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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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.
The preliminary coding schema was discussed and revised and verified by the two researchers before all data within each theme and sub-theme was examined and agreed to by all research team members. This ensured the data themes were clearly based on the relationships and linking across the different codes derived from the included studies. Boyatzis R (1998) Transforming Qualitative Information SAGE, Thousand Oaks.

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%),\textsuperscript{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."\textsuperscript{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% \textsuperscript{26, 32, 35, 41} and the final study\textsuperscript{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,\textsuperscript{22} and in Jones et al.,\textsuperscript{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\textsuperscript{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\textsuperscript{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, or staff, or both.

3.1.2 Theme 2: Culture and Connection

The second theme Culture and Connection (n = 13), 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% and the last study scored 25%. These included interventions that centred on facilitating family members’ attendance at their critically-ill relative’s bedside (Presence) or facilitating physical touch (Action). A number of interventions were directed specifically towards providing Support to family members in the form of psychological care, support groups, or daily clinics. Two studies incorporated family members as part of the patient’s treatment regime and demonstrated Partnering in care.

3.1.3 Theme 3: Service delivery

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

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}; \textit{Culture and Connection}; and \textit{Service delivery}.

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}; \textit{Communication}; and \textit{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.\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.

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.\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.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)

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

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

Studies included in the review (n = 42)
**Fig. 1.** Literature searches, screening and selection of articles for inclusion.

**Table 1**

Definition of research terms used in the review.

<table>
<thead>
<tr>
<th>Research Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>Patient, family-centred care (PFCC)</em></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”. 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><em>Intensive Care Unit (ICU)</em></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><em>Intervention</em></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>
</tr>
<tr>
<td><em>Outcomes</em></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><em>Patients</em></td>
<td>Any adult, aged ≥18 years of age, male or female, receiving treatment in an ICU.</td>
</tr>
<tr>
<td><em>Family member</em></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>
</tr>
</tbody>
</table>
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>Limitation</th>
<th>MMAT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abbasi et al., 48 Japan</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., 23 France</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>CCFNI-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 information they imparted to families.</td>
<td>Blinding of participants not stated. Conflict of interest not stated.</td>
<td>100%</td>
</tr>
<tr>
<td>Banning, 17 USA</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 Individuation of both inventories were evaluated.</td>
<td>Nurses’ education was the most efficacious program intervention.</td>
<td>Reduced generalisability. Inconsistent fidelity reported. No power calculations or group</td>
<td>75%</td>
</tr>
</tbody>
</table>
patients; nurses. A group of needs was consistently ranked as most important by family members. Demographics reported.

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Site</th>
<th>N</th>
<th>Pre-test, Post-test</th>
<th>Intervention</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bishop et al., 19 USA</td>
<td>Pre-test, post-test design</td>
<td>Single site</td>
<td>72</td>
<td>35 pre-intervention</td>
<td>Education &amp; presence of family members during dressing changes.</td>
<td>PGSS - All metrics measured improved during the intervention period.</td>
</tr>
<tr>
<td>Black et al., 21 Northern Ireland</td>
<td>Comparative time series design</td>
<td>Single site</td>
<td>170</td>
<td>87 intervention</td>
<td>Nurse-facilitated family participation in psychological care of patients.</td>
<td>ICDSC (29 vs 77% scored &gt;4) TISS-28-no significant differences between groups SIP-Intervention group sig lower at all time points.</td>
</tr>
</tbody>
</table>

