Australian Critical Care xxx (xxxx) xxx

Contents lists available at ScienceDirect

Australian Critical Care

journal homepage: www.elsevier.com/locate/aucc

Review paper

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

Boukje M. Dijkstra, RN MSc [a, b, *], Karin M. Felten-Barentsz, PT MSc [a, c], Margriet J.M. van der Valk, MSc [a], Thomas Pelgrim, MSc [a], Hans G. van der Hoeven, MD PhD [b], Lisette Schoonhoven, PhD FEANS [d, e], Remco H.A. Ebben, RN PhD [a], Lilian C.M. Vloet, RN PhD FEANS [a, f, g]

[a] *Research Department Emergency and Critical Care, HAN University of Applied Sciences, Faculty of Health and Social Studies, Nijmegen, the Netherlands;* [b] *Intensive Care Unit, Radboud University Medical Center, Nijmegen, the Netherlands;* [c] *Department of Rehabilitation - Physical Therapy, Radboud Institute for Health Sciences, Radboud University Medical Center, Nijmegen, the Netherlands;* [d] *Nursing Science, Julius Center for Health Sciences and Primary Care, University Medical Center Utrecht, Utrecht University, Utrecht, the Netherlands;* [e] *School of Health Sciences, Faculty of Environmental and Life Sciences, University of Southampton, Southampton, UK;* [f] *IQ Healthcare, Radboud Institute for Health Sciences, Radboud University Medical Center, Nijmegen, the Netherlands;* [g] *Foundation Family and Patient Centered Intensive Care, Alkmaar, the Netherlands*

ARTICLE INFORMATION

Article history:
Received 6 September 2021
Received in revised form
7 February 2022
Accepted 7 February 2022

Keywords:
Intensive care unit
Essential care
Family participation
Family-centred care
Relatives

ABSTRACT

Background: Family participation in essential care activities may benefit both patients and relatives.
Objectives: In this integrative review, we aimed to identify needs, perceptions, preferences, and capacities regarding family participation in essential care in intensive care units (ICUs) from the patient's, relatives', and ICU healthcare providers' perspective.
Review method used: An integrative review method was used.
Data sources: PubMed, CINAHL, EMBASE, MEDLINE, Cochrane, Web of Science, and reference lists of included articles were searched, from inception to January 25, 2021.
Review methods: We included studies on family participation in essential care activities during ICU stay which reported associated needs, perceptions, preferences and capacities. Quality assessment was performed with the Kmet Standard Quality Assessment Criteria developed for evaluating primary research papers in a variety of fields, and an extensive qualitative thematic analysis was performed on the results.
Results: Twenty-seven studies were included. Quality scores varied from 0.45 to 0.95 (range: 0–1). Patients' needs, perceptions, preferences, and capacities are largely unknown. Identified themes on needs and perceptions were relatives' desire to help the patient, a mostly positive attitude among all involved, stress regarding patient safety, perceived beneficial effects, relatives feeling in control—ICU healthcare providers' concerns about loss of control. Preferences for potential essential care activities vary. Relatives want an invitation and support from ICU healthcare providers. Themes regarding capacities were knowledge, skills, education and training, and organisational conditions.
Conclusions: Implementation of family participation in essential care requires education and training of relatives and ICU healthcare providers to address safety and quality of care concerns, though most studies lack further specification.

1. Introduction

A stay in the intensive care unit (ICU) is stressful for patients. It has been estimated that 50% of ICU survivors suffer from post–intensive care syndrome (PICS), which includes impairments of physical, cognitive, or mental nature. Physical problems include

* Corresponding author at: HAN University of Applied Sciences, Faculty of Health and Social Studies, Research Department Emergency and Critical Care, Postbus 6960, 6503 GL, Nijmegen, the Netherlands.
E-mail address: Boukje.Dijkstra@han.nl (B.M. Dijkstra).

https://doi.org/10.1016/j.aucc.2022.02.003

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

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

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

2. Methods

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

2.1. Search strategy

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

2.2. Study selection procedure

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

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

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

2.3. Quality assessment

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

2.4. Data extraction

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

2.5. Data analysis

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

3. Results

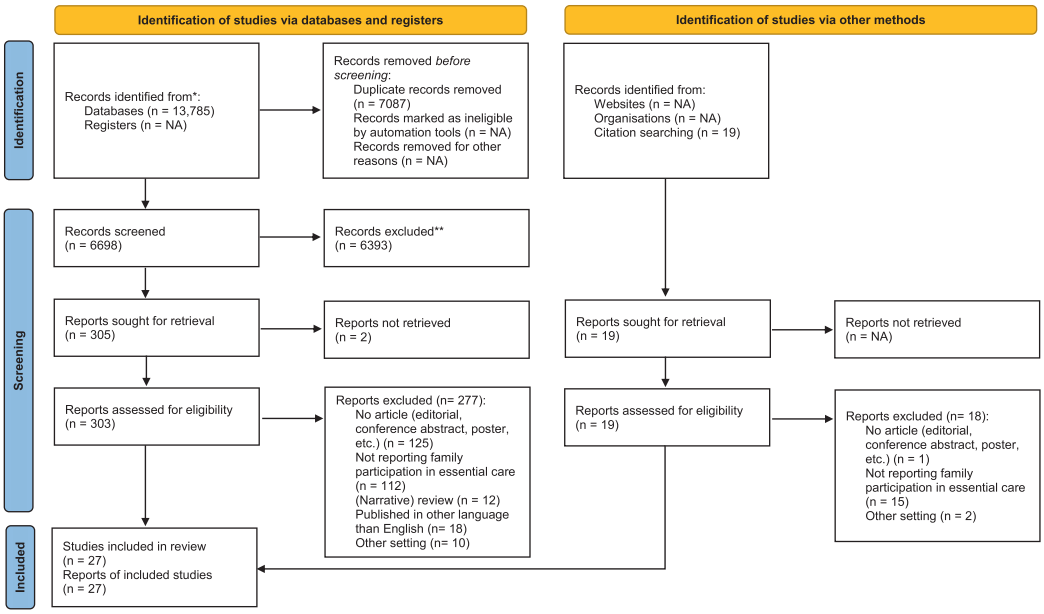
3.1. Review statistics

After duplicate removal, 6698 records were screened. A total of 324 full-text articles were assessed, 305 from database searching and 19 from reference lists, and 27 studies were included (see Fig. 1). A list of excluded articles (n = 297) is provided in Appendix 2.

