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Citation for published version:

Digital Object Identifier (DOI):
10.1016/j.aucc.2016.08.002

Link:
Link to publication record in Edinburgh Research Explorer

Document Version:
Peer reviewed version

Published In:
Australian Critical Care

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

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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.\(^1\).\(^3-6\) 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.
3. Results

From a total of 1,643 articles retrieved from the database searches and additional sources, there were 955 unique records. Of these, 48 (5%) met all inclusion criteria and were assessed for methodological quality on the MMAT. Based on the outcome of these assessments, 42 studies were included in the integrative review (Figure 1).

The articles were published between 1987 and 2016, with over half published since 2000 (n=29), and 14 since 2010 (Table 2). The studies emanated chiefly from the United States of America (USA) (n=23), with four studies each from France and Australia. The research methods employed by the researchers varied. However, quantitative methods predominated (n= 35), of which there were nine randomised control trials, 14 before/after studies, and the remainder descriptive studies. There were six mixed-method studies and one qualitative study (Table 2).

There were a wide spread of sample sizes: 11 studies had less than 50 participants; 13 had greater than 150 participants, of which six had over 300 in the sample. There were five groups of study participants: patients (n=1); family members (n=28); patients and families (n=7); family members and nurses/health care professional (n=3); and patients, family members and nurses/health care professional (n =3).

Authors of 15 studies (35%) stated the theory underpinning their research. There was broad diversity: three used PFCC concepts - respect, collaboration, and support; two were founded on systems theory; and the remaining ten studies each used a different theoretical perspective. The 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%), 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." 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% and the final study 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, and in Jones et al., 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 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 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. \textsuperscript{59, 60} 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. \textsuperscript{61} 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: \textit{Interacting; Culture and
Connection; and Service delivery.}

\textbf{4.1 Interacting}

Interacting is a connection between parties that results in a shared effect, \textsuperscript{46} and three sub-
themes were identified: \textit{Information; Communication; and Education.}

\textbf{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. \textsuperscript{62} Recently, Jones et al\textsuperscript{35} 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 \textit{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,\textsuperscript{22, 29, 42} during the patient’s ICU stay,\textsuperscript{34} on withdrawal of treatment,\textsuperscript{37, 41}
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.

\subsection*{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. 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. 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. Mitchell et al developed a care bundle encompassing non-technical care activities for family members Partnering with nurses, whilst in others, 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). 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. This form of intervention functions to shift what is nurses’ ‘turf’ in the ICU, 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. Interestingly, White et al’s 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. 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. In contrast, where service delivery included interventions designed to improve the physical environment, families were present more and their, and patients’ satisfaction, increased. However, offering a ‘relatives’ clinic’ did not significantly improve family satisfaction. This may be due to already high satisfaction, 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 well-being, but also drives consumer perceptions of service quality. 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.83

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)
Fig. 1. Literature searches, screening and selection of articles for inclusion.

Table 1

<table>
<thead>
<tr>
<th>Research Term</th>
<th>Definition</th>
</tr>
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</table>
| Patient, family-centred care (PFCC)                | 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”.
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. |
| Intensive Care Unit (ICU)                         | 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. |
| Intervention                                       | 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. |
| Outcomes                                           | Any outcome related to patients, families, treatment, or nursing. Can include outcomes in ICU, or at any time-point after discharge. |
| Patients                                           | Any adult, aged ≥18 years of age, male or female, receiving treatment in an ICU. |
| Family member                                      | 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. |
Table 2

Summary of reviewed articles, limitations, and MMAT scores.