Reduced generalisability. Possible selection bias, family choice to participate. No random allocation or blinding. Conflict of interest not stated. HREC not reported. Reduced generalisability. Convenience sample-possible selection bias. No random allocation, allocation concealment or blinding stated.
<table>
<thead>
<tr>
<th><strong>Bokinski e, 24</strong> USA</th>
<th>Pre-test, post-test design</th>
<th>Single site, N = 22 13 intervention 9 standard care Family members of patients in a neuroscience ICU.</th>
<th>Implementation of a pretransferrer conference to diminish the anxiety level of family members.</th>
<th>STAI – mean scores of control group higher at post-test. Mean scores of intervention group decreased at post-test.</th>
<th>Reduced generalisability. Pretransfer conferences significantly reduced anxiety in family members of ICU patients.</th>
<th>100%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Burns et al., 200324</strong> USA</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>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>Satisfacton with care – No differences between groups Probability of choosing a specific treatment plan – Improved in the intervention group.</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 provided.</td>
<td>100%</td>
</tr>
<tr>
<td><strong>Chaboyere et al., 200756 57</strong> Australia</td>
<td>Pre-test, post-test design</td>
<td>Single site, N=115 patients</td>
<td>The liaison nurse provided practical</td>
<td>STAI – No differences</td>
<td>This study was unable to</td>
<td>Reduced generalisability. No random allocation</td>
</tr>
<tr>
<td>Chavez &amp; Faber, 1987</td>
<td>Pre-test, post-test design</td>
<td>25 USA</td>
<td>26</td>
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<tr>
<td>N = 40</td>
<td>A pre-visit education-orientation program was presented to the family member.</td>
<td>Bio factors – heart-rate-intervention group sig lower</td>
<td>A pre-visit education-orientation program may be an effective intervention for alleviating family stress.</td>
<td>Reduced generalisability.</td>
<td></td>
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</tr>
<tr>
<td>20</td>
<td>Standard care</td>
<td>Intervent group scored significantly higher in understanding diagnosis.</td>
<td>SSS.</td>
<td>Allocation concealment &amp; blinding of patients not described. Nursed not blind to group allocation.</td>
<td></td>
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<tr>
<td>20</td>
<td>Standard care</td>
<td></td>
<td></td>
<td>Attrition not stated.</td>
<td></td>
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<tr>
<td>Family</td>
<td></td>
<td></td>
<td></td>
<td>Potential selection bias – some family members too distraught to provide consent. No power calculations.</td>
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<tr>
<td>members</td>
<td></td>
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<td>Inclusion/exclusion criteria not described.</td>
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<td>of</td>
<td></td>
<td></td>
<td></td>
<td>Conflict of interest not stated.</td>
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<td>patients</td>
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</tbody>
</table>
Choi & Bosch, 2013
USA

Between group observational design

Single site (neurological ICU)

N = 81

41 intervention

One was designed in a family centred manner & the other was a traditionally designed ICU ward.

Patients were observed on two wards. 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).

Behaviou r mapping-

The patient-centred unit was associated with increased family presence in the patient rooms & increased family interaction with patients.

Reduced generalisability.

No blinding of assessors.

Research grant from Academy of Architectur e for health – potential conflict of interest.

HREC not reported.

Connors et al., 1995
USA

RCT

Multi-site N = 4,804

2652 intervention

2152 standard care

Critically ill patients, associated family & staff members.

Facilitation of communication between physician, patient & family members by designated & trained research nurses.


The intervention failed to improve patient outcomes or hospital resources.

Allocation concealment & blinding of participants not reported.
Cray, 1989\textsuperscript{26}  
USA 27

Observational design  
Single site  
$N = 76$

Families of patients in a medical ICU.

All families were offered a family education of ICU intervention program. Program evaluation questions. The majority of families agreed classes were helpful. Nursing leadership indicated there had been fewer communication conflicts between staff & families & encouraged a conscious effort to support & inform the families.

A structured & well-planned family intervention program was designed to increase staff nurses’ knowledge & sensitivity to the needs of families who are in crisis. Reduced generalisability. No random allocation or blinding reported. Attrition not stated. No power calculations, demographics or inclusion/exclusion criteria reported. Conflict of interest not reported. No formal HREC acquired.

Curtis et al., 2011\textsuperscript{27}  
USA 28

Cluster RCT  
Multi-site  
$N = 824$  
524 Interventions  
Education & promotion of clinician behaviour  
FSICUQ, QD&D LOS

No significant This quality-improvement intervention had Not blinded. Groups not balanced at baseline. Nurses

50%
<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Site</th>
<th>N</th>
<th>Intervention</th>
<th>Outcome</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<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 information booklet</td>
<td>no effect on family- &amp; nurse-assessed outcomes.</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 (354 intervention, 185 standard care)</td>
<td>Intensive Communication System was implemented - included a family meeting, held away from the bedside,</td>
<td>LOS was not significantly reduced for the intervention group. No significant relations hip with</td>
<td>No random allocation. Blinding not stated. Group demographics differed at baseline.</td>
</tr>
</tbody>
</table>
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.

