Patient, family-centred care interventions within the adult ICU setting

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Patient, family-centred care interventions within the adult ICU setting: An integrative review

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Abstract

Objectives: Patient, Family-Centred Care (PFCC) is internationally advocated as a way to improve patient care. The aim of this integrative review was to extend the knowledge and understanding by synthesising empirical evidence of PFCC interventions within the adult intensive care unit (ICU) setting.

Review method used: An integrative review methodological framework was employed, permitting the inclusion of all research designs. A comprehensive and systematic search, selection, quality appraisal,
Patient, family-centred care interventions within the adult

ABSTRACT

Objectives: Patient, Family-Centred Care (PFCC) is internationally advocated as a way to improve
patient care. The aim of this integrative review was to extend the knowledge and understanding by synthesising empirical evidence of PFCC interventions within the adult intensive care unit (ICU) setting.

**Review method used:** An integrative review methodological framework was employed, permitting the inclusion of all research designs. A comprehensive and systematic search, selection, quality appraisal, and data extraction of research was conducted to synthesise knowledge and identify research gaps.

**Data sources:** A systematic search of the following databases was conducted: MEDLINE; CINHAL; PsycINFO; Cochrane Library; Web of Science – Current Contents Connect; Web of Science – Core Collection; The Joanna Briggs Institute EBP Database; ProQuest Sociological Abstracts; and ProQuest Dissertation and Theses Global. Primary research in adult ICUs was included.

**Review methods:** Data extracted from the studies included authors, year, country of origin, design, setting, sample, intervention, data collection strategies, main findings, and limitations. Study quality was assessed using the Mixed Methods Appraisal Tool.

**Results:** Forty-two articles met the inclusion criteria and were included in the review. Only a third of the papers stated the theory underpinning their study. Three themes emerged, with interventions predominantly around *Interacting* with the target sample; *Culture and Connection*, and *Service delivery* interventions were also identified. Few studies integrated more than one dimension of PFCC.

**Conclusions:** Research into PFCC interventions is diverse; however, few researchers present a multi-dimensional approach incorporating a culture shift to enact PFCC throughout the ICU trajectory. There is an opportunity for future research to describe, develop, and test instruments that measure PFCC based on its multiple dimensions and not on one component in isolation. Importantly, for PFCC to successfully individualise quality patient care, a commitment and enactment of partnerships between health care professionals, patients, and family members is imperative.

**Keywords:** adult; critical care nursing; family-centred care; patient-centred care; patient, family-centred care; review literature; treatment outcome
1. Introduction

Engaging patients and families in health care is an imperative driven by health care providers in response, in part, to international organisations such as the World Health Organisation\(^1\) and national government priorities, together with professional critical care nurses organisations.\(^2\) Leaders of these organisations recognise the importance of partnering with health care recipients and, within Australia and elsewhere, require agencies to demonstrate where and how consumers of healthcare are involved.\(^1\).

The Australian Commission on Safety and Quality in Healthcare\(^5\) is explicit in the need for health care providers to have strategies in place to demonstrate their inclusivity of patients’ and families’ involvement to enable both individualised and optimum patient care.\(^7\)

Aside from the regulatory accreditation requirements placed on health care providers, within the critical care environment, families have long been recognised as a significant resource and viewed as legitimate receivers of nursing care. Family-centred care has evolved – initially from the paediatric area into adult care areas including Intensive Care Units (ICUs) – and in more recent times, the term “patient, family-centred care” (PFCC) is favoured within the ICU setting. PFCC makes clear that the patient is embedded in the family system and it is therefore essential to be inclusive of both patient and their family. The earlier terms of family-centred care and equally, patient-centred care, imply similar sentiments of empowerment for patients and their families. However, semantics are important and thus the inclusive term PFCC is advocated and used in this review. PFCC is defined as “an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families”.\(^8\) Family member is broadly defined in this review as whomever the patient considers his/her family member to be – someone with a lasting and sustained relationship with the patient.\(^9\)

Recently, Olding and colleagues\(^10\) conducted a broad review of 124 studies examining patient and family member involvement in ICU – an important concept underpinning PFCC. They described five elements of family and patient involvement: (i) presence, (ii) having needs met/being supported, (iii) communication, (iv) decision-making, and (v) contributing to care. They highlight, along with others,\(^7\) a lack of research into broader organisational factors that necessarily influence how and when
family members can be involved in care.

In order to progress PFCC, there is a need to understand how it is operationalised and, to date, this has not been well articulated. The authors of this integrative review aimed to extend knowledge and understanding by synthesising empirical evidence of PFCC interventions within the adult ICU setting in regards to the impact on ICU patients or families in, and beyond ICU, and to identify research gaps.

2. Methods

2.1 Design

An integrative methodological framework was employed, permitting the inclusion of all research designs, including experimental and non-experimental studies, and ensuring comprehensiveness. The review process was designed and conducted in consultation with the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) statement, and the Cochrane Handbook for Systematic Reviews of Interventions.

2.2 Definition of research terms

Following the definition of terms, appropriate search terms, key-words, and medical subject headings (MeSH), were identified. The recognised Problem, Intervention, Comparison/Control, Outcome (PICO) process framework was also applied to identify specific terms (Table 1). Searches of the following nine electronic databases were conducted in February 2016, and then again in April 2016: MEDLINE (via EBSCO); CINHAL (via EBSCO); PsycINFO (via Ovid); Cochrane Library; Web of Science – Current Contents Connect; Web of Science – Core Collection; The Joanna Briggs Institute EBP Database; ProQuest Sociological Abstracts; and ProQuest Dissertation and Theses Global (Supplementary Material). Searches were restricted to articles published in English. No date limitations were applied. Reference lists of included articles were searched, and studies known to be relevant were checked for their inclusion.

[Insert Tables 1]
2.3 Study selection

Empirical studies involving PFCC interventions with adult ICU patients or families, which were evaluated in terms of the impact on ICU patients or families in, and beyond ICU, were included. Studies were excluded if they were conducted in paediatric, emergency, coronary care, or cancer ICUs/departments. Following screening to remove duplicates, retrieved articles were assessed against inclusion/exclusion criteria (MM and FC), and full-texts of eligible studies sourced.

2.4 Methodological quality assessment

The methodological quality of all eligible studies was rated using the Mixed Methods Appraisal Tool (MMAT) – Version 2011. The MMAT can assess studies of varying research design, providing an overall quality score of zero, 25, 50, 75 or 100%, with a higher score indicating better quality. No studies were excluded based on their MMAT scores. Previous pilot work supports the content validity, efficiency, and reliability of the MMAT. Two team-members independently rated studies, with a third person used when consensus on assessment scores could not be reached.

2.5 Data extraction

A standardised data collection form, constructed with reference to Cochrane guidance, was used to extract the following data from eligible studies: author (year, country); design; sample; cohort; intervention; measures; main findings; limitations; and MMAT score.