<table>
<thead>
<tr>
<th>Author/Country</th>
<th>Design</th>
<th>Setting/Sample</th>
<th>Intervention</th>
<th>Measure</th>
<th>Main Finding</th>
<th>Limitations</th>
<th>MMAT</th>
</tr>
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<tbody>
<tr>
<td>Abbasi et al., 48Japan</td>
<td>RCT</td>
<td>Multi-site-1 hospital, 2 ICUs, N = 50</td>
<td>Application of a regular family visiting program to increase patient stimulation.</td>
<td>GCS after 6 days (8.8m vs 6.8, p = 0.001)</td>
<td>Regular family visiting program induced stimulation of comatose patients.</td>
<td>Allocation concealment &amp; blinding of participants not stated.</td>
<td>100%</td>
</tr>
<tr>
<td>Azoulay et al., 23France</td>
<td>RCT</td>
<td>Multi-site N = 175</td>
<td>Families in the intervention group received a family information leaflet (FIL) at the first visit.</td>
<td>CCFNINO</td>
<td>No significant difference between groups; Poor comprehension (11.5 vs 41%, p &lt; 0.0001); HADS-no significant difference between groups.</td>
<td>The FIL improved the effectiveness of the intervention they imparted to families.</td>
<td>Blinding of participants not stated. Conflict of interest not stated.</td>
</tr>
<tr>
<td>Banning, 17USA</td>
<td>Exploratory comparative design</td>
<td>Single site N = 73</td>
<td>Implementation of family centred care program &amp; education of nurses</td>
<td>CCFNI FNI</td>
<td>Individaul items of both inventories were evaluated.</td>
<td>Nurses' education was the most efficacious program intervention.</td>
<td>Reduced generalisability. Inconsistency fidelity reported. No power calculations or group</td>
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<tr>
<td>Study Authors</td>
<td>Setting</td>
<td>Design</td>
<td>Patient Population</td>
<td>Intervention</td>
<td>Outcomes</td>
<td>Study Limitations</td>
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<tr>
<td>Bishop et al., 19 USA</td>
<td>Single site</td>
<td>Pre-test, post-test</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.</td>
<td>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>Black et al., 21 Northern Ireland</td>
<td>Single site</td>
<td>Comparative time series</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 psychological</td>
<td>Reduced generalisability. Convenience sample-possible selection bias. No random allocation, allocation concealment or blinding stated.</td>
</tr>
<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</td>
<td>Implementation of a pretransfer conference to diminish the anxiety level of family members.</td>
<td>Mean scores of control group higher at post-test.</td>
<td>Reduced generalisability. Allocation concealment, blinding &amp; attrition not stated. Non-equivalent group numbers. Conflict of interest not stated. Inclusion/exclusion criteria not stated.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Burns et al., 2003</td>
<td>Quasi experimental design</td>
<td>Multi-site N = 873</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>Mean scores of intervention group decreased at post-test.</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. Power calculations not stated. Groups not balanced. Conflict of interest not stated.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chaboye r et al., 2007</td>
<td>Pre-test, post-test design</td>
<td>Single site N = 115</td>
<td>The liaison nurse provided practical STAI – No differences.</td>
<td>STAI – No differences.</td>
<td>This study was unable to</td>
<td>Reduced generalisability. No random allocation</td>
<td></td>
</tr>
</tbody>
</table>

USA | Pre-test, post-test design | Interventions in a neuroscie nce ICU. | 9 standard care | Family members of patients in a neuroscie nce ICU. | Mean scores of intervention group decreased at post-test. | Implementation of a pretransfer conference to diminish the anxiety level of family members. | Reduced generalisability. Allocation concealment, blinding & attrition not stated. Non-equivalent group numbers. Conflict of interest not stated. Inclusion/exclusion criteria not stated. |

Australia | Pre-test, post-test design | 13 interventi on | Standard care | Family members of patients in a neuroscie nce ICU. | Mean scores of intervention group decreased at post-test. | Implementation of a pretransfer conference to diminish the anxiety level of family members. | Reduced generalisability. Allocation concealment, blinding & attrition not stated. Non-equivalent group numbers. Conflict of interest not stated. Inclusion/exclusion criteria not stated. |

Australia | Pre-test, post-test design | N = 115 | The liaison nurse provided practical | STAI – No differences. | This study was unable to | Reduced generalisability. No random allocation |

USA | Pre-test, post-test design | Interventions in a neuroscie nce ICU. | 9 standard care | Family members of patients in a neuroscie nce ICU. | Mean scores of intervention group decreased at post-test. | Implementation of a pretransfer conference to diminish the anxiety level of family members. | Reduced generalisability. Allocation concealment, blinding & attrition not stated. Non-equivalent group numbers. Conflict of interest not stated. Inclusion/exclusion criteria not stated. |
(62 control, 53 intervention) 
N=100 families (52 control, 48 intervention). ICU patients & families.

Demonstrate a significant relation between groups.

Chavez & Faber, 1987 25, 26 USA

Pre-test, post-test design

Single site

N = 40

20 intervention

20 standard care

Family members of patients admitted into the ICU or coronary care unit.

A pre-visit education - orientation program was presented to the family member.