Davidson et al., 201030 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.

de Havenon et al., 201531 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.
control Family members of patients in a neuro critical care unit. 

**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

Single site

*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 assessment(s) of
<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Family &amp; staff</th>
<th>Methodology</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Garrouste-Oregeas et al., 2014</td>
<td>Grounded theory design</td>
<td>Family members of medical-surgical ICU patients who were ventilated for longer than 48 hours.</td>
<td>Single site, N = 32</td>
<td>A patient diary was completed by family members &amp; staff while the patient was ventilated &amp; 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 &amp; humanization experience of staff &amp; patient. The diary served as a vector that connected the patient, family, &amp; staff into a single coherent story. It contributed to support the family members in the ICU &amp; to restore the functional &amp; social role of the family.</td>
</tr>
<tr>
<td>Study</td>
<td>Design</td>
<td>Site</td>
<td>N</td>
<td>Intervention</td>
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<tr>
<td>Halm et al., 1990&lt;sup&gt;50&lt;/sup&gt; USA51</td>
<td>Mixed methods design</td>
<td>Single site</td>
<td>55</td>
<td>Support group session to share feelings &amp; experiences in coping with illness</td>
</tr>
<tr>
<td>Jacob et al., 2016&lt;sup&gt;51&lt;/sup&gt; USA52</td>
<td>Mixed methods design</td>
<td>Single site</td>
<td>45</td>
<td>Continuous visitation policy was in place along with private family rooms with overnight facilities connected to patient’s room</td>
</tr>
</tbody>
</table>
**Jacobowski et al., 2010**<sup>33</sup>  
USA<sup>34</sup>  

- Pre-test, post-test design  
- Single site  
- N = 227  
- 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 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.

---

**Johnson & Frank, 1995**<sup>34</sup>  
USA<sup>34</sup>  

- Pre-test, post-test design  
- Single site  
- N = 40  
- 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>Relative Education</th>
<th>Further Education</th>
<th>Participants</th>
<th>N</th>
<th>Intervention</th>
<th>Comparator</th>
<th>Outcome Measures</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jones et al., 2004</td>
<td>Block et al.</td>
<td>ICU</td>
<td>104</td>
<td>Multisite RCT</td>
<td>N = 104</td>
<td>46 physical recovery, 46 standard care, 58 intervention, 58 standard care</td>
</tr>
<tr>
<td>Study Reference</td>
<td>Study Design</td>
<td>Sample</td>
<td>Intervention</td>
<td>Outcome</td>
<td>Comments</td>
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<tr>
<td>Jones et al., 2012</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>
<td>Providing an ICU diary to patients &amp; their relatives. Patients received their diaries 1 month post ICU discharge.</td>
<td>50%</td>
</tr>
<tr>
<td>Jorgerde et al., 2013</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-making.</td>
<td>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.</td>
<td>75%</td>
</tr>
</tbody>
</table>

Allocation concealment & participant blinding not reported. Possible selection bias. Conflict of interest not stated. Power calculations not reported.
| **Kirchhof et al., 2008**<sup>37</sup> | Pre-test, post-test design | Single site, N = 22 | A structured message was provided orally & as written information based on 4 key terms related to withdrawal of life support. | Evaluating 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. 75% |
|---|---|---|---|---|---|
| **Canada**<sup>38</sup> | | 11 intervention | | | |
| **Family members of ICU patients who were having life support withdrawn.** | | | | | |

