

BMJ Open Interventions to promote family member involvement in adult critical care settings: a systematic review

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ABSTRACT

Objective To identify, appraise and synthesise evidence of interventions designed to promote family member involvement in adult critical care units; and to develop a working typology of interventions for use by health professionals and family members.

Design Mixed-method systematic review.

Data sources Bibliographic databases were searched without date restriction up to June 2019: MEDLINE, EMBASE and CINAHL; the Cochrane Central Register of Controlled Trials, Joanna Briggs and Cochrane Libraries. Back issues of leading critical care and patient experience journals were manually searched, as were the reference lists of included studies. All evaluation studies of relevant intervention activities were included; all research designs and outcome measures were eligible. Due to heterogeneity in interventions, designs and outcome measures, the synthesis followed a narrative approach. Service users met with the research team termly.

Results Out of 4962 possible citations, a total of 20 studies were included. The overall evidence base was assessed as moderate to weak. Six categories of interventions were identified: environmental unit changes (n=2), web-based support (n=4), discussion-based support (n=6), multicomponent support (n=4), participation in rounds (n=3) and participation in physical care (n=1). Clinical and methodological heterogeneity across studies hindered meta-analysis, hence a narrative synthesis was pursued. Six main outcomes were identified, grouped under two categories: (i) involvement outcomes: communication (*mean difference* ranged from 6.39 to 8.83), decision-making (*mean difference* ranged from -0.8 to 5.85), satisfaction (*mean difference* ranged from 0.15 to 2.48); and (ii) health outcomes: family trauma (*mean difference* ranged from -7.12 to 0.9), family well-being (*mean difference* ranged from -0.7 to -4), patient outcomes (*relative risk* ranged from 1.27 to 4.91). The findings from the qualitative studies were thematically analysed to identify features of the interventions that participants perceived to influence effectiveness. Synthesised into five overarching categories (practicality, development, interaction, reflexivity and bridging), these can serve as principles to inform the future design and development of more refined family member involvement interventions.

Conclusions Future interventions should be developed with much closer family member input and designed by considering the key features we identified. We call for

Strengths and limitations of this study

- We completed a comprehensive mixed-method systematic review of available evidence on interventions for family member involvement in adult critical care.
- We involved a service users and carers group throughout the systematic review process, which included 16 hours of in-depth group discussions.
- Study screening, selection, quality assessment and data extraction were completed independently and in duplicate by two review authors.
- Methodological and clinical heterogeneity across studies prevented us from pursuing a meta-analysis.
- Qualitative evidence was synthesised thematically to identify features of the interventions that participants perceived to influence effectiveness.

future interventions to be multilayered and allow for a greater or lesser level, and different kinds, of involvement for family members. Choice of intervention should be informed by a baseline diagnostic of family members' needs, readiness and preparedness for involvement. **PROSPERO registration** CRD42018086325.

BACKGROUND

Family member involvement in healthcare is recognised by policy-makers and the public as an invaluable aspect of healthcare provision. The move towards the more structured integration of family members is consistent with the call for greater patient-centred care, long invoked by a (2001) report from the Institute of Medicine.¹ Emphasising the potential benefits in actively involving family members in decision-making processes and care management was regarded as a key contributor to the reduction of the risk of medical error and a broader improvement in quality. The idea that a 'fully-engaged' public² should be encouraged has also been evident in UK contexts; however, governmental scrutiny over the proceeding decade revealed that this has yet to be comprehensively realised. Two strategic reports from NHS England^{3 4}

explored a practical move towards a healthcare system which is built around the patient, incorporating families representing a key means of achieving this.

For the purposes of the present review, family member involvement refers to the activities of different professionals to improve care by ensuring family members are involved in decision-making, sharing of information, power and responsibility for patient needs and choices. Family member involvement is especially relevant in the intensive care unit (ICU), where it can have profound consequences for care decisions, delivery and outcomes; this is partly because ICU patients are rarely in a position to communicate directly with clinicians and recollect their ICU experience, which means that the responsibility for this often lies with their family members. While this is a concern in healthcare systems worldwide, and especially in the UK, a recent mixed-methods study found there is still great variation in family satisfaction across ICUs in England, Wales and Northern Ireland.⁵

Studies over the past decade have confirmed that family members can have a positive influence on a patients' care and recovery from ICU; but also that family members themselves can be affected even after discharge.^{6–11} In particular, within the first few days after ICU admission, family members can show signs of anxiety, depression and stress; report difficulties in understanding the information clinicians try to communicate with them, and those who suffered a bereavement are at risk of generalised anxiety, panic attacks, depression and post-traumatic stress disorder (PTSD).⁷ For example, one study⁶ surveyed family members of patients who have been in ICU to find that 90 days after discharge more than a third (34%) of them suffered from PTSD symptoms. In addition, they noted higher rates (48%) among those family

members who indicated the information they were given was incomplete.

While there is a growing evidence base on patients, family members and clinicians' perceptions of involvement in ICU care, we are still missing a standardised, evidence-based approach to facilitate this process. Indeed, a recent scoping review¹⁰ sought to investigate the extent and range of literature on this topic, finding evidence of a growth in papers with over 100 reports identified. However, they did not seek to assess the quality of the evidence nor did they examine the type of interventions available, and key features that foster effectiveness. While this is an area of growing interest, we are still unclear about the range and quality of interventions available to promote family member involvement in ICUs.

METHODS

Our review sought to answer the following question: What are the available interventions, and which are most effective, for fostering family member involvement in adult critical care settings? Four objectives were set: (a) undertake a comprehensive and systematic search of published and unpublished studies reporting on interventions that promote involvement in adult critical care; (b) robustly assess the quality of empirical evidence for all included studies; (c) generate a detailed description and synthesis of interventions and their associated outcomes; and (d) classify interventions and outcomes in order to develop a typology of interventions, outlining key factors that support or impede involvement.

Study eligibility criteria

We included evaluation studies of any design, including experimental and quasiexperimental studies, as well as action research, case study and ethnographic designs. We considered reports of any kind of interventions as long as they were intended to promote the participation of family members in adult critical care. We included studies that reported on a mixture of relevant outcomes, including standard measures such as the Hospital Anxiety and Depression Score (HADS); and non-standard but important indicators such as family satisfaction. We excluded non-evaluation papers and those with populations, outcomes and settings that did not match our brief. One study reported on a bundled intervention including awakening and breathing coordination, delirium monitoring and management, early mobility and family-centred care; this study had to be excluded because we could not discern outcomes specifically linked to the family involvement component of the bundle.

Search for evidence

We searched (June 2019) MEDLINE, EMBASE, CINAHL and the Cochrane Central Register of Controlled Trials following a systematic approach without date restriction. We also performed searches for clinical studies through the WHO Trials Registry. We hand searched recent back

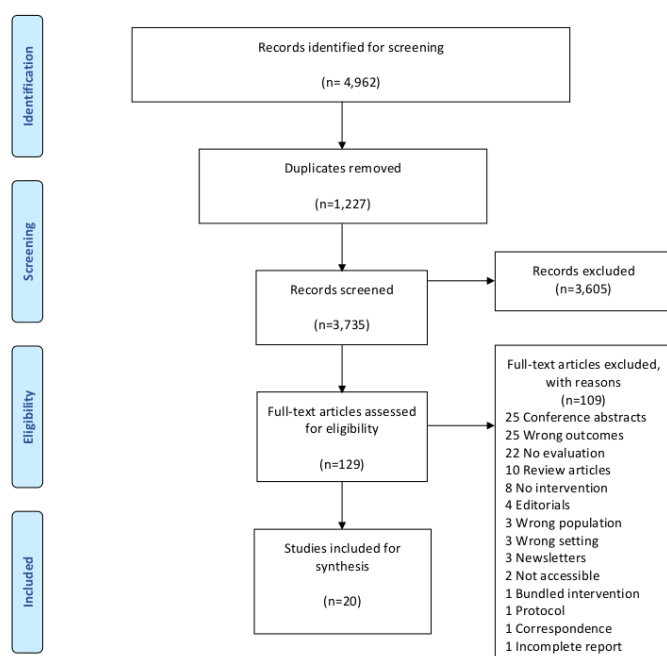


Figure 1 Flow diagram.