Bio factors – heart-rate-intervention group sig lower

Intervention group scored significantly higher in understanding diagnosis.

An education orientation program may be an effective 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>Patients</th>
<th>Behaviours</th>
<th>Findings</th>
<th>Generalisability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Choi &amp; Bosch, 2013 USA</td>
<td>Between group observational design</td>
<td>Single site $N = 81$</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>Patient 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>The patient-centred unit was associated with increased family presence in the patient rooms &amp; increased family interaction with patients.</td>
<td>Reduced generalisability. No blinding of assessors. Research grant from Academy of Architecture for health – potential conflict of interest. HREC not reported.</td>
</tr>
<tr>
<td>Connors et al., 1995 USA</td>
<td>RCT</td>
<td>Multi-site $N = 4,804$</td>
<td>Facilitation of communication between physician, patient &amp; family members by designated &amp; trained research nurses.</td>
<td>1. Physician understanding of patient preferences – timing of DNR documentation; 2. Agreement of (DNR) orders; 3. Pain; 4. Undesirable states - time spent in an intensive care unit (ICU), comatose, or</td>
<td>The intervention failed to improve patient outcomes or hospital resources.</td>
<td>Allocation concealment &amp; blinding of participants not reported.</td>
</tr>
<tr>
<td>Study</td>
<td>Design</td>
<td>Site</td>
<td>Sample Size</td>
<td>Intervention</td>
<td>Outcome</td>
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<tr>
<td>Cray, 1989</td>
<td>Observational design</td>
<td>Single site</td>
<td>N = 76</td>
<td>All families were offered a family education of ICU intervention program.</td>
<td>Program evaluation questions. The majority of families agreed classes were helpful. Nursing leadership indicated there had been fewer communication conflicts between staff &amp; families &amp; encouraged a conscious effort to support &amp; inform the families.</td>
<td></td>
</tr>
<tr>
<td>Curtis et al., 2011</td>
<td>Cluster RCT</td>
<td>Multi-site</td>
<td>N = 824 524</td>
<td>Education &amp; promotion of clinician behaviour</td>
<td>FSICUQ QD&amp;D LOS Not significant</td>
<td></td>
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<tr>
<td></td>
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<td></td>
<td>This quality-improvement intervention had</td>
<td>Not blinded. Groups not balanced at baseline. Nurses</td>
<td></td>
</tr>
<tr>
<td>Study</td>
<td>Design</td>
<td>Setting</td>
<td>Intervention</td>
<td>Measure</td>
<td>Results</td>
<td>Comments</td>
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<tr>
<td>Daly et al., 1994&lt;sup&gt;29&lt;/sup&gt; USA 30</td>
<td>Mixed methods design</td>
<td>Single site</td>
<td>N = 60</td>
<td>20 informati on booklet</td>
<td>no effect on family- &amp; nurse-assessed outcome</td>
<td>Reduced generalisability. No random allocation. Participant blinding not reported. Attrition not stated. Potentially under powered. Conflict of interest not stated. HREC approval not reported.</td>
</tr>
<tr>
<td>Daly et al., 2010&lt;sup&gt;28&lt;/sup&gt; USA 29</td>
<td>Pre-test, post-test design</td>
<td>Multi-site</td>
<td>N = 489</td>
<td>354 intervention</td>
<td>LOS was not significantly reduced for the intervention group. No significant relations hip with</td>
<td>Strong evidence that the dynamics of decision making surrounding goals of care &amp; aggressiveness of intervention</td>
</tr>
</tbody>
</table>

300 standard care Family members & nurses of patients dying in ICU or within 30 hours of discharge. Change to improve ICU end of life care. Differences on any measures. No effect on family- & nurse-assessed outcomes. Response rates different between hospitals.
within 5 days of ICU admission & at least weekly thereafter. The odds of receiving an end point of tracheostomy are sufficiently complex that no single communication intervention is likely to have equivalent effects with all family members, in all environments.