2.6 Data analysis

Qualitative thematic analysis was undertaken in order to develop emergent themes from the patterns identified in the included studies. The analytic model used the processes of open coding, creating categories and abstraction for the development of themes on a manifest level (Boyatzis, 1998). The included articles were read and re-read independently by two researchers (MM, FC) with independent thematic analysis where data were grouped around central, recurrent ideas and themes.
144 (Boyatzis, 1998). The preliminary coding schema was discussed and revised and verified by the two
145 researchers before all data within each theme and sub-theme was examined and agreed to by all
146 research team members. This ensured the data themes were clearly based on the relationships and
147 linking across the different codes derived from the included studies. Boyatzis R (1998) Transforming
148 Qualitative Information SAGE, Thousand Oaks.
149
150 3. Results
151
152 From a total of 1,643 articles retrieved from the database searches and additional sources,
153 there were 955 unique records. Of these, 48 (5%) met all inclusion criteria and were assessed for
154 methodological quality on the MMAT. Based on the outcome of these assessments, 42 studies were
155 included in the integrative review (Figure 1).
156
157 [Insert Figure 1 and Table 2]
158
159 The articles were published between 1987 and 2016, with over half published since 2000
160 (n=29), and 14 since 2010 (Table 2). The studies emanated chiefly from the United States of America
161 (USA) (n=23), with four studies each from France and Australia. The research methods employed by
162 the researchers varied. However, quantitative methods predominated (n= 35), of which there were nine
163 randomised control trials, 14 before/after studies, and the remainder descriptive studies. There were
164 six mixed-method studies and one qualitative study (Table 2).
165
166 There were a wide spread of sample sizes: 11 studies had less than 50 participants; 13 had
167 greater than 150 participants, of which six had over 300 in the sample. There were five groups of
168 study participants: patients (n=1); family members (n=28); patients and families (n=7); family
169 members and nurses/health care professional (n=3); and patients, family members and nurses/health
170 care professional (n =3).
171
172 Authors of 15 studies (35%) stated the theory underpinning their research. There was broad
173 diversity: three used PFCC concepts - respect, collaboration, and support\textsuperscript{16-19}; two were founded on
174 systems theory\textsuperscript{20, 21}; and the remaining ten studies each used a different theoretical perspective. The
175 outcome measures were prominently psychological assessment instruments (e.g., State Trait Anxiety
Inventory; Hospital Anxiety Depression Scale) (n=15 studies), and family satisfaction (FSICU) and needs (CCFNI) (n=4 studies respectively).

3.1 Themes:

The essence of the study interventions were synthesised into themes, linking commonalities (Table 3). Three themes emerged and included Interacting, Culture and Connection and Service delivery with sub-themes developed for the first two themes as outlined below.

3.1.1 Theme 1: Interacting

[Insert Table 3]

The predominant theme was Interacting (n = 26, 62%),\(^{16, 18, 22-45}\) where study interventions were designed to have an effect or an action on study participants. According to the American Psychological Association’s Dictionary, interaction is defined as "a relationship between two or more people, systems or groups that results in mutual or reciprocal influence."\(^{46,}\) The verb, interacting therefore describes this action.

The studies within this theme were generally of high quality as assessed using the MMAT with 19 of the 26 scoring either 100% or 75%. There were four with 50% \(^{26, 32, 35, 41}\) and the final study\(^{18}\) scored 25%. The theme Interacting incorporated three sub-themes (Information, Communication and Education), with the interventions depicting engagement with families with varying degrees of reciprocity. For example, the Information interventions involved minimal intercommunication or cooperation with family members who were provided material and/or facts. In a large, multi-site French study, family members were provided with a standardised information leaflet with no other component to the intervention,\(^{22}\) and in Jones et al.,\(^{36}\) family members were provided with a manual for self-help on recovery from ICU.

The studies within the Communication sub-theme, however, clearly demonstrated intent to engender mutual exchanges beyond giving information or facts. De Havenon et al.’s\(^ {31}\) pilot study assessed audiovisual versus in-person family meetings in relation to family member satisfaction and decision-making. This intervention necessitated mutual exchange and communication amongst family members and ICU staff. Similarly, Burns et al\(^ {24}\) initiated social workers’ interviews of families...
deemed ‘at risk’ in order to preempt family needs and to enhance satisfaction with care and decision-making. The Education sub-theme illustrated interventions involving instructions as a part of a process of imparting or receiving knowledge by either family members,\textsuperscript{18} or staff,\textsuperscript{27, 39} or both.\textsuperscript{16}

3.1.2 Theme 2: Culture and Connection

The second theme Culture and Connection (n = 13),\textsuperscript{17, 19-21, 47-55} with four sub-themes (Presence, Action, Support and Partnering), included interventions that created a broad implementation of the values and philosophy of PFCC to promote engagement. The studies within this theme were also generally of high quality as assessed using the MMAT with 10 of the 13 scoring either 100\% or 75\%. There were two studies scoring 50\%\textsuperscript{52, 53} and the last study\textsuperscript{48} scored 25\%. These included interventions that centred on facilitating family members’ attendance at their critically-ill relative’s bed-side (Presence) or facilitating physical touch (Action\textsuperscript{54}). A number of interventions were directed specifically towards providing Support to family members in the form of psychological care,\textsuperscript{55} support groups,\textsuperscript{50} or daily clinics.\textsuperscript{52} Two studies incorporated family members as part of the patient’s treatment regime and demonstrated Partnering in care.\textsuperscript{17, 20}

3.1.3 Theme 3: Service delivery

The third theme of Service delivery (n = 5)\textsuperscript{48, 52, 56-58} included studies around ICU ward design\textsuperscript{48, 57, 58} and staff deployment in the form of a specialist nurse position aimed to reduce family member transfer anxiety.\textsuperscript{56} The studies within this theme had two studies with 100\%\textsuperscript{56, 57}, and one each scoring 75\%\textsuperscript{58}, 50\%\textsuperscript{52} 25\%\textsuperscript{48} as assessed using the MMAT. The relevant economic estimates were reported in one study,\textsuperscript{57} whereas others focused on family member or patient outcome measures, including satisfaction, time with their relative, and noise levels.\textsuperscript{48, 52, 56, 58}

4. Discussion

Currently, researchers have predominantly focused on individual features of PFCC and have in many studies achieved positive patient and/or family outcomes. What is uncertain, however, is if
the researchers reflect that their interventions are founded on principles of PFCC. Only one-third of authors stated their theoretical base, which limits understanding of PFCC within a broader context, including the effective transition of interventions into practice. This theoretical deficit may also be related to a lack of reliable measures of PFCC, as researchers draw on individual components rather than a multidimensional perspective. Previous research examining the psychometric properties of a scale developed for the paediatric population did not support the use of a modified scale for an adult population. We recommend further development of PFCC instruments to support the evaluation of rigorous interventional research to promote the manner in which we engage family and patients in care. From the 42 studies reviewed, three main themes emerge and include: Interacting; Culture and Connection; and Service delivery.

4.1 Interacting  

Interacting is a connection between parties that results in a shared effect, and three sub-themes were identified: Information; Communication; and Education.

4.1.1 Information  

Historically family members have been shown to experience high levels of anxiety and distress during their relative’s admission to ICU. Recently, Jones et al noted that psychological distress in patients correlated with psychological distress in family members. If family members are to be true collaborators in the care of the patient, they must be armed with adequate information to reduce their anxiety and enable them to make informed decisions and advocate for their relative. This is acknowledged as integral to the provision of PFCC. The studies within the Information theme provides further evidence that the admission of the patient to an ICU has significant impact on the family, and that they require information in a variety of formats throughout all stages of the patient’s illness, recovery, or death.