3.2. Study characteristics

Study characteristics, including design, country, and population, are presented in Tables 1 and 2. The included studies consisted of 11 quantitative studies—five prospective/observational,[25–29] three pretest–posttest,[30–32] two pilot/feasibility,[33,34] and one cross-sectional study[35]—six mixed-methods studies,[36–41] and 12 qualitative studies.[5,8,39,41–49]

Please cite this article as: Dijkstra BM et al., Family participation in essential care activities: Needs, perceptions, preferences, and capacities of intensive care unit patients, relatives, and healthcare providers—An integrative review, Australian Critical Care, https://doi.org/10.1016/j.aucc.2022.02.003



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

Fig. 1. PRISMA 2020 flow diagram for new systematic reviews which included searches of databases, registers, and other sources *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. PRISMA, Preferred Reporting Items for Systematic reviews and Meta-Analyses.

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

3.3. Quality assessment

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

3.4. Themes

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

For each theme, results are summarised separately for each of the three populations (patients, relatives, and ICU healthcare providers) (also see Tables 3, 4, and 5). If a certain population is not listed within a specific theme, then no studies were found for that population related to that theme.

3.5. Needs and perceptions

3.5.1. Desire to help the patient and feel useful

The first theme, the desire to help the patient and feel useful, was described in 10 studies. Relatives wanted or were willing, when invited, to help the patient, feel useful, and be allowed to participate.[5,26,36–38,42,44,46,48,49]

3.5.2. (Positive) attitude

The second theme (positive) attitude, among patients, relatives, and ICU healthcare providers was described in 12 studies.

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

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

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

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

3.5.3. Stress

The third theme, stress, among relatives and ICU healthcare providers was described in 14 studies. Several conditions that are (potentially) stressful for relatives and ICU healthcare providers were described.

Some relatives were afraid to touch the patient, in fear of causing harm; others had concerns about annoying or creating

Table 1
Characteristics of quantitative and mixed-methods studies (n = 17).

1st author (year) Country	Aim	Design	Setting (n)	Population (n)	Method	Total quality score (Kmet, 0–1)
Ågård (2009) Denmark	To describe how Danish ICU nurses perceive personal knowledge and skills (self-efficacy), outcome expectations to interacting with relatives, and the possible consequences of involving relatives in caring activities.	Cross-sectional	Medical-surgical adult ICU at a university hospital (1)	ICU nurses (68)	Survey	0.86
Al-Mutair (2014) Saudi Arabia	To describe healthcare providers' attitudes to family involvement during routine care and family presence during resuscitation or other invasive procedures in adult intensive care units in Saudi Arabia.	Descriptive	Mixed-surgical adult ICUs at eight different hospitals (8)	ICU healthcare providers (468; nurses, physicians, and respiratory therapists)	Survey	0.70
Azoulay (2003) France	To investigate the opinions and experience of ICU caregivers and family members about involvement of families in the care of ICU patients, irrespective of their prognosis.	Prospective, observational	48% medical-surgical, 40% medical, and 12% surgical ICUs. 61.6% at university hospitals (78)	ICU healthcare providers (2754; nurses, nursing assistants, physical therapists, and physicians) Relatives (544) Patients (357)	Survey, interviews	0.75
Davidson (2010) USA	To evaluate the feasibility of an intervention for support for families of mechanically ventilated adults, grounded in a new midrange nursing theory titled "Facilitated Sense making".	Pilot study, feasibility	Mixed-use ICU of a trauma centre (1)	Relatives (22)	Survey	0.50
Eldredge (2004) USA	To describe spouses' helping behaviours at the ICU bedside and explore how well preferences for closeness and helpfulness explain variation in spouses' emotional outcomes during their partners' illness.	Mixed methods	Medical ICU/CCU in a tertiary care community hospital (1)	Relatives (88)	Survey, structured interviews	0.75
Garrouste-Orgeas (2010) France	To assess opinions of caregivers, families, and patients about involvement of families in the care of ICU patients; to evaluate the prevalence of symptoms of anxiety and depression in family members; and to measure family satisfaction with care.	Mixed methods	Medical-surgical ICU of a tertiary care hospital (1)	Patient–family pairs (101) ICU healthcare providers (nurses [21], nursing assistants [7], physicians [17])	Survey, structured interviews	0.89
Hammond (1995) Australia	To describe the positive and negative attitudes of intensive care nurses and the relatives of critically ill patients towards the involvement of relatives in giving physical care to their loved ones in the ICU, and also to elicit areas of care that would be appropriate for relatives to become involved in and to determine any perceived benefits of lay participation in care.	Mixed methods	General district hospital ICU (1)	ICU nurses (27) Relatives (20)	Survey, checklist, open and biographical questions	0.70
Hetland (2017) USA	To (1) report patient care activities nurses commonly offer to family caregivers to perform; (2) explore the impact of nurse and organisational characteristics on barriers and facilitators to family engagement in	Prospective, observational	The American Association of Critical Care Nurses, 30% worked in an academic setting (not described)	ICU nurses (433)	Survey	0.95

	care; and (3) examine the relationships among ICU environment, patient acuity, nurse workflow, and attitudes towards family engagement in the care of the critically ill.					
Kean* (2014) Australia	To describe families' and nurses' experiences of having a family member provide physical care to the ICU patient and to compare how ICU nurses in Australia and the UK perceive families in ICUs.	Mixed methods, quasi-experimental	Metropolitan tertiary adult ICUs (2)	ICU nurses (52)	Survey	0.50
Loudet (2017) Argentina	To determine the effectiveness of a quality management program in reducing the incidence and severity of pressure ulcers in critical care patients.	Pretest–posttest	Medical-surgical ICU within a university-affiliated hospital (1)	Patients (124)	Patient care reports	0.86
McConnell (2015) Australia	To uncover the barriers and enablers that critical care nurses experience to involving relatives in ICU patient care.	Mixed methods	Tertiary adult ICU of a private hospital (1)	ICU nurses (questionnaire: 70, interviews: 6)	Survey, semistructured interviews	0.55
Mitchell (2009) Australia	To evaluate the effects on family-centred care of having critical care nurses partner with patients' families to provide essential care to patients.	Pretest–posttest	Medical and surgical ICUs in two metropolitan teaching hospitals (2)	Relatives (174)	Survey	0.71
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, semistructured interviews	0.73
Skoog (2016) USA	To increase engagement of patients' family members by implementing FSM in cardiothoracic ICU and to measure the effect of FSM on family members anxiety levels during the ICU stay.	Pretest–posttest	Cardiothoracic ICU in a large regional heart centre (1)	Relatives (64)	Survey	0.77
Smithburger (2017a) USA	To determine opinions and willingness of healthcare providers to involve patients' relatives in nonpharmacologic delirium prevention activities in the ICU, and of patients' relatives to be involved.	Prospective, observational	Medical ICU from academic medical centre (1)	Relatives (60) ICU nurses (60) Physicians (58)	Survey	0.75
Wong* (2021) Australia	To understand families' preferences and observed participation in patient care in an adult ICU.	Mixed methods	ICUs in public hospital (2)	Relatives (30)	Survey	0.67
Wyskiel (2015) USA	To assess family and provider openness to expanding the care team to include family participation and introduce the Family Involvement Menu as a tool to facilitate family engagement.	Prospective, observational	Surgical and medical ICU and an inpatient unit from two academic medical centres (2)	Relatives (37) ICU healthcare providers (37, 95% nurses)	Survey	0.70

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

Please cite this article as: Dijkstra BM et al., Family participation in essential care activities: Needs, perceptions, preferences, and capacities of intensive care unit patients, relatives, and healthcare providers—An integrative review, Australian Critical Care, https://doi.org/10.1016/j.aucc.2022.02.003

Table 2
Characteristics of qualitative studies (n = 12).

