU University of Applied Sciences, Utrecht, the Netherlands

ARTICLE INFO

Keywords:

Critical care
Family
Support
Empowerment
Rehabilitation
Physiotherapy

ABSTRACT

Purpose: Providing an overview of studies on family participation in physiotherapy-related tasks of critically ill patients, addressing two research questions (RQ): 1) What are the perceptions of patients, relatives, and staff about family participation in physiotherapy-related tasks? and 2) What are the effects of interventions of family participation in physiotherapy-related tasks?

Material and methods: Qualitative, quantitative and mixed-methods articles were identified using PubMed, Embase and CINAHL. Studies reporting on family participation in physiotherapy-related tasks of adult critically ill patients were included. A convergent segregated approach for mixed-methods reviews was used.

Results: Eighteen articles were included; 13 for RQ1, and 5 for RQ2. The included studies were quantitative, qualitative and mixed-method, including between 8 and 452 participants. The descriptive studies exhibit a general appreciation for involvement of relatives in physiotherapy-related tasks, although most of the studies reported on family involvement in general care and incorporated diverse physiotherapy-related tasks. One study explored the effectiveness of family participation on a rehabilitation outcome and showed that the percentage of patients mobilizing three times a day increased.

Conclusion: Positive attitudes were observed among patients, their relatives and staff towards family participation in physiotherapy-related tasks of critically ill patients. However, limited research has been done into the effect of interventions containing family participation in physiotherapy-related tasks.

© 2020 Elsevier Inc. All rights reserved.

1. Introduction

An admission to the Intensive Care Unit (ICU) can be associated with various complications, including ICU acquired weakness (ICU-AW) and delirium [1–3]. These complications are related to the duration of mechanical ventilation and forced immobility. Prolonged immobility in the ICU can trigger ICU-AW due to various mechanisms including functional denervation resulting from nerve injury caused by sepsis-induced release of cytokines, and disuse atrophy [1,2]. Up to 40% of muscle strength can be lost within the first week of immobilization [4]. Survivors of critical illness often experience long-lasting impairments in physical, cognitive and/or mental health [1,5–7]. Fortunately, several lines of evidence confirmed the benefit of early physiotherapy-related of critically ill patients. Physiotherapy-related interventions (e.g. physiotherapy and mobilization) in the ICU can improve patients' physical function, shorten ICU length of stay, decrease medical complications

and might reduce some adverse psychological effects [1,3,6,8,9]. However, the psychological impact of an ICU admission is not limited to the patients, but appears to affect the mental health of relatives as well. Family members are at high risk of anxiety, posttraumatic stress disorder, depression and complicated grief, which adversely effects quality of life of the whole family [10–17].

The ICU Liberation Bundle is often used in the daily care of critically ill patients; both early mobilization/exercise and family engagement are elements of this bundle [18,19]. There is evidence that involvement of relatives could be beneficial for patients their relatives, and staff [20,21]. Previous studies on family involvement have primarily focused on family needs, involvement and experiences in the broad sense [13,20,22–24]. These studies highlighted the families' desire to be involved in the care of their loved one and their wish that staff considers to give family members a role in the care of their critically ill relative. Family involvement in the ICU mostly involves improving communication and dissemination of information (e.g. physician-family conversations and shared decision making), open family visiting hours, or interventions including family participation in nursing care activities [23,25,26]. Engaging families may enhance psychological wellbeing for both patient and relatives, may decrease the strain of families during a

* Corresponding author at: Department of Rehabilitation, Physiotherapy Science and Sport, UMC Utrecht, Utrecht University, Heidelberglaan 100, Utrecht 3584 CX, the Netherlands.

E-mail address: l.m.m.vandelft@umcutrecht.nl (L.M.M. van Delft).

crisis, and may possibly improve family member's ability to cope with the patient's situation [16,23,27,28]. However, it is not clear what the added values are of family participation at an early stage in the physiotherapy-related process (e.g. early mobilization, exercises). Family involvement in physiotherapy-related tasks could optimize patients' physical function by increasing the frequency and thereby impact of physical activity [24], in addition to the psychological benefits. Physical therapists generally treat patients once per day, between 15 and 45 min, which is fairly short and intense [3,8,29]. In addition, nurses often lack the time to help patients with their exercises or mobilization [30,31]. Since family is not often consulted to assist during physiotherapy while they are present at the bedside, it can be valuable when relatives are involved in physiotherapy-related tasks, resulting in a win-win situation.

Before developing and evaluating the feasibility of an intervention on family participation in physiotherapy-related tasks, it is important to gain insight into possible tasks, and the opinions of patients, their relatives and ICU staff concerning the involvement of family in the physiotherapy care of critically ill patients. Therefore, the aim of this systematic review is to identify, describe, and summarize evidence from studies reporting on family participation in physiotherapy-related tasks in ICU patients. The following two research questions (RQ) were formulated:

- RQ 1: What are the perceptions of patients, their relatives and staff on family participation in physiotherapy-related tasks of critically ill patients?
- RQ 2: What are the effects of interventions involving ICU family participation in physiotherapy-related tasks on patient outcomes, their relatives and/or staff?

2. Material and methods

2.1. Design

This mixed methods systematic review included qualitative, quantitative, and mixed method studies reporting on family participation in physiotherapy-related tasks in the ICU. The review was guided by the steps of the PRISMA statement and the method for mixed methods review of the Joanna Briggs Institute [32,33]. To ensure transparency of the methods employed, this review was registered at the International Prospective Register of Systematic Reviews (PROSPERO) database (number CRD42020146739).

2.2. Search strategy, eligibility criteria and study selection

Up to 5 November 2020 eligible qualitative, quantitative and mixed methods articles were identified using the electronic databases PubMed, Embase and CINAHL. The search strategy for the electronic databases included the terms and keywords within the following domains "family" or "relatives" or "visitors to patients" AND "participation" or "involvement" or "empowerment" AND "Intensive Care (Unit)" or "critical care" or "critical(ly) ill". In the search strategy were also some excluding terms included: neonatal ICU, paediatric ICU and palliative care. The search was limited to full text studies published in English in the last twenty years (1999–2020), as family participation is fairly new and ICU physiotherapy increased in recent years. The complete search strategy can be found in Appendix 1.