Table 1 Included studies

Author	Year	Country and setting	Design	Sample size	Research approach	Intervention
Allen <i>et al</i> ³²	2017	USA—surgical ICU	Non-randomised, before and after study	Patients: n=847 Family members: n=429	Quantitative	Engaging family members on rounds
Almoosa <i>et al</i> ²²	2009	USA—medical ICU	Prospective, two-centre observational study	Patients: n=85 Family members: n=85	Quantitative	Cariopulmonary Resuscitation (CPR) discussions
Choi and Bosch ¹⁶	2013	USA—neuro ICU and trauma ICU	Comparative observational study	Patients: n=81 Family members: n=81	Quantitative	Patient and family-centred unit design
Cray ²⁸	1989	USA—medical ICU	Post hoc evaluation study	Patients: n=76 Family members: n=76	Quantitative	Family intervention programme
Dalal <i>et al</i> ¹⁸	2015	USA—medical ICU (oncology unit)	Post hoc evaluation study	Patients: n=26 Family members: n=77	Quantitative	Patient-centred toolkit
Davidson <i>et al</i> ²⁹	2010	USA—mixed ICU	Feasibility study	Patients: n=30 Family members: n=22	Quantitative	Family support programme, based on facilitated sensemaking
Dykes <i>et al</i> ¹⁹	2017	USA—medical ICU	Non-randomised, before and after study	Patients: n=58 Family members: n=156	Quantitative	Patient engagement communication and technology (PROSPECT)
Ernecoff <i>et al</i> ²⁰	2016	USA—medical ICU	Qualitative interview study	Family members: n=30 Staff members: n=28	Qualitative	Tablet-based support tool
Garroute-Orgeas <i>et al</i> ²³	2016	France—surgical ICU	Randomised-controlled trial with nested qualitative study	Patients: n=100 Family members: n=88	Mixed-methods	Proactive participation of a nurse in family conferences
Hollman Frisman <i>et al</i> ²⁴	2018	Sweden—ICU	Qualitative interview study	Patients: n=8 Family members: n=10	Qualitative	Health-promoting conversations
Huang <i>et al</i> ²⁵	2018	USA—neuroscience ICU	Prospective, single-centred observational study	Family members: n=263	Quantitative	Primary care physician involvement in decision-making in the ICU
Huffines <i>et al</i> ²¹	2013	USA—surgical ICU	Non-randomised, before and after study	Family members: n=48	Quantitative	Family supportive care algorithm
Marshall <i>et al</i> ³⁰	2016	Australia—general ICU	Feasibility study	Family members: n=51	Qualitative	Multifaceted family-centred nutrition intervention

Continued

Table 1 Continued

Author	Year	Country and setting	Design	Sample size	Research approach	Intervention
Jacobowski <i>et al</i> ³³	2010	USA—medical ICU	Non-randomised, before and after study	Family members: n=111	Quantitative	Family rounds
Prichard and Newcomb ³⁵	2015	USA—trauma ICU	Quasi-experimental pilot study	Family members: n=30	Quantitative	Hand massage
Randall-Curtis <i>et al</i> ²⁶	2016	USA—general ICU	Randomised-controlled trial	Patients: n=168 Family members: n=268	Quantitative	Communication facilitator
Rippin <i>et al</i> ¹⁷	2015	USA—neuroscience ICU	Comparative observational study	Family members: n=54 Staff members: n=18	Qualitative	Family-centred unit design
Shaw <i>et al</i> ²⁷	2014	USA—general ICU	Non-randomised, before and after study	Patients: n=121 Family members: n=121	Quantitative	Multidisciplinary team training to enhance family communication in the ICU
Weber <i>et al</i> ³⁴	2018	USA—neuroscience ICU	Non-randomised, before and after implementation study	Family members: n=141	Quantitative	Family rounds
White <i>et al</i> ³¹	2018	USA—two neuro ICU, two mixed ICU, one medical ICU	Multicentre, stepped-wedge, cluster-randomised	Patients: n=1420 Family members: n=1106	Quantitative	Multicomponent family-support intervention

CPR, Cardiopulmonary resuscitation; ICU, intensive care unit; PROSPECT, Promoting Respect and Ongoing Safety through Patient Engagement Communication and Technology .

issues of key critical care and patient experience e-journals, scanned reference lists of identified reviews and included articles; searched our personal libraries and consulted with experts in the field. GoogleScholar was also searched. Non-commercially published (Grey) literature was sought through the OpenGrey and the GreyLit Report databases. A standardised search strategy was developed with the input of an information specialist and applied to all databases, utilising both MeSH and free-text terms (online supplemental file).

Data management, screening, extraction and quality assessment

Search results were imported into Covidence, the standard production platform for Cochrane Reviews. Two reviewers (AX and SF) independently screened all citations in duplicate against the inclusion criteria. Any disagreement was resolved through discussion or by involving a third reviewer (JP). Reasons for excluding papers read in full were recorded and a preferred reporting items for systematic reviews and meta-analyses

flowchart was completed. Standardised data extraction forms were used by two reviewers (SF and AX) to independently extract key information. Any disagreements found at this stage were also resolved through a consensus approach, or the involvement of a third reviewer (JP). We assessed each included paper for methodological rigour using an established rating approach utilised successfully in a number of previous mixed-method systematic reviews.^{12 13} This rating approach assesses ‘quality of study’ to consider: appropriate fit between study design/research questions and use of appropriate analyses; and, ‘quality of information’ to assess for a clear rationale for the intervention, good contextual information and risk of bias. Quality assessment was undertaken independently by two reviewers (AX and SF) in duplicate. For each quality domain, we described the procedures reported in the paper, using verbatim quotes as necessary.

Data synthesis

The overall approach to the synthesis followed a segregated methodologies approach.¹⁴ Accordingly, a separate

synthesis of quantitative and qualitative data was initially completed followed by a mixed-method synthesis. Quantitative studies were grouped depending on study design, and results summarised using descriptive statistics. Because heterogeneity precluded statistical combination through a meta-analysis, a narrative approach to the quantitative synthesis was pursued. Synthesis of qualitative data followed the best-fit framework approach, involving identification and grouping of thematic categories around factors influencing effectiveness of family member involvement interventions.¹⁵ The mixed-method synthesis utilised the quantitative data to inform on the measured effects, while the qualitative data informed on the perceived effects. In this way, the qualitative and quantitative data acted as complementary rather than as confirmatory of each other. A key element of the mixed-method synthesis was to classify interventions and outcomes in order to develop a typology of family involvement interventions in ICU. To develop the typology, we identified categories for the different interventions used in the studies by noting their distinguishing characteristics. We also formed and refined key family involvement features of the interventions, such as required time commitment from families and staff, opportunities and challenges, and cost. We tabulated these alongside an indication of the quality level of the current body of evidence, and the expected impact on important engagement and clinical outcomes. The typology was developed in collaboration with a service users and carers group over two face-to-face meetings, during which the overall findings of the review and ways of representing these visually were discussed. The resulting typology is illustrated in a matrix-like format presenting the intervention categories in a continuum from low to high involvement.

