


REVIEW

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

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Abstract

Aims and 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 6698 records were screened, and 322 full-text studies were assessed. Seven studies were included, describing an intervention to support family participation. Four studies had a pretest-posttest design, two were pilot feasibility studies and one was observational. The 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,

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Funding information

Nederlandse Organisatie voor
Wetenschappelijk Onderzoek

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.

Relevance to clinical practice: The review contributed further insight into interventions aiming at family participation in essential care activities in the intensive care unit and their outcomes.

No patient or public contribution: Neither patients nor public were involved.

KEYWORDS

essential nursing care, family-centred care, family participation, intensive care unit, intervention, relatives

1 | INTRODUCTION

Intensive care unit (ICU) stay and treatment is stressful for both adult patients and relatives (Jeziarska, 2014). 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) (Geense et al., 2021; Harvey & Davidson, 2016; Needham et al., 2012). 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 (Davidson et al., 2012). Family participation in essential care activities may benefit both patients and relatives (Abdul Halain et al., 2022; Davidson et al., 2012; McAdam et al., 2008).

Family participation in adult ICU patient care is receiving increasing attention from both researchers and healthcare providers, though terms, concepts and approaches differ (Al-Mutair et al., 2013; Davidson et al., 2017; Frivold et al., 2022; Heydari et al., 2020; Liput et al., 2016; Mitchell et al., 2016; Olding et al., 2016). Previous reviews have focused on the broader concepts of family involvement (Xyrichis et al., 2021), possible barriers for Patient and Family Centered Care (PFCC) (Kiwanuka et al., 2019) and the effect of PFCC interventions, including ethics, diary or information/educational interventions (Bohart et al., 2022). 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' (Olding et al., 2016). 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. (2016) most active form 'contribution to care' corresponds to family participation in essential patient care activities. Relatives may participate in activities, including communication, amusement/distraction, comfort, personal care, breathing, mobilisation and

What does this paper contribute to the wider global community?

- Relatives and patients may benefit from family participation in essential care activities.
- Most included studies lacked a detailed description of the applied intervention, hindering replication by critical care nurses.
- Family participation in the intensive care unit is associated with a reduction of mental health symptoms of anxiety and PTSD.
- Use of additional outcome measures may match better with the possible effects of family participation in essential care activities in the intensive care unit.

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 (Dijkstra et al., 2022, 2023; Kitson et al., 2010; Wyskiel, Weeks, et al., 2015).

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 the 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 (Bleijenberg et al., 2018). Recent guidelines for Family-Centred Care (FCC) (Davidson et al., 2017) 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, individualised to their situation (Dijkstra et al., 2022).

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

2 | METHODS

We performed an integrative review to allow the inclusion of both quantitative and qualitative studies (Whittemore & Knafel, 2005). This review was conducted in compliance with the Cochrane Handbook for Systematic Reviews of Interventions (Higgins & Green, 2011), and reported in concordance with the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) statement (Moher et al., 2009) (Supplementary file 1: Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist). A description of the design, search strategy, study selection procedure, quality assessment, data extraction and data synthesis have been published in an earlier review (Dijkstra et al., 2022).

2.1 | 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 S1.

2.2 | 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, resuscitation or invasive procedures. In addition, 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.

2.3 | Quality assessment

The quality of studies was assessed with a tool developed by Kmet et al. (2004). 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) 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.

2.4 | 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.

(Hoffmann et al., 2014) by two researchers (BD, LV). The checklist contains 12 items to describe an intervention 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 (Hoffmann et al., 2014).

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.

3 | RESULTS

3.1 | Review statistics

After removal of duplicates, 6698 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 S2.