Articles were eligible for inclusion if they concerned family participation on the ICU, contained one or more physiotherapy-related tasks (i.e. passive/active exercises such as range of motion, foot flexion, limb exercises, positioning, mobilization/transfer/ambulation, or respiratory techniques/breathing training) as part of their family participation intervention and/or reported results on relative involvement in physiotherapist-related tasks (see Appendix 1 for all included physical

rehabilitation activities). Relatives were not necessarily limited to family members, but could also be other persons with a close relationship to the patient. Studies solely focusing on family involvement in conversations, medical decisions, ICU rounds, nursing tasks (e.g. washing, bathing, feeding), occupational tasks, or studies on family visiting hours, were excluded. Other exclusion criteria were articles focusing on end-of-life care, palliative care or terminal care; and reviews, theses, letters to the editor, editorials and opinion articles.

For the selection of articles, the steps of the PRISMA statement were followed [33]. The search strategy was used to obtain possible eligible articles. In addition, reference tracking was performed by the primary author based on previously published reviews and all finally included articles. Further, articles were screened for eligibility on title and abstract independently by two researchers (LvD and CV). When one or both authors estimated that the article was eligible for inclusion, a full paper copy of the article was obtained. The eligibility of these full text articles were discussed until consensus was reached between the researchers.

2.3. Assessment of methodological quality

The methodological quality of the included articles was assessed independently by two researchers (LvD and KV). The ratings were then compared and discussed in a quality appraisal meeting. The methodological quality was assessed using the Mixed Method Appraisal Tool (MMAT), a universally utilized, validated tool for mixed methods systematic reviews [34–36]. The MMAT has been designed to appraise the methodological quality of studies for a complex systematic review that contains mixed, qualitative, and quantitative (subdivided into three subdomains: randomized controlled, nonrandomized, and descriptive) studies. Methodological quality was assessed using the relevant criterion for each method of investigation. For this study the user guide Version 2018 was followed [35] and therefore an overall quality score was not reported. However, higher quality studies were those that satisfied more criteria. A detailed presentation of the ratings per study is provided in Appendix 3. Studies were included in this review regardless of their methodological quality to minimize the risk of study selection bias.

2.4. Data extraction

Data was extracted from included studies by the primary author. The included articles were divided per research question. Per research question a table with extracted data and quality assessment results was made. Data extraction included the objective, design and setting, participants, intervention, main findings of significance to the review questions and methodological quality.

2.5. Data syntheses and integration

This review followed the convergent segregated approach to synthesis and integration, according to the Joanna Briggs Institute methodology for mixed methods systematic reviews [32]. In this study the findings were analysed separately for the two research questions. Per research question a separate quantitative and qualitative analysis was done, where the aim was to synthesize the results where possible. Both quantitative and qualitative findings are presented in narrative form, including tables to aid in data presentation. For the final integration of the resulting quantitative evidence and qualitative evidence a narrative summary was used.

3. Results

3.1. Study inclusion

Searching the electronic databases yielded a total of 2811 articles. After removal of duplicates, title and abstracts were screened, resulting in 56 studies which were assessed in full text. Additionally, three articles were identified from hand searching. Finally, of the 59 full text articles, 18 studies were included in the review: 13 articles for RQ 1 on the perspectives of patients, relatives and staff [11,21,37-47], and five articles for RQ 2 on the effectiveness of family participation in physiotherapy-related tasks [48-52]. See Fig. 1 for the PRISMA Flow Diagram.

3.2. Characteristics of included studies

The included studies were quantitative studies [11,39,48,49,51,52], mixed methods investigations [21,37,50,53] and qualitative studies [38,40,41,44-47,54]. Most of the studies were conducted in the

United States [38-40,47,48,50-52]. Studies considered staff only [21,39,40,47,53,54], family only [38,44,49-52], or both family and staff [37,41,46]. Two investigations also included patients [11,45], next to family and staff, and one other study focused on patients only [48]. The number of participants included in each study varied between 8 and 452. Studies included for RQ 1 were all descriptive ($n = 13$). Of the intervention studies included for RQ 2, there were four pre-post studies [48,49,51,52] and one mixed methods observational study [50]. An overview of the characteristics of the included publications is presented in Appendix 2.

3.3. Methodological quality

The overall methodological quality of the included studies varied widely. Of the studies included for RQ1, the majority satisfied all applicable MMAT quality criteria, indicating strong study quality [11,38-40,44-47,54]. Three studies had a 'no' response to just one criterion; they had high risk of nonresponse bias [37,53] or provided insufficient