Despite variability apparent in the timing of information as an intervention (from pre-admission or early admission, during the patient’s ICU stay, on withdrawal of treatment,
on transfer to the ward,\textsuperscript{44} or discharge to home\textsuperscript{35}) the provision of information or understandable explanations in a ‘take-away’ format that families can revisit was found to be a positive strategy. Further, augmenting written information with face-to-face meetings appears to be effective in providing families with information that is personalised and tailored to their needs.\textsuperscript{22, 29}

As evident in this review, and a dedicated systematic review,\textsuperscript{63} the use of diaries or journals to improve family member’s psychological wellbeing appears a useful additional strategy to support family members during the patient’s ICU admission; this requires further exploration beyond initial qualitative studies.\textsuperscript{32, 35, 38, 63-66} It is evident that written patient progress in diaries and journals provide an information source, and an outlet for family members to personally customise the information received or to be recipients of customised information.

4.1.2 Communication

This sub-theme comprised studies where a comprehensive approach was adopted/tested to facilitate improved communication with patients or their families. If information giving is viewed as the first step in the pathway to PFCC, then communication extends the path. Communication is the exchange of information to create mutually understood meanings. This is evident in the reviewed studies where the majority addressed communication interventions or strategies to improve decision-making processes in the intensive care environment. This was achieved through: family conferences;\textsuperscript{23, 24, 28, 45} identification and mitigation of conflict in decision-making processes;\textsuperscript{24} structured communication pathways/bundles;\textsuperscript{26, 40, 43} and family attendance at rounds.\textsuperscript{33} Interestingly, the use of virtual technology to enhance communication with families\textsuperscript{31} showed no effect on family member satisfaction or patient outcomes, such as length of ICU stay – it may be that families would prefer face-to-face engagement and require time to consider the information provided, and implications of this for their critically-ill relative.

Importantly, the strategies evident in this theme were not single interventions but were delivered in a continual or phased manner throughout the patient’s ICU stay. Despite the variability evident in interventions tested, it is argued that the development of PFCC requires effective, ongoing
communication. This enables clinicians, patients and families to work to form common ground to develop mutually agreed health plans.  

4.1.3 Education  

Education can be defined as the process of imparting or sharing knowledge. In this context, the process of providing education to family members ranged from exchanges and education during dressings to comprehensive programs. The common element in the latter studies was the use of structured programs where clinicians were trained, family members were engaged and supported, and their responses were monitored. Although not all studies reported positive effects, it is suggested that family members experience a greater sense of control and greater participation in decision-making when they interact with clinicians through a continuous structured program intervention.  

4.2 Culture and Connection  

The theme Culture and Connection consists of four sub-themes: (1) Presence, (2) Action, (3) Partnering, and (4) Support, which provide evidence that a cultural shift to PFCC is both needed and gradual in its widespread adoption. Shared values with involvement of key stakeholders are essential; it takes time and whole-of-team commitment to be successfully adopted.  

4.2.1 Presence  

Interventions that focused on the Presence of family members in ICU were based on prior evidence suggesting an overall benefit of family members’ being in ICU for patients, nurses and themselves. ICU visitation is a topic that has been researched, discussed and debated for decades, and yet it still warrants investigation as it fails to be universally adopted. Importantly, the scope in the reviewed studies includes different stakeholder’s perspectives (patients, family members, nurses and physicians), or specifically facilitating child visitation. Child visiting in adult ICUs remains a contentious issue, despite evidence suggesting that it supports a child’s understanding of their family member’s critical illness.
Allowing families to be present at important moments/events, such as during brain stem testing, proved so successful in meeting families’ needs with no lasting adverse effects (90 days afterward), that the study was stopped prematurely and adopted into usual practice.\(^{53}\) It would be important to test the generalisability of this intervention beyond one ICU.

### 4.2.2 Action

Other researchers chose interventions to connect with families in different ways. One focused on family member’s *Action* by teaching them to massage their relative (under supervision) and suggested that this had a positive impact on patients’ vital signs and Glasgow Coma Scale scores.\(^{54}\) It needs to be questioned if the effect is linked to the family member or the intervention. Lack of detail regarding the intervention will make replication difficult.

### 4.2.3 Partnering

*Partnering* for care activities is yet another approach to enable PFCC.\(^{17,20}\) Mitchell et al\(^{17}\) developed a care bundle encompassing non-technical care activities for family members *Partnering* with nurses, whilst in others,\(^{20}\) the focus was on family members providing psychological support to their relative. In both scenarios, family member’s familiarity with the patient and *Partnering* with nurses supported delivering PFCC and improved outcomes for patients.

*Partnering* with families occurred in other ways including the importance of sharing the healthcare space (ICU).\(^{48,51}\) The unit layout of a neurological ICU included accommodation for families adjacent to the patient’s room, allocating private space for each family to retreat to if, and when, needed.\(^{51}\) This form of intervention functions to shift what is nurses’ ‘turf’ in the ICU,\(^{78}\) to one that needs to be negotiated. Allocating space to families when building ICUs allows healthcare to shift from a paternalist worldview with a patient attached to a family, to one where healthcare delivery acknowledges the patient as embedded in a family/social system and, thus, shifts healthcare delivery to a PFCC model in which the family is the natural partner of healthcare professionals.

### 4.2.4 Support

*Support* interventions were trialled with mixed results.\(^{50,52,55}\) Interestingly, White et al’s\(^{55}\) complex intervention offered family members emotional, communication, decision-making, and anticipatory grief support. A new nursing role was created that focused on developing longitudinal
relationships with families and clinicians and demonstrated that it is not the frequency of communications/interactions, but the quality that mattered.

4.3 Service delivery

Service delivery interventions have been developed and trialed to improve PFCC with mixed results. Whilst limited research was available, the specialist liaison-nursing role did not reduce patient and family anxiety around transfer from ICU.\textsuperscript{56} This may have been a consequence of study specific factors (e.g., limited hours for liaison nurse, sample size, tool reliability), or in relation to liaison nurse’s competing priorities around managing unstable patients and averting adverse events.\textsuperscript{56, 79, 80} In contrast, where service delivery included interventions designed to improve the physical environment, families were present more,\textsuperscript{48, 58} and their, and patients’ satisfaction, increased.\textsuperscript{58} However, offering a ‘relatives’ clinic’ did not significantly improve family satisfaction.\textsuperscript{52} This may be due to already high satisfaction,\textsuperscript{52} or that the intervention was designed around ICU schedules (between 2pm and 3pm) rather than around families.

Facility costs for the re-design of ICUs are significant. Importantly, consulting with past-patients and families from design inception is critical to implementing a PFCC perspective. The physical environment can not only foster a sense of wellbeing, but also drives consumer perceptions of service quality.\textsuperscript{81, 82} There is a need for further research to ensure the Intensive Care environment remains contemporary, inclusive and evidence-based.

5. Implications for research

This review has highlighted the lack of rigor in many of the studies, which do not theoretically contextualize their research. This provides an opportunity for future research to describe, develop, and test instruments that measure PFCC based on its multiple dimensions and not on one component in isolation, such as communication. Communication interventions exemplify PFCC only when they enhance family member and patient engagement in their health care plans and decisions in partnership with health care professionals. Enacting integration of this triad provides fertile ground for future
research. Similarly, PFCC culture needs to be articulated based on evidence, which is currently lacking. Understanding and progressing PFCC can only occur when outcome measures are relevant to physical and/or psychological benefits to patients and/or family members. A meta-analysis of studies using the same instrument, similar interventions, and outcomes measures could possibly resolve uncertainty of intervention effectiveness.