<table>
<thead>
<tr>
<th><strong>Kloos &amp; Daly, 2008</strong>&lt;sup&gt;39&lt;/sup&gt;</th>
<th>Mixed methods design</th>
<th>Single site, N = 91</th>
<th>Family maintained a patient progress journal.</th>
<th>STAI Family interviews for thematic analysis: 1) positive &amp; negative family member emotions, 2) positive &amp; negative observation. Anxiety was significantly lower after 3 days but was <strong>not different by group</strong>. Nurses can affect uncertainty by adjusting the</th>
<th>Reduced generalisability. Allocation concealment &amp; blinding of outcome assessors not reported. Power calculations not stated. Small convenience sample. 75%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>USA</strong>&lt;sup&gt;41&lt;/sup&gt;</td>
<td></td>
<td>40 intervention</td>
<td></td>
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<tr>
<td><strong>Families of patients undergoing CABG surgery.</strong></td>
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<tr>
<td>Study</td>
<td>Design</td>
<td>Setting</td>
<td>Sample Size</td>
<td>Intervention</td>
<td>Description</td>
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<tr>
<td>Knapp et al., USA</td>
<td>Quasi-experimental</td>
<td>Single site N = 84</td>
<td></td>
<td></td>
<td>Staff were trained to guide families using a family bundle to assist them to evaluate, plan, involve, communicate &amp; support.</td>
</tr>
<tr>
<td></td>
<td>design</td>
<td></td>
<td>45</td>
<td></td>
<td>STAI Ways of coping questionnaire. The perception of needs.</td>
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<td></td>
<td></td>
<td>39</td>
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<td></td>
<td></td>
<td>Family members</td>
<td></td>
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<td>critically ill trauma</td>
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<td>patients from the surgical ICU.</td>
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<td></td>
<td>86</td>
<td></td>
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<tr>
<td>Kondali et al., USA</td>
<td>Quasi-experimental</td>
<td>Single site N = 112</td>
<td></td>
<td></td>
<td>Staff were trained in a set of care processes to be implemented during a patients stay. The core</td>
</tr>
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<td></td>
<td>design</td>
<td></td>
<td>86</td>
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<tr>
<td></td>
<td></td>
<td>Intervention</td>
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<td>26</td>
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<td>Family members</td>
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</table>
urological 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><strong>Lautrette et al., 2007</strong></th>
<th><strong>RCT</strong></th>
<th><strong>Multi-site</strong></th>
<th><strong>A proactive communication intervention consisting of a structured family end-of-life conference &amp; a 15-page bereavement information brochure.</strong></th>
<th><strong>IES HADS</strong></th>
<th><strong>Providing relatives of patients who are dying in the ICU with a brochure on bereavement &amp; using a proactive communication strategy that includes longer conferences &amp; more time for family members to talk may</strong></th>
<th><strong>Unclear allocation concealment. Blinding not reported.</strong></th>
<th><strong>No confirmation of families who read brochure. No baseline mood assessment. Financial support disclosed.</strong></th>
<th><strong>France</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>N = 108</strong></td>
<td><strong>56 intervention 52 standard care</strong></td>
<td><strong>Family members of dying ICU patients.</strong></td>
<td><strong>Staff compliance with intervention questionable. Power calculations not reported.</strong></td>
<td><strong>50%</strong></td>
<td></td>
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<tr>
<td>Study</td>
<td>Design</td>
<td>Sample Size</td>
<td>Intervention</td>
<td>Outcome Measure</td>
<td>Outcome Description</td>
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<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</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>
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<tr>
<td>USA43</td>
<td></td>
<td>87</td>
<td></td>
<td>Visual analogue scale Patient perception of ICU tour questionnaire</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>
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<tr>
<td>Medland et al., 1998</td>
<td>Pre-test, post-test design</td>
<td>N = 30</td>
<td>A structured communication program consisting SWOC - significant difference on pre &amp; post</td>
<td>The intervention reduced the number</td>
<td>Reduced generalisability. No random allocation. Possible</td>
<td></td>
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</tbody>
</table>
Family members of ICU patients. of 3 components: 1. Discussion with nurse 24 hours after admission, 2. Information brochure, 3. Daily phone call from patient’s nurse.

scores for experimental group, 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.

Selection bias. Under powered. Control group significantly more satisfied with care at baseline & a larger portion of them had previous ICU experience.

Mitchell & Courtney 2004
Australia

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.