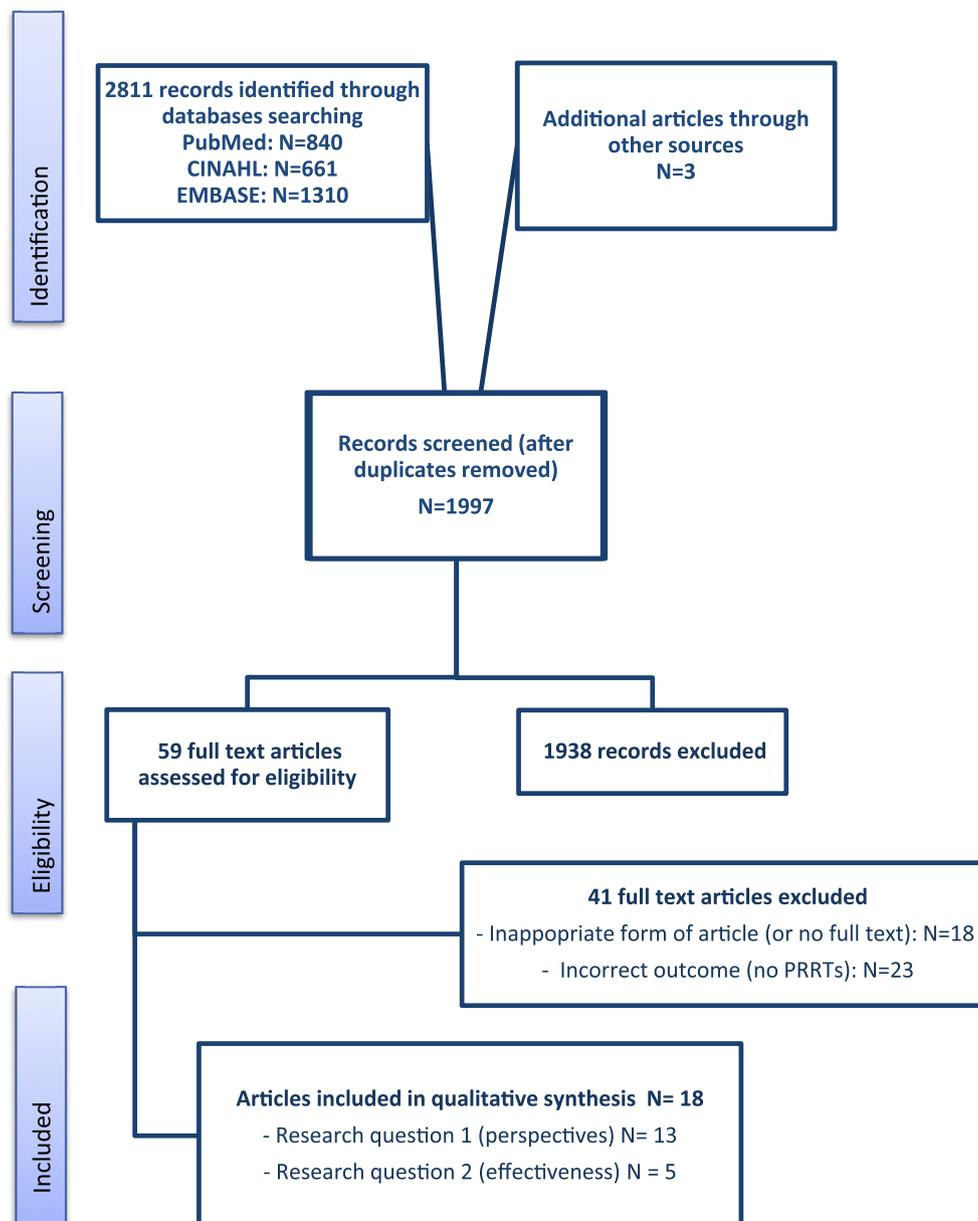


Fig. 1. The PRISMA Flow Diagram.

information about their results (interpretation) and discussion of findings [41]. Only one investigation [21] for RQ 1 had multiple 'no' or 'not reported' responses to the quality criteria; there was insufficient detail in the used method and interpretation and integration of the results. Of the included articles for RQ 2, none of the studies satisfied all criteria. There were issues with the chosen measurements [48,50], samples that were not fully representative of the target population [48,51], risks of nonresponse bias [48,50,51], statistical analysis that were not always appropriate to answer the research question [48,50,51], cofounders which were not accounted for in the analysis [49] and suboptimal integration of the qualitative and quantitative results [50]. Only the studies of Mitchell et al. [49] and Amass et al. [52] met almost all MMAT criteria. The remaining three studies [48,50,51] had many 'no' or 'not reported' responses, and one of these studies even satisfied none of the quality criteria [48]. The individual results of the quality appraisal are reported in Appendix 3.

3.4. Main findings

Most of the included studies described family involvement in (hands-on) bedside care and incorporated physiotherapy-related tasks in their intervention, survey or interviews. Diverse physiotherapy-related activities were reported in the included studies: Range of Motion/passive foot flexion [21,40,50,51], (limb) exercises (passive/active) [21,37,41,44,49], turning/positioning the patient [11,37–39,44,52,53] and/or mobilization/ambulation/transfer [11,39,45–48,54]. Two studies reported family participation in breathing exercises as a possible task [44,54]. In addition to these physiotherapy-related tasks, massage was mentioned very often as activity that families could perform [11,38–40,44,45,49–53]. See Fig. 2 for an overview of all reported activities (total and per research question).

3.4.1. Perspectives of patients, their relatives and staff on family participation in physiotherapy-related related tasks

3.4.1.1. Qualitative evidence. Qualitative evidence about the perceptions of patients, their relatives and staff on family participation in physiotherapy-related tasks was reported in nine studies [21,38,40,41,44–47,54]. Diverse major and minor themes were identified in these studies. Due to the many different themes regarding

physiotherapy-related tasks, the qualitative findings could not be synthesized. An overview of the individual data is outlined in Table 1. Most of the studies mentioned passive tasks (i.e. massage, passive exercises, range of motion) as an optional activity for relatives to participate in [21,38,40,41,44,45]. More active activities that were named as acceptable for relatives to be involved in were helping with turning/repositioning of the patient [38,44], assisting with mobilization, walking and transfers [45–47,54], breathing exercises [44,54], and active limb exercises [44]. In addition to the content of family participation, two studies addressed why family participation in physiotherapy-related tasks can be of added value; reducing workload, and reassuring and comfort the patient [21,44]. One study reported factors which nurses have to take into account when they involve relatives in activities; functional factors (e.g. physical strength), psychological and emotional factors (e.g. willingness and emotional stability), knowledge (e.g. learning ability) [40] (see Table 1).

3.4.1.2. Quantitative evidence. Quantitative findings from surveys, presented from the perspective of patients, relatives and staff could be merged and are presented in Table 2. The overall findings demonstrates a general appreciation for the value of family participation in physiotherapy care of critically ill patients; in total, 77% of the patients favoured participation of their family in their care [11]. The other 23% of the patients who were not favourable to participation of their family in their care gave diverse reasons (see Table 2). In addition, 85 to 97% of the family members were willing to participate [11,37], and between 90 and 100% of the staff agreed with the concept [10,18,33]. One study [11] demonstrated that, of 97 family members who were willing to participate in care, only 14 (13.8%) relatives spontaneously provided or asked staff to help them participate.

Concerning physiotherapy-related tasks especially, four studies showed that passive activities (e.g. passive exercises and massage) were the most favourable tasks by both patients, their relatives and staff [11,37,39,53]; between 70 and 90% of all patients, relatives and staff were favourable to family participation in these activities. More active activities, i.e. changing a patients' position, mobilization out of bed and ambulation, were received less positive. In total, 66% of the patients [11] and 71 to 77% of the relatives [11,37] agreed with family participating in changing the patients' position or in the transfer to a chair. Besides, between 40% (nurses) to 81% (physicians) of the staff were favourable for families helping in these activities [11,37,39,53].