1st author (year) country	Aim	Design	Setting (n)	Population (n)	Method	Total quality score (Kmet 0–1)
Blom (2013) Sweden	To explore participation and support as experienced by close relatives of patients at an ICU.	Phenomenological	ICU at a moderately large hospital (1)	Relatives (7)	Semistructured interviews	0.55
Engström (2011) Sweden	To describe critical care nurses' experiences of relatives' involvement in the nursing care of patients in an ICU.	Qualitative content analysis	An ICU (1)	ICU nurses (8)	Semistructured interviews	0.65
Hupcey (1999) USA	To investigate how families and nurses interact to increase or decrease the family's involvement in the ICU.	Grounded theory	Large, tertiary ICU (1)	Patients (30) Relatives (11) ICU nurses (10)	Unstructured interviews	0.45
Kean* (2014) UK	To examine families' experiences with critical illness in the ICU and nurses' perceptions of families and to compare how ICU nurses in the UK and Australia perceive families in ICUs.	Grounded theory	Tertiary ICU (1)	ICU nurses (20)	Focus groups	0.60
Kydonaki (2020) UK	To understand the different factors that impact the involvement of relatives in ICU patient care from the perspective of patients, relatives, and ICU nurses, to inform the enactment of a PFCC intervention to support the patient −relative−nurse partnership in care involvement.	Thematic analysis	ICUs in tertiary university hospitals (2)	Patients (19) Relatives (21) ICU nurses (15)	Semistructured interviews and focus groups	0.65
McAdam (2008) USA	To describe the contributions to care that family members perform while their loved one is at high risk of dying in the ICU.	Exploratory, descriptive analysis	Tertiary ICUs (2)	Relatives (25)	Interviews	0.45
Mitchell (2010) Australia	To describe families' experiences of providing physical care to their critically ill relatives with bedside nurses' support.	Content analysis	Large, tertiary ICU (1)	Relatives (10)	Semi-structured interviews	0.85
Smithburger (2017b) USA	To gain insight into opinions of patients' relatives regarding active participation in delirium prevention activities to inform specific recommendations for involving patients' relatives in such activities.	Thematic analysis	Medical ICU at an academic medical centre (1)	Relatives (10)	Interviews	0.55
Wåhlin (2009) Sweden	To compare intensive care patients' experiences of empowerment with relatives' and staff beliefs.	Content analysis	General ICUs (2)	Relatives (10)	Interviews	0.70
Wong (2019) Australia	To explore relatives' experiences of their interactions in an ICU to develop a grounded theory that can be used by critical care nurses to improve PFCC.	Grounded theory	Large, tertiary ICU (1)	Relatives (25)	Interviews	0.90
Wong (2020) Australia	To describe relatives' perspectives of participation in patient care in an adult ICU.	Thematic analysis	Tertiary ICUs (2)	Relatives (30)	Naturalistic observations and semistructured interviews	0.80
Wong* (2021) Australia	To understand families' preferences and observed participation in patient care in an adult ICU.	Naturalistic observation	ICUs in public hospital (2)	Relatives (30)	Naturalistic observation	0.55

Abbreviations: ICU: intensive care unit; PFCC: patient- and family-centred care;
* Study divided into a quantitative and qualitative part.

Table 3
Needs, perceptions, preferences, and capacities with regard to family participation in essential care from the patient's perspective.

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

Abbreviations: FP: family participation in essential care; ICU: intensive care unit.

Table 4
Needs, perceptions, preferences, and capacities with regard to family participation in essential care from the relatives' perspective.

1st author (year) country	Population (n)	Needs	Perceptions	Preferences	Capacities
Azoulay (2003) France	Relatives (544)	• 33.4% wanted to participate, most common reasons: feeling that relationship with patient made care natural (70.2%), a **desire to help the patient** (84%), and a desire to help ICU HCPs (58.3%)	• The most common reason for not wanting to participate was that ICU HCPs did their job perfectly (85.4%) • FP may provide relatives with a feeling of closeness to the patient, **alleviate stress,** and generate a feeling of **usefulness**		• Lack of adequate **information** about what FP actually entails • **Education** of **relatives**, who are not healthcare providers, to address patient **safety** and **quality of care** concerns • Independent predictors of the wish for FP were patient-related (**less severe status** at admission and **longer ICU stay**); family-related (younger age, non-European descent, and **previous ICU admission**), and factors related to emotional burden and to effectiveness of information (symptoms of depression in relatives and more time wanted for information) • FP requires extended **visiting hours**
Blom (2013) Sweden	Relatives (7)	• Being allowed to participate (variation in need to participate)	• Feeling discouraged to participate due to differences in **approach** between ICU HCPs		• Inviting atmosphere, created by ICU HCPs (especially ICU nurses) • **Open and flexible attitude** from ICU HCPs • Good **communication** • **Information** and **support** from ICU nurse
Davidson (2010) USA	Relatives (22)		• **Personal care supplies** were helpful	• Different aspects of the Family Support Program were welcomed	• Most engaged when receiving **information** about how to participate at the bedside

Eldredge (2004) USA	Relatives (88)	• 55% wanted to take an **active role** to help or comfort patient	• 80% reported that care activities helped them to **feel positive or productive**
			• 13% reported that patients did not want them to do anything
			• 11% reported that helping at the bedside made them feel **apprehensive, useless, or helpless**
			• 21% did not meet their caregiving goals:
			  • 33% felt **incapable** of helping
			  • 53% felt they were not needed
					• ICU nurses can help relatives **clarify and achieve goals** for helpfulness