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Site</th>
<th>N</th>
<th>Family Characteristics</th>
<th>Intervention Description</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Davidsson et al., 2010&lt;sup&gt;30&lt;/sup&gt; USA 31</td>
<td>Mixed methods design</td>
<td>Single site</td>
<td>22</td>
<td>Family members of adult mechanically ventilated ICU patients.</td>
<td>Families were provided a kit of supplies &amp; the primary investigator or coached families on how to obtain information, interpret surroundings, &amp; participate in care. CCFNI Family support program evaluation - all items offered within the intervention were found useful to some family members.</td>
<td>Reduced generalisability. No blinding of outcome assessors. Under powered. Hospital affiliations &amp; funding reported.</td>
</tr>
<tr>
<td>de Havenon et al., 2015&lt;sup&gt;31&lt;/sup&gt; USA 32</td>
<td>Pilot between group design</td>
<td>Single site</td>
<td>88</td>
<td>29 intervention</td>
<td>Implementation of family meetings through skype Family meeting survey - no significant An audio-visual intervention was welcome</td>
<td>Reduced generalisability. Blinding not reported.</td>
</tr>
</tbody>
</table>
Family members of patients in a neuro critical care unit. Conferencing to increase family satisfaction & improve decision making. Differences between groups on satisfaction or decision making. 60-70% of respondents responded positively to all questions.

**Douglas et al., 1996**

**RCT**

| Single site | 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 generalisability.** Allocation concealment & blinding not stated. Conflict of interest not stated. |

| USA | N = 152 | N = 149 | 100% | 100% |

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

**Observational design**

| Single site | 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 generalisability.** No blinding of outcome assessors. Validity assessments of... | **Reduced generalisability.** 100% |
Family & staff of Medical surgical ICU patients. 

**bly by families.** It induced only moderate discomfort among ICU workers, due to the potential for care interruption, in particular for nurses. Questionnaires not conducted. Conflict of interest stated.

Garrouste-Oregeas et al., 2014\textsuperscript{32} France\textsuperscript{33} 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.
**Halm et al., 1990**

- **Mixed methods design**
- **Single site**
- **N = 55**
- **Intervention**
- **30 standard care**
- **25 family members**
- **Adult family members who visited patients after surgery in a surgical intensive care unit.**

Family members attended a 90-minute support group session to share feelings & experiences in coping with illness.

STAI Family interview for thematic analysis -

**Common Themes** = 1. Satisfaction with nursing & medical staff.
2. Reliving the illness experience. 3. Fear of the unknown. 4. Coping responses. 5. Acceptance of critical illness.

Experimental group had a significant reduction in anxiety between pre & post measures. Positive subjective perceptions of the support group from all experimental participants.

Reduced 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.

**Jacob et al., 2016**

- **Mixed methods design**
- **Single site**
- **N = 45**
- **Family members of patients in neuroscience ICU.**

A continuous visitation policy was in place along with private family rooms with overnight facilities connected to patient’s room.

CCNI FS-ICU Interviews

Family members rated their needs as being met at a high level, unlike in prior studies in units with limitations on family visitation.

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 environments.
<table>
<thead>
<tr>
<th>Study</th>
<th>Intervention and Design</th>
<th>Setting</th>
<th>Sample Size</th>
<th>Main Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jacobowski et al., 2010</td>
<td>Pre-test, post-test design, Single site, N = 227</td>
<td>USA</td>
<td>Family members of ICU patients, involved in family rounds involving the family member being present during rounds whilst the multidisciplinary team presented patient information from the previous 24 hours.</td>
<td>Participating in family rounds was associated with higher family satisfaction regarding frequency of communication with physicians &amp; support during decision making. Participation decreased 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.</td>
</tr>
<tr>
<td>Johnson &amp; Frank, 1995</td>
<td>Pre-test, post-test design, Single site, N = 40</td>
<td>USA</td>
<td>Family of cardiac ICU patients, received a telephone call twice daily to inform them of the status of the patient.</td>
<td>STAI – greater reduction in anxiety for the intervention group (26.65 vs 9.5, p &lt; 0.05). HADS SF-36 IES No between. Reduced generalisability. Allocation concealment &amp; blinding not reported. Small sample size. Reluctance of nurses to participate.</td>
</tr>
<tr>
<td>Jones et al., 2004&lt;sup&gt;36&lt;/sup&gt;</td>
<td>Block RCT</td>
<td>Multi-site intervention&lt;br&gt;N = 104 58&lt;br&gt;46&lt;br&gt;standard care&lt;br&gt;Family members of ICU patients.</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&lt;br&gt;HADS&lt;br&gt;SF-36</td>
</tr>
<tr>
<td>Study</td>
<td>Setting</td>
<td>Sample Size</td>
<td>Intervention</td>
<td>Outcome Measures</td>
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<tr>
<td>Jones et al., 2012&lt;sup&gt;35&lt;/sup&gt;</td>
<td>Observational pilot study</td>
<td>Multi-site $N = 30$</td>
<td>Providing an ICU diary to patients &amp; their relatives. Patients received their diaries 1 month post ICU discharge.</td>
<td>PTSS-14 - a significant difference was found between groups at 3-month follow-up ($P = .03$).</td>
</tr>
<tr>
<td>Jorgerden et al., 2013&lt;sup&gt;38&lt;/sup&gt;</td>
<td>Pre-test, post-test design</td>
<td>Single site $N = 597$</td>
<td>Patient &amp; family members migrated from an old ward like ICU environment to a new 36 single room ICU environment featuring low noise, single rooms &amp; improved family facilities.</td>
<td>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-</td>
</tr>
</tbody>
</table>