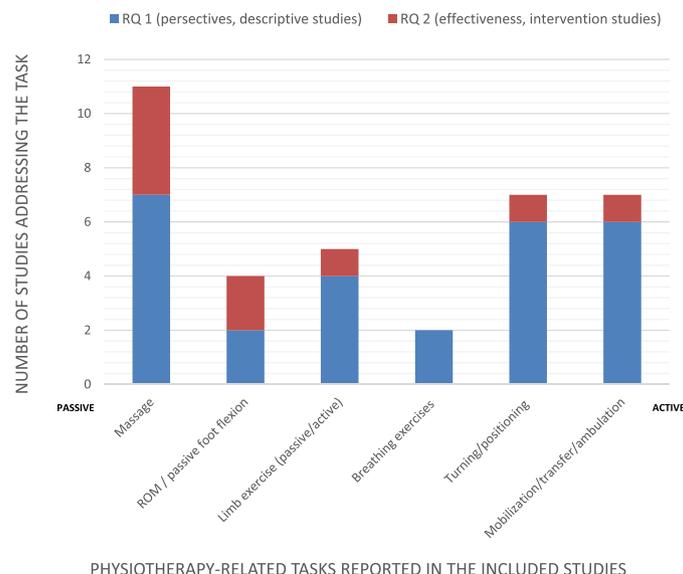


Fig. 2. Number of studies addressing types of Physiotherapy-related tasks.

Table 1
Qualitative evidence: major themes, minor themes and quotations.

Study	Major theme(s)	Minor theme(s)	Quotations
Hetland et al. 2018 [40]	Assessment for involving family in patient care	(1) Extent to which nurses encourage families to participate in care (2) Determining which family caregivers should be involved in patient care • Functional factors (e.g. physical strength) • Psychological and emotional factors (e.g. willingness, emotional stability) • Knowledge (e.g. learning ability) (3) Choosing methods of family involvement • Basic care activities such as range of motion	Not applicable
Kean et al. 2014 [21]	Workload	Not applicable	“Performing cares such ROM (range of movement), exercises , enabled me more time to attend other duties”
Beer, de et al. 2017 [41]	Togetherness & Partnership	Doing things together, involving families in care	“We allow them to do passive exercises, touch, to do thing that can stimulate the patient”
McAdam et al. 2008 [38]	Voluntary caregiver	Actual care that families want to provide: massaging, repositioning and assisting with turning	Not applicable
Engström et al. 2011 [42]	Realising the significance of relatives' involvement	Relatives participated by helping the staff and being of practical use in care: such as helping the patient with breathing training, transfer or mobilization .	Not applicable
Wong et al. 2019 [44]	Families as part of the team Family roles during recovery	Wanting the best: families performed some care tasks because they believed the staff may have been unavailable; massage, repositioning Providing psychosocial and emotional care: activities as massage were used to reassure and comfort the patient Supporting the patient's treatment: participation in massage, repositioning and helping with passive limb exercises . Their breathing exercises and active limb exercises to maintain muscle strength	Not applicable
Kydonaki et al. 2019 [45]	Perceived factors for enacting patient and family centered care	Care activities that families, patients and nurses found acceptable for relatives to be involved in: – Massage – Assist with mobilization when extubated	Not applicable
Jafarpoor et al. 2020 [46]	Non-Agreed Involvement in Clinical Care	Family Willingness to Participate Compulsory Care Assignment	“If you ask me, the nurse did a big favor and called me, inviting me to come in to help the patient walk ... I think it is really great if they let us do some things for our patients. In this way, patients get better and we ourselves also feel good.” “When I am examining patients or performing physiotherapy , family members stand next to me. They can thus learn such procedures . As I provide care for another patient, family members can also do and repeat the same on their patients for 10 min and I have the chance and also more time to take care of other patients ... this means using resources at hand.”
Hamilton et al. 2020 [47]	Engagement	Family engagement	“Involving relatives in developing written material about treatment in the ICU. Relatives take care in daily procedures, e.g. mobilization , shaving, brushing teeth etc.” “Involving the family to actively participate in patient care, especially with mobilization and physiotherapy . Speaking and counselling family members in addition to the daily briefing at any time possible when they are with the patient”.

3.4.2. The effects of interventions reporting family participation in physiotherapy-related tasks on patients, their relatives, or staff

3.4.2.1. *Quantitative evidence.* Five intervention studies were included for this research question (see Table 3) [48–52]. Four studies implemented and evaluated an intervention which existed of a combination of activities for family participation including some, mostly passive, physiotherapy-related tasks (i.e. passive foot flexion, range of motion, massage and/or assist with turning/positioning), using diverse clinical outcomes, all targeting relatives (psychological outcomes) [49–52]. One study investigated the effect of family participation in an early

mobilization protocol, with the amount of patients' daily mobilization sessions as clinical outcome [48]. None of the studies included clinical outcomes of patients' physical functioning. In addition, most studies did not demonstrate any process outcomes. Only the study of Mitchell et al. [49] provided some process data; they showed that physical care was provided by 81 (82%) family members. Of the provided tasks, massage was the most common activity provided by relatives; 29% of all activities done. The clinical outcomes showed that relatives who participated in the intervention group experienced more family centered care; they reported higher scores on the family-centered care scale ($p < .001$) than the control group. Another comparable

Table 2
Quantitative evidence: engagement of relatives in rehabilitation related tasks.