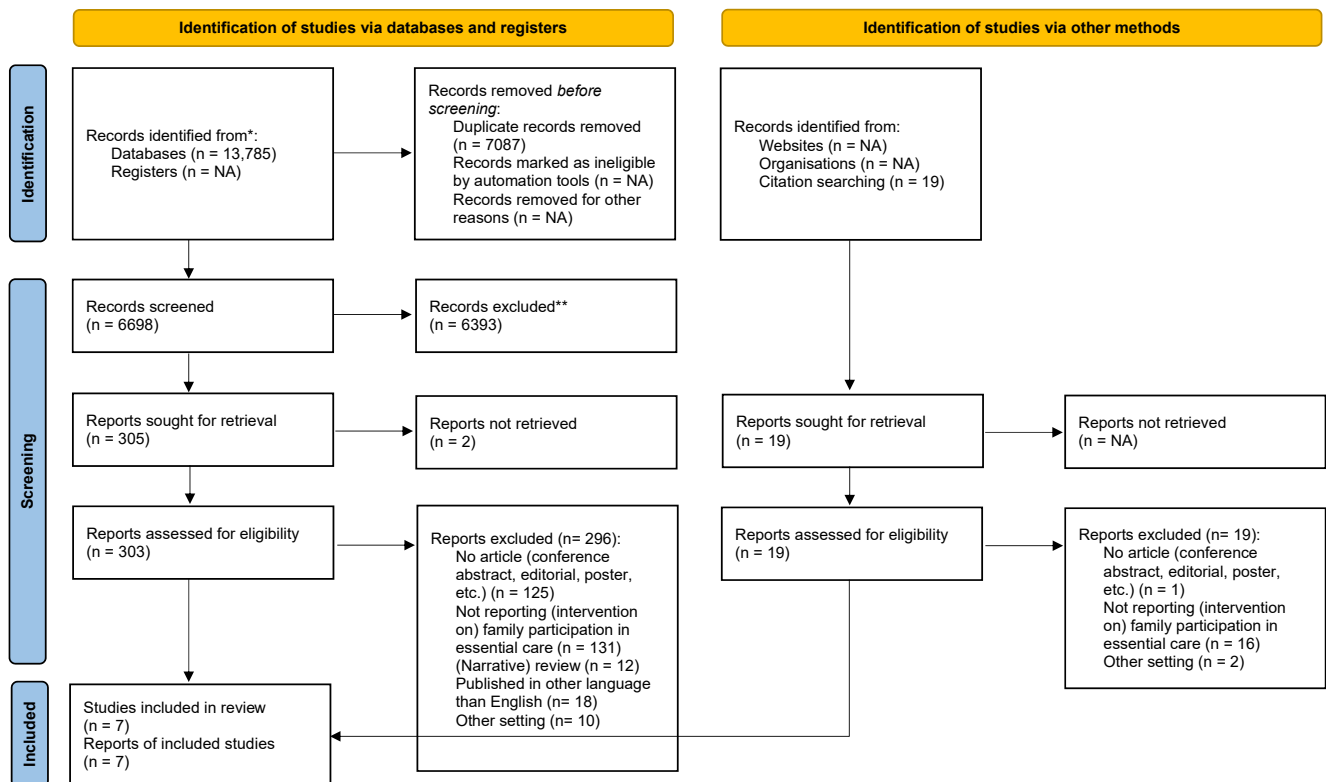
3.2 | Study characteristics

Study characteristics, including aim, design, country, setting, population and method are presented in Table 1. The studies were conducted in the United States ($n=4$, Amass et al., 2020; Davidson et al., 2010; Skoog et al., 2016; Wyskiel, Chang, et al., 2015), Australia ($n=2$, Mitchell et al., 2009, 2017), Argentina ($n=1$, Loudet et al., 2017) and Italy ($n=1$; this study was conducted in both Italy

and the USA, Amass et al., 2020). Most studies addressed relatives ($n=6$, Amass et al., 2020; Davidson et al., 2010; Mitchell et al., 2009, 2017; Skoog et al., 2016; Wyskiel, Chang, et al., 2015); some included patients ($n=3$, Amass et al., 2020; Loudet et al., 2017; Mitchell et al., 2017) and/or ICU nurses or ICU healthcare providers ($n=2$, Mitchell et al., 2017; Wyskiel, Chang, et al., 2015). Four studies had a pretest-posttest design (Amass et al., 2020; Loudet et al., 2017; Mitchell et al., 2009; Skoog et al., 2016), two were pilot feasibility studies (Davidson et al., 2010; Mitchell et al., 2017) and one was a prospective observational study (Wyskiel, Chang, et al., 2015). Three studies were multicenter studies (Amass et al., 2020; Mitchell et al., 2009; Wyskiel, Chang, et al., 2015), four were mono-center studies (Davidson et al., 2010; Loudet et al., 2017; Mitchell et al., 2017; Skoog et al., 2016).