Patient and public involvement

From the outset, the development of this project was grounded in patient and public involvement (PPI) since family member involvement in ICU has been identified as a priority area for research by the James Lind Alliance (<http://www.jla.nihr.ac.uk>) through a priority setting partnership involving patients, carers and clinicians. ICU clinicians and patients raised our awareness on the lack of evidence-based advice on interventions that promote family involvement in ICU, and the challenges this introduces to daily practice. We included a PPI expert on our team (SB) and a frontline ICU clinician (MT) with whom we developed the project application and review protocol. We also invited feedback on our initial plans from the UK ICUSTeps Charity ensuring that the project was attuned to the sensitivities and concerns of service users. As part of the review process, a service users and carers group was established, the members of which were recruited through promotion in social media, the UK ICUSTeps charity and the National Institute for Health Research INVOLVE website. Consisting of eight ICU survivors and carers, the group was consulted through each step of the process and engaged in four strategically positioned meetings leading

to over 16 hours of focused and in-depth face-to-face discussions concerning the design, conduct, reporting and dissemination of the review. By having an engaged service user and carer group work with us throughout the completion of this review, we were able to look beyond the evidence by exploring the experiences and views of service users about the different interventions identified.

RESULTS

Overview of included studies

Search results

Out of 4962 possible citations, a total of 20 studies were included (figure 1). Published between 1989 and 2018, they were predominantly from North American contexts (n=17), and from a range of ICU settings including surgical, neuroscience, medical oncology and trauma ICUs. One study came from a French setting, and others from Swedish and Australian ICU settings.

Study designs

Most of the studies followed a quantitative approach (n=15), but we also included four qualitative and one mixed-methods study (see table 1). Specifically, quantitative studies included randomised-controlled trials, cluster-randomised and stepped-wedge trials, non-randomised before and after studies and prospective observational multicentre studies. Qualitative data from all studies came from semistructured interviews. Sample sizes across the quantitative studies ranged from 30 to 1106 family members; and in the qualitative studies from 10 to 54 family members.

Intervention types

Interventions were grouped based on their distinguishing characteristics (summarised in table 2), and positioned within a continuum of low to high involvement: (i) environmental unit changes (n=2),^{16,17} (ii) web-based support (n=4),¹⁸⁻²¹ (iii) discussion-based support (n=6),²²⁻²⁷ (iv) multicomponent support (n=4),²⁸⁻³¹ (v) participation in rounds (n=3)³²⁻³⁴ and (vi) participation in physical care (n=1).³⁵ Environmental unit change interventions consisted of complete structural redesign of an existing ICU with the specific objective being enhanced family member presence. Web-based and electronic interventions were approaches which utilised information and communication technology to facilitate information sharing and asynchronous communication. Discussion-based interventions generally consisted of one off or repeated face-to-face conversations which took place in the unit between family members and healthcare professionals. Multicomponent interventions comprised more than one technique to engage, educate and communicate with family members in the ICU. Family involvement in rounds interventions enabled the family members to attend and watch the daily rounds process, with opportunity to raise questions and clarify issues. Physical participation in care consisted of physical touch between

Table 2 Intervention characteristics

Author	Activity type	Intervention	Purpose	Procedure	Participants	Beneficiary	Outcomes
Allen <i>et al</i> 2017 ³²	Rounds based	Family member involvement in rounds	Engaging and integrating ICU patients' family members and surrogates on daily rounds	On admission to the ICU, a family member was invited to participate on daily rounds with the critical care team	Family members, nurses, physicians	Family members, nurses, physicians	<ul style="list-style-type: none"> ▲ Significantly increased family member knowledge ▲ Strengthened relationship between family members and doctors ▲ Nurses reported greater work enjoyment ▲ Improved communication ▲ Reduction in workload ▲ Increased support for patient and family-centred care ▲ Increased physician satisfaction post intervention
Almoosa <i>et al</i> 2009 ²²	Discussion based	Cardiopulmonary Resuscitation (CPR) discussions	The implementation of structured, informed CPR specific conversations with family members and surrogates from relevant physicians	Physician initiated CPR conversation about: chest compressions, electrical cardioversion, mechanical ventilation	Physicians, residents, fellows or family	Family members	<ul style="list-style-type: none"> ▲ Satisfaction with CPR discussions was higher after the intervention
Choi and Bosch 2013 ¹⁶	Unit design	Patient and family-centred unit design	Unit redesign undertaken to enable physical space to more broadly facilitate family interaction with patient, and family interaction with staff	The intervention unit included larger spaces and more comfortable accommodations for visitors	Family members	Family members and patients	<ul style="list-style-type: none"> ▲ Increased family interactions with patient ▲ Increased family interactions with staff
Cray <i>et al</i> 1989 ²⁸	Multicomponent	Family intervention programme	Multicomponent intervention to enhance family involvement in, and understanding of, their loved one's condition in ICU	Intervention components included: family conference, telephone conversation, visit by nurse, follow-up visit to the intermediary care unit	Family members, clinical nurse specialists	Family members	<ul style="list-style-type: none"> ▲ Strong agreement that the intervention helped family members to understand their loved one's illness and benefit other families ▲ High satisfaction with intervention components
Dalal <i>et al</i> 2016 ¹⁸	Web based/electronic	Patient-centred toolkit (PCTK)	The PCTK was a suite of web-based patient-facing and provider-facing tools designed to facilitate collaborative decision-making by providing access to tailored educational content and facilitating patient-provider communication	The PCTK was accessible by patients, caregivers and providers from any web-enabled device connected to the hospital's secure intranet	Patients and caregivers	Patients and family members	<ul style="list-style-type: none"> ▲ The majority of patients and caregivers surveyed were satisfied or extremely satisfied with the intervention
Davidson <i>et al</i> 2010 ²⁹	Multicomponent	Family-support programme, based on facilitated sensemaking	A systems-based patient-centred care and engagement programme	The intervention consisted of two main components: personalised instruction and provision of family visiting kits	Family members, Clinical nurse specialists	Family members	<ul style="list-style-type: none"> ▲ High rate of instrument reliability ▲ A breakdown of the top 10 needs of family members ▲ A ranking of interventions' helpfulness ▲ Identification of any additional needs

Continued

Table 2 Continued

Author	Activity type	Intervention	Purpose	Procedure	Participants	Beneficiary	Outcomes
Dykes <i>et al</i> 2017 ¹⁹	Web based/ electronic	Promoting respect and ongoing safety through patient engagement communication and technology (PROSPECT)	A systems-based patient-centred care and engagement programme designed to enhance patient and care partner experience in the ICU	60-min training session to facilitate patient-centred care in healthcare professionals. A web-based toolkit to apply the training, delivery of the patient satisfaction model from nurses to patients in ICU	Nurses and patients	Nurses and patients	<ul style="list-style-type: none"> ▲ Relative reduction in the rate of adverse effects ▲ Improvements in patient satisfaction ▲ Improvements in care partner satisfaction
Ernecoff <i>et al</i> ²⁰ 2016	Web based/ electronic	Tablet-based and video-driven communication and decision support tool	A tool was conceptualised to: (1) prepare the family for conversations with clinicians, (2) give clinicians tailored information about the family and patient in advance of the family meeting, (3) promote a personalised relationship between clinician and family, and (4) provide general decision support to surrogates	The sections of the tool for surrogates were: (1) orienting surrogates to the ICU, (2) explaining principles of surrogate decision-making, (3) providing a question prompt list and opportunity to write down questions, (4) a values clarification exercise, (5) education about treatment pathways (eg, life-prolonging treatment, comfort-focused treatment and a time-limited trial of ICU care), (6) eliciting surrogates prognostic information, and (7) providing psychosocial resources	Family members (surrogates)	Family members	<ul style="list-style-type: none"> ▲ Enhancing and supplementing communication between surrogates and the clinical team ▲ Leveraging surrogates' downtime before and between clinician-family meetings ▲ Helping surrogates to consider the patient's values and treatment options ▲ Allowing for repetition and review of information
Garrouste-Orgeas <i>et al</i> 2016 ²³	Discussion based	Proactive participation of a nurse in family conferences	Integration of nursing staff in family conferences focused around: naming emotions, expressing understanding, showing respect, articulating support for the patient and exploring the family's emotional state	All family members who wished to attend were escorted to the room. Briefly, an open question was asked first to encourage the family members to express themselves. A substantial proportion of the time was devoted to listening to the family, and the professionals used simple words to enhance comprehension. At the end of the conference, the family was allowed enough time to ask all the questions they had	Physicians, nurses, family members	Family members	<ul style="list-style-type: none"> ▲ Family members reported that the conferences allowed them to receive and assimilate information ▲ Be listened to regarding both their positive and negative feelings ▲ Receive compassion and respect