Allocation concealment & participant blinding not reported. Possible selection bias. Conflict of interest not stated. Power calculations not reported. Reduced generalisability. Blinding not reported. Groups not balanced at baseline. Possible selection bias.
Kirchhof et al., 200837
Canada38

Pre-test, post-test design
Single site
$N = 22$
11 intervention
11 standard care
Family members of ICU patients who were having life support withdrawn.

A structured message was provided orally & as written information based on 4 key terms related to withdrawal of life support.

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.

The information provided was considered helpful.

Reduced generalisability.
Allocation concealment & blinding not reported.
Possible selection bias.
Standardisation of message delivery not monitored.

Kloos & Daly, 200838
USA39

Mixed methods design
Single site
$N = 91$
40 intervention
51 standard care
Families of patients undergoing CABG surgery.

Family maintained a patient progress journal.

STAI Family interview for thematic analysis:
1) positive & negative family member emotions,
2) positive & negative observations.

Anxiety was significantly lower after 3 days but was not different by group.

Nurses can affect uncertainty by adjusting the

Reduced generalisability.
Allocation concealment & blinding of outcome assessors not reported.
Power calculations not stated.
Small convenience sample.
<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Setting</th>
<th>Sample Size</th>
<th>Interventions</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knapp et al., 2013&lt;sup&gt;39&lt;/sup&gt;</td>
<td>Quasi-experimental</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 The perception of needs. 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&lt;sup&gt;40&lt;/sup&gt;</td>
<td>Quasi-experimental</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 No significant difference in family satisfaction between pre- &amp; post- ICU stay. Reduced generalisability. No random allocation or blinding. Interventions group significantly longer ICU stay.</td>
</tr>
</tbody>
</table>
Staff compliance with intervention questionable. Power calculations not reported.

Lautrette et al., 2007

A proactive communication intervention consisting of a structured family end-of-life conference & a 15-page bereavement information brochure.

Providing relatives of patients who are dying in the ICU with a brochure on bereavement & using a proactive communication strategy that includes longer conferences & more time for family members to talk may

Unclear allocation concealment. Blinding not reported. No confirmation of families who read brochure. No baseline mood assessments. Financial support disclosed.

<table>
<thead>
<tr>
<th>Lautrette et al., 2007</th>
<th>RCT Multi-site</th>
<th>N = 108</th>
</tr>
</thead>
<tbody>
<tr>
<td>France</td>
<td>56 intervention</td>
<td>52 standard care</td>
</tr>
<tr>
<td>Family members of dying ICU patients.</td>
<td>IES HADS</td>
<td>50%</td>
</tr>
<tr>
<td>Study</td>
<td>Design</td>
<td>N</td>
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<tr>
<td>Lynn-McHale et al., 1997</td>
<td>Pre-test, post-test design</td>
<td>183</td>
</tr>
<tr>
<td>Medland et al., 1998</td>
<td>Pre-test, post-test design</td>
<td>30</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. of calls from family members, but not control group AIP- Sig difference between pre & post scores for experimental group only. Daily incoming phone call count - sig more phone calls received per day from control group family members. Daily incoming phone call count - sig more phone calls received per day from control group family members.

