Factors influencing family member perspectives on safety in the intensive care unit: a systematic

review

Running title: ICU family safety perceptions

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Abstract

Purpose: Patient safety has developed as a strong marker for health care quality. Safety matters are

important in the intensive care unit (ICU) where complex clinical decisions are made, intensive

technology is used, and families hold a unique role. The aim of this review was to identify and

describe factors that influence family member's perceptions of safety in the adult intensive care

unit.

Data sources: Searches were conducted during September – November 2018, and repeated July

2020 using CINAHL, MEDLINE (EBSCO), PubMed, and PsycINFO databases.

Study selection: Published primary studies undertaken in adult ICUs and involving adult family

member participants exploring safety or feeling safe. No date restrictions were applied.

Data extraction: A data extraction form collected information about sample, study design, data

collection methods and results from each paper. Methodological quality was assessed using the

QualSyst tools for qualitative and quantitative studies. Narrative synthesis was undertaken.

Results of data synthesis: Twenty papers were included with 11 papers published since 2010. The

majority of papers reported on qualitative studies (n=16). Four factors were identified that

influenced whether family members felt that the patient was safe in ICU: family visiting, information

and communication, caring, and professional competence.

Conclusion: In detailing specific practices that make families feel safe and unsafe in ICU, these

review findings provide a structure for clinicians, educators and researchers to inform future work,

and gives opportunity for the family role in patient safety to be reconsidered.

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Key words: Intensive care unit, critical care, families, family members, safety, surveillance

Introduction

Patient safety has been identified as a major issue in healthcare [1] with increasing focus on the involvement of patients and service users in this area [2]. Patient safety in the intensive care unit (ICU) has traditionally been understood by using objective measures, such as infection rates, adverse events and ICU readmissions [3]. More recently there has been increasing focus on understanding safety from the perspective of staff [4] and from patients [5].

However, families too hold a unique role in the ICU, and less is known about what makes families feel their relative is safe in this environment. Family members often sit in vigil at the patient's bedside acting as proxy decision makers, patient's wishes experts, patient protectors, and family spokespersons in the ICU [6,7]. This results in family members being crucial in a patient's recovery [5], and able to provide rich description of the ICU environment and the witnessed actions and behaviours. Indeed, it is recognised that the experience of patient and family members can, and should, be used to improve intensive care [8].

It is therefore important that patients and families feel safe. Indeed, it could be argued that the need for patients and families to feel safe is possibly as important as the need to be safe. This is an important distinction as 'feeling safe', defined as "an emotional state where perceptions of care contribute to a sense of security and freedom from harm during an inpatient hospitalisation" [9 p172] is different from physical safety [10]. In feeling safe, family members may be more willing to leave the bedside to get rest, with potential consequences for their own health. This is a significant consideration given that family members of ICU patients can experience posttraumatic stress disorder, especially if previously healthy [11] and for those visiting longer-term patients in ICU [12].

Over the past few decades, studies have examined family needs [13], assessed family member satisfaction [14], and explored family trust [15] in ICU. However, to our knowledge, no systematic review has been published concerning family member perception of safety in ICU. We aim to

address this gap. Identifying how families make judgments about whether their loved one is safe in ICU will allow clinicians to make the safety of care more evident, foster an environment where families feel safe, and create a climate in which concerns about safety can be raised by families. This systematic review of the literature addresses the research question: 'What factors influence family member's perceptions of safety in the adult intensive care unit?'

Methods

This systematic review conforms to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement [16].

Literature search strategy

A search was conducted using the Cumulative Index to Nursing and Allied Health Literature (CINAHL), Excerpta Medica (Embase), MEDLINE (EBSCO), PubMed, and PsycINFO. Searches were conducted between September 2018 to November 2018, and repeated July 2020. Only papers written in English were included due to lack of translation services. In order to capture all papers in the area of interest, no date restrictions were placed.

Key search terms related to the population (adult family members), phenomena of interest (feeling safe), context (adult intensive care unit) and study design (qualitative, quantitative and mixed methods empirical peer-reviewed papers). The definition of 'family member' used in the Family Reported Experiences Evaluation (FREE) study: "...a person with a close familial, social or emotional relationship with the patient and is not restricted solely by next of kin" [17] is reflected in the search terms. Thesaurus terms or similar MeSH terms of key search words were used as were combined terms using Boolean operators. Systematic reviews were not included but reference lists were

screened for any primary studies not already identified. The search strategy used for MEDLINE is shown in Table 1.