Garrouste-Orgeas (2010) France	Relatives (101	• 97% was willing to participate in care, 3.9% refused to participate	o The family satisfaction score was high (11.0 ± 1.2)		• 13.8% of the relatives provided care spontaneously or asked to participate • 50% felt that 24-**h visitation policy** facilitated FP • **Previous ICU experience** and age (55 −59 range) were associated with a desire to participate in care
Hammond (1995) Australia	Relatives (20)	• 85% would like to participate in physical care	• 85% would like to participate in physical care • Adapting to the demanding ICU environment	• 25% did not want to participate in **'personal care'** (e.g. incontinence or vomit) • 10% indicated that	• Identifying parameters of **new caring role** • **Personal choice** for individual lay involvement • Adequate **information** for relatives to become involved

				participation depended on their **relationship** with the patient and the patient's severity of illness	
Hupcey (1999) USA	Relatives (11)		• Participated not to feel **helpless** • Considered protecting or looking out for the patient their role		
Kydonaki (2020) UK	Relatives (21)		• Most relatives considered care in ICU complex, lacking expertise and FP was unsafe • Personal and family attributes, such as age, gender, type of relationship, sense of dignity, and level of intimacy, could explain the different perceptions of the level of FP		• Most relatives believed ICU nurses should invite them to participate, two initiated FP themselves
	Patients and/or relatives and/or ICU nurses		• ICU environment: unknown, intimidating, and scary to relatives and patients, due to ventilators and monitors, complexity of care, and/or risk of infection for patient, causing them to feel overwhelmed and apprehensive • Patients, relatives, and nurses agreed that 'ICU nurses have control of care in ICU' and 'there is a fine line as to what can be expected from relatives to do'	• All involved were comfortable with combing hair, oral care, massaging with cream, bed bathing upper body, washing hair, assist with mobilisation when extubated • Most were less comfortable with bed bathing (intimate care), technical care	Time and frequent communication between relatives and ICU nurses to develop a relationship
McAdam (2008) USA	Relatives (25)		• More **support** and **appreciation** of FP may provide relatives opportunities for **intimacy** and promote a sense of belonging in the technical environment of an ICU		• Additional work for ICU HCPs due to frequent interactions with relatives
Mitchell (2009) Australia	Relatives (174)				• **Good communication**, **collaboration** and **support** between relatives, patient, and the ICU nurse to enable relatives to decide what care activities to participate in • **Communication** is an essential element in meeting family's needs • **Cooperation, enthusiasm, and support** of the ICU nurse is essential (partnership between relatives and ICU nurses) • ICU nurses allowed relatives to select the level and complexity of care provided: **individualised FP** to the patient's and relatives' situation (offering opportunity, not putting any pressure, using a **flexible approach**) • FP should occur at a level/frequency **best suited** to the relatives
Mitchell (2010) Australia	Relatives (10)	• To **be involved** • To **feel useful**			
Mitchell (2017) Australia	Relatives (61)		• The components of the intervention were not difficult or onerous		

(*continued on next page*)

Table 4 (*continued*)

1st author (year) country	Population (n)	Needs	Perceptions	Preferences	Capacities
Skoog (2016) USA	Relatives (64)		• Education on FP (applying lip balm and hand moisturiser) made relatives **feel comfortable** and **less anxious** • Some relatives were **afraid to touch** the patient (receiving mechanical ventilation and connected to various catheters, monitors, and intravenous medications) because they **feared they could cause harm**		
Smithburger (2017a) USA	Relatives (60)		• A minority was concerned that ICU HCPs may **get angry** or **annoyed** • A minority was **afraid to** pull out an intravenous catheter or tube		• A minority **did not know how to help** • **One-on-one discussion** with ICU HCPs on delirium and possible delirium−prevention activities
Smithburger (2017b) USA	Relatives (10)	• Wanted the patient to know **they were there** and **patient's needs were addresse**d throughout the day (specifically: calming and reorienting the patient when agitated or confused)			• **Invitation to participate** and direction in care from the ICU nurse would aid in their level of comfort • One-on-one discussion and reminder with healthcare providers on delirium and possible activities to **prevent confusion**, coupled with reminders, video could serve as follow-up • Clear **communication** about rules and expectations
Wåhlin (2009) Sweden	Relatives (10)		• FP was **empowering** for some relatives		
Wong (2019) Australia	Relatives (25)		• Contributing towards the recovery and well-being of the patient allowed relatives to **regain control** and **resilience of their situation** and made them **feel useful**		
Wong (2020) Australia	Relatives (30)	• Close proximity to the patient for opportunities to participate in physical care activities • Many relatives wanted to participate in care as a strategy to help themselves **cope with their ICU experience**	• Many relatives reported that it made them '**feel better**', **reduced their feelings of helplessness and negativity**, and they felt **reassured**		
Wong (2021) Australia	Relatives (30)		• Family participation in physical care was observed to occur more frequently by a partner or parent (18; 16) than offspring or siblings (8; 2)	• One-third of the relatives (n = 10; 33%) preferred shared participation in physical patient care with ICU HCPs, one relative (3%) preferred to participate with limited involvement of ICU HCPs, the majority of relatives (n = 18;	

Please cite this article as: Dijkstra BM et al., Family participation in essential care activities: Needs, perceptions, preferences, and capacities of intensive care unit patients, relatives, and healthcare providers—An integrative review, Australian Critical Care, https://doi.org/10.1016/j.aucc.2022.02.003

			60%) preferred a passive level of participation • Type of family participation: Physical care: mouth care, eye care, pressure care, hygiene care, range of movement exercises, moisturising hands/feet, feeding, suctioning, brushing teeth Psychosocial care: sitting at bedside, holding patient's hand, talking, reading, watching TV together Communication: conversations about treatments, conversations with other family members, interpreting/ explaining care and treatments to patient; conversations about activities outside the hospital
Wyskiel (2015) USA	Relatives (37)	• 95% was **interested** in FP • 92% felt **comfortable** with FP • 89% felt **included in the healthcare team**	

Abbreviations: FP: family participation in essential care; ICU: intensive care unit; ICU HCP: ICU healthcare provider.

Please cite this article as: Dijkstra BM et al., Family participation in essential care activities: Needs, perceptions, preferences, and capacities of intensive care unit patients, relatives, and healthcare providers—An integrative review, Australian Critical Care, https://doi.org/10.1016/j.aucc.2022.02.003

Table 5
Needs, perceptions, preferences, and capacities with regard to family participation in essential care from the ICU healthcare providers' perspective.