3.3 | 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 (Amass et al., 2020; Loudet et al., 2017; Mitchell et al., 2009, 2017; Skoog et al., 2016; Wyskiel, Chang, et al., 2015). The majority also provided



*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. *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. [Colour figure can be viewed at wileyonlinelibrary.com]

TABLE 1 Characteristics of the intervention studies ($n=7$).

First 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
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.

TABLE 2 Quality of the intervention studies (n=7). [Colour Table can be viewed at wileyonlinelibrary.com]

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?	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)
Amass (2020) Italy/USA	+	+	+	±	N/A	N/A	N/A	+	+	+	+	-	+	±	0.82
Davidson (2010) USA	±	±	±	±	N/A	N/A	N/A	±	+	±	-	N/A	±	±	0.50
Loudet (2017) Argentina	+	+	+	±	N/A	N/A	N/A	+	+	+	+	-	+	+	0.86
Mitchell (2009) Australia	+	+	+	+	-	-	-	±	+	+	+	±	+	+	0.71
Mitchell (2017) Australia	+	+	+	+	+	-	-	±	N/A	+	+	+	±	±	0.73
Skoog (2016) USA	+	±	±	+	N/A	N/A	N/A	+	+	+	+	N/A	+	±	0.77
Wyskiel (2015) USA	+	±	±	±	N/A	N/A	N/A	±	+	±	-	N/A	+	±	

Note: ⊕, Yes; ±, Partial; ⊖, No.

Abbreviations: N/A: not applicable.

sufficient information on the design and method of subject selection (Amass et al., 2020; Loudet et al., 2017; Mitchell et al., 2009, 2017). Three studies reported sufficiently on subject characteristics (Mitchell et al., 2009, 2017; Skoog et al., 2016). Outcome measures were well defined in three studies (Amass et al., 2020; Loudet et al., 2017; Skoog et al., 2016), the others scored partial on this item (Davidson et al., 2010; Mitchell et al., 2009, 2017; Wyskiel, Chang, et al., 2015). Most studies described appropriate analytic methods (Amass et al., 2020; Loudet et al., 2017; Mitchell et al., 2009, 2017; Skoog et al., 2016) and results in sufficient detail (Amass et al., 2020; Loudet et al., 2017; Mitchell et al., 2009; Skoog et al., 2016; Wyskiel, Chang, et al., 2015). Two studies reported conclusions supported by the results (Loudet et al., 2017; Mitchell et al., 2009), the others scored partial on this item (Amass et al., 2020; Davidson et al., 2010; Mitchell et al., 2017; Skoog et al., 2016; Wyskiel, Chang, et al., 2015).

3.4 | Interventions

Seven studies described an intervention to support family participation (Amass et al., 2020; Davidson et al., 2010; Loudet et al., 2017; Mitchell et al., 2009, 2017; Skoog et al., 2016; Wyskiel, Chang, et al., 2015). Five studies offered relatives various possible essential care activities to participate in (Amass et al., 2020; Davidson et al., 2010; Mitchell et al., 2009; Skoog et al., 2016; Wyskiel, Chang, et al., 2015), such as hair care, passive limb exercises and assisting with repositioning, aiming to support relatives.

Davidson et al. (2010) developed a Family Supportive Program using the 'Facilitated Sense Making model', providing relatives instructions for participation. Skoog et al. (2016) 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. (2010), relatives were provided with family visiting kits, containing a family workbook, cognitive recovery tools, personal care items and information on relevant

websites. They also received a personalised 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 (e.g. 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 (Davidson et al., 2010).