Continued



Table 2 Continued

Author	Activity type	Intervention	Purpose	Procedure	Participants	Beneficiary	Outcomes
Hollman Frisman <i>et al</i> 2018 ²⁴	Discussion based	(Nurse led) Health-promoting conversations with families	The aim of the conversations was to create a context for change related to the families' problems and resources	Discussion of the aim of the conversation series and the families' and nurses' expectations about the conversations and each other's roles. The three conversation sessions focused on topics that the families considered important, and the dialogue and questioning intended to identify resources within and outside the family. At the end of each conversation, the nurse offered a short reflection on how the family members had experienced the session. A closing letter was sent to the family 2–3 weeks after the last conversation to summarise further possibilities for reflection	Nurses and family members	Family members	<ul style="list-style-type: none"> ▲ Health-promoting conversations led to increasing emotional openness ▲ Enhanced consciousness regarding illness ▲ Greater family member satisfaction ▲ A valuable sense of confirmation ▲ General promotion of family well-being
Huang <i>et al</i> 2018 ²⁵	Discussion based	Primary care physician (PCP) involvement in decision-making in the ICU	The study evaluated survey results which measured family member satisfaction with general ICU care and shared decision-making between primary care physicians and family members	Examined involvement of the patient's primary care physician and shared decision-making	Primary care physicians	Family members	<ul style="list-style-type: none"> ▲ A higher proportion reporting PCP involvement felt completely satisfied with their inclusion in the ICU decision-making process
Huffines <i>et al</i> 2013 ²¹	Web based/ electronic	Family supportive care algorithm	The goal of the interventions in the 24-hour bundle was to inform families about the importance of their participation in decision-making and to inform them of the resources available to help them participate in decision-making	Within 24 hours of admission, a member of the intensivist team met with the family. Also within the first 24 hours after a patient's SICU admission, the patient's family was encouraged to watch an on-demand 10 min video. 72 hours: Reaffirm and ensure family is supported. Encouraged to participate in decision-making in rounds. 96 hours: Implement a family meeting with the multidisciplinary team.	Bedside nurses	Family members	<ul style="list-style-type: none"> ▲ Mixed to positive outcomes when measuring family satisfaction ▲ Staff teamwork ▲ Participation in decision-making ▲ Frequency of support

Continued

Table 2 Continued

Author	Activity type	Intervention	Purpose	Procedure	Participants	Beneficiary	Outcomes
Marshall <i>et al</i> 2016 ³⁰	Multicomponent	Multifaceted, family-centred nutrition intervention	To assist families in discussing nutritional goals with health professionals	Consisted of: family interviews, focused education sessions, and nutrition diaries	Dieticians, family nurses	Families and patients	<ul style="list-style-type: none"> ▲ Perceptions around how nutrition education can be improved ▲ The diversity of experience relating to the provision of in-hospital nutrition therapy ▲ Continuity of existing family member involvement approaches ▲ The importance of families as advocates
Jacobowski <i>et al</i> 2010 ³³	Rounds based	Family rounds	To enhance communication between medical and nursing staff and the families of ICU patients	The attending physician provided a summary for the family using understandable, lay language and the family was offered an opportunity to ask questions of the team	Physicians, nurses, family members	Physicians, nurses, family members	<ul style="list-style-type: none"> ▲ Communication regarding condition improved significantly as did decision-making support ▲ There was a decline in the number of family members who thought that they had sufficient time to address their questions and concerns
Prichard and Newcomb 2015 ³⁵	Physical	Hand massage	To provide physical relief to patients in the ICU through hand massage	Participants were taught to administer hand massage in compliance with the M technique, a registered method of simple, structured touch that has been used on critically ill patients with positive effects. For this study, the technique was used on hands. Participants applied the intervention twice daily for 5 min per session for 3 consecutive days	Family members, patients	Family members, patients	<ul style="list-style-type: none"> ▲ Anxiety was greatly reduced in the treatment group
Randall-Curtis <i>et al</i> 2016 ²⁶	Discussion based	Communication-facilitator	To understand the family's concerns, needs and communication characteristics	Consisted of facilitated: interviews, meetings, communication and emotional support; as well as facilitator participation in family conferences and 24-hour follow-up	Nurse or social worker trained to improve communication between the ICU team and the family by acting as a communication facilitator or navigator	Family members	<ul style="list-style-type: none"> ▲ Adjusted depression scores were lowered alongside ICU costs

Continued

Table 2 Continued

Author	Activity type	Intervention	Purpose	Procedure	Participants	Beneficiary	Outcomes
Ripppin <i>et al</i> 2015 ¹⁷	Unit design	Family-centred unit (FCU) design	Unit designed to prioritise and engage the family in the ICU context	The FCU physically integrated family into the fabric of the unit. Nurses worked between centralised nursing stations and decentralised alcoves just outside patient rooms for improved monitoring and safety. Rooms were larger (245 sq ft) with more space around the bedside	Nurses and family members	Family members	<ul style="list-style-type: none"> ▲ Reduction in problematic bedside copresence (or overcrowding) ▲ A continuity of preintervention distribution patterns in which nurse and family remained clustered in their respective 'domains' ▲ Nurse perspectives which acknowledged the unpredictability and complexity of the ICU and the subsequent mixed results which this newly implemented unit design encouraged
Shaw <i>et al</i> 2014 ²⁷	Discussion based	Multidisciplinary team (MDT) training to enhance family communication in the ICU	The training material was selected to improve communication. The training was also designed to foster team building and improve collaborative relationships among clinicians from multiple disciplines	Training included how to conduct and participate in patient/family conferences, addressing goals of care and giving critical information in the intensive care setting so that all caregivers might speak to patients and their families with a common voice. The training was designed to address known drivers of family satisfaction, as well as to address each of the 21 items being measured in the staff confidence survey	ICU team members	MDT team members and family members	<ul style="list-style-type: none"> ▲ Staff confidence and family satisfaction were shown to significantly improve
Weber <i>et al</i> 2018 ⁴⁴	Rounds based	Family rounds	To improve family satisfaction in ICU experience by integrating them into rounds processes	After each session, the nursing leader recorded (1) whether family rounds occurred (2), how many families participated, and (3) how many patients the ICU team had rounded on that morning	Nursing staff	Family members	<ul style="list-style-type: none"> ▲ Family reported improved satisfaction with decision-making, frequency of communication, receiving emotional support and with coordination of care ▲ Percentage improvements in satisfaction scores were not large enough to reach statistical significance
White <i>et al</i> 2018 ³¹	Multicomponent	Multicomponent family-support intervention	Collaborative intervention between nursing staff and family members designed to support caregivers in the ICU	Nurses received advanced communication training. A family-support pathway was instituted. Intensive support for implementation was provided to each ICU by a quality-improvement specialist to incorporate the family-support pathway into clinicians' workflow	Nursing staff, ICU team, family members	Family members and nursing staff	<ul style="list-style-type: none"> ▲ Significant improvements were noted with family satisfaction regarding: the quality of communication with clinicians, and ▲ The intervention led to an average reduction in the length of stay in the ICU of 3 days

CPR, Cardiopulmonary resuscitation; ICU, intensive care unit; PCP, Primary care physician.

family members and patients being utilised for reciprocal benefit.