1st author (year) country	Population (n)	Needs	Perceptions	Preferences	Capacities
Ågård (2009) Denmark	ICU nurses (68)		• General belief that FP can **benefit** both patient and relatives	• Less willing to involve relatives in **more direct and comprehensive care activities**	• Based on **assessments** for FP on a number of complex, individual, and situational aspects (patient, relative, ICU nurse, and other staff) • Proficient interactions with relatives in ICU require competences based on **knowledge and skills** as well as **attitude and values**
Al-Mutair (2014) Saudi Arabia	ICU nurses Physicians Respiratory therapists (468)		• 44.9% agreed that relatives should be allowed to participate on request • ICU HCPs who did not support FP perceived the **presence of relatives as stressful**		• 64.5% had had sufficient **training** to involve relatives • 63.3% had sufficient **time** to be able to involve relatives in care • Lack of **resources** • Lack of **hospital policies** and **guidelines** • Lack of **staff and public education** • ->Development of written **guidelines and policies**, and **education**al programmes
Azoulay (2003) France	ICU HCPs (2,754)		• 88.2% felt that relatives should participate ICU HCPs who were not in favour believed that FP might: • add to the suffering of relatives (65.8%) • cause accidental extubation (65.5%) • negatively affect the **quality of care** (51.2%) • lead to relatives to take too prominent a place (50%)	• 60.7% had actually involved relatives in care (87.4% (feeding), 38.4% (bathing), 24% (tracheal suctioning)) • 61.5% believed all family members could participate, 23.5% family members and friends and 15% spouses	
Davidson (2010) USA	ICU nurses				• **Educational** programs providing **ICU nurses** with instructions for FP
Engström (2011) Sweden	ICU nurses (8)		• Appreciation of relatives' involvement and seen as **resource** for both patients and ICU nurses (relatives' calming effect on patients, helping patients orientate themselves) • **ICU environment** (unpleasant and **frightening** for relatives as a result of equipment, alarms, patients' changed appearance [due to swelling, tube, sedation])	• Protecting the patients' autonomy and **integrity** (also depending on relationship between patient and relative) • Protecting the patients' **rest** (balance between involvement and rest)	• **Lack of time** • Open **communication** to align needs of relatives (**variation in desire to participate**; balance between involvement and rest) with needs of patient (autonomy and integrity [also depending on **relationship** between patient and relative], rest) and work situation of ICU nurses
Garrouste-Orgeas (2010) France	ICU HCPs (45)		• Most ICU HCPs were favourable to FP in at least one care activity: 90% of the nurses, 94% of the nursing assistants, and 100% of the physicians o 10% of the ICU nurses unfavourable to FP expressed concerns about **interacting with relatives** during care activities and **possible occurrence of adverse events**		
Hammond (1995) Australia	ICU nurses (27)		• 96.3% agreed with the concept of FP • FP may provide ICU nurses with the opportunity **to build a relationship with relatives**	• 44.4% indicated that relatives should not be involved in '**embarrassing' nursing care** (such as incontinence and catheter care), for maintaining privacy and dignity of the patient	• FP requires a **role adaptation for ICU nurses**
Hetland (2017) USA	ICU nurses (433)		• Had a **positive attitude** towards FP and did not view it as a hindrance to their clinical performance • Agreed that allowing relatives to participate in patient care could improve patient **safety**, decision-making, and overall **quality of care** as well as **improve relatives' levels of stress, anxiety, and fear**	• Were most likely to ask relatives to participate in **less complex daily care activities** (such as applying lotion, feeding the patient, washing the patient's hands, and communicating with the patient); and less likely in more **intimate or invasive care activities** (such as toileting, perineal care, symptom	• Expressed concern about **safety** of some care activities • 66% reported having a **unit culture** that valued FP • Most participants '(strongly) disagreed' when asked if their unit had **policies and procedures** to support FP • **Higher age, higher degree earned, more ICU experience**, hospital location (rural), unit

		• Had mixed feelings about the extent to which relatives should be involved in light of **high patient acuity**	assessment, tracheostomy care, and endotracheal tube suctioning) • Expressed concern about **appropriateness** of some care activities	type (paediatric), and **staffing ratios (lower)** had higher QFIFE scores: characteristics that positively influenced ICU nurses' attitudes towards FP • ->A close examination of ICU family culture, staffing decisions, patient acuity, and other work environmental factors to develop solutions to alleviate time constraints and promote a milieu that supports family engagement in ICU • ->**Evidence-driven policies and procedures**, supported by current practice guidelines, to help standardise patient care and support nurses' decisions on how to involve family members • Additional **education and training** may be needed for nurses to understand their role in **communicating opportunities and safely** guiding FP in the ICU • **Maintaining control** over both their ability to provide **patient care and the relatives** • Make relatives feel comfortable and **encourage their involvement** • FP depended on **individual ICU nurses' perception of the patient's physiological and psychological responses to FP and acuity (instability or numerous lines and machines)** • **Longer term patients** (and **developing a relationship with relatives**) • **Lack of time and ability** to care for relatives • The **patient's condition** and **receptiveness and coping ability of relatives** influence the decision to involve relatives • Some limit FP to **long-term patients**, others comment that it depends on the **individual situation** and the amount of involvement the **relatives want** • 81% considered FP had **minimal effect on their workload** • To **control their working time and space** • The i**nvitation** to participate should be initiated by ICU nurses (allowing them to **remain in control over their work environment**, and evidence suggests that when relatives would like to participate, they do not ask to) • 'Vision' that the **integration of relatives in today's healthcare system** (including ICUs) is mandatory as relatives will become caregivers during an often prolonged recovery trajectory • **Specific strategies** to support ICU nurses in the integration of relatives into the ICU
Hupcey (1999) USA	ICU nurses (10)	• **Decrease in confusion or agitation in patients** through relatives		
Kean (2014) UK/Australia	ICU nurses (52/20)	• 98% considered the concept of **FP should be part of 'usual care'** in ICU • Open visitation policies **impact ICU nurses' working conditions**, with a constant flow of visitors inhibiting and delaying patient care (attending (information) needs of relatives and allowing relatives to be with the patient or protecting the patient's privacy) • Difference of opinion between bedside ICU nurses more often considering **'the patient' remaining the focus of care,** while nurses with managerial responsibility defining relatives and the patient as the unit of care		
Kydonaki (2020) UK	ICU nurses (15)	• Felt accountable for patient and family care and some were hesitant involving FM in care for two main reasons: 1) to avoid the risk of slips and errors and 2) to protect relatives from the burden of caring	• For FP in physical care activities, all felt more comfortable inviting relatives after the acute phase, the level of involvement being determined by the relative	

(*continued on next page*)

Table 5 (*continued*)