Selection process

The selection process was conducted in four stages: (i) study identification (ii) screening (iii) eligibility and (iv) inclusion (Figure 1). After removal of duplicates (CE), all studies retrieved were screened by title and abstract to ensure inclusion criteria were met, and that there was relevancy to the review aims (CE and MC). Reasons for exclusion were recorded. Remaining studies underwent full-text review (SS and MC). Where it was less clear whether the criteria were met, a third reviewer (RE) independently reviewed the papers and a decision made following discussion (SS, MC, RE).

Data extraction

A modified data extraction form was developed based on the Centre for Reviews and Dissemination data extraction form and Cochrane collaboration [18]. The form collected key author and study information from each paper. The form was piloted on three of the included papers to ensure consistency in approach amongst the review team. Data were independently extracted by SS and MC and jointly reviewed.

Quality appraisal

The QualSyst tool for qualitative studies [19], a validated ten-item checklist, was used to assess quality of qualitative research papers (Table 2). The QualSyst tool for quantitative studies [19], a validated fourteen-item checklist, was used to assess the quality of quantitative research papers (Table 3). Papers with a low quality appraisal score (<0.60) were excluded. Methodological quality of all full text papers was assessed by two independent reviewers (SS and MC) and quality scores compared and agreed. A third reviewer (RE) was available for independent review if consensus was not gained.

Data synthesis

Tables were used to summarise study design, objectives, sample size, methods, and findings for included studies. Our intention was to undertake quantitative analysis. However, the heterogeneity of the included papers did not allow this. Findings from qualitative and quantitative studies were synthesised using a Cochrane-style narrative synthesis [20]. In this, two reviewers (MC and SS) independently identified variables about feeling safe in the study results and findings. Meetings were then held with MC, SS and RE where variables with a similar pattern were grouped together enabling development of key themes. Final themes were agreed once consensus had been reached.

Results

The search strategy identified 1374 papers after removing duplicate records. Following review of titles and abstracts, 56 papers underwent full-text review. At this stage, 36 papers were excluded (Figure 1). Twenty papers were identified and included in this review (Table 4).

Study characteristics

Studies were undertaken in nine different countries: Australia (n=2), Brazil (n=3), Canada (n=1), Demark/Sweden (n=1), Finland (n=1), Greece (n=1), Ireland (n=1), Sweden (n=2), USA (n=8). The earliest publication dates were pre-2000 (n=3), with six papers published in 2001-2010 and a further eleven papers published in 2010-2020.

Eleven papers focussed on specific clinical contexts when exploring safety from the family member perspective. These were often critical times when the patient and family members were either transitioning between places of care e.g. admission into ICU, discharge out of ICU, or transitioning at critical times of life and death changes e.g. resuscitation, at end of life. The remaining papers (n= 9) explored family members experiences more generally in the ICU.

Of the 20 papers, 16 used qualitative research approaches where data were collected through interviews and/or focus groups. Three papers reported on quantitative research: one paper a prospective observational study and two survey papers. One paper [26] reported on validation of a scale and was included as the scale explored many aspects of safety and advanced our understanding through its theoretical framework. Sample sizes for the qualitative studies ranged from 5 to 129 and for the quantitative studies from 50 to 449. Nine of the 20 studies were conducted at a single site.

Quality assessment

Quality assessment scores ranged from 0.6-1.0. No quality assessed studies were excluded from the review. Overall quality of the studies was high with many papers (n=11) having scores 0.9-1.0. Only four studies had scores between 0.6-0.75.

Studies included in the review generally had good detail about the research question, study objectives and an appropriate study design. However, not all studies made connection to a theoretical framework or the wider body of knowledge. A further weakness in some work was the lack of justification for the sampling strategy with inadequate description of data collection methods and analytic approaches, and, in qualitative papers, insufficient detail attending to reflexivity.

Synthesis of results

In this review, four key factors were important to ICU family members in feeling the patient was safe. These were: family visiting, information and communication, caring, and professional competence (Figure 2).

A common understanding across papers was the sense of anxiety that the ICU environment created [33]. This was exacerbated when failures in care were frequently observed by family members. In Fisher et al.'s study [24], 32 of 70 participants (46%) identified at least one preventable breakdown

in care that included: delayed or inadequate treatment; inadequate nursing care; and rude or uncaring providers. Therefore, understanding what family members perceive as problematic is important to improve safety in the ICU.