6. Limitations

There are several limitations including the inability to assess studies written in languages other than English, which may have introduced selection bias. Studies were included by the two lead authors independently and in consultation, with consideration that the intervention focussed on PFCC and, although they are experienced researchers in the field, there may have been important studies that others may have included. Conversely, being inclusive of studies that focused on a component of PFCC allowed us to provide a broad and comprehensive review of current intervention studies in the area of PFCC. It was deemed inappropriate to screen using the nine-item checklist utilised for the Cochrane review of family-centred care studies in paediatric settings which had its focus on children and parents.³³

Many of the reviewed quantitative studies were limited in their ability to show the true effect and generalisability of their interventions due to study designs, small samples, and single sites. The broad variety of participants, outcome measures, and instruments made comparisons difficult.

7. Conclusion

Multi-dimensional interventional research that is grounded in PFCC theory and provides strategies throughout and beyond the ICU trajectory are limited. This is the first integrative review to systematically examine PFCC interventions within the adult ICU population and thus adds to the body of knowledge. Current research focusses on individual aspects of PFCC, with few highlighting the need for a culture shift to see PFCC comprehensively enacted. Three themes emerged including Interacting, Culture and Connection, and Service delivery. Importantly, PFCC supports individualised
quality patient care, requires a commitment and the enactment of a culture of partnership between health care professionals, patients and family members, and exemplifies inclusivity and empowerment.

Acknowledgements

The authors warmly thank Vinah Anderson for help with data extraction and preparation of tabulated data. Thanks are also expressed to Katrina Henderson (Griffith University Healthcare Librarian) for her assistance in devising the search strategies.

Appendix A. Supplementary Material

Supplementary Tables associated with this article can be found online.
References


Records identified through database searching (n = 1,642)

Additional records identified through other sources (n = 1)
Known research n = 1

Records after duplicates removed (n = 955)

Records screened (n = 955)

Records excluded (n = 907)

Full-text articles assessed for eligibility (n = 48)

Records excluded based on full-text (n = 6)
Ongoing study n = 1; No intervention n = 1; Not patient/family-centered care n = 2; Did not meet MMAT screening questions n = 1; Not conducted in an Intensive Care Unit n = 1

Studies included in the review (n = 42)
Table 1
Definition of research terms used in the review.

<table>
<thead>
<tr>
<th>Research Term</th>
<th>Definition</th>
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<tbody>
<tr>
<td>Patient, family-centred care (PFCC)</td>
<td>PFCC is defined as “an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families”.⑧ Can include terms related to: Patient-Centred Care; Family-Centered Care; family nursing; ‘doing’ family; family facilitation; family intervention; carer involvement; family participation; and family involvement.</td>
</tr>
<tr>
<td>Intensive Care Unit (ICU)</td>
<td>Refers to the department in a hospital/or healthcare facility that provides intensive treatment medicine. Can include terms related to: Intensive care unit; Critical care unit; High dependency unit, or Critical Care Nursing.</td>
</tr>
<tr>
<td>Intervention</td>
<td>Any intervention identifiable as falling within the domain of PFCC. Can include terms related to: nursing interventions; strategies; bundles; innovations; partnerships; interactions; co-production; collaboration; teamwork; professional family relations; and professional patient relations. May include a control/usual care/comparison group.</td>
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<tr>
<td>Outcomes</td>
<td>Any outcome related to patients, families, treatment, or nursing. Can include outcomes in ICU, or at any time-point after discharge.</td>
</tr>
<tr>
<td>Patients</td>
<td>Any adult, aged ≥18 years of age, male or female, receiving treatment in an ICU.</td>
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<tr>
<td>Family member</td>
<td>Broadly defined as whomever the patient considers his/her family - someone with a lasting and sustained relationship with the patient. Can include terms related to: next of kin; relative; loved one; carer; family.</td>
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<tr>
<td>Author/Country</td>
<td>Design</td>
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<td>Abbasi et al., Japan</td>
<td>RCT</td>
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<tr>
<td>Azoulay et al., France</td>
<td>RCT</td>
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<tr>
<td>Banning, USA</td>
<td>Exploratory comparative design</td>
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patients; ICU nurses. A group of needs was consistently ranked as most important by family members.

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Setting</th>
<th>Participants</th>
<th>Methodology</th>
<th>Outcomes</th>
<th>Findings</th>
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<tbody>
<tr>
<td><strong>Bishop et al., 19</strong> USA</td>
<td>Pre-test, post-test design</td>
<td>Single site</td>
<td>$N = 72$</td>
<td>Education &amp; presence of family members during dressing changes.</td>
<td>PGSS - All metrics measured improved during the intervention period.</td>
<td>Including family members in care delivery, aids in optimizing patients’ outcomes. Reduced generalisability. Possible selection bias, family choice to participate. No random allocation or blinding. Conflict of interest not stated. HREC not reported.</td>
</tr>
<tr>
<td><strong>Black et al., 21 Northern Ireland</strong></td>
<td>Comparative time series design</td>
<td>Single site</td>
<td>$N = 170$</td>
<td>Nurse-facilitated family participation in psychological care of patients.</td>
<td>ICDSC (29 vs 77% scored &gt;4) TISS-28-no sig differences between groups SIP-Intervention group sig lower at all time points.</td>
<td>Family participation in the psychological care strengthened resistance against the stressors experienced by the patient during critical illness &amp; improved psycholo</td>
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<tr>
<td>Study</td>
<td>Design</td>
<td>Setting</td>
<td>Sample Size</td>
<td>Intervention</td>
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<tr>
<td>Bokinski et al., 2003</td>
<td>Pre-test, post-test design</td>
<td>Single site, N = 22 13 intervention 9 standard care</td>
<td></td>
<td>Implementation of a pretransfer conference to diminish the anxiety level of family members in a neuroscience ICU.</td>
<td>Pretransfer conferences significantly reduced anxiety in family members of ICU patients.</td>
<td></td>
</tr>
<tr>
<td>Burns et al., 2003</td>
<td>Quasi experimental design</td>
<td>Multi-site, N = 873 172 intervention 701 standard care ICU patients &amp; surrogates deemed to be at high risk for conflict.</td>
<td></td>
<td>Social workers interviewed families of patients deemed at high risk for decisional conflict &amp; provided feedback to the clinical team, who then implemented measures to address the problems identified.</td>
<td>The intervention did facilitate deliberative decision making in cases deemed at high risk for conflict. No impact on patient or surrogate satisfaction with care.</td>
<td></td>
</tr>
<tr>
<td>Chaboyer et al., 2007</td>
<td>Pre-test, post-test design</td>
<td>Single site, N = 115 patients</td>
<td></td>
<td>The liaison nurse provided practical care.</td>
<td>STAI – No differences. This study was unable to demonstrate generalisability. Reduced effectiveness was attributed to sample size.</td>
<td></td>
</tr>
</tbody>
</table>
(62 control, 53 intervention) 
N=100 families (52 control, 48 intervention).
ICU patients & families.