1st author (year) country	Population (n)	Needs	Perceptions	Preferences	Capacities
			• Many viewed themselves as their patient's advocates with the objective of providing care without interruptions, reflected in their need of controlling to some extent when a relative can be present and involved in care • Some felt exposed and frustrated at times when some relatives were constantly present	• Spent time observing family dynamics and levels of intimacy, previous experience with patient care (patients with long-term conditions), as well as the type of relationship with the patient before inviting a relative to participate	
	Patients and/or relatives and/or ICU nurses		• ICU environment: unknown, intimidating, and scary to relatives and patients, due to ventilators and monitors, complexity of care, and/or risk of infection for patient, causing them to feel overwhelmed and apprehensive • Patients, relatives, and nurses agreed that 'ICU nurses have control of care in ICU' and 'there is a fine line as to what can be expected from relatives to do'	• All involved were comfortable with combing hair, oral care, massaging with cream, bed bathing upper body, washing hair, and assist with mobilisation when extubated • Most were less comfortable with bed bathing (intimate care), technical care	Time and frequent communication between relatives and ICU nurses to develop a relationship
Loudet (2017) Argentina	ICU HCPs		• **Reduction of burden on limited nursing staff**		
McConnell (2015) Australia	ICU nurses (70/6)		Relatives' perspective: • Perceived **fragility** and **vulnerability** • Fear of **increasing their stress levels** • **Loudness** and **obnoxiousness** (causing stress for ICU nurse and patient) ICU nurses' perspective: • **Personal attitudes** towards FP (personal values) • **Negative past experiences** with FP • Felt **uncomfortable** performing activities in front of relatives	Patient's perspective: • **Privacy** (linked to relative-patient relationship)	Patient's perspective: • Safety • Short term length of ICU stay Relatives' perspective: • **Fear** of relatives injuring themselves when participating and possible **legal consequences** ICU nurses' perspective: • Less ICU **nursing experience** • **Education** of ICU nurses on (understanding possible benefits of) FP ICU environment factors: • Compact-**sized rooms** • **Work interruption** by relatives in a busy environment • **Lack of time** to explain care activities to relatives • Lack of hospital **policy/guidelines** • Development of directed strategies to reduce barriers • Physical **ICU environment** (patient treatment (turns, doctors' review, assessments, examinations))
Mitchell (2017) Australia	ICU nurses (11)		• Were **supportive** of all aspects of the intervention • Relatives were seen as important **care partners**, and their involvement afforded positive outcomes for the patient and themselves • **Relatives' fear** or discomfort with FP • Negative ICU nurses' **attitudes**		
Smithburger (2017a) USA	ICU nurses (60)		•A majority believed FP in delirium prevention would benefit the patient through a **reduced incidence of ICU delirium** because of increased time devoted to delirium prevention Belief that relatives: • **Fear** the setting, including machines, catheters, and ICU sounds • Are apprehensive about **getting in the way** of ICU HCPs		• **Lack of time** to explain delirium or delirium prevention Belief that relatives: • **Lack knowledge** about delirium and prevention strategies and **need education** • Do not understand about delirium and prevention • **Could harm** the patient

		• Experience **stress** or **anxiety** associated with preventative care • A majority believed FP in delirium prevention would benefit the patient through a **reduced incidence of ICU delirium** because of increased time devoted to delirium prevention	• **Lack of time** to explain delirium or delirium prevention • Belief that **relatives lack knowledge** about delirium and prevention strategies and need education
Physicians (58)			
Wyskiel (2015) USA	ICU HCPs (37)	• 78% **comfortable** with inviting relatives to participate • 70% routinely invited relatives to participate some of the time, 16% did so consistently • **More time** for other nursing tasks (35%) • Some relatives were not invited to participate for being perceived **scared** (19%), **uncomfortable** (19%), and **unwilling** (14%)	• Relatives were least likely to be involved in **physical therapy** (32%), **bathing** (27%), and **mouth care** (19%) due to reasons such as 'anxiety about patient falling', 'bathing because they may be uncomfortable with their families in that state', and 'not wanting to hurt them'	• Opportunity to **educate** family members in patient care (16%), better preparing them for transition of care and discharge • The Family Involvement Menu could help engage relatives as part of the healthcare team • Opportunities for relationship building (19%) • **Lack of time** (14%)

Abbreviations: FP: family participation in essential care; ICU: intensive care unit; ICU HCP: ICU healthcare provider; QFIFE: Questionnaire on Factors That Influence Family Engagement.

additional work for ICU healthcare providers due to frequent interactions with relatives.[8,32,46,32]

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

3.5.4. Perceived effects

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

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

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

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

3.5.5. Feeling in control—loss of control

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

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

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

3.6. Preferences and capacities

3.6.1. Potential essential care activities

The sixth theme, potential essential care activities, was described in 18 studies. Preferences for essential care activities varied between and among relatives and ICU healthcare providers.

More than 70% of the patients were comfortable with eye care, hydrating lips, moistening of the oral cavity, and applying body lotion being performed by relatives[37] (see Table 6).

Twelve studies elicited possible essential care activities from the relatives' perspective.[5,8,28,31,37,38,41,44–46,48,49] Studies providing sufficient details on descriptive statistics are presented in Table 6. Preferences for essential care activities varied between relatives, making identification of a uniform list impossible.

ICU healthcare providers favoured several essential care activities, again preferences varied.[5,28,31,33,35,37,38,43,44] In the studies of Azoulay et al. and Hetland et al., ICU healthcare providers actually invited relatives to perform specific activities[26,27] see Table 6. There is no agreement on essential care activities that can be performed by relatives.

The majority of patients, relatives, and ICU healthcare providers endorsed participation in eye care, moistening of the oral cavity,

Please cite this article as: Dijkstra BM et al., Family participation in essential care activities: Needs, perceptions, preferences, and capacities of intensive care unit patients, relatives, and healthcare providers—An integrative review, Australian Critical Care, https://doi.org/10.1016/j.aucc.2022.02.003

Table 6
Possible essential care activities from the patient's, relatives', and ICU healthcare providers' perspective[a].

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

[a] Azoulay et al. (2003) (22), Garrouste-Orgeas et al. (2010) (29), Hammond (1995) (30), and Hetland et al. (2017) (33) provided quantitative data in sufficient detail for this table.
[b] Garrouste-Orgeas et al. (2010) (29) and Hammond (1995) (30) described essential care activities that were in favour, from the patient's, relatives' and ICU healthcare providers' perspective.
[c] Azoulay et al. (2003) (22) and Hetland et al. (2017) (33) described essential care activities that ICU healthcare providers' actually invited relatives to participate in >**75% (bold)** *<50% (italic)*.

and applying lip balm and body lotion; however, there was no agreement on participation in bathing and hair washing.[37,38,45]

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

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

3.6.2. Invitation and support: an individualised approach

The seventh theme, invitation and support: an individualised approach, was described in 10 studies. Relatives require an invitation and support, individualised to their situation.

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

3.6.3. Knowledge, skills, education, and training

The eighth theme, knowledge, skills, education, and training, was described in 12 studies. Relatives and ICU healthcare providers require knowledge, skills, education, and training to enable safe family participation in essential care.

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

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

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

3.6.4. Characteristics of patients and relatives

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

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

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

3.6.5. Organisational conditions

The 10th theme, organisational conditions, was described in 11 studies. Several organisational characteristics and factors had either a positive or a negative influence on family participation, according to ICU healthcare providers.

Please cite this article as: Dijkstra BM et al., Family participation in essential care activities: Needs, perceptions, preferences, and capacities of intensive care unit patients, relatives, and healthcare providers—An integrative review, Australian Critical Care, https://doi.org/10.1016/j.aucc.2022.02.003

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

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

4. Discussion

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

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

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

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

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

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

According to several survey studies, education and training were deemed necessary to address safety and quality of care concerns,[27,40] though no further specifications were presented; specific safety concerns relate to accidental removal of tubes, catheters, or intravenous lines.[26,32] Both review and guidelines described family education, but they did not include studies addressing education of relatives on family participation.[13,17] Smithburger et al. propose the use of one-on-one discussions between ICU healthcare providers and relatives to educate and train relatives.[28] Depending on the activities that are deemed appropriate, other educational strategies, such as brochures, 'training-on-the-job', and videos may also be useful and require further research.