In the study of Skoog et al. (2016), 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 (Skoog et al., 2016).

In the study of Amass et al. (2020) 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 (e.g. 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' (Amass et al., 2020).

In the study of Mitchell et al. (2009) ICU nurses helped relatives to participate in combinations of essential care activities, such as hair combing, hand massage and bathing, after negotiation between ICU

TABLE 3 Description of intervention according to TIDieR items. [Colour Table can be viewed at wileyonlinelibrary.com]

First author (year) country	Item 1 <i>brief name</i>	Item 2 <i>why</i>	Item 3 <i>what</i> (<i>materials</i>)	Item 4 <i>what</i> (<i>procedures</i>)	Item 5 <i>who</i> <i>provided</i>
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'	Researcher, without further description
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	Personalised 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	Clinical nurse specialist (investigator)
Loudet	+	+	-	+	+

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)
⊕	⊕	⊕	⊖	N/A	N/A	N/A
-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 ($p < .05$ 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	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
Face-to-face at bedside 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	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

(Continues)

TABLE 3 (Continued)

First author (year) country	Item 1 brief name	Item 2 why	Item 3 what (materials)	Item 4 what (procedures)	Item 5 who provided
(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 communication 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	'Family prevention bundle': ICU staff
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	ICU nurses, after instruction about the project, and their role to support relatives
Mitchell	+	+	+	+	+
(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	Research nurse (bachelor degree and post graduate qualification in critical care nursing)

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': training from ICU staff -No further description	14-bed medical-surgical ICU within a university-affiliated hospital	'Family prevention bundle': for a minimum of 2h per day, twice a day, 7 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 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	+	+
Face-to-face at bedside 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

(Continues)

TABLE 3 (Continued)

First author (year) country	Item 1 brief name	Item 2 why	Item 3 what (materials)	Item 4 what (procedures)	Item 5 who provided
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	Advanced practice nurse in cardiology department
Wyskiel	+	+	+	-	-
(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	ICU nurses, no further description of their background, expertise or specific training

Note: +, Yes; +, Partial; -, No.

Abbreviations: N/A: not applicable; FIM: family involvement menu; FSM: facilitated sense making; PTSD: Post-Traumatic Stress Disorder; PU: pressure ulcer.

nurses and relatives, taking the patients' condition and context into consideration. Use of possible materials is not described (Mitchell et al., 2009).

In the study of Wyskiel, Chang, et al. (2015), 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. (2017) and Loudet et al. (2017) had a more specific aim: to reduce delirium and the incidence and severity of pressure ulcers in ICU patients.

In the study of Mitchell et al. (2017), 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 the patient (where, why, day, date, and time); (2) to speak about current family events and reminisce on events of known interest to the patient and (3) check that patient had glasses on and hearing aids in (if applicable). Relatives were asked to fill in data collection slips (Mitchell et al., 2017).

In the study of Loudet et al. (2017), 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 pressure ulcer assessment, treatment, monitoring, registration and communication. One component was the 'family prevention bundle' with the involvement of relatives, after training from ICU staff. Relatives performed pre-specified, limited activities, including daily skin monitoring for new lesion detection

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)
+	+	+	-	N/A	N/A	N/A
Face-to-face at bedside 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
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

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 (Loudet et al., 2017).

Assessment of all interventions, using the TIDieR framework (Hoffmann et al., 2014) (see Table 3) showed several limitations. Only Mitchell et al. (2017) provided sufficient detail using the TIDieR framework. Five interventions endorsed FCC, by promoting family involvement and participation (Davidson et al., 2010; Mitchell et al., 2009, 2017; Skoog et al., 2016; Wyskiel, Chang, et al., 2015). One study was grounded in the new midrange nursing theory 'Facilitated Sensemaking' (Davidson et al., 2010). 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 (Amass et al., 2020; Loudet et al., 2017; Mitchell et al., 2009; Wyskiel, Chang, et al., 2015). One study did not report on which professional(s) provided the intervention (Wyskiel, Chang, et al., 2015).