**Mitchell & Courtney 2004**

Australia 45

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.
<table>
<thead>
<tr>
<th>Mitchell et al., 2009</th>
<th>Pre-test-post-test design</th>
<th>Single site intervention</th>
<th>FCCS Families were assisted with some of their relative’s care with nurses’ support &amp; individualised to suit each family.</th>
<th>Reduced generalisability.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australia 18</td>
<td></td>
<td>N = 174 99 intervention</td>
<td>75 standard care Families of ICU patients whose stay &gt; 48 hours.</td>
<td>Conveniences sampling &amp; baseline differences between groups (controlled for).</td>
</tr>
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<td>Financial support disclosed.</td>
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</table>

Significantly reduced uncertainty scores. The structured individualised method of transfer is recommended. Partnering with patients’ families significantly improved respect, collaboration, support, & overall scores. Intervention family members of patients perceived more respect, collaboration, & support than did control family members.
<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Country</th>
<th>Sample Size</th>
<th>Intervention Details</th>
<th>Outcome Measures</th>
<th>Generalizability Challenges</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mitchell &amp; Aitken 2016&lt;sup&gt;19&lt;/sup&gt;</td>
<td>Mixed methods design</td>
<td>Australia</td>
<td>20</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>Reduced generalizability. Conveniences sampling may have led to selection bias. No assessment on staff accommodation of flexible visiting hours. Financial support disclosed.</td>
</tr>
<tr>
<td>Nicholson et al., 1993&lt;sup&gt;21&lt;/sup&gt;</td>
<td>Pilot study</td>
<td>USA</td>
<td>22</td>
<td>Child visitation intervention.</td>
<td>MAS, PCS, STAI, Mood adjective checklist, LES, FFS</td>
<td>Reduced generalizability. No random allocation. Blinding &amp; attrition not reported. Financial support disclosed.</td>
</tr>
<tr>
<td>Study</td>
<td>Design</td>
<td>Site</td>
<td>Sample Size</td>
<td>Intervention Description</td>
<td>Outcome Measures</td>
<td>Findings</td>
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<tr>
<td>Steel et al., 2008&lt;sup&gt;52&lt;/sup&gt;</td>
<td>Quasi-experimental</td>
<td>Single site</td>
<td>N = 149 70 79</td>
<td>Relatives invited to attend family clinic sessions. Flyers left in the waiting room.</td>
<td>CCFSS</td>
<td>No significant difference between groups on satisfaction.</td>
</tr>
<tr>
<td></td>
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<td></td>
<td>Reduced generalisability. No random allocation. Blinding not reported.</td>
</tr>
<tr>
<td>Tawil et al., 2014&lt;sup&gt;53&lt;/sup&gt;</td>
<td>RCT</td>
<td>4 ICU’s in one hospital</td>
<td>N = 58 38 20</td>
<td>Presence or absence at bedside throughout the brain death evaluation with a trained chaperone.</td>
<td>IES GHQ Understanding brain death questionnaire</td>
<td>Family presence during brain death evaluation improves understanding of brain death with no apparent adverse impact on psychological well-being.</td>
</tr>
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<td></td>
<td></td>
<td>Allocation concealment &amp; blinding not reported.</td>
</tr>
<tr>
<td>Vahedian-Azimi et al., 2014&lt;sup&gt;54&lt;/sup&gt;</td>
<td>RCT</td>
<td>Single site</td>
<td>N = 90 45 45</td>
<td>60-minute full body massage by a trained family member via Vital signs - Systolic BP, Diastolic BP, several Massage</td>
<td>Vital signs via family members had several Vital signs - Systolic BP, Diastolic BP, several Massage</td>
<td>Reduced generalisability. Financial support disclosed.</td>
</tr>
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45 standard care ICU patients with a long stay (>10days).

family member. Respiratory on rate, Pulse Rate & GCS

positive effects on the patients’ clinical conditions, & should be recognized as one of the most important clinical considerations.

White et al., 2012 USA

Mixed methods design

Single site N = 45

15 patients
15 family
15 staff

Incapacitated ICU patients at high risk of death or functional impairment.

The intervention delivered 4 kinds of support: emotional support, communication support, decision support, & anticipatory grief support.

Intervention 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.

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 Centered Care Survey; FFS = Family Functioning Scale; FSS = Family Functioning Scale; ICCS = 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; KADD = Katz Activities of Daily Living; LES = Life Event Scale; LOS = Length of Stay; MAS = Manifest Anxiety Scale; MOS SSS = The R & M 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; SAi = 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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Notes: *Studies allocated to two themes/sub-themes

Supplementary material - Search strategy.