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

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

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

Most studies were conducted in Australia (n = 9), the USA (n = 9), and Europe (n = 8), in which western norms and values will have played a role. In the Saudi study, local healthcare providers supported family involvement during routine care more than did expatriate healthcare providers. The authors attributed this to a better understanding of the needs of relatives related to sharing the

Please cite this article as: Dijkstra BM et al., Family participation in essential care activities: Needs, perceptions, preferences, and capacities of intensive care unit patients, relatives, and healthcare providers—An integrative review, Australian Critical Care, https://doi.org/10.1016/j.aucc.2022.02.003

same culture, norms, and values.[25] Some details on ethnic background of patients and/or relatives were provided in seven studies,[8,26,32,36,37,45,49] though none of these authors addressed possible cultural influences. Olding et al. established a lack of attention to ways in which gender, ethnicity, age, and socioeconomic status may influence practices and preferences around patient or family involvement as well.[9]

ICU care has gone through some substantial developments in the past decades, in terms of patient acuity, ICU treatment, visiting policies, and family engagement opportunities. Eleven studies were published before 2011 (four before 2006), and changes in ICU care may influence the interpretation of results; however, in terms of needs, perceptions, preferences, and capacities regarding family participation in essential care, older studies have provided valuable content.

4.1. Limitations

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

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

5. Conclusion

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

CRediT authorship contribution statement

Boukje Dijkstra: Conceptualisation, Methodology, Validation, Formal analysis, Writing - original draft **Karin Felten-Barentsz:** Formal analysis, Writing - review & editing **Margriet van der Valk:** Formal analysis, Writing - review & editing **Thomas Pelgrim:** Methodology, Validation, Writing - review & editing **Johannes van der Hoeven:** Formal analysis, Writing - review & editing **Lisette Schoonhoven:** Formal analysis, Writing - review & editing **Remco Ebben:** Formal analysis, Writing - review & editing **Lilian Vloet:** Conceptualisation, Methodology, Validation, Formal analysis, Writing - review & 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. This work was supported by the Foundation Innovation Alliance, Regional Attention and Action for Knowledge Circulation, under project number RAAK-PUB03.011.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.aucc.2022.02.003.

References

[1] Harvey MA, Davidson JE. Postintensive care syndrome: right care, right Now...and later. Crit Care Med 2016;44:381–5.
[2] Needham DM, Davidson J, Cohen H, Hopkins RO, Weinert C, Wunsch H, et al. Improving long-term outcomes after discharge from intensive care unit: report from a stakeholders' conference. Crit Care Med 2012;40:502–9.
[3] Jezierska N. Psychological reactions in family members of patients hospitalised in intensive care units. Anaesthesiol Intensive Ther 2014;46:42–5.
[4] McKiernan M, McCarthy G. Family members' lived experience in the intensive care unit: a phemenological study. Intensive Crit Care Nurs 2010;26:254–61.
[5] Mitchell ML, Chaboyer W. Family Centred Care–a way to connect patients, families and nurses in critical care: a qualitative study using telephone interviews. Intensive Crit Care Nurs 2010;26:154–60.
[6] Davidson JE, Jones C, Bienvenu OJ. Family response to critical illness: post-intensive care syndrome-family. Crit Care Med 2012;40:618–24.
[7] van Beusekom I, Bakhshi-Raiez F, de Keizer NF, van der Schaaf M, Busschers WB, Dongelmans DA. Healthcare costs of ICU survivors are higher before and after ICU admission compared to a population based control group: a descriptive study combining healthcare insurance data and data from a Dutch national quality registry. J Crit Care 2018;44:345–51.
[8] McAdam JL, Arai S, Puntillo KA. Unrecognized contributions of families in the intensive care unit. Intensive Care Med 2008;34:1097–101.
[9] 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;19:1183–202.
[10] Kitson A, Conroy T, Wengstrom Y, Profetto-McGrath J, Robertson-Malt S. Defining the fundamentals of care. Int J Nurs Pract 2010;16:423–34.
[11] Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M. Developing and evaluating complex interventions: the new Medical Research Council guidance. Bmj 2008;337:a1655.
[12] Bleijenberg N, de Man-van Ginkel JM, Trappenburg JCA, Ettema RGA, Sino CG, Heim N, et al. Increasing value and reducing waste by optimizing the development of complex interventions: enriching the development phase of the Medical Research Council (MRC) Framework. Int J Nurs Stud 2018;79:86–93.
[13] 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;45:103–28.
[14] Al-Mutair AS, Plummer V, O'Brien A, Clerehan R. Family needs and involvement in the intensive care unit: a literature review. J Clin Nurs 2013;22:1805–17.
[15] Goldfarb MJ, Bibas L, Bartlett V, Jones H, Khan N. Outcomes of patient- and family-centered care interventions in the ICU: a systematic review and meta-analysis. Crit Care Med 2017;45:1751–61.
[16] 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;44:1191–7.
[17] Mitchell ML, Coyer F, Kean S, Stone R, Murfield J, Dwan T. Patient, family-centred care interventions within the adult ICU setting: an integrative review. Aust Crit Care 2016;29:179–93.
[18] Xyrichis A, Fletcher S, Philippou J, Brearley S, Terblanche M, Rafferty AM. Interventions to promote family member involvement in adult critical care settings: a systematic review. BMJ Open 2021;11:e042556.
[19] [Internet]. Available from: Institute for Patient- and Family-Centred Care. 2015. http://www.ipfcc.org/faq.html.
[20] Whittemore R, Knafl K. The integrative review: updated methodology. J Adv Nurs 2005;52:546–53.
[21] Higgins JP, GSe T. Cochrane Handbook for systematic reviews of interventions version 5.1.0 [updated march 2011]. Cochrane Collab 2011. http://handbook.cochrane.org. https://training.cochrane.org/handbook.
[22] Moher D, Liberati A, Tetzlaff J, Altman DG. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. Bmj 2009;339:b2535.
[23] Kmet LMLR, Cook LS. Standard quality assessment criteria for evaluating primary research papers from a variety of fields. Edmonton: Alberta Heritage Foundation for Medical Research (AHFMR); 2004. HTA Initiative #13, http://www.ahfmr.ab.ca/frames3.html.
[24] Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006;3:77–101.
[25] Al Mutair A, Plummer V, O'Brien AP, Clerehan R. Attitudes of healthcare providers towards family involvement and presence in adult critical care units in Saudi Arabia: a quantitative study. J Clin Nurs 2014;23:744–55.
[26] Azoulay E, Pochard F, Chevret S, Arich C, Brivet F, Brun F, et al. Family participation in care to the critically ill: opinions of families and staff. Intensive Care Med 2003;29:1498–504.
[27] Hetland B, Hickman R, McAndrew N, Daly B. Factors influencing active family engagement in care among critical care nurses. AACN Adv Crit Care 2017;28:160–70.
[28] Smithburger PL, Korenoski AS, Kane-Gill SL, Alexander SA. Perceptions of family members, nurses, and physicians on involving patients' families in delirium prevention. Crit Care Nurse 2017;37:48–57.
[29] Wyskiel RM, Chang BH, Alday AA, Thompson DA, Rosen MA, Dietz AS, et al. Towards expanding the acute care team: learning how to involve families in care processes. Fam Syst Health 2015;33:242–9.