Quality of evidence

The overall evidence base was assessed to be moderate to weak, with only a few exceptions of high-quality quantitative and qualitative studies (tables 3 and 4). The main weaknesses of the quantitative studies were related to inadequate randomisation and blinding, and lacking a control group for comparison purposes. The qualitative studies were in the main of a better quality, with key weaknesses being related to inadequate researcher reflexivity and theorisation of findings.

Quantitative results

Six main outcome categories were identified from the studies analysed for the review, grouped under two groups. Involvement outcomes: communication, decision-making, satisfaction; and health outcomes: family well-being, family trauma, patient outcomes. A summary of key results is provided below, with detailed reporting of outcome measures available in the tables; in online supplemental tables 1–6 the outcome measures are presented according to intervention type.

Involvement outcomes

Communication (table 5): improved communication was considered as an outcome in five studies,^{27 31–34} the majority of which involved family participation in rounds, reporting on four measurement tools. Three studies^{27 33 34} utilised the Family Satisfaction ICU (FS ICU 24) tool, specifically reporting on three dimensions: honesty of information, frequency of doctor communication and frequency of nurse communication. One study³¹ reported on the Quality of Communication tool and another used a self-developed questionnaire.³² Mean improvements were found in all studies, although not all results reached statistical significance. The biggest effect was seen on the frequency of doctor communication, with one study of family participation in rounds showing a statistically significant improvement of 60% (relative risk, RR: 1.60, CI: 1.18 to 2.17, $p=0.004$).³³

Decision-making (table 6): six of the included studies^{21 22 25 27 33 34} looked at decision-making as an outcome, most of which were discussion-based interventions, through six measurement tools. The ‘decision making’ subscale of the FS ICU 24 revealed improvements in three studies although only one,²⁷ targeting the whole interprofessional team, found a statistically significant result (MD: 5.85, $p=0.05$). Inclusion in decision-making was also considered, as the percentage change in family members reporting complete satisfaction or giving the highest score, with one study²⁵ which involved the patient’s primary physician showing a statistically significant improvement of 23% (RR: 1.23, CI: 1.03 to 1.49, $p=0.05$). Studies also noted improvements with regard to ‘control over patient care’ (RR: 1.31, CI: 1.07 to 1.61, $p=0.02$),²⁵ ‘support in decision-making’ (RR: 1.39, CI:

1.09 to 1.79)²¹ and ‘share in decisions about care planning’ (23%, RR: 1.52, CI: 1.03 to 2.24, $p=0.009$).²¹

Satisfaction (table 7): satisfaction was considered as an outcome in nine studies^{18 19 21 25 27 28 31 33 34} using six different measures, and reporting on a mixture of discussion-based, rounds-based, multicomponent-based and web-based interventions. The majority of studies ($n=4$) measured family satisfaction with care using the FS-ICU, while the remaining studies used self-developed tools. One of the studies¹⁹ also used the HCAHPS (Hospital Consumer Assessment of Healthcare Providers and Systems) Survey. This is a national, standardised, publicly reported survey of patients’ perspectives of hospital care in the USA. Mean improvements on the FS ICU were found in all studies, ranging from 1.49 to 5.7, although only one¹⁹ which used a web-based engagement intervention reached statistical significance (MD: 5.7, CI: 2.31 to 9.09, $p<0.05$). Statistically significant improvements were also noted on the HCAHPS (RR: 1.33, CI: 1.10 to 1.55, $p<0.05$).¹⁹

Health outcomes

Family well-being was considered through measurements for anxiety and depression.

Anxiety (table 8): four studies, which encouraged family participation in discussions and personal care, considered anxiety as an outcome^{23 26 31 35} using three different ways for measurement. Three studies^{23 31 35} used the HADS. The fourth study²⁶ used the Generalised Anxiety Disorder Assessment (GAD-7). All four studies identified a reduction in family members’ anxiety scores post the intervention, with the effect ranging from -0.34 to -4 . The minimal clinically important difference of HADS has been suggested to be between -1.5 and -2 ; therefore, the reduction noted in these papers could be of clinical significance. However, only two of these studies found statistical significance.^{23 35}

Depression (table 9): depression was an outcome also reported by three of the above studies^{23 26 35} using two measures. Two studies^{23 35} used the depression subscale of the HADS, while another²⁶ used the Patient Health Questionnaire (PHQ-9). Both studies that used the HADS identified a reduction in depression among family members, although only one²³ reached statistical significance ($p=0.04$) with a median reduction of 3.5. Results on the PHQ-9 also showed a statistically significant mean reduction in scores at 6 months (MD: -2.3 , CI: -4.30 to -0.42 , $p=0.01$).²⁶

Family trauma (table 10): three studies considered the impact of interventions (multicomponent-based, web-based and discussion-based) on family member ICU-induced trauma using four different measurement tools:^{23 26 31} PTSD Checklist, Impact of Event Scale (IES) and Peritraumatic Dissociative Experience Questionnaire. All three studies identified a trend showing a beneficial effect of family involvement interventions on severity of trauma through reduced severity scores, ranging from a reduction of -3 to -7 points on the various scales; however, none of these results reached statistical significance.



Table 3 Quality assessment—quantitative studies

Study id	Aim of evaluation	Research design	Sample size	Power calculation	Number of groups	Method of allocation	Allocation concealment	Blinding	Loss to follow-up	Data collection method	Significance measures	Data analysis method	Reported biases or confounders	Relevance	Ethics	Strength of design	Strength of numbers	Quality of information	Quality of study	Overall weighting
Allen 2017 ³²	+	-	-	-	-	-	-	-	-	-	+	+	+	+	+	?	?	?	?	Low
Almoosa 2009 ²²	+	+	+	+	-	-	-	+	+	+	+	+	+	+	+	?	?	?	?	Moderate
Choi 2013 ¹⁶	+	-	+	-	-	-	-	-	-	-	+	+	-	+	?	?	?	?	?	Low
Cray 1989 ²⁸	+	-	?	?	?	?	?	?	?	?	+	-	+	+	?	+	+	+	-	Low
Dalal 2016 ¹⁸	-	-	-	-	-	-	-	-	-	-	+	+	+	+	?	?	?	?	?	Very low
Davidson 2010 ²⁹	+	+	+	-	-	-	-	+	+	+	+	+	+	+	?	?	?	?	?	Moderate
Dykes 2017 ¹⁹	+	-	-	+	-	-	-	-	+	+	+	+	+	+	?	?	?	?	?	Low
Garroute-Orgeas 2016 ³³	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	Very high
Huang 2018 ²⁵	+	+	+	+	-	-	-	-	+	+	+	+	+	+	-	+	+	+	+	Moderate
Huffines 2013 ²¹	+	+	+	-	-	-	-	+	+	+	+	+	+	+	?	?	?	?	?	Moderate
Jacobowski 2010 ³³	+	?	+	+	?	?	?	?	+	+	+	+	+	+	?	+	+	+	?	Moderate
Marshall 2016 ³⁰	+	+	?	?	-	-	-	-	+	+	+	+	+	+	+	+	+	+	+	Moderate
Prichard 2015 ³⁵	+	?	+	?	-	-	-	?	+	+	+	+	+	+	?	+	+	+	?	High
Randall-Curtis 2016 ²⁶	+	+	+	+	+	+	+	?	+	+	+	+	+	+	+	+	+	+	+	Very high
Shaw 2014 ²⁷	+	+	+	+	?	?	?	-	+	+	+	+	+	+	?	+	+	+	?	High
Weber 2018 ³⁴	+	+	+	+	?	?	?	?	+	+	+	+	+	+	?	?	?	?	?	High
White 2018 ³¹	+	+	+	+	+	+	+	?	+	+	+	+	+	+	+	+	+	+	+	Very high