**Chavez & Faber, 1987**

<table>
<thead>
<tr>
<th>Study Details</th>
<th>Design</th>
<th>Setting</th>
<th>Sample Size</th>
<th>Intervention</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>USA</strong></td>
<td>Pre-test, post-test design</td>
<td>Single site</td>
<td>N = 40</td>
<td>A pre-visit education-orientation program was presented to the family member.</td>
<td>Bio factors – heart-rate-intervention on group sig lower. Interventions on group scored significantly higher in understanding diagnosis. SSS.</td>
</tr>
</tbody>
</table>

**An education-orientation program may be an effective initial intervention for alleviating family stress.**

- Reduced generalisability.
- Allocation concealment & blinding of patients not described.
- Nursed not blind to group allocation.
- Attrition not stated.
- Potential selection bias – some family members too distraught to provide consent. No power calculations.
- Inclusion/exclusion criteria not described.
- Conflict of interest not stated.
<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Site</th>
<th>Observational groups</th>
<th>Observational design</th>
<th>Intervention</th>
<th>Behaviours</th>
<th>Generalisability</th>
<th>Conflict of interest</th>
</tr>
</thead>
<tbody>
<tr>
<td>Choi &amp; Bosch, 2013</td>
<td>Between group observational design</td>
<td>Single site</td>
<td>N = 81</td>
<td>Intervention (neurological ICU)</td>
<td>Patients were observed on two wards. One was designed in a family-centred manner &amp; the other was a traditionally designed ICU ward.</td>
<td>Behaviour mapping - Patients in the family-centred care unit spent significantly more time with their family members in patient rooms than did patients in the traditional unit (M = 37.77 vs 23.89).</td>
<td>Reduced generalisability.</td>
<td>No blinding of assessors. Research grant from Academy of Architecture for Health – potential conflict of interest. HREC not reported.</td>
</tr>
<tr>
<td>Study</td>
<td>Intervention</td>
<td>Design Type</td>
<td>Setting</td>
<td>N</td>
<td>Families of Patients</td>
<td>Program Intervention</td>
<td>Evaluation Questions</td>
<td>Program Evaluation</td>
</tr>
<tr>
<td>-------------------------------</td>
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</tr>
<tr>
<td>Cray, 1989 USA 27</td>
<td>Observational design</td>
<td>Single site N = 76</td>
<td>Families of patients in a medical ICU</td>
<td></td>
<td>All families were offered a family education of ICU intervention program.</td>
<td>A structured &amp; well-planned family intervention program was designed to increase staff nurses’ knowledge &amp; sensitivity to the needs of families who are in crisis.</td>
<td>Program evaluation questions</td>
<td>The majority of families agreed classes were helpful.</td>
</tr>
<tr>
<td>Curtis et al., 2011 USA 28</td>
<td>Cluster RCT</td>
<td>Multi-site N = 824 524</td>
<td>Intervention</td>
<td>Education &amp; promotion of clinician behaviour</td>
<td>This quality-improvement intervention had Not blinded. Groups not balanced at baseline. Nurses</td>
<td>FSICUQ QD&amp;D LOS No significant</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
300 standard care  
Family members & nurses of patients dying in ICU or within 30 hours of discharge.

Daly et al., 1994<sup>29</sup>  
USA 30

Mixed methods design  
Single site  
N = 60

Of the two intervention groups, one group received a family ICU information booklet & the other received the booklet & had the option of attending a 1-hour family group session.

CCFNI STAI Qualitative evaluative questions
No statistically significant differences between groups.

Pamphlet & family sessions rated as helpful by most participants.  
Receiving information rated as the most important need by most families.

Reduced generalisability. No random allocation. Participant blinding not reported. Attrition not stated. Potentially under powered. Conflict of interest not stated. HREC approval not reported.

Daly et al., 2010<sup>28</sup>  
USA 29

Pre-test, post-test design  
Multi-site  
N = 489

Intensive Communication System was implemented - included a family meeting, held away from the bedside,  
LOS was not significantly reduced for the intervention group.  
No significant relations hip with

Strong evidence that the dynamics of decision making surrounding goals of care & aggressiveness of intervention.

No random allocation. Blinding not stated. Group demographics differed at baseline.

75%
| Davidso
n et al.,
2010<sup>30</sup>
USA 31 | Mixed methods
design | Single site
N = 22
Family members
of adult mechanically
ventilated ICU
patients. | Families were
provided a kit of
supplies & the
primary investigator
or coached families
on how to obtain
information, interpret
surroundings, &
participate in care. | CCFNI Family
support program
evaluation - all
items offered
within the
intervention were
found useful to
some family
members. | Families will use
this format of support
& find it helpful. The
journal was least
useful & personal
care supplies
given to the
family for use at the
bedside were most
helpful. | Reduced generalisability. No
blinding of outcome assessors.
Underpowered.
Hospital affiliations & funding
reported. | 100% |
| de Havenon
et al.,
2015<sup>31</sup>
USA 32 | Pilot between
group design | Single site
N = 88
29 intervention | Implementation of
family meetings
through skype | Family meeting
survey - no significant
An audio-visual
intervention was
welcome | Reduced generalisability.
Blinding not reported. | 25% |
conferences calling to increase family satisfaction & improve decision making. 60-70% of respondents responded positively to all questions. Family demographics not reported. Attrition not stated. Power calculations & inclusion/exclusion criteria not stated.

**Douglas et al., 1996**

USA

RCT Single site $N = 152$

100 intervention

52 standard care

Family of critically ill ICU patients.

Survival rates were compared between patients in a special care unit (SCU – low technology, family centred) & a traditional ICU. Survival analytic techniques – no differences in cumulative mortality rates. Significant cost savings are associated with using the SCU instead of the ICU. These savings can be accomplished with no loss of effectiveness, as measured by survival.

Reduced 100% generalisability. Allocation concealment & blinding not stated. Conflict of interest not stated.

**Garrouste-Orgeas et al., 2008**

France

Observational design

$N = 192$

149 family members

43 ICU staff members

To evaluate family & staff perceptions of unrestricted visitation.

HADS Reported perceptions of 24-hour visitation (family & staff). The 24-hr visitation policy was perceived favourably.

Reduced 100% generalisability. No blinding of outcome assessors. Validity assessments of
Family & staff of Medical surgical ICU patients. It induced only moderate discomfort among ICU workers, due to the potential for care interruption, in particular for nurses. Conflict of interest stated.

Garrouste-Oregeas et al., 2014 France

Grounded theory design

Single site

$N = 32$

Family members of medical-surgical ICU patients who were ventilated for longer than 48 hours.

A patient diary was completed by family members & staff while the patient was ventilated & given to the patient if they recovered or the family member otherwise.

Family member interviews for thematic analysis.

Three aggregate dimensions emerged: communication, emotional experience & humanization experience of staff & patient.

The diary served as a vector that connected the patient, family, & staff into a single coherent story. It contributed to support the family members in the ICU & to restore the functional & social role of the family.

Reduced generalisability. No blinding of outcome assessors. Attrition not stated. Conflict of interest or financial disclosure not reported.
<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Setting</th>
<th>Participants</th>
<th>Intervention</th>
<th>Instruments</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Halm et al., 1990³⁰</td>
<td>Mixed</td>
<td>Single site</td>
<td>Family members attended a 90-minute support group session to share feelings &amp; experiences in coping with illness.</td>
<td>Single site</td>
<td>25 intervention</td>
<td>Family interview for thematic analysis - <strong>Common Themes</strong>: 1. Satisfaction with nursing &amp; medical staff. 2. Reliving the illness experience. 3. Fear of the unknown. 4. Coping responses. 5. Acceptance of critical illness. Experimental group had a <strong>significant reduction in anxiety</strong> between pre &amp; post measures. Positive subjective perceptions of the support group from all experimental participants. Reducing generalisability. Allocation concealment not reported. Blinding of outcome assessors not reported. Attrition not stated. Difference in timing of data collection between groups may have produced bias. Underpowered. HREC approval not reported.</td>
</tr>
<tr>
<td>Jacob et al., 2016⁵¹</td>
<td>Mixed</td>
<td>Single site</td>
<td>Family members rated their needs as being met at a high level, unlike in prior studies in units with limitations on family visitation.</td>
<td>Single site</td>
<td>30 standard care</td>
<td>A continuous visitation policy was in place along with private family rooms with overnight facilities connected to patient’s room. Reduced generalisability. Only surveyed family members who spent a lot of time with patients. Newly renovated ICU with family facilities. Results may be different in older environment.</td>
</tr>
</tbody>
</table>
Jacobowski et al., 2010
USA34

Pre-test, post-test
design
Single site
N = 227
111 intervention
116 standard care
Family members of ICU patients.