Family visiting: feeling safe by being close to the patient

Four of the reviewed studies identified the importance for family members of being close to their relative in the ICU. Being at the bedside enabled close observation of their relative's condition, enabling family members to oversee care delivered [21]. Seeing the patient allowed family members to come to their own conclusion about the condition of the patient [34] and helped alleviate relative's fears that adverse events may happen whilst they were not there. Seeing the patient with their own eyes and making an assessment as to their condition helped reassure family members. Indeed, for some this was as, if not, more important than meetings with medical staff [21]. This activity held an important function to keep family members feeling their relative was safe and was especially important in situations where there was lack of trust with clinicians [34]. Family members also reported experiencing increasing anxiety and fearfulness if they were excluded from the bedside and kept waiting outside the ICU [25], where witnessing increased staff entering the intensive care led to concerns that it was their family member who had deteriorated. This led to family members fearing poor outcomes or neglect of their loved one [23], further reinforcing the feeling of the patient being unsafe.

Information and communication: feeling safe through knowledge and understanding

An important factor raised in six of the papers was for families to have information direct from staff caring for their relative. Family members perceived themselves to be in an emotional and distressed state in ICU with reduced ability to understand information. This resulting in a sense of uncertainty [40]. If information was shared, for example, about the equipment and technology, then family members felt comforted. If there was perception that information was being withheld, then families became suspicious and mistrustful of staff [40], and fearful about patient safety.

Communication was extremely important for families. Knowing what had been done and what was to be expected gave families a sense of understanding and control and made them feel safe and calm. In Egerod's [23] qualitative study using content analysis of diaries written by close family members (n = 15), families use words such as: 'afraid, [in a] state of alarm, danger, coming unravelled, worried and devastating.' (p.59) to describe their concern when communication was lacking. Family members had expectations about receiving updates in a timely manner. If this did not occur, then families became frightened [36]. This was especially noted at critical transitions, such as during patient transfer [30]. Results from Water's [38] quantitative study also highlighted the importance of communication evidenced in highest mean scores for professional nursing support including key communication actions, for example, assuring families that best care is being delivered, and giving understandable information about medical and nursing procedures. Similar results were demonstrated in Maxwell et al.'s [31] descriptive, exploratory study where family members rated areas of communication as highly significant (P <.05) when considering their needs in the ICU.

Family members wanted information to be communicated in a clear and honest way [25]. When family members received 'adequate' information they reported reduced stress levels, and this helped family members cope in ICU with family members feeling that the patient was safe [26].

Caring: feeling safe when witnessing and receiving care

The nature of the caring experience was a key feature raised by family members and was identified in many of the papers. The main aim of family members in ICU was to ensure the best possible care was given [25]. One study explicates this further by identifying good caring as family members witnessing staff demonstrating responsibility and commitment to the care of their family member, thereby bringing about a sense of calm for family members [27]. When care for, and about, the

patient was demonstrated, families felt confident and this led to a sense of security. Family participation in care also helped families feel safe and secure in the ICU [21,32].

Clearly developed relationships with staff, underpinned by positive interactions, made family members feel safe. Positive interactions were characterised as doctors and nurses recognising and speaking about the suffering of family members [33]. The concept of patient and family member dignity was another important facet of caring. In Jacelon & Henneman's [28] qualitative descriptive study, dignity was maintained through actions such as: maintaining connections with the family on a personal level; keeping the patient comfortable and clean. Sometimes even small acts or omissions could inform these assessments [37]. If a nurse explained what they were doing and why, this was perceived as a comfort to family members, allowing them to be confident in the care and to relax [39].

If such connections with staff were lacking, this added to family distress [33] and resulted in families feeling less confident in the ICU. The importance of experiencing good care and interpersonal relations with staff was particularly heightened during transitional times where patients were moved from one ICU to another or from ICU to a ward area [23]. At time of transfer from the ICU, family members felt vulnerable, anxious, and stressed [22, 30].

Professional competence: feeling safe with capable and skilful staff

Four of the included papers spoke to how professional competence, or the lack of it, influenced how families felt in the ICU. In Nelms & Eggenburger's [33] phenomenological study, some family members described how they felt they had to watch over their relative to protect them from errors in care where as families described how they felt assured and felt safe if clinicians acted in a competent way [21]. Witnessing attentive care delivered by skilful professionals who acted quickly to treat changing needs, brought comfort to family members [25].