3.5 | Outcomes

Five studies offered relatives to participate in various essential care activities (Amass et al., 2020; Davidson et al., 2010; Mitchell et al., 2009; Skoog et al., 2016; Wyskiel, Chang, et al., 2015), 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 (Amass et al., 2020; Skoog et al., 2016), depression and PTSD (Amass et al., 2020) to satisfaction (Amass et al., 2020). Family participation was associated with a significant reduction in (situational) anxiety scores (Amass et al., 2020, Skoog et al., 2016) and PTSD symptoms in relatives (Amass et al., 2020). Family satisfaction showed a trend toward a positive relationship between family participation and satisfaction (Amass et al., 2020, see Table 4).

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.

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	<p>Primary:</p> <p>1) PTSD at 90 day follow-up post-death/discharge of patient (relatives)</p> <p>Secondary:</p> <p>2) Symptoms of depression and anxiety (at enrolment and at 90 day follow-up) (relatives)</p> <p>3) Family satisfaction at 90 day follow-up (relatives)</p> <p>Other data collected:</p> <p>4) Rituals employed by relatives during both phases (ICU nurses)</p> <p>5) Survey evaluating perception on work flow during intervention phase (ICU nurses)</p>	<p>1) IES-r (22-item)</p> <p>2) HADS (14-item)</p> <p>3) FS-ICU24 (24-item)</p> <p>4) Recording daily observations of prespecified rituals during each shift</p> <p>5) Survey (7-item)</p>	<p>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, $p = .041$))</p> <p>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, $p = .787$)).</p> <p>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 ($p = .068$).</p> <p>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, $p = .519$)).</p> <p>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 ($p = .019$).</p> <p>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, $p = .110$).</p> <p>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, $p = .021$); for 'satisfied with care question', the mean response was not significantly different (adjusted difference –0.08, CI –0.36–0.21, $p = .606$) and for 'had control over the care', the mean adjusted response change was not significant (0.22, CI –0.6–0.51, $p = .124$).</p> <p>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) Significant increase in all categories of care rituals from usual care to intervention phases ($p < .05$ 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%)</p> <p>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).</p>

TABLE 4 (Continued)

1st author (year) country	Outcomes (population/level)	Measurement instruments/questionnaires/tools/operationalisation	Results
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 ($\alpha = .96$). 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.
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 ($p < .05$). A logistic regression model showed that the intervention program acted as a protective factor for the development of PUs ($p = .000$). 2) Number of relatives participating was: Pre-intervention group: 5 (9%); Post-intervention group: 39 (57%); a significant increase in number of relatives participating ($p < .05$).
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 (QR, 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; $p = .002$).

(Continues)

TABLE 4 (Continued)

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%) ($p = .87$). 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.
Skog (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); a non-significant difference ($p = .46$).
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 physical therapy (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.

helpfulness and supportiveness (Davidson et al., 2010), perceived respect, collaboration and support (Mitchell et al., 2009), and perception, comfort level, experience and interest in the implementation of family participation among relatives (Wyskiel, Chang, et al., 2015). Relatives perceived various intervention items as useful and helpful, and personal care supplies were considered most helpful (Davidson et al., 2010). In the study of Mitchell et al. (Mitchell et al., 2009), relatives in the intervention group perceived more respect, collaboration and support. According to Wyskiel, Chang, et al. (2015), 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 (Amass et al., 2020; Mitchell et al., 2009, 2017), or number of relatives participating (Loudet et al., 2017). Amass et al. (2020) found a significant increase in all care activities in the intervention group. In both studies of Mitchell et al., most relatives participated in care activities (Mitchell et al., 2009, 2017), individualised to their situation, with help from the bedside ICU nurse (Mitchell et al., 2009). Relatives did not consider these care activities difficult or onerous, although recording of these activities was low (Mitchell et al., 2017). The number of relatives participating increased significantly in the post-intervention group (Loudet et al., 2017).