Family rounds involved the family member being present during rounds whilst the multidisciplinary team presented patient information from the previous 24 hours.

FSICUQ - Overall satisfaction scores did not differ between families.

Participation in family rounds was associated with higher family satisfaction regarding frequency of communication with physicians & support during decision making. Participation decrease d satisfaction regarding time for decision making.

Reduced generalisability. No blinding. Poor explanation of power. Selection bias possible – participants self-selected. Financial support from health institutes.

Johnson & Frank, 1995
USA35

Pre-test, post-test design
Single site
N = 40
20 Intervention
20 standard care
Family of cardiac ICU patients.

A family member received a telephone call twice daily to inform them of the status of the patient.

STAI – greater reduction in anxiety for the intervention group (26.65 vs 9.5, p <0.05)
HADS
SF-36
IES

No between

High levels of psychological distress in patients were found to be correlated with high levels in

Reduced generalisability. Allocation concealment & blinding not reported. Small sample size. Reluctance of nurses to participate.
<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Setting</th>
<th>Intervention Details</th>
<th>Measures</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jones et al., 2004&lt;sup&gt;36&lt;/sup&gt;</td>
<td>Block RCT</td>
<td>Multi-site</td>
<td>A 6-week self-help manual containing information about recovery from ICU, psychological information &amp; practical advice, given 1 week after discharge.</td>
<td>STAI, HADS, SF-36</td>
<td>No difference was shown in the rate of depression, anxiety, or PTSD-related symptoms between the study groups. Patients, randomised to the rehabilitation manual reported improved physical recovery &amp; some degree of psychological benefit.</td>
</tr>
</tbody>
</table>
Jones et al., 2012[^35]

Observational pilot study

<table>
<thead>
<tr>
<th>Multi-site</th>
<th>N = 30</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intervention</td>
<td>15</td>
</tr>
<tr>
<td>15 standard care</td>
<td></td>
</tr>
<tr>
<td>Family members of ICU patients</td>
<td></td>
</tr>
</tbody>
</table>

Providing an ICU diary to patients & their relatives. Patients received their diaries 1 month post ICU discharge. PTSS-14 - a significant difference was found between groups at 3-month follow-up ($P = .03$). Providing patients with diaries is a simple & practical intervention that these results suggest may reduce the level of PTSD-related symptom for relatives of patients after critical illness.

Allocation concealment & participant blinding not reported. Possible selection bias. Conflict of interest not stated. Power calculations not reported.

Jorgerden et al., 2013[^58]
The Netherlands[^59]

Pre-test, post-test design

<table>
<thead>
<tr>
<th>Single site</th>
<th>N = 597</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intervention</td>
<td>278</td>
</tr>
<tr>
<td>319 standard care</td>
<td></td>
</tr>
<tr>
<td>Family members &amp; patients of an ICU</td>
<td></td>
</tr>
</tbody>
</table>

Patient & family members migrated from an old ward like ICU environment to a new 36 single room ICU environment featuring low noise, single rooms & improved family facilities. FS-ICU Family satisfaction increased from 69.5 to 74.1, $p = 0.02$. Patients satisfaction rates increased from 63.6 to 69.6, $p = 0.02$. Satisfaction with care. Satisfaction with decision-making.

Reduced generalisability. Blinding not reported. Groups not balanced at baseline. Possible selection bias.
<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Setting</th>
<th>Participants</th>
<th>Intervention</th>
<th>Outcome measures</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kirchhoff et al., 2008</td>
<td>Pre-test, post-test design</td>
<td>Single site</td>
<td>$N = 22$</td>
<td>A structured message was provided orally &amp; as written information based on 4 key terms related to withdrawal of life support.</td>
<td>Evaluation of experience of withdrawal: Significant differences between groups on only 2 questions. Profile of mood states-control had higher scores for negative mood but did not reach significance.</td>
<td>Reduced generalisability. Allocation concealment &amp; blinding not reported. Possible selection bias. Standardisation of message delivery not monitored.</td>
</tr>
<tr>
<td>Kloos &amp; Daly, 2008</td>
<td>Mixed methods design</td>
<td>Single site</td>
<td>$N = 91$</td>
<td>Family maintained a patient progress journal.</td>
<td>STAI Family interviews for thematic analysis: 1) positive &amp; negative family member emotions, 2) positive &amp; negative observations</td>
<td>Anxiety was significantly lower after 3 days but was not different by group. Nurses can affect uncertainty by adjusting the</td>
</tr>
<tr>
<td>Study</td>
<td>Design</td>
<td>Setting</td>
<td>Sample Size</td>
<td>Intervention</td>
<td>Outcome Measures</td>
<td>Key Findings</td>
</tr>
<tr>
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<tr>
<td>Knapp et al., 2013</td>
<td>Quasi-experimental design</td>
<td>Single site</td>
<td>N = 84</td>
<td>Staff were trained to guide families using a family bundle to assist them to evaluate, plan, involve, communicate &amp; support.</td>
<td>STAI Ways of coping questionnaire</td>
<td>Significantly higher coping score on two subscales for the intervention group - Distancing &amp; Accepting Responsibility. No significant difference between groups on state or trait anxiety. Reduced generalisability. Blinding of participants or outcome assessors not mentioned. Small sample size. All staff members did not complete education program.</td>
</tr>
<tr>
<td>Kondali et al., 2015</td>
<td>Quasi-experimental design</td>
<td>Single site</td>
<td>N = 112</td>
<td>Staff were trained in a set of care processes to be implemented during a patient's stay. The core</td>
<td>FS-ICU</td>
<td>No significant difference in family satisfaction between the pre- &amp; post- ICU stay. Reduced generalisability. No random allocation or blinding. Interventions group significantly longer ICU stay.</td>
</tr>
</tbody>
</table>
of neurological ICU patients. The intervention was a multidisciplinary family conference within 72 hours. Minimal increase in percentage of families reporting a family conference, from 46.5% to 52.5% following the intervention (p = 0.565).