In Potinkara & Paunonen's [35] qualitative study, everyday nursing situations that strengthened the feeling of security in families were explored. The most important determinants of safe, high quality nursing care were associated with professional nursing competence, for example, familiarity with the technology and procedures, knowledge of patient's condition and assessment, and displaying professional attitudes (clear understanding of nursing role and profession). Interestingly, similar results were demonstrated in Hunziker et al.'s [27] prospective observational cohort study where 449 family members across nine ICUs completed the Family Satisfaction with Care in the Intensive Care Unit instrument (FS-ICU). Whilst dissatisfaction with elements of care including concern and caring of family members by staff, and ease of getting information, were independently associated with an overall low satisfaction with care, family dissatisfaction with nursing competence was one of the independent factors most strongly associated with low overall family satisfaction (odds ratio for dissatisfaction = 5.9, 95% confidence interval 2.3–15.2).

In concluding the results of this review, it is interesting to note that all the above areas resonate with the safety dimension items in the Comfort scale for family members of people in critical state of health (ECONF), validated in Freitas et al.'s [26] study. In this methodological study, the safety dimension demonstrated very good (α =0.89) internal consistency and included aspects of family visiting, information and communication, caring, and professional competence.

Discussion

Whilst this review identifies an early and developing interest in this field, the concept of 'feeling safe' currently has little theoretical underpinning and lacks consensus about how it can be identified and studied. With no specific tool to measure 'feeling safe', a wide range of critical care scales, for example, family satisfaction with care instrument, Molter and Leske's Critical Care Family Needs Inventory [41] were used, as well as more generic life change and stress coping scales. In the

qualitative studies, a range of questions were asked about security, coping and comfort in the ICU that raised issues about feeling safe. Safety was not a primary focus for many of the studies. Safety findings were often incidental in the data, described by family members as situations that left them vulnerable, uncomfortable, or not feeling safe. More work is needed to explore whether 'feeling safe' is a distinct phenomenon or associated with unmet needs or lack of coping in family members.

The review identified four important factors that influenced family member's perceptions of safety in the adult ICU. The need for ICU family members to visit and be close to their relative is well-recognised in the literature [42, 43] with some evidence of improved patient outcomes if families are present [44]. However, there is also acknowledgment of the increased pressure and stress that families can place on bedside staff [45]. Noting this, results from this review add to existing literature about the family need to safeguard the patient in ICU [46, 47]. In understanding that some families may not feel safe to leave their relative in ICU, clinicians can work with families to identify a family visiting model that works for patient, family members and clinicians.

The importance of information and communication has been a cornerstone of patient- and family-centred care in ICU for some time. Numerous observational studies have suggested the need for improved communication with family members, identifying family dissatisfaction if this does not occur [48, 49]. Areas that can result in family members feeling unsafe, for example, lack of regular, honest information about procedures, care, and the technology, resonate with areas that lead to family dissatisfaction. This review reinforces that not only does poor communication lead to dissatisfaction, it can leave family members feeling anxious and unsafe. This is an important consideration; initiatives such as family support groups during the ICU admission may be a useful adjunct to regular interactions with individual families [50].

Compassionate and careful caring practices are known to be supportive to both patients and families alike [51]. The importance of caring skills identified in our results align with the clinical skills identified in Ågård et al. [52]. However, results from our review helps understanding about the

response of families if care-less practices are evidenced, or perceived as being evident, by family members. Perhaps less explored in the literature, and less debated clinically, is the impact of professional incompetence and how it makes family members feel in the ICU. The presence or absence of professional actions, described in this review by family members as making them feel safe, align with many of the principles espoused on professional Codes of Conduct. It is therefore timely to acknowledge, once again, the extent of surveillance undertaken by family members at the bedside, and the impact that a perceived lack of professional competence can have. Induction and education programmes, perhaps co-designed with family members, provide opportunities to address this across professional groups in ICU.

Finally, the experiences and reports of patients and families are often absent from hospital patient safety matters [53]. One area receiving attention is development of patient measures of safety (PMOS) questionnaire that assesses eight key domains related to safety from a patient perspective [54]. Some of the domains explored in PMOS e.g. communication and team work, organisation of care planning, information flow resonate strongly with themes arising in this review. However, whilst PMOS have been explored within other hospital settings [55], this review has profiled areas of safety particular to intensive care e.g. family visiting and staff competence and from the perspective of family members. As detailed earlier, this is an important consideration in this setting and raises possibility of development of patient and family measures of safety in this context. As explored here, ICU family members have a unique perspective on patient safety and what makes them feel that the patient is safe. Recognising that ICU family members are often hesitant to talk about feeling unsafe [53], there is need for educative and supportive work to assure families about raising concerns. Formally integrating family experience of ICU surveillance and safety is not only central to patient-and family-centred care, it may help address the gap between incident reporting and quality improvement.