	ICU staff	Relatives	Patients
Overall	<ul style="list-style-type: none"> It was generally believed by nurses that family participation can benefit both the patient and relatives, if relatives can sometimes assist in selected minor caring activities: the majority ranked 10 or 11 (out of 11) [43] 96% of the staff agreed with concept of involving families in physical care [37] 98% of the nurses considered the concept of inviting family members to be a part of the patients' care should be part of usual care [21] ICU staff were favourable to family participation in at least one activity was 100% for physicians, 90% for nurses, and 94% for nursing assistants [11] 81% of the nurses considered having family provide some patient care had minimal effect on their workload [21] 	<ul style="list-style-type: none"> 85% of the relatives wanted to be involved in physical care of the patient [37] 97% of the family members were willing to participate in care [11] 13.8% of the family members spontaneously provided patient care or asked the ICU staff to help them participate in care [11] 	<ul style="list-style-type: none"> 77% of the patients were favourable to participation in care of family members. Reasons of the 23% of the patients not wanting care from their families were: desire to preserve their image (70%), unwillingness to be assisted (50%), unwillingness to cause embarrassment (70%), nurses are better skilled (60%), safety (40%), physical modesty (50%) [11]
Passive exercises	<ul style="list-style-type: none"> 88.8% of the nurses agreed with passive limb exercises [37] 	<ul style="list-style-type: none"> 88.2% of the relatives agreed with passive limb exercises [37] 	
Massage	<ul style="list-style-type: none"> Rehabilitation care activities offered to families: around 70% of the nurses offered massages [36] 70% (physician) to 90% (nursing assistant) of the staff were favourable to family participation by preventing pressure sores by featuring massages [11] Massage the hands, feet, arms and legs of the patient: the majority of nurses ranked 9 or more (out of 11) [43] 	<ul style="list-style-type: none"> 75% was favourable to family participation by preventing pressure sores by featuring massages [11] Of the 13.8% of the family members spontaneously provided care, they all (100%) participated in massages [11] 	<ul style="list-style-type: none"> 70% of the patients was favourable to family participation by preventing pressure sores by featuring massages [11]
Positioning, turning	<ul style="list-style-type: none"> 55.5% of the nurses agreed with helping with turning and positioning the patient [37] Rehabilitation care activities offered to families: turning (>50% of the nurses) [39] 50% (nurse) to 81% (physician) of the staff were favourable of families helping staff change the position in bed or transfer to a chair [11] Family assisting the nurse in positioning of the patient: most of the nurses ranked 6 or more (out of 11) [43] 	<ul style="list-style-type: none"> 70.6% of the relatives agreed with helping with turning and positioning the patient [37] 77% was favourable of families helping change the position in bed or transfer to a chair [11] Of the 13.8% of the family members spontaneously provided care, they participated in helping staff change the patients position (64%) [11] 	<ul style="list-style-type: none"> 66% of the patients was favourable of families helping staff change the position in bed or transfer to a chair [11]
Mobilization, transfer, ambulation	<ul style="list-style-type: none"> Rehabilitation care activities offered to families: ambulation, <40% of the nurses [39] 50% (nurse) to 81% (physician) of the staff were favourable of families helping staff change the position in bed or transfer to a chair [11] 	<ul style="list-style-type: none"> 77% was favourable of families helping staff change the position in bed or transfer to a chair [11] 	<ul style="list-style-type: none"> 66% of the patients was favourable of families helping staff change the position in bed or transfer to a chair [11]

intervention study [52] showed that relatives symptoms of PTSD were significantly less frequent, 90 days after ICU discharge, after implementation of the intervention. In addition, the nurses were positive about the intervention; they reported that the quality of care improved, that the intervention did not interfere with care of the patient and that it improved communication with family. However, this study did also not report information about the effect of the physiotherapy-related tasks specifically. Furthermore, the study of Skoog et al. [51] demonstrated that the overall mean state anxiety levels of 56 relatives decreased after the intervention ($p = .001$). However, this study did not use a control group and no results were reported on the effect of the physiotherapy related outcomes specifically. Lastly, the study of Rukstele et al. [48] showed that the proportion of patients receiving three mobilization sessions per day changed from 66% to 94% following the initiative to involve family in this task [48].

3.5. Integration of evidence

Most of the included studies described family involvement in general hands-on bedside care and incorporated diverse aspects of physiotherapy care, which varied from passive activities to more active activities (see Fig. 2). The results exhibit a general appreciation for involvement of relatives in physiotherapy-related tasks, however information about the effectiveness of physiotherapy-related tasks specifically is very limited.

3.5.1.1. Passive physiotherapy-related tasks (massage, range of motion/passive foot flexion, passive exercises). The results of the syntheses support family participation in massage and range of motion (or passive foot flexion), as this was found feasible by most patients, relatives and staff [11,38–40,44,45,50,51,53]. In addition, massage was the most common activity of the intervention provided by families [49]. However, no results were reported on the effect of these activities specifically, and none of the intervention studies satisfied all MMAT quality criteria. Passive (limb) exercises was also often reported to be feasible [21,37,41,44]; one study [37] demonstrated that more than 88% of the nurses and relatives agreed with passive limb exercises. However, in an intervention study, only 1% of all performed activities concerned limb exercises [49], and no results were reported about the effect of these exercises.

3.5.1.2. Active physiotherapy-related tasks (active exercises, positioning, mobilization, transfer and ambulation). Active physiotherapy-related tasks that were only named in descriptive studies as possible tasks for relatives were active limb exercises (to maintain strength) [44] and breathing exercises [44,54]. The activities helping with repositioning in bed and mobilization out of bed were, in addition to positive descriptive results [11,37–39,44,46,47,53], also part of interventions for family participation. Repositioning was included in one intervention study, but no results were reported about this task [52]. Regarding mobilization, one study [48] investigated the effect of families participating in early mobilization, showing a change from 66 to 94% in the amount of

Table 3
Quantitative evidence of intervention studies.

Study	Intervention	Participants	Overall results: process and clinical outcomes	Results on physiotherapy-related tasks
Rukstele et al. 2013 [49]	Involving family in the early mobilization protocol (daily nursing mobilization): invite, educate, support	Patients	<i>Process outcomes:</i> N.A. <i>Clinical outcomes:</i> At baseline 66% of patients received 3 activity/ mobilization sessions per day. After the intervention period, this increased to 94%	See overall results
Mitchell et al. 2009 [49]	Combination of activities for family participation, tailored to the family, nurses helped family to participate in care (e.g. massage and limb exercises)	Relatives	<i>Process outcomes:</i> Care was provided by 82% of the family members <i>Clinical outcomes:</i> Family in the intervention group perceived higher scores on the overall family-centered care scale ($p < .001$), and for the subscales respect, support and collaboration ($p < .001$)	<i>Process outcomes:</i> - Most common care activity provided by families was massage, 29% of all activities -Limb exercises was done 1% of all activities N.A.
Davidson et al. 2010 [50]	Family Support Program: personalized instructions on helpful visiting activities and provision of family visiting kits (including description of activities to perform at the bedside as desired; e.g. cognitive activities, passive foot flexion, range of motion, massage)	Relatives	<i>Process outcomes:</i> N.A. <i>Clinical outcomes:</i> N.A. <i>Other:</i> the Family Support Program evaluation showed that all items offered within the intervention were found helpful to some family members, however exact numbers and activities were not demonstrated.	N.A.
Skoog et al. 2016 [51]	Facilitated Sense Making intervention card (FSM): teach and assist family in activities they can perform for their ill loved one (e.g. passive foot flexion, range of motion, hand massage)	Relatives	<i>Process outcomes:</i> N.A. <i>Clinical outcomes:</i> The overall mean state anxiety levels decreased significantly after FSM ($P = .001$). The overall mean trait anxiety levels before and after FSM did not differ significantly ($P = .46$)	N.A.
Amass et al. 2020 [52]	Family Care Rituals (FRC); information booklet containing 7 domains in which relatives may participate: e.g. massage and assist with turning and positioning.	Multiple: relatives and nurses	<i>Process outcomes:</i> N.A. <i>Clinical outcomes:</i> <ul style="list-style-type: none"> – Relatives: Symptoms of PTSD, 90 days after ICU discharge, were significant higher pre-intervention than post-intervention (39.2% vs 27.1%, $p = .046$). No significant difference in symptoms of depression, anxiety or satisfaction score. – Nurses: Statement quality of care was improved; post intervention scored 3.98 out of 5, statement that the intervention did not interfere with care of the patient scored 4.42 out of 5, statement that intervention improved communication with family scored 4 out of 5. 	N.A.

patients receiving three mobilization sessions a day, however, this article met none of the MMAT quality criteria.