+, low concern; -, high concern; ?, unclear. Quality assessment tool elaborated in Xyrichis et al.¹³

Table 4 Quality assessment – qualitative studies

Study id	Relevance and usefulness										Overall weighting	
	Aim of evaluation	Sampling	Data collection	Data analysis	Research relations	Findings	Transferability	Ethics	Quality of information	Quality of study		
Ernecoff ²⁰	+	+	+	+	-	+	+	+	+	+	+	High
Frisman ²⁴	+	+	+	+	-	+	+	+	+	+	+	High
Garroute-Orgeas ²³	+	+	+	+	-	+	+	+	+	+	+	High
Marshall ³⁰	+	+	+	+	-	+	?	+	?	?	?	Moderate
Rippin ¹⁷	+	?	+	+	?	+	+	-	?	?	?	Low

*+, low concern; -, high concern; ?, unclear. Quality assessment tool elaborated in Xyrichis et al.¹³

Patient outcomes (table 11): three kinds of patient outcomes were reported in three studies involving multicomponent-based, web-based and discussion-based interventions: patient mortality,^{22 31} adverse events¹⁹ and length of stay.^{19 31} A statistically significant increase in mortality was reported in two studies; specifically one study found an actual percentage increase in the intervention group of 31% (RR: 4.91, CI: 1.55 to 15.51, p<0.05),²² while the other of 7.5% (RR: 1.27, CI: 1.09 to 1.48, p=0.008).³¹ A relative reduction in adverse events per 1000 patient days of 29% was also reported⁹ with an actual mean difference of -17 (CI: -6.95 to -27.05, p<0.05). Length of stay was examined in two studies with conflicting results: one reported a statistically significant reduction (MD: -0.77, CI: -0.69 to -0.87, p<0.001),³¹ while another did not find any statistically significant difference.¹⁹

Qualitative results

Features that influence effectiveness

The findings from the qualitative studies (n=5) were analysed thematically to identify features of the interventions that participants perceived to influence effectiveness. These included accessibility, simplicity, supplementarity, contextualisation, interprofessionality, consistency, relationship and confidence development. Synthesised into five overarching categories, these can serve as principles to inform the future design and development of more refined family member involvement interventions in ICU: (a) practicality, (b) development, (c) interaction, (d) reflexivity and (e) bridging. We present a high-level summary of these below, with a more detailed qualitative report to be made available in a forthcoming publication.

Practicality: identified as a theme in three studies,^{20 23 24} this included intervention accessibility, simplicity, long-term application and repetition. Practicality points to effective interventions needing to be readily available with clear instructions, which are as close to universally identifiable as possible. This may enable the intervention to be used as many times as necessary, benefiting family members over and beyond an individual encounter.

Development: in four studies^{17 20 24 30} developing family members' contextual knowledge, or insight, was particularly valuable for effective intervention delivery. Insight was key to developing shared understanding among all those engaged in the treatment process. Insight should go beyond an understanding of the patient's condition to encompass the diverse perspectives of healthcare professionals and the emotional strain which family members naturally undergo.

Interaction: three studies^{17 20 24} noted that interventions, either explicitly or implicitly, should encourage verbal and physical interaction between clinicians and family members. However, interprofessional discussions among ICU clinicians, and specifically between medical and nursing staff, appeared equally important. Interventions that foster quality interaction at all levels appear essential for the family to be coherently integrated into the structure of the ICU.

Table 5 Communication outcome measures

Study	Jacobowski <i>et al</i> 2010	Weber <i>et al</i> 2018	Shaw <i>et al</i> 2014	White <i>et al</i> 2018	Allen <i>et al</i> 2017
Intervention measure	Family rounds	Family rounds	Team training	Multifamily support	Family on rounds
FS ICU 24—frequency of nurse communication	% highest score Pre: 64% Post: 57% Change: -7%, p=0.30 RR: 0.89, CI: 0.70 to 1.12	% top scores Control: 62% Intervention: 78% Change: 16%, p>0.05 RR: 1.24, CI: 0.98 to 1.58	Mean score Pre: 79.2 Post: 87.18 Change: 7.98, p=0.04*		
FS ICU 24—frequency of doctor communication	% highest score Pre: 38% Post: 60% Change: 22%, p=0.004* RR: 1.60, CI: 1.18 to 2.17	% top scores Control: 43% Intervention: 56% Change: 13%, p>0.05 RR: 1.31, CI: 0.90 to 1.89	Mean score Pre: 67.86 Post: 76.69 Change: 8.83, p=0.04*		
FS ICU 24—honesty of information			Mean score Pre: 77.78 Post: 87.08 Change: 9.30, p=0.01*		
Quality of communication (QOC)				Mean score Control: 62.7 Intervention: 69.1 Change: 6.39, p=0.001* CI: 2.57 to 10.20	
Communication improvement					Pre: n=49 (100%) Post: n=47 (100%) Change 0%, p=0.68 RR: 1

FS ICU, family satisfaction intensive care unit; MD, mean difference; RR, relative risk.

Reflexivity: while effective interventions bring people together, three studies^{17 23 24} noted they should also benefit the individual family member, who has the opportunity for personal growth in the path towards meaningful family member integration. Specific examples of reflexivity in the featured interventions were identified in the confirmatory exchanges between family members and healthcare professionals, as family members were able to explore their own role within the ICU, the relationships which they had independently developed with their clinicians and how they could use this unique knowledge as a form of leverage in their communication with ICU professionals.

Bridging: effective interventions should also provide key and otherwise unavailable pathways to encourage family member integration. In two studies,^{20 23} the supplementary capacity, which effective interventions offer was of particular value when consistent or predictable communication could not be guaranteed. While information

availability is important, acknowledging the many difficulties which family members themselves face, and offering ways to overcome these, may ultimately enhance integration and experience.

Proposed typology

Utilising the learning gained from the current review, and the insights of our service users and carers group, we propose a typology of interventions (figure 2) to be considered when promoting family member involvement in ICU. Presented in a matrix, we position types of interventions along a continuum of low to high involvement (environmental unit changes, web-based support, discussion-based support, multicomponent support, participation in rounds and participation in physical care) along with their key characteristics (type of ICU, family time commitment, professional input, cost, opportunities and challenges), level of evidence (low, moderate and high) and impact on key involvement and health outcomes (satisfaction, decision-making, communication, family well-being,

Table 6 Decision-making outcome measures

Study	Huang <i>et al</i> 2018	Shaw <i>et al</i> 2014	Weber <i>et al</i> 2018	Jacobowski <i>et al</i> 2010	Huffines <i>et al</i> 2013	Almoosa <i>et al</i> 2009
Intervention measure	Primary physician involvement	Team training	Family rounds	Family rounds	Support care algorithm	Cardiopulmonary resuscitation (CPR) discussions
FS ICU 24—decision-making	Mean (SD) Control: 80.07 (12.76) Intervention: 81.06 (15.1) Change: 0.99, p=0.16 CI: -3.00 to 4.98	Mean score Pre: 77.47 Post: 83.32 Change: 5.85, p=0.05*	Mean score (SD) Control: 85.1 (16.3) Intervention: 88.6 (14.6) Change: 3.5, p=0.20 CI: -1.98 to 8.98			
Inclusion in decision-making	% completely satisfied Control: 61.4% Intervention: 75.9% Change: 14.5%, p=0.05* RR: 1.23, CI: 1.03 to 1.49			% highest score Pre: 66% Post: 76% Change: 10%, p=0.12 RR: 1.15, CI: 0.96 to 1.38		
Control over patient care	% completely satisfied Control: 55.6% Intervention: 73.6% Change: 18%, p=0.02* RR: 1.31, CI: 1.07 to 1.61					
Support in decision-making				% highest score Pre: 49% Post: 69% Change: 20%, p=0.005* RR: 1.39, CI: 1.09 to 1.79		
Share in decisions about care planning					% scoring excellent Pre: 45% Post: 68% Change: 23%, p=0.009* RR: 1.52, CI: 1.03 to 2.24	
Time to decision						Days mean (SD) Control: 7.4 (3.2) Intervention: 6.6 (6.5) Change: -0.8 days CI: -1.48 to 3.08

FS ICU, family satisfaction intensive care unit; MD, mean difference; RR, relative risk.

family trauma and patient outcomes). We completed an initial face and content validation with our project's service users group consisting of ICU survivors and family members, and advisory board consisting of ICU professionals, but would still caution that the typology remains in need of further empirical validation in different ICU settings.