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>Australia 18</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-test-post-test design</td>
<td>Single site intervention</td>
</tr>
<tr>
<td>$N = 174$</td>
<td>$99$ intervention</td>
</tr>
<tr>
<td>$75$ standard care</td>
<td>Families of ICU patients whose stay $&gt; 48$ hours.</td>
</tr>
<tr>
<td>Families were assisted with some of their relative’s care with nurses’ support &amp; individualised to suit each family.</td>
<td>FCCS Partnering with patients’ family significantly improved the respect, collaboration, support, &amp; overall scores.</td>
</tr>
<tr>
<td>Intervention family members of patients perceived more respect, collaboration, &amp; support than did control family members.</td>
<td>Reduced generalisability.</td>
</tr>
<tr>
<td>Mitchell et al., 2009</td>
<td>Australia 18</td>
</tr>
<tr>
<td>Pre-test-post-test design</td>
<td>Single site intervention</td>
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<tr>
<td>$N = 174$</td>
<td>$99$ intervention</td>
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<td>$75$ standard care</td>
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<td>Reduced generalisability.</td>
</tr>
<tr>
<td>Mitchell &amp; Aitken</td>
<td>Mixed methods design</td>
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<tr>
<td>Australia 20</td>
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<td></td>
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<tr>
<td>Nicholas et al., 1993</td>
<td>Pilot study</td>
</tr>
<tr>
<td>USA 22</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Study Reference</td>
<td>Study Design</td>
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<td>------------------</td>
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</tr>
<tr>
<td>Steel et al., 2008&lt;sup&gt;52&lt;/sup&gt; UK&lt;sup&gt;53&lt;/sup&gt;</td>
<td>Quasi-experimental</td>
</tr>
<tr>
<td>Tawil et al., 2014&lt;sup&gt;53&lt;/sup&gt; USA&lt;sup&gt;54&lt;/sup&gt;</td>
<td>RCT</td>
</tr>
<tr>
<td>Vahedian-Azimi et al., 2014&lt;sup&gt;54&lt;/sup&gt; Iran&lt;sup&gt;55&lt;/sup&gt;</td>
<td>RCT</td>
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</table>
standard care ICU patients with a long stay (>10 days).

**Respiratory 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 generalisability. No blinding or power calculations reported. No control group to examine the effectiveness of the intervention. Possible selection bias.

Financial support disclosed.

<table>
<thead>
<tr>
<th>White et al., 2012</th>
<th>Mixed methods design</th>
<th>Single site</th>
<th>The intervention delivered 4 kinds of support: emotional support, communication support, decision support, &amp; anticipatory grief support.</th>
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<tr>
<td><strong>White et al., 2012</strong></td>
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<td>Reduced generalisability. No blinding or power calculations reported. No control group to examine the effectiveness of the intervention. Possible selection bias. Financial support disclosed.</td>
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**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 & 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; QCC = 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 ($n = 42$).

<table>
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<tr>
<th>Themes by Title</th>
<th>Sub-Themes</th>
<th>Studies per Sub-Theme ($n =$)</th>
<th>Empirical Sources</th>
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<td>Communication</td>
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<td>Bokinskie et al. (1992),(^{24}) Burns et al. (2003),(^{25}) Connors et al. (1995),(^{46}) Cray et al. (1989),(^{27}) Daly et al. (2010),(^{29}) de Havenon et al. (2015),(^{32}) Jacobowski et al. (2010),(^{34}) Kondali et al. (2015),(^{41}) Medland et al. (1998),(^{44})</td>
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<td>Banning et al. (2012),(^{17}) Bishop et al. (2013),(^{19}) Curtis et al. (2011),(^{28}) Knapp et al. (2013),(^{40}) Chavez and Faber (1987),(^{26})</td>
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<td>Culture &amp; Connection ($n = 13$)</td>
<td>Presence</td>
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<td>Abbasi et al. (2009),(^{48}) *Choi &amp; Bosch (2013),(^{49}) Garrowte-Oregeas (2008),(^{50}) Nicholson et al. (1993),(^{22}) Tawil et al. (2014),(^{54}) Jacob et al. (2016),(^{52}) Mitchell &amp; Aitken (2016),(^{20})</td>
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<td>Support</td>
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<td>White et al. (2012),(^{56}) Halm et al. (1990),(^{51}) *Steel et al. (2008),(^{53})</td>
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<td>Partnering</td>
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<td>Mitchell et al. (2009),(^{18}) Black et al. (2011),(^{21})</td>
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<td>Service Delivery ($n = 5$)</td>
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<td>Chaboyer et al. (2007),(^{57}) *Choi &amp; Bosch (2013),(^{49}) Douglas et al. (1996),(^{58}) Jorgerden et al. (2013),(^{59}) *Steel et al. (2008),(^{53})</td>
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**Notes:** *Studies allocated to two themes/sub-themes*