4. Discussion

We evaluated the evidence for family participation in physiotherapy-related tasks of critically ill patients. In summary, this review supports that positive attitudes exist among patients, relatives and staff towards the participation of family members in physiotherapy-related care. However, limited research has been done to the feasibility and effectiveness of interventions focusing on participation in (active) physiotherapy-related tasks.

Concerning the perceptions of patients, their relatives and staff about family participation in physiotherapy-related tasks, studies mostly focussed on the opinion of ICU staff and families of critically ill patients. In 2001, the Institute of Medicine strongly recommended that healthcare delivery systems should become patient-centered rather than clinician- or disease-centered, with treatment recommendations and decision making tailored to patients' preferences and beliefs [55]. Patient-centered care is the practice of caring for patients in ways that are meaningful and valuable to the individual patient. It includes listening to, informing and involving patients in their care [55–57]. Since patients-centered care is becoming more important on ICU's as well [56,57], patients' opinions about family involvement in the ICU care are crucial and should be investigated in more detail before developing an intervention in this field.

Interesting is that most relatives are willing to participate in care, while only a few spontaneously provide or ask staff to help them

participate [11]. This result emphasizes the potential of interventions to offer family participation in a structured way. Also interesting is the difference between nurses and physicians concerning family helping with mobilization out of bed; overall nurses are less positive towards it. Possibly, nurses limit family participation in mobilization care because of their concern about patient safety like the possible occurrence of adverse events such as removal of invasive devices during mobilization, but also lack of time or concern about interacting with families may play a role [11,40,58]. This could also explain why more passive activities (e.g. massage, range of motion, passive exercises) are more favourable than mobilization. In addition to the safety of these tasks, a reason might be the fact that the passive tasks could be performed in all (awake, sedated and intubated) critically ill patients.

Unfortunately involving families in physiotherapy-related tasks raises a number of concerns and possible barriers for the feasibility. Barriers reported in studies focusing on family participation in ICU patient care are patient safety, family competence, and responsibility [40,44,55,56]. Involving relatives in physical activities may increase the risk for adverse events [55]. Not all relatives are capable of participating because their emotional, psychological or physical capacity. Staff members must assess this properly and families should receive structured information, training before participation, and evaluation moments [40,44,45,55,56]. Staff members believe it is important to maintain control over the situation and patient, since they are ultimately responsible, which is challenging in clinical practice [40,45]. Besides patients' safety, patients' privacy have to be taken seriously, since ICU patients are often not wearing clothes [56]. However, this may be more a barrier when relatives are participating in nursing tasks such

as washing. In addition, sometimes relatives and/or patients may want to maintain their normal relationship as partners. Not everyone wants to participate in the care. Type of relationship, younger age, non-European descent and previous ICU admission may influence the willingness to participate [40,55,56].

Evidence on the feasibility and effectiveness of interventions focusing on family participation in physiotherapy-related tasks is still low. Physiotherapy-related tasks are not often included, and active tasks even less, in interventions towards ICU family participation. The intervention studies included in this review (RQ 2) were all pre-post or observational designs, no randomized trials, and did not satisfy all criteria for methodological quality. In addition, none of the studies included outcomes of patients' physical functioning, most studies focused on relatives. Besides, most of them did not demonstrate any process outcomes (e.g. how many times did relatives participate), which makes the interpretation of the clinical outcomes difficult.

Since both early mobilization, exercise and family engagement are part of the ICU Liberation Bundle, the combination is an important and promising topic, resulting in need for further research in this area. To increase the impact of patients' physical therapy by family participation, it is important to investigate the feasibility of more active physiotherapy-related tasks. Involving relatives in interventions such as active limb exercises, and thereby increase the frequency of physical activity during the day, may promote patients' physical recovery. If the aim is reducing adverse psychological effects only (patient or family), then tasks such as massage or passive range of motion, which are interventions without direct evidence on improving patient physical performance, may be sufficient.

The goal of the intervention, and clinical outcomes, should be clearly defined before selecting the activities for relatives to participate in. To improve patients' physical functioning during and after critical illness, relatives should be willing to participate in helping with active exercises and/or mobilization. Therefore, it is of high importance that future studies should collect process outcomes in addition to clinical outcomes: do relatives want to participate in (active) physiotherapy-related tasks, and if yes, how many times are they participating (e.g. amount of moments that they are doing exercises with the patient), and what tasks are they participating in? Since there is not much literature focusing on this specific topic, a proper pilot study is needed to thoroughly evaluate the feasibility before conducting a large-scale implementation and effectiveness study. When family participation in (active) physiotherapy-related tasks of critically ill patients seems feasible, the effectiveness need to be evaluated on clinical outcomes such as patient's physical functioning.

A strength of this review is that it is first review regarding family participation in physiotherapy-related care of critically ill patients. Previous reviews on ICU family participation focussed on family involvement in the broad way (e.g. nursing tasks, medical decisions, communication) [20,22–24]. Another strength is that it included both qualitative, quantitative and mixed-method studies, and involved patients, relatives and staff to provide new evidence about family participation in physiotherapy-related tasks. Since the included studies did not focus purely on physiotherapy-related tasks, it was difficult to extract physiotherapy-related results specifically, which might be seen as a limitation of this review.

5. Conclusions

In conclusion, the findings of this review support our hypothesis that it is worth investigating if it is feasible to involve family in physiotherapy-related tasks. Patients, relatives and staff appear to have a positive view towards the participation of relatives in the physiotherapy care of critically ill patients, but currently limited research has been done to the feasibility and effectiveness of interventions focusing on family participation in physiotherapy-related tasks. Before conducting a proper pilot study, it is important to listen carefully to

the needs of staff, family and patients, to develop the intervention accordingly.