DISCUSSION

The diverse nature of the family involvement interventions we identified, the heterogeneity of research designs

found and the varying methodological quality of available studies meant there was not a single intervention that stood out as the recommended way forward. Overall, the available evidence suggests that rounds-based interventions can benefit communication outcomes; multi-component and web-based interventions can increase family satisfaction and, discussion-based interventions can benefit decision-making and family well-being. However, interventions can be of varying cost, require different kinds and levels of input and time commitment

Table 7 Satisfaction outcome measures

Study	Huang <i>et al</i> 2018	Shaw <i>et al</i> 2014	Dykes <i>et al</i> 2017	Weber <i>et al</i> 2018	Huffines <i>et al</i> 2013
Intervention measure	Primary physician involvement	Staff teamwork training	Web-based engagement	Family rounds	Supportive care algorithm
FS ICU 24—global score	Mean (SD) Control: 84.91 (12.17) Intervention: 86.4 (11.76) Change: 1.49 p=0.16 CI: -2.14 to 5.12	Mean score Pre: 83.21 Post: 85.69 Change: 2.48 p=0.32	Mean score Pre: 84.3 (3) Post: 90 (1.9) Change: 5.7 p<0.05* CI: 2.31 to 9.09	Mean score (SD) Control: 86.0 (16.0) Intervention: 90.8 (10.7) Change: 4.8 p=0.20 CI: -0.12 to 9.72	
HCAHPS			% top score 9–10 Pre: 71.8% Post: 93.3% Change 21.5 p<0.05* RR: 1.33, CI: 1.10 to 1.55		
Support given				% top scores Control: 54% Intervention: 71% Change: 17% p>0.05 RR: 1.32, CI: 0.99 to 1.75	% scoring excellent Pre: 60% Post 75% Change: 15% p=0.14 RR: 1.23, CI: 0.91 to 1.65
Study	White <i>et al</i> 2018	Cray 1989	Dalal <i>et al</i> 2015	Jacobowski <i>et al</i> 2010	
Intervention measure	Multicomponent family-support programme	Family-support programme	Patient-centred toolkit	Family rounds	
Patient Perception of Patient Centeredness (PPPC)	Mean score Control: 1.8 Intervention: 1.7 Change: -0.15, p=0.006* CI: -0.26 to -0.04				
Satisfaction with intervention		% Satisfied 100% agreed (76/76)	% Satisfied 72% (13/18)		
Time to ask questions				% highest score Pre: 40% Post: 23% Change: -17%, p=0.02* RR: 0.57, CI: 0.37 to 0.90	

FS ICU, family satisfaction intensive care unit; HCAHPS, Hospital Consumer Assessment of Healthcare Providers and Systems; MD, mean difference; PPPC, Patient Perception of Patient Centeredness ; RR, relative risk.

from clinicians and family members, and impact on different kinds of outcomes. Given the current state of the evidence, we discourage proposing a single intervention as the ‘gold standard’ and instead encourage the use of our typology to inform decisions based on individual ICU teams’ context, needs and available resources.

At this stage, we suggest our typology is used as a reflective tool to aid ICU teams make evidence-informed decisions about potential interventions they may wish to consider adopting locally. In the first instance, teams are advised to discuss the kinds of engagement and/or clinical outcomes their unit wants to improve as a priority so they can focus and limit their choice of intervention types.

They could then consider the evidence level, cost and key opportunities and challenges offered by each intervention type to help them make fully informed decisions as well as manage expectations. Finally, they could consider the time investment expected of ICU professionals and of family members for the different intervention types; for example, in geographically remote areas where family visiting is a challenge and staff shortage is significant, the team may favour trialling an intervention with less time commitment.

Through focussing on the different types of available interventions, their associated involvement and clinical outcomes, features perceived to influence effectiveness,

Table 8 Anxiety outcome measures

Study	Garrouste <i>et al</i> 2016	Prichard and Newcomb 2015	White <i>et al</i> 2018	Randall-Curtis <i>et al</i> 2016
Intervention measure	Interprofessional family conference	Hand massage	Multifamily support	Communication facilitator
HADS—anxiety	90 days, median (IQR) Control: 8 [4.5–12] Intervention: 4 [1–9] Change: –4, p=0.01* % with anxiety score>8 Control: 52.3% (n=23) Intervention: 33.3% (n=14) Change: 19%, p=0.08 RR: 0.95, CI: 0.63 to 1.44	Mean change in score Control: –0.4 Intervention: –3.87 Change: –3.47, p=0.002* CI: –5.5 to –1.4		
HADS—global score			Mean score Control: 12.0 Intervention: 11.7 Change: –0.34, p=0.61 CI: –1.67 to 0.99	
GAD 7—anxiety				Mean score 3 months Control: 3.0 Intervention: 2.3 Change: –0.7, p=0.50 CI: –2.91 to 1.42 Mean score 6 months Control: 2.7 Intervention: 1.8 Change: –0.9, p=0.43 CI: –3.10 to 1.32

GAD-7, Generalised Anxiety Disorder Assessment; HADS, Hospital Anxiety and Depression Score; IP, interprofessional; MD, mean difference; RR, relative risk.

and proposing an overarching typology of family involvement interventions, the current review makes a significant contribution to the available literature. Past review work in this area largely focused on interventions that can support family members of critically ill patients;^{36–39} these included providing care and treatment options for family members to counter the negative effects arising out of a loved one being hospitalised, or dying, in ICU. Available

guidelines often suggest a long list of initiatives to support family members without full consideration or instruction on the contextual requirements of these suggestions or the kind of impact likely to be achieved by these. While prior reviews concluded, as have we, that the evidence in this field needs development and strengthening, these did not offer a granulated analysis of the evidence level for different kinds of interventions or presented these in

Table 9 Depression outcome measures

Study	Garrouste <i>et al</i> 2016	Prichard and Newcomb 2015	Curtis <i>et al</i> 2016
Intervention measure	Interprofessional family conference	Hand massage	Communication facilitator
HADS—depression	At 90 days, median (IQR) Control: 5.5 [1–11.5] Intervention: 2 [0–6] Change: –3.5, p=0.04* % sign. Depression score>8 Control: 38.6% (n=17) Intervention: 23.8% (n=10) Change: 14.8%, p=0.14 RR: 0.61, CI: 0.31 to 1.18	Mean change in score Control: –0.3 Intervention: –2.5 Change: –2.2, p=0.10 CI: –0.49 to 4.7	
PHQ-9 depression			Mean score 3 months Control: 4.9 Intervention: 3.1 Change: –1.8, p=0.09 CI: –3.89 to 0.31 Mean score 6 months Control: 4.7 Intervention: 2.4 Change: –2.3, p=0.01* CI: –4.30 to –0.42

HADS, Hospital Anxiety and Depression Score; IP, interprofessional; MD, mean difference; PHQ-9, Patient Health Questionnaire; RR, relative risk.