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Setting</th>
<th>Intervention</th>
<th>Outcome</th>
<th>Allocation</th>
<th>Blinding</th>
<th>Confirmation</th>
<th>Mood Assessment</th>
<th>Financial Support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lautrette et al., 2007</td>
<td>RCT</td>
<td>Multi-site, N = 108</td>
<td>A proactive communication intervention consisting of a structured family end-of-life conference &amp; a 15-page bereavement information brochure.</td>
<td>IES HADS</td>
<td>Unclear</td>
<td>No</td>
<td>No</td>
<td>Disclosed</td>
<td></td>
</tr>
<tr>
<td>France</td>
<td></td>
<td>56 intervention, 52 standard care</td>
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<tr>
<td></td>
<td></td>
<td>Family members of dying ICU patients.</td>
<td></td>
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</table>

Staff compliance with intervention questionable. Power calculations not reported.
<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Sample Size</th>
<th>Intervention</th>
<th>Outcome Measures</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lynn-McHale et al., 1997</td>
<td>Pre-test, post-test design</td>
<td>$N = 183$</td>
<td>Pre-operative teaching (30 minutes) &amp; an ICU tour (15 minutes)</td>
<td>STAI Visual analogue scale, Patient perception of ICU tour questionnaire</td>
<td>Patients &amp; family of both groups had a decrease in anxiety on all measures after teaching, but there were no differences between groups - the decrease was not due to an ICU tour. The majority of patients perceived the tour as beneficial &amp; recommended a tour for future patients.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>87</td>
<td></td>
<td></td>
<td>No random allocation or blinding. Possible selection bias – non-tour group allocated because they were unable to tour. High rate of attrition.</td>
</tr>
<tr>
<td>Medland et al., 1998</td>
<td>Pre-test, post-test design</td>
<td>Single site $N = 30$</td>
<td>A structured communication program consisting</td>
<td>SWOC - significant difference on pre &amp; post</td>
<td>The intervention reduced the number of bereavement.</td>
</tr>
<tr>
<td>USA</td>
<td></td>
<td>15</td>
<td>intervention</td>
<td></td>
<td>Reduced generalisability. No random allocation. Possible</td>
</tr>
</tbody>
</table>
of 3 components: 1. Discussion with nurse 24 hours after admission, 2. Information brochure. 3. Daily phone call from patient’s nurse. 

**of calls from family members**, without compromising family satisfaction with care or access to information.

Daily incoming phone call count - sig more phone calls received per day from control group family members.

**Mitchell & Courtney 2004**

Pre-test, post-test design

Single site

N = 162

82 intervention

80 standard care

Families transferring from intensive care to a general ward.

A structured individualised transfer method

PPUS-FM

SAI MOS

SSS

Families at the time of transfer experience uncertainty & anxiety, which are significantly related. The intervention

Reduced generalisability. Blinding not reported. Degree of illness was significantly higher in the control group at baseline.
<p>| Mitchell et al., 2009 | Pre-test-post-test design | Single site intervention | Families were assisted with some of their relative’s care with nurses’ support &amp; individualised to suit each family. | FCCS Partnering with patients’ family significantly improved the respect, collaboration, support, &amp; overall scores. Intervention family members of patients perceived more respect, collaboration, &amp; support than did control family members. | Reduced generalisability. Convenience sampling &amp; baseline differences between groups (controlled for). Financial support disclosed. | 75% |</p>
<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Setting</th>
<th>N</th>
<th>Interventions</th>
<th>Data Collection</th>
<th>Findings</th>
<th>Strengths</th>
<th>Weaknesses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mitchell &amp; Aitken, 2016</td>
<td>Mixed methods design</td>
<td>Single site</td>
<td>N = 302</td>
<td>The intervention had patient visiting hours change from 9 h per day to 21 h.</td>
<td>FS-ICU Interviews, Focus groups, Research designed survey</td>
<td>More flexible visiting times can be incorporated into usual ICU practice in a manner that is viewed positively by all stakeholders.</td>
<td>Reduced generalisability.</td>
<td>Conveniences sampling may have led to selection bias. No assessment on staff accommodation of flexible visiting hours. Financial support disclosed.</td>
</tr>
<tr>
<td>Australia 20</td>
<td></td>
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</tr>
<tr>
<td>Nicholson et al., 1993</td>
<td>Pilot study</td>
<td>Single site</td>
<td>N = 20</td>
<td>Child visitation intervention.</td>
<td>MAS PCS STAI Mood adjective checklist LES FFS</td>
<td>The intervention group experienced a significant reduction in perceived behavioral &amp; emotional changes compared with those in the standard</td>
<td>Reduced generalisability.</td>
<td>No random allocation. Blinding &amp; attrition not reported. Financial support disclosed.</td>
</tr>
<tr>
<td>USA 22</td>
<td></td>
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</tbody>
</table>
Steel et al., 2008\textsuperscript{52} UK53

Quasi-experimental

Single site  
$N = 149$

intervention  
70 standard care  
Family members of patients in an ICU.

 Relatives invited to attend family clinic sessions. Flyers left in the waiting room.

CCFSS No significant difference between groups on satisfaction. Most participants from both groups were satisfied or very satisfied.

Reduced generalisability. No random allocation. Blinding not reported. No baseline comparison conducted. Selection bias possible. Under powered.

Tawil et al., 2014\textsuperscript{53} USA54

RCT

4 ICU’s in one hospital  
$N = 58$

intervention  
38 standard care  
Family members of ICU patients undergoing brain death evaluation.

Presence or absence at bedside throughout the brain death evaluation with a trained chaperone.

IES GHQ Understanding brain death questionnaire

Family presence during brain death evaluation improves understanding of brain death with no apparent adverse impact on psychological well-being.

Allocation concealment & blinding not reported. Financial support disclosed. Families’ allocation to present condition had longer stays than absent condition.

Vahedian-Azimi et al., 2014\textsuperscript{54} Iran55

RCT

Single site  
$N = 90$

intervention  
45 Vital signs - Systolic BP, Diastolic BP,

60-minute full body massage by a trained family members had several Massage via family members had

Reduced generalisability. Financial support disclosed.
| White et al., 2012 | 155 USA56 | Mixed methods design | Single site | The intervention delivered | PPPCC KADL LOS QOC DSS DCS Mortality Semi structure interview s. | Intervent ion was feasible, acceptable, & perceived by clinicians & surrogates to increase families’ ability to articulate the patients’ values. | Reduced 100% generalisability. No blinding or power calculations reported. No control group to examine the effectiveness of the intervention. Possible selection bias. Financial support disclosed. |
|---|---|---|---|---|---|---|---|---|
| N = 45 | patients | 15 family | 15 staff | Incapacitated ICU patients | at high risk of death or functional impairment. | 4 kinds of support: emotional support, communication support, decision support, & anticipatory grief support. | | |
| 45 standard care ICU patients with a long stay (>10 days). | family member. | Respiratory rate, Pulse Rate & GCS | \(49\) | |

Notes: AIP = The Assessment of Information Provided; CCFNI = Critical Care Family Needs Inventory; CCFSS = Critical Care Family Satisfaction Survey; DCS = Decisional Conflict Scale; DSS = Decision Self-Efficacy Scale; FCCS = Family Centred Care Survey; FFS = Family Functioning Scale; FS-ICU = Family Satisfaction in the ICU Questionnaire; GCS = Glasgow Coma Scale; GHQ = General Health Questionnaire; HADS = Hospital Anxiety & Depression Scale; ICDSC = Intensive Care Delirium Screening Checklist; IES = Impact of Events Scale; KADL = Katz Activities of Daily Living; LES = Life Event Scale; LOS = Length of Stay; MAS = Manifest Anxiety Scale; MOS SSS = The R&L Medical Outcomes Study, Social Support Scale; MMAT = Mixed Methods Appraisal Tool; NMI = Needs Met Inventory; PCS = Perceived Change Scale; PGSS = Press Ganey Satisfaction Survey; PPPCC = Patient-Perceived Patient Centeredness of Care Measure for Surrogate Decision Makers; PPUS-FM = Uncertainty in Illness – Family; PTSS = 14-Post Traumatic Stress Syndrome 14; QD&D = Quality of Death & Dying; QOC = Quality of Communication; SA1 = State Anxiety Inventory; SF-36 = Short Form-36; SIP = Sickness Impact Profile; SSS = Subjective Stress Scale; STAI = State Trait Anxiety Inventory; SWOC = Satisfaction With Overall Care Questionnaire; TISS-28 = Therapeutic Intervention Scoring System-28.
Themes and sub-themes identified from reviewed articles \((n = 42)\).