Two studies included patient outcomes: pressure ulcers and delirium (Loudet et al., 2017; Mitchell et al., 2017), with the intervention resulting in a significant reduction in the incidence and severity of pressure ulcers (Loudet et al., 2017) but not in the prevalence of delirium (Mitchell et al., 2017).

Three studies measured perceptions from the ICU healthcare providers' perspective, acceptability (Mitchell et al., 2017) and perception (Amass et al., 2020; Wyskiel, Chang, et al., 2015), appropriateness of specific care activities, comfort level, experience and interest in the implementation of family participation were assessed (Wyskiel, Chang, et al., 2015). ICU nurses generally favoured family participation (Mitchell et al., 2017). 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' (Amass et al., 2020). Most ICU healthcare providers supported family participation, and several activities were considered appropriate; however, few actually invited relatives to participate all the time (Wyskiel, Chang, et al., 2015).

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 (Davidson et al., 2010; Mitchell et al., 2017).

4 | 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 (Azoulay et al., 2003; Blom et al., 2013; Liput et al., 2016; McAndrew et al., 2022; Oczkowski et al., 2017; Olding et al., 2016); 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 such as anxiety (Amass et al., 2020; Skoog et al., 2016) and PTSD (Amass et al., 2020). Zante et al. (2020) 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 (Zante et al., 2020). A recent study advised critical care nurses to encourage relatives to participate in care (Avci & Ayaz-Alkaya, 2022). 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 (Heydari et al., 2020; Liput et al., 2016).

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 (Amass et al., 2020; Skoog et al., 2016). Other studies measured helpfulness and supportiveness (Davidson et al., 2010), perceived respect, collaboration, and support (Mitchell et al., 2009), and perception, comfort level, experience and interest in family participation (Wyskiel, Chang, et al., 2015), however with unvalidated scales. Furthermore, both Davidson et al. (2010) and Wyskiel, Chang, et al. (2015) used an adapted or shortened version of the Critical Care Family Needs Inventory (CCFNI) (Leske, 1991), focusing on the need for information, proximity, comfort, assurance and support. According to Olding et al. (2016), 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 (Dijkstra et al., 2022). Amass et al. (2020) used three questions from the FS-ICU (Wall et al., 2007): 'included in the decision making', 'satisfied with care', 'had control over the care', that were considered likely to impact 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 (Rensen

et al., 2017; Thermaenius et al., 2019). These scales illustrate that relatives' needs may have developed over time, and focus may have moved toward 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 (Davidson et al., 2010, Mitchell et al., 2017); 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.

4.1 | 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 the 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.

5 | 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 considered.

AUTHOR CONTRIBUTIONS

Boukje Dijkstra: conceptualization, methodology, validation, formal analysis, writing – original draft Karin Felten-Barentsz: formal analysis, writing – review and editing Margriet van der Valk: formal analysis, writing – review and editing Thomas Pelgrim: methodology, validation, writing – review and editing Johannes van der Hoeven: formal analysis, writing – review and editing Lisette Schoonhoven: formal analysis, writing – review and editing Remco Ebben: formal analysis, writing – review and editing Lilian Vloet: conceptualization, methodology, validation, formal analysis, writing – review and editing, funding acquisition.

ACKNOWLEDGEMENTS

The authors wish to thank Irma van Houts for her contribution to the development of specific parts of the search strategy.

FUNDING INFORMATION

This project was funded by the Dutch Research Council (NWO) (RAAK.PUB03.011).

CONFLICT OF INTEREST STATEMENT

None.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

Not applicable.

CONSENT FOR PUBLICATION

Not applicable.

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SUPPORTING INFORMATION

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

How to cite this article: Dijkstra, B. M., Felten-Barentsz, K. M., van der Valk, M. J. M., Pelgrim, T., van der Hoeven, J. G., Schoonhoven, L., Ebben, R. H. A., & Vloet, L. C. M. (2023). Family participation in essential care activities in adult intensive care units: An integrative review of interventions and outcomes. *Journal of Clinical Nursing*, 32, 5904–5922. <https://doi.org/10.1111/jocn.16714>