Table 10 Trauma outcome measures

Study	Garrouste <i>et al</i> 2016	Curtis <i>et al</i> 2016	White <i>et al</i> 2018
Intervention measure	Interprofessional family conference	Communication facilitator	Multicomponent family support
PDEQ	Median (IQR) Control: 14.5 ⁽¹¹⁻²³⁾ Intervention: 13 [0-17] Change: -1.5, p=0.17		
IES-R	At 90 days, median (IQR) Control: 24 [12.5-45] Intervention: 21 ⁽⁹⁻³³⁾ Change: -3, p=0.24		
IES-PTSD (0-88)		Mean score Control: 20.3 Intervention: 21.2 Change: 0.90, p=0.49 CI: 1.66 to 3.47	
PCL-PTSD			Mean score 3 months Control: 31.6 Intervention: 29.8 Change: -1.7, p=0.47 CI: -6.65 to 3.12 Mean score 6 months Control: 30.6 Intervention: 27.1 Change: -3.5, p=0.056 CI: -7.12 to 0.09

IES, Impact of Event Scale; MD, mean difference; PCL, Post-Traumatic Stress Disorder Checklist; PDEQ, Peritraumatic Dissociative Experience Questionnaire; PTSD, Post-Traumatic Stress Disorder.

a visual and user-friendly way to inform future work. Such work has helped spark the current movement around family involvement in ICU but remains somewhat limiting in that it does not adequately distinguish between family *support* and family *involvement*, often conflating the two. Consequently, conclusions of past work lack clarity on what can be done to involve as well as support family members.

We expect our typology to introduce some much-needed clarity in this field of research, as well as inform

the development of future interventions and research studies. Importantly, the typology may be used by individual ICUs to inform discussions among professionals, and with family members, about which kinds of family involvement interventions they may wish to adopt, trial and implement in their units.

We add to this field of research by adopting strict methodological standards in the current review, to reduce risk of reviewer bias and strengthen transparency. Many of the available guidelines for family involvement in ICU

Table 11 Patient outcome measures

Study	Almoosa <i>et al</i> 2009	White <i>et al</i> 2018	Dykes <i>et al</i> 2017
Intervention measure	Cardiopulmonary resuscitation (CPR) discussions	Multifamily support	Patient engagement
Death	Control: 8% (3/39) Intervention: 37% (17/45) Change: 31%, p<0.05* RR: 4.91, CI: 1.55 to 15.51	Control: 28.5% (249/873) Intervention: 36% (197/547) Change: 7.5%, p=0.008* RR: 1.27, CI: 1.09 to 1.48	
Length of stay		Mean days Control: 13.5 Intervention: 10.4 Change: -3.1, p<0.001*	Mean (median) (range) Pre: 4.9 (2) (1-108), n=881 Post: 5.0 (2) [1-115], n=904 Change: 0.1(0), p=0.61
Adverse events			Pre: 59/1000 patient days Post: 42/1000 patient days Change: -17, % reduction: 29% CI: -6.95 to -27.05, p<0.05*

RR, relative risk.

are based on a scoping review methodology, which can be methodologically limiting especially in lacking independent and duplicate screening, data extraction and quality assessment; though with notable exceptions.⁴⁰ A further way in which we sought to build on others' work was by examining the full spectrum of involvement interventions, rather than focussing on singular aspects such as decision-making. Moreover, we opted to include service users throughout the review process, rather than limiting their involvement to the final stages of peer checking results. This allowed our service users to contribute throughout the process, see how the review was developing, appreciate the technical side of the review process and of the available evidence and importantly to contribute actively in the development of the final typology.

The involvement of a service users and carers group led to us to identify a key, fundamental flaw of existing family involvement interventions and research: in our assessment, these tend to treat family members as a homogeneous group of individuals, rather than as heterogeneous units. Specifically, different family members may have different involvement needs and preferences influenced by their previous experiences, knowledge, mental and physical health and socioeconomic state. In addition, the notion of a family member extends beyond the 'next of kin' or 'personal consultee' to encompass extended family, carers and friends. Moreover, our service users emphasised that the dynamics within family units are

crucial to shaping the experience, benefit and satisfaction of family members with ICU care and their level of involvement.

Current family involvement interventions and initiatives appear to be applied in ICUs following a blanket approach, without adequate consideration of particular family members' needs and preparedness for involvement. This may result in some family members benefiting while others experiencing harm, which goes some way in explaining the wide CIs identified in our review that often cross the line of no difference. Indeed, within the PTSD literature, systematic reviews have long concluded that interventions applied universally to victims of trauma, such as compulsory debriefing, should cease and be replaced with a 'screen and treat' model.⁴¹ We therefore invite researchers and clinicians to consider the aforementioned issues carefully in future initiatives for involving family members in ICU.

The current review should be considered in the context of its limitations. These include lack of a meta-analysis, and research published in languages other than English, and from lower- and middle-income countries.

CONCLUSION

We examined interventions for family member involvement in ICUs, assessed the quality level of the available evidence, presented key results grouped by kinds of outcomes and interventions, and identified key features stakeholders

Intervention Types	Features	ICU setting	Family time commitment	Professional input	Opportunities & Challenges	Cost	Evidence level	Engagement outcomes			Clinical outcomes		
								Satisfaction	Decision making	Communication	Wellbeing	Trauma	Patient outcomes
Environmental unit changes Unit change interventions consisted of complete structural redesign of an existing ICU with the objective being enhanced family member presence		General	Low	Low	+ Communication + Interaction - Exposure - Privacy	High	Low	Low impact	Very low impact	Low impact	Very low impact	Very low impact	Very low impact
Web-based support Web based and electronic interventions were approaches which utilised information and communication technology to facilitate information sharing and asynchronous communication		General/ Specialist	Moderate	Moderate	+ Knowledge + Efficiency - IT proficiency	Moderate	Moderate	High impact	Low impact	Very low impact	Very low impact	Very low impact	Low impact
Discussion-based support Discussion based interventions generally consisted of one off or regular face to face conversations which took place in the unit between family members and healthcare professionals		General/ Specialist	Moderate	High	+ Support + Wellbeing + Decision making - Training	Moderate	High	Moderate impact	Very high impact	High impact	Moderate impact	Moderate impact	Low impact
Multicomponent support Multicomponent interventions comprised more than one technique to engage, educate and communicate with family members in the ICU		General/ Specialist	High	High	+ Family trauma + Pt outcomes - Complexity - Resources	High	High	Moderate impact	Very low impact	Low impact	Moderate impact	Low impact	Moderate impact
Participation in medical rounds Family involvement in rounds interventions enabled the family members to attend and watch the daily rounds process, with opportunity to raise questions and clarify issues		General ICU	High	Moderate	+ Knowledge + Efficiency - Time - Satisfaction	Low	High	Moderate impact	Very low impact	High impact	Low impact	Very low impact	Very low impact
Participation in physical care Physical participation in care interventions consisted of physical touch between family members and patients being utilised for reciprocal benefit		General ICU	High	Low	+ Satisfaction + Wellbeing - Confidence	Low	Low	High impact	Very low impact	Very low impact	Moderate impact	Very low impact	Very low impact

Figure 2 Typology of family involvement interventions.

perceived to influence intervention success. We summarised our results in the form of a typology, which we offer here as a first step towards developing a more systematic programme of research on interventions for family involvement in ICU. Based on the learning gained from the current review, we argue that future interventions should be developed with much closer family member input and designed by considering the key success features we identified. Importantly, we call for future interventions to be multilayered to allow for a greater or lesser level, and different kinds, of involvement for family members; the decision of which should be informed by a baseline diagnostic of family members' readiness and preparedness for involvement.

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