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<tr>
<th>Themes by Title ((n = _____))</th>
<th>Sub-Themes</th>
<th>Studies per Sub-Theme ((n = _____))</th>
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<td>Action</td>
<td>1</td>
<td>Vahedian-Azimi et al. (2014).55</td>
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<td>Support</td>
<td>3</td>
<td>White et al. (2012),56 Halm et al. (1990),51 *Steel et al. (2008).53</td>
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<td>Partnering</td>
<td>2</td>
<td>Mitchell et al. (2009),18 Black et al. (2011).21</td>
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Notes: *Studies allocated to two themes/sub-themes

Supplementary material - Search strategy.

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<td></td>
<td>#3 (MH &quot;Intensive Care Units&quot;)</td>
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#4 (MH "Intensive Care")
#5 (MH "Critical Care")
#6 (MH "Critical Care Nursing")
#7 (AB "person centered care" OR TI "person centered care" OR AB "person centred care" OR TI "person centred care" OR AB "family centered care" OR TI "family centered care" OR AB "family centred care" OR TI "family centred care" OR AB "patient centered care" OR TI "patient centered care" OR AB "patient centred care" OR TI "patient centred care")
#8 (AB "famil* nurs*" OR TI "famil* nurs*" OR AB "do* family" OR TI "do* family" OR AB "famil* facilit*" OR TI "famil* facilit*" OR AB "famil* intervent*" OR TI "famil* intervent*" OR AB "carer* involv*" OR TI "carer* involv*" OR AB "famil* participat*" OR TI "famil* participat*" OR AB "famil* involv*" OR TI "famil* involv*")
#9 (AB "Intensive care unit*" OR TI "Intensive care unit*" OR AB "Intensive care" OR TI "Intensive care" OR AB "Critical care" OR TI "Critical care" OR AB "Critical care unit*" OR TI "Critical care unit*" OR AB "Critical care nursing" OR TI "Critical care nursing" OR AB "High dependency unit*" OR TI "High dependency unit")
#10 (AB "treatment* outcome*" OR TI "treatment* outcome*" OR AB "nurs* outcome*" OR TI "nurs* outcome*" OR AB "patient* outcome*" OR TI "patient* outcome*" OR AB "famil* outcome*" OR TI "famil* outcome*" OR AB "effect*" OR TI "effect")
#11 (AB "kin" OR TI "kin" OR AB "relative*" OR TI "relative*" OR AB "loved one*" OR TI "loved one*" OR AB "carer*" OR TI "carer*" OR AB "critically ill patient*" OR TI "critically ill patient*" OR AB "family member*" OR TI "family member*" OR AB "significant other*" OR TI "significant other")
#12 (AB "nurs* intervention*" OR TI "nurs* intervention*" OR AB "strateg*" OR TI "strateg*" OR AB "innovation" OR TI "innovation" OR AB "bundle*" OR TI "bundle")
#13 (AB "partner*" OR TI "partner*" OR AB "interact*" OR TI "interact*" OR AB "co-product*" OR TI "co-product*" OR AB "collaborat*" OR TI "collaborat*" OR AB "teamwork" OR TI "teamwork" OR AB "professional famil* relations*" OR TI "professional famil* relations*" OR AB "professional patient* relations*" OR TI "professional patient* relations*")
#14 (#1 OR #2 OR #7 OR #8)
#15 (#3 OR #4 OR #5 OR #6 OR #9)
#16 (#10 OR #11 OR #12 OR #13)
#17 (#14 AND #15 AND #16)

CINAHL Plus with Full text (EBSCO Host)
#1 (MH "Patient Centered Care")
#2 (MH "Family Centered Care")
#3 (MH "Intensive Care Units")
#4 (MH "Critical Care")
#5 (MH "Nursing Outcomes")
#6 (MH "Nursing Interventions")
#7 (AB "person centered care" OR TI "person centered care" OR AB "person centred care" OR TI "person centred care" OR AB "family centered care" OR TI "family centered care" OR AB "family centred care" OR TI "family centred care")
At least 88,000 articles were identified. Of these, 1,000 were selected for further scrutiny. The study team identified 153 unique articles that met the inclusion criteria.

The research question was addressed in 138 of the included articles, with 15 being excluded due to methodological limitations or data availability. The themes emerging from the analysis were grouped into five categories: (1) "person centered care," (2) "family centered care," (3) "patient centered care," (4) "treatment outcome," and (5) "family involvement in care decisions." Each category was further refined to include specific subtopics such as "nursing interventions," "strategies," "collaboration," and "partnerships." The analysis also highlighted the importance of "kin" and "significant other" in patient-centered care.

The study findings suggest that there is a growing body of research on family-centered care, particularly in the context of intensive care units. The research questions addressed include the effectiveness of interventions, the role of healthcare professionals, and the impact on patient and family outcomes. The analysis also underscores the need for more research on the experiences of family members and the implications for nursing practice.

The study has several limitations, including the potential for selective bias in the literature selection process. Despite these limitations, the findings provide valuable insights into the complex interplay between patient, family, and healthcare provider perspectives in the intensive care setting.
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<th># &amp; Topic/Title</th>
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Web of Science: Current Collection
[Limiters: English Language]
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| EBP Database (Ovid) | #3 (Map to subject heading [intensive care units/])  
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|                     | #5 (Map to subject heading [critical care/])  
|                     | #6 (Map to subject heading [nursing/])  
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|                     | #8 ("famil* nurs*, tx, or famil* nurs*, ti or do* family, tx, or do* family, ti, or famil* facilit*, tx, OR famil* facilit*, ti, or famil* intervent*, tx, or famil* intervent*, ti, or carer* involv*, tx, or carer* involv*, ti, or famil* participat*, tx, or famil* participat*, ti, or "famil* involv*", tx, or "famil* involv*", ti.)  
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|                     | #15 (#3 OR #4 OR #5 OR #9)  
|                     | #16 (#6 OR #10 OR #11 OR #12 OR #13)  
|                     | #17 (#14 AND #15 AND #16)  
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|                     | #2 AB,TI, SU("famil* nurs*") OR AB,TI, SU("do* family") OR AB,TI, SU("famil* facilit*") OR AB,TI, SU("famil* intervent*") OR AB,TI, SU("carer* involv*") OR AB,TI, SU("famil* participat") OR AB,TI, SU("famil* involv*")
#3 AB,TI, SU("Intensive care unit") OR AB,TI, SU("Intensive care") OR AB,TI, SU("Critical care") OR AB,TI, SU("Critical care unit") OR AB,TI, SU("Critical care nursing") OR AB,TI, SU("High dependency unit")
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#9 (#4 OR #5 OR #6 OR #7)
#10 (#3 AND #8 AND #9)

Notes: CINAHL = Cumulative Index of Nursing and Allied Health Literature; MH = MeSH 2015; AB = Abstract; TI = Title; SU = Subject heading; ab = Abstract; ti = Title; kw = Keyword; tx = Text

All databases were searched between 3rd and 4th of February 2016, and then again on 24th and 25th of April 2016 for recency of results.