**Supplementary material** - Search strategy.

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<td>#2 (MH &quot;Family Nursing&quot;)</td>
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<tr>
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<td>#3 (MH &quot;Intensive Care Units&quot;)</td>
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#5 (MH "Critical Care")
#6 (MH "Critical Care Nursing")
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#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")
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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)
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Cochrane Library

[Limiters: None]  #1 (MeSH descriptor: [Patient-Centered Care] this term only)
#2 (MeSH descriptor: [Family Nursing] this term only)
#3 (MeSH descriptor: [Intensive Care Units] this term only)
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#8 ("famil* nurs*" or "do* family" or "famil* facilit*" or "famil* interven*" or "carer* involv*" or "famil* participat*" or "famil* involv*":ti,ab,kw (Word variations have been searched))
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<td>#2 (Map to subject headings [Intensive care/])</td>
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<td>#2 (Map to subject heading [family nursing/])</td>
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EBP Database
(Ovid)  
[Limiters: None]

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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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#10 ("treatment* outcome*, tx. OR treatment* outcome*, ti. or "nurs* outcome*, tx. or "nurs* outcome*, ti. or "patient* outcome*, tx. or "patient* outcome*, ti. or "famil* outcome*, tx. or "famil* outcome*, ti. or "effect*", tx. or "effect*", ti.)
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#14 (#1 OR #2 OR #7 OR #8)
#15 (#3 OR #4 OR #5 OR #9)
#16 (#6 OR #10 OR #11 OR #12 OR #13)
#17 (#14 AND #15 AND #16)

Sociological
Abstracts
(ProQuest)
[Limiters: None]

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#5 AB,TI, SU("kin") OR AB,TI,SU("relative") OR AB,TI,SU("loved one") OR AB,TI,SU("carer") OR AB,TI,SU("critically ill patient") OR AB,TI,SU("family member") OR AB,TI,SU("significant other")
#6 AB,TI, SU("nurs* intervention") OR AB,TI,SU("strateg") OR AB,TI,SU("innovation") OR AB,TI,SU("bundle")
#7 AB,TI, SU("partner") OR AB,TI,SU("interact") OR AB,TI,SU("co-product") OR AB,TI,SU("collaborat") OR AB,TI,SU("teamwork") OR AB,TI,SU("professional famil* relations") OR AB,TI,SU("professional patient relations")
#8 (#1 OR #2)
#9 (#4 OR #5 OR #6 OR #7)
#10 (#3 AND #8 AND #9)

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#1 AB,TI, SU("person centered care") OR AB,TI,SU("person centred care") OR AB,TI,SU("family centered care") OR AB,TI,SU("family centred care") OR AB,TI,SU("patient centered care") OR AB,TI,SU("patient centred care")
#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")
#4 AB,TI, SU("treatment* outcome") OR AB,TI,SU("nurs* outcome") OR AB,TI,SU("patient* outcome") OR AB,TI,SU("famil* outcome") OR AB,TI,SU("effect")
#5 AB,TI, SU("kin") OR AB,TI,SU("relative") OR AB,TI,SU("loved one") OR AB,TI,SU("carer") OR AB,TI,SU("critically ill patient") OR AB,TI,SU("family member") OR AB,TI,SU("significant other")
#6 AB,TI, SU("nurs* intervention") OR AB,TI,SU("strateg") OR AB,TI,SU("innovation") OR AB,TI,SU("bundle")
#7 AB,TI, SU("partner") OR AB,TI,SU("interact") OR AB,TI,SU("co-product") OR AB,TI,SU("collaborat") OR AB,TI,SU("teamwork") OR AB,TI,SU("professional famil* relations") OR AB,TI,SU("professional patient relations")
#8 (#1 OR #2)
#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.