Please cite this article as: Dijkstra BM et al., Family participation in essential care activities: Needs, perceptions, preferences, and capacities of intensive care unit patients, relatives, and healthcare providers—An integrative review, Australian Critical Care, https://doi.org/10.1016/j.aucc.2022.02.003

[30] Loudet CI, Marchena MC, Maradeo MR, Fernandez SL, Romero MV, Valenzuela GE, et al. Reducing pressure ulcers in patients with prolonged acute mechanical ventilation: a quasi-experimental study. Rev Bras Ter Intensiva 2017;29:39–46.
[31] 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;18:543–52. quiz 53.
[32] 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;36:84–9.
[33] 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;33:177–89.
[34] Mitchell ML, Kean S, Rattray JE, Hull AM, Davis C, Murfield JE, et al. A family intervention to reduce delirium in hospitalised ICU patients: a feasibility randomised controlled trial. Intensive Crit Care Nurs 2017;40:77–84.
[35] Agard AS, Maindal HT. Interacting with relatives in intensive care unit. Nurses' perceptions of a challenging task. Nurs Crit Care 2009;14:264–72.
[36] Eldredge D. Helping at the bedside: spouses' preferences for helping critically ill patients. Res Nurs Health 2004;27:307–21.
[37] 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;25:634–40.
[38] Hammond F. Involving families in care within the intensive care environment: a descriptive survey. Intensive Crit Care Nurs 1995;11:256–64.
[39] 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;23:663–72.
[40] McConnell B, Moroney T. Involving relatives in ICU patient care: critical care nursing challenges. J Clin Nurs 2015;24:991–8.
[41] Wong P, Redley B, Bucknall T. Families' control preference for participation in patient care in adult intensive care. Intensive Crit Care Nurs 2021;62:102953.
[42] Blom H, Gustavsson C, Sundler AJ. Participation and support in intensive care as experienced by close relatives of patients: a phenomenological study. Intensive Crit Care Nurs 2013;29:1–8.
[43] Engström B, Uusitalo A, Engström A. Relatives' involvement in nursing care: a qualitative study describing critical care nurses' experiences. Intensive Crit Care Nurs 2011;27:1–9.
[44] Hupcey JE. Looking out for the patient and ourselves–the process of family integration into the ICU. J Clin Nurs 1999;8:253–62.
[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 2020;29:1115–28.
[46] Smithburger PL, Korenoski AS, Alexander SA, Kane-Gill SL. Perceptions of families of intensive care unit patients regarding involvement in delirium-prevention activities: a qualitative study. Crit Care Nurse 2017;37:e1–9.
[47] Wahlin I, Ek AC, Idvall E. Empowerment in intensive care: patient experiences compared to next of kin and staff beliefs. Intensive Crit Care Nurs 2009;25:332–40.
[48] Wong P, Liamputtong P, Koch S, Rawson H. Searching for meaning: a grounded theory of family resilience in adult ICU. J Clin Nurs 2019;28:781–91.
[49] Wong P, Redley B, Digby R, Correya A, Bucknall T. Families' perspectives of participation in patient care in an adult intensive care unit: a qualitative study. Aust Crit Care 2020;33:317–25.
[50] Verhaeghe S, Defloor T, Van Zuuren F, Duijnstee M, Grypdonck M. The needs and experiences of family members of adult patients in an intensive care unit: a review of the literature. J Clin Nurs 2005;14:501–9.
[51] Wetzig K, Mitchell M. The needs of families of ICU trauma patients: an integrative review. Intensive Crit Care Nurs 2017;41:63–70.
[52] King J, O'Neill B, Ramsay P, Linden MA, Darweish Medniuk A, Outtrim J, et al. Identifying patients' support needs following critical illness: a scoping review of the qualitative literature. Crit Care 2019;23:187.
[53] Zante B, Camenisch SA, Schefold JC. Interventions in post-intensive care syndrome-family: a systematic literature review. Crit Care Med 2020;48:e835–40.
[54] Adams A, Mannix T, Harrington A. Nurses' communication with families in the intensive care unit - a literature review. Nurs Crit Care 2017;22:70–80.
[55] Geense WW, van den Boogaard M, van der Hoeven JG, Vermeulen H, Hannink G, Zegers M. Nonpharmacologic interventions to prevent or mitigate adverse long-term outcomes among ICU survivors: a systematic review and meta-analysis. Crit Care Med 2019;47:1607–18.
[56] van Mol MM, Boeter TG, Verharen L, Kompanje EJ, Bakker J, Nijkamp MD. Patient- and family-centred care in the intensive care unit: a challenge in the daily practice of healthcare professionals. J Clin Nurs 2017;26:3212–23.
[57] Oczkowski SJW, Au S, des Ordons AR, Gill M, Potestio ML, Smith O, et al. A modified Delphi process to identify clinical and research priorities in patient and family centred critical care. J Crit Care 2017;42:243–7.
[58] Cahill NE, Murch L, Cook D, Heyland DK. Implementing a multifaceted tailored intervention to improve nutrition adequacy in critically ill patients: results of a multicenter feasibility study. Crit Care 2014;18:R96.
[59] Knauert MP, Redeker NS, Yaggi HK, Bennick M, Pisani MA. Creating naptime: an overnight, nonpharmacologic intensive care unit sleep promotion protocol. J Patient Exp 2018;5:180–7.
[60] Linke CA, Chapman LB, Berger LJ, Kelly TL, Korpela CA, Petty MG. Early mobilization in the ICU: a collaborative, integrated approach. Crit Care Explor 2020;2:e0090.
[61] Heydari A, Sharifi M, Moghaddam AB. Family participation in the care of older adult patients admitted to the intensive care unit: a scoping review. Geriatr Nurs 2020;41:474–84.

Please cite this article as: Dijkstra BM et al., Family participation in essential care activities: Needs, perceptions, preferences, and capacities of intensive care unit patients, relatives, and healthcare providers—An integrative review, Australian Critical Care, https://doi.org/10.1016/j.aucc.2022.02.003