Ethical approval and consent to participate

The study protocol was assessed and approved by the medical ethics committee of the UMC Utrecht (study protocol number 16-250).

Consent for publication

Not applicable

Funding

Not applicable.

Declaration of Competing Interest

The Author(s) declare(s) that there is no conflict of interest.

Acknowledgements

Not applicable.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.jcrr.2020.11.014>.

References

- [1] Hermans G, Van den Berghe G. Clinical review: intensive care unit acquired weakness. *Crit Care* 2015;19:274.
- [2] Piva S, Fagoni N, Latronico N. Intensive care unit-acquired weakness: unanswered questions and targets for future research. *F1000Res* 2019;8.
- [3] Pandharipande PP, Ely EW, Arora RC, Balas MC, Boustani MA, La Calle GH, et al. The intensive care delirium research agenda: a multinational, interprofessional perspective. *Intensive Care Med* 2017;43(9):1329–39.
- [4] Parry SM, Puthucherry ZA. The impact of extended bed rest on the musculoskeletal system in the critical care environment. *Extrem Physiol Med* 2015;4:16.
- [5] Rawal G, Yadav S, Kumar R. Post-intensive care syndrome: an overview. *J Transl Int Med* 2017;5(2):90–2.
- [6] Parker A, Sricharoenchai T, Needham DM. Early rehabilitation in the intensive care unit: preventing physical and mental health impairments. *Curr Phys Med Rehabil Rep* 2013;1(4):307–14.
- [7] Fuke R, Hifumi T, Kondo Y, Hatakeyama J, Takei T, Yamakawa K, et al. Early rehabilitation to prevent postintensive care syndrome in patients with critical illness: a systematic review and meta-analysis. *BMJ Open* 2018;8(5):e019998.
- [8] Needham DM, Korupolu R, Zanni JM, Pradhan P, Colantuoni E, Palmer JB, et al. Early physical medicine and rehabilitation for patients with acute respiratory failure: a quality improvement project. *Arch Phys Med Rehabil* 2010;91(4):536–42.
- [9] Reid JC, Unger J, McCaskell D, Childerose L, Zorko DJ, Kho ME. Physical rehabilitation interventions in the intensive care unit: a scoping review of 117 studies. *J Intensive Care* 2018;6:80.
- [10] Alflheim HB, Hofso K, Smastuen MC, Toien K, Rosseland LA, Rustoen T. Post-traumatic stress symptoms in family caregivers of intensive care unit patients: a longitudinal study. *Intensive Crit Care Nurs* 2019;50:5–10.
- [11] Garrouste-Orgeas M, Willems V, Timsit JF, Diaw F, Brochon S, Vesin A, et al. Opinions of families, staff, and patients about family participation in care in intensive care units. *J Crit Care* 2010;25(4):634–40.
- [12] Pochard F, Azoulay E, Chevret S, Lemaire F, Hubert P, Canoui P, et al. Symptoms of anxiety and depression in family members of intensive care unit patients: ethical hypothesis regarding decision-making capacity. *Crit Care Med* 2001 Oct;29(10):1893–7.
- [13] Kynoch K, Chang A, Coyer F, McArdle A. Developing a model of factors that influence meeting the needs of family with a relative in ICU. *Int J Nurs Pract* 2019;25(1):e12693.
- [14] Jennifer L, McAdam R, Dorrie K, Fontaine R, Douglas B, White M, et al. Psychological Symptoms of Family Members of High-Risk Intensive Care Unit Patients. *Am J Crit Care* 2012;21(6):386–94.
- [15] Davidson JE. Family-centered care: meeting the needs of patients' families and helping families adapt to critical illness. *Crit Care Nurse* 2009;29(3):28–34 [quiz 5].
- [16] Davidson JE, Jones C, Bienvenu OJ. Family response to critical illness: postintensive care syndrome-family. *Crit Care Med* 2012;40(2):618–24.