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[Limiters:
Human, English Language] #4 (MH "Intensive Care")
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#6 (MH "Critical Care Nursing")
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#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")
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[Limiters: None]
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| PsycINFO (Ovid) | #1 (Map to subject headings [Family Intervention/]) |
| #2 (Map to subject headings [Intensive care/]) |
| #3 (Map to subject headings [Nursing/]) |
| #4 ("person centered care".ab. or "person centered care".ti. or "person centred care".ab. or "person centred care".ti. or "family centered care".ab. or "family centered care".ti. or "family centered care".ab. or "family centred care".ti. or "patient centered care".ab. or "patient centered care".ti. or "patient centred care".ab. or "patient centred care".ti.) |
| #5 ("famil* nurs*".ab. or "famil* nurs*.ti. or do* family .ab. or do* family .ti. or famil* facil* .ab. or famil* facil*.ti. or famil* intervent* .ab. or famil* intervent*.ti. or carer* involv* .ab. or carer* involv*.ti. or famil* participat* .ab. or famil* participat*.ti. or "famil* involv*".ab. or "famil* involv*".ti.) |
| #6 ("Intensive care unit*".ab. or "Intensive care unit*".ti. or "Intensive care".ab. or "Intensive care".ti. or "Critical care".ab. or "Critical care".ti. or "Critical care unit*".ab. or "Critical care unit*".ti. or "Critical care nursing".ab. or "Critical care nursing".ti. or "High dependency unit*".ab. or "High dependency unit*".ti.) |
| #7 ("treatment* outcome* .ab. OR treatment* outcome*".ti. or "nurs* outcome*".ab. or "nurs* outcome*".ti. or "patient* outcome*".ab. or "patient* outcome*".ti. or "famil* outcome*".ab. or "famil* outcome*".ti. or "effect*".ab. or "effect*".ti.) |
| #8 ("kin".ab. or "kin".ti. or "relative*".ab. or "relative*".ti. or "loved one*".ab. or "loved one*".ti. or "carer*".ab. or "carer*".ti. or "critically ill patient*".ab. or "critically ill patient*".ti. or "family member*".ab. or "family member*".ti. or "significant other*".ab. or "significant other*".ti.) |
| #9 ("nurs* intervention*".ab. or "nurs* intervention*".ti. or "strateg*".ab. or "strateg*".ti. or "innovation".ab. or "innovation".ti. or "bundle*".ab. or "bundle*".ti.) |
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<td>#4 AB, TI, SU(&quot;treatment* outcome&quot;) OR AB, TI, SU(&quot;nurs* outcome&quot;) OR AB, TI, SU(&quot;patient* outcome&quot;) OR AB, TI, SU(&quot;famil* outcome&quot;) OR AB, TI, SU(&quot;effect&quot;)</td>
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<td>#5 AB, TI, SU(&quot;kin&quot;) OR AB, TI, SU(&quot;relative&quot;) OR AB, TI, SU(&quot;loved one&quot;) OR AB, TI, SU(&quot;carer&quot;) OR AB, TI, SU(&quot;critically ill patient&quot;) OR AB, TI, SU(&quot;family member&quot;) OR AB, TI, SU(&quot;significant other&quot;)</td>
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<td>#6 AB, TI, SU(&quot;nurs* intervention&quot;) OR AB, TI, SU(&quot;strateg&quot;) OR AB, TI, SU(&quot;innovation&quot;) OR AB, TI, SU(&quot;bundle&quot;)</td>
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<td>#7 AB, TI, SU(&quot;partner&quot;) OR AB, TI, SU(&quot;interact&quot;) OR AB, TI, SU(&quot;co-product&quot;) OR AB, TI, SU(&quot;collaborat&quot;) OR AB, TI, SU(&quot;teamwork&quot;) OR AB, TI, SU(&quot;professional famil* relations&quot;) OR AB, TI, SU(&quot;professional patient relations&quot;)</td>
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<td>#8 (#1 OR #2)</td>
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<tr>
<td>#9 (#4 OR #5 OR #6 OR #7)</td>
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<tr>
<td>#10 (#3 AND #8 AND #9)</td>
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<th>ProQuest Dissertation and Theses Global</th>
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<tr>
<td>#1 AB, TI, SU(&quot;person centered care&quot;) OR AB, TI, SU(&quot;person centred care&quot;) OR AB, TI, SU(&quot;family centered care&quot;) OR AB, TI, SU(&quot;family centred care&quot;) OR AB, TI, SU(&quot;patient centered care&quot;) OR AB, TI, SU(&quot;patient centred care&quot;)</td>
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**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.