- [17] Bench S, Cornish J, Xyrichis A. Intensive care discharge summaries for general practice staff: a focus group study. *Br J Gen Pract* 2016;66(653):e904–12.
- [18] EW E. The ABCDEF bundle: science and philosophy of how ICU liberation serves patients and families. *Crit Care Med* 2017;45(2):321–30.
- [19] Pun BT, Barnes-Daly MA, et al. Caring for critically ill patients with the ABCDEF bundle: results of the ICU liberation collaborative in over 15,000 adults. *Crit Care Med* 2019;47(1):3–14. <https://doi.org/10.1097/CCM.0000000000003482>.
- [20] Al-Mutairi AS, Plummer V, O'Brien A, Clerehan R. Family needs and involvement in the intensive care unit: a literature review. *J Clin Nurs* 2013;22(13–14):1805–17.
- [21] Kean S, Mitchell M. How do intensive care nurses perceive families in intensive care? Insights from the United Kingdom and Australia. *J Clin Nurs* 2014;23(5–6):663–72.
- [22] Liput SA, Kane-Gill SL, Seybert AL, Smithburger PL. A review of the perceptions of healthcare providers and family members toward family involvement in active adult patient care in the ICU. *Crit Care Med* 2016;44(6):1191–7.
- [23] Olding M, McMillan SE, Reeves S, Schmitt MH, Puntillo K, Kitto S. Patient and family involvement in adult critical and intensive care settings: a scoping review. *Health Expect* 2016;19(6):1183–202.
- [24] Haines KJ. Engaging Families in Rehabilitation of People Who Are Critically Ill: An Underutilized Resource *Phys Ther* 2018 Sep;198(9):737–44.
- [25] Mackie BR, Mitchell M, Marshall PA. The impact of interventions that promote family involvement in care on adult acute-care wards: an integrative review. *Collegian* 2018;25(1):131–40.
- [26] Xyrichis A, Fletcher S, Brearley S, Philippou J, Purssell E, Terblanche M, et al. Interventions to promote patients and families' involvement in adult intensive care settings: a protocol for a mixed-method systematic review. *Syst Rev* 2019;8(1):185.
- [27] Koller PA. Family needs and coping strategies during illness crisis. *AACN Clin Issues Crit Care Nurs* 1991 May;2(2):338–45.
- [28] McKiernan M, McCarthy G. Family members' lived experience in the intensive care unit: a phenomenological study. *Intensive Crit Care Nurs* 2010;26(5):254–61.
- [29] Sosnowski K, Lin F, Mitchell ML, White H. Early rehabilitation in the intensive care unit: an integrative literature review. *Aust Crit Care* 2015;28(4):216–25.
- [30] Kim C, Kim S, Yang J, Choi M. Nurses' perceived barriers and educational needs for early mobilisation of critical ill patients. *Aust Crit Care* 2019;32(6):451–7.
- [31] Hoyer EH, Brotman DJ, Chan KS, Needham DM. Barriers to early mobility of hospitalized general medicine patients. *Am J Phys Med Rehabil* 2015;94(4):304–12.
- [32] Lizarondo LSC, Carrier J, Godfrey C, Rieger K, Salmond S, Apostolo J, et al. Chapter 8: Mixed methods systematic reviews. *Joanna Briggs Institute Reviewer's Manual*. : The Joanna Briggs Institute 2017. Available from: <https://reviewersmanual.joannabriggs.org/>; 2017.
- [33] Moher DLA, Tetzlaff J, Altman DG. The PRISMA Group. Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLoS Med* 2009;6(7).
- [34] Pluye P, Gagnon MP, Griffiths F. A scoring system for appraising mixed methods research, and concomitantly appraising qualitative, quantitative and mixed methods primary studies in mixed studies reviews. *Int J Nurs Stud* 2009;46:529–46.
- [35] Hong QN, Fàbregues S, Bartlett G, Boardman F, Cargo M, et al. Mixed methods appraisal tool (MMAT), version 2018. Registration of copyright (#1148552), Canadian Intellectual Property Office, Industry Canada. 2018. Available from: <http://mixedmethodsappraisaltoolpublic.pbworks.com/>.
- [36] Pace R, Pluye P, Bartlett G. Testing the reliability and efficiency of the pilot Mixed Methods Appraisal Tool (MMAT) for systematic mixed studies review. *Int J Nurs Stud* 2012;49:47–53.
- [37] Hammond F. Involving families in care within the intensive care environment: a descriptive survey. *Intensive Crit Care Nurs* 1995 Oct;11(5):256–64.
- [38] McAdam JL, Arai S, Puntillo KA. Unrecognized contributions of families in the intensive care unit. *Intensive Care Med* 2008;34(6):1097–101.
- [39] Hetland B, Hickman R, McAndrew N, Daly B. Factors influencing active family engagement in care among critical care nurses. *AACN Adv Crit Care* 2017;28(2):160–70.
- [40] Hetland B, McAndrew N, Perazzo J, Hickman R. A qualitative study of factors that influence active family involvement with patient care in the ICU: survey of critical care nurses. *Intensive Crit Care Nurs* 2018;44:67–75.
- [41] de Beer J, Brysiewicz P. The conceptualization of family care during critical illness in KwaZulu-Natal. *South Africa Health SA Gesondheid* 2017;22:20–7.
- [42] Engström B, Uusitalo A, Engström. Relatives' involvement in nursing care: a qualitative study describing critical care nurses' experiences. *Intensive Crit Care Nurs* 2011;27(1):1–9.
- [43] Agård AS, Maindal HT. Interacting with relatives in intensive care unit. Nurses' perceptions of a challenging task. *Nurs Crit Care* 2009;14(5):264–72.
- [44] Wong P, Redley B, Digby R, Correira A, Bucknall T. Families' perspectives of participation in patient care in an adult intensive care unit: a qualitative study. *Aust Crit Care* 2020;33(4):317–25.
- [45] Kydonaki K, Kean S, Tocher J. Family Involvement in Intensive care: a qualitative exploration of critically ill patients, their families and critical care nurses (INpuT study). *J Clin Nurs* 2019;29(7–8):1115–28.
- [46] Jafarpoor H, Vasli P, Manoochehri H. How is family involved in clinical care and decision-making in intensive care units? A qualitative study. *Contemp Nurse* 2020:1–15.
- [47] Hamilton R, Kleinpell R, Lipman J, Davidson JE. International facilitators and barriers to family engagement in the ICU: results of a qualitative analysis. *J Crit Care* 2020;58:72–7.
- [48] Rukstele CD, Gagnon MM. Making strides in preventing ICU-acquired weakness: involving family in early progressive mobility. *Crit Care Nurs Q* 2013;36(1):141–7.
- [49] Mitchell M, Chaboyer W, Burmeister E, Foster M. Positive effects of a nursing intervention on family-centered care in adult critical care. *Am J Crit Care* 2009;18(6):543–52 [quiz 53].
- [50] Davidson JE, Daly BJ, Agan D, Brady NR, Higgins PA. Facilitated sensemaking: a feasibility study for the provision of a family support program in the intensive care unit. *Crit Care Nurs Q* 2010 Apr-Jun;33(2):177–89.
- [51] Skoog M, Milner KA, Gatti-Petito J, Dintyala K. The impact of family engagement on anxiety levels in a cardiothoracic intensive care unit. *Crit Care Nurse* 2016;36(2):84–9.
- [52] Amass TH, Villa G, Omahony S, Badger JM, McFadden R, Walsh T, et al. Family care rituals in the ICU to reduce symptoms of post-traumatic stress disorder in family members—a Multicenter, multinational, before-and-after intervention trial. *Crit Care Med* 2020;48(2):176–84.
- [53] Agård AS, Maindal HT. Interacting with relatives in intensive care unit. Nurses' perceptions of a challenging task. *Nurs Crit Care* 2009 Sep-Oct;14(5):264–72.
- [54] Engstrom B, Uusitalo A, Engstrom A. Relatives' involvement in nursing care: a qualitative study describing critical care nurses' experiences. *Intensive Crit Care Nurs* 2011;27(1):1–9.
- [55] Medicine Io. Crossing the quality chasm: A new health system for the 21st century. Washington, DC: National Academies Press; 2001.
- [56] Davidson JE, Powers K, Hedayat KM, Tieszen M, Kon AA, Shepard E, et al. Clinical practice guidelines for support of the family in the patient-centered intensive care unit: American College of Critical Care Medicine Task Force 2004–2005. *Crit Care Med* 2007;35(2):605–22.
- [57] Davidson JE, Aslakson RA, Long AC, Puntillo KA, Kross EK, Hart J, et al. Guidelines for family-Centered Care in the Neonatal, Pediatric, and adult ICU. *Crit Care Med* 2017;45(1):103–28.
- [58] Hodgson CL, Capell E, Tipping CJ. Early mobilization of patients in intensive care: organization, communication and safety factors that influence translation into clinical practice. *Crit Care* 2018;22(1):77.