Strengths and limitations

A strength of this review was use of a comprehensive search undertaken across a range of databases to increase potential for capture of appropriate studies. As this area of research develops, consensus on use of terms related to 'feeling safe' and clearer definitions may be developed. A significant strength is that papers included in this review were of a sound quality. However, the evidence has been synthesised mainly from qualitative studies, generally considered to be weak in the hierarchy of evidence. Integration of methodological triangulation may enhance understanding towards developing and testing specific interventions in the area.

Conclusion

Family members feel safe in ICU when they are able to visit, are in receipt of clear and honest information through frequent communication with clinicians and supported by caring and professionally competent staff. However, there is need for families to be supported in informally raising concerns about safety with doctors and nurses, and opportunity to more formally consider integration of family perspectives into hospital quality improvement programmes.

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Data Availability

No new data were generated or analysed in support of this review.

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Table 1: Search strategy for MEDLINE

| Feeling | Safety | Intensive Care Unit |
|-------------|--|---|
| Feel* | Safe* | Intensive Care Unit* |
| Emotion* | Vulnerab* | ICU |
| Experienc* | Risk | Critical Care Unit* |
| Perception* | Patient Safety | CCU |
| View* | Competen* | Critical Care |
| attitude | Satisf* | Intensive Therapy |
| | | Unit* |
| | harm | ITU |
| | | Intensive Care |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | Feel* Emotion* Experienc* Perception* | Feel* Emotion* Vulnerab* Experienc* Risk Perception* Patient Safety View* Competen* |

| Care* | | |
|-------|--|--|
| | | |

Table 2: Checklist for assessing the quality of qualitative studies

| Crite | ria | YES | PARTIAL | NO | | | | |
|-------|--|-----|---------|-----|--|--|--|--|
| | | (2) | (1) | (0) | | | | |
| | | | | | | | | |
| 1 | Question / objective sufficiently described? | | | | | | | |
| 2 | Study design evident and appropriate? | | | | | | | |
| 3 | Context for the study clear? | | | | | | | |
| 4 | Connection to a theoretical framework / wider body of | | | | | | | |
| | knowledge? | | | | | | | |
| 5 | Sampling strategy described, relevant and justified? | | | | | | | |
| 6 | Data collection methods clearly described and systematic? | | | | | | | |
| 7 | Data analysis clearly described and systematic? | | | | | | | |
| 8 | Use of verification procedure(s) to establish credibility? | | | | | | | |
| 9 | Conclusions supported by the results? | | | | | | | |
| 10 | Reflexivity of the account? | | | | | | | |
| SCO | RE = Total all columns and calculate marks out of 20 e.g. 20/20 = 1. | | | | | | | |
| If <0 | If <0.60 then exclude. | | | | | | | |

 Table 3: Checklist for assessing the quality of quantitative studies

| Crit | Criteria | | PARTIAL | NO | N/A |
|------|---|-----|---------|-----|-----|
| Crit | zi i a | (2) | (1) | (0) | |
| | | | | | |
| 1 | Question / objective sufficiently described? | | | | |
| 2 | Study design evident and appropriate? | | | | |
| 3 | Method of subject/comparison group selection or source of | | | | |
| | information/input variables described and appropriate? | | | | |
| 4 | Subject (and comparison group, if applicable) characteristics | | | | |
| | sufficiently described? | | | | |
| 5 | If interventional and random allocation was possible, was it | | | | |
| | described? | | | | |
| 6 | If interventional and blinding of investigators was possible, | | | | |
| | was it reported? | | | | |
| 7 | If interventional and blinding of subjects was possible, was it | | | | |
| | reported? | | | | |
| 8 | Outcome and (if applicable) exposure measure(s) well | | | | |
| | defined and robust to measurement / misclassification bias? | | | | |
| | Means of assessment reported? | | | | |

| | | 1 | 1 | |
|------|---|---|---|--|
| | | | | |
| 9 | Sample size appropriate? | | | |
| 10 | Analytic methods described/justified and appropriate? | | | |
| 11 | Some estimate of variance is reported for the main results? | | | |
| 12 | Controlled for confounding? | | | |
| 13 | Results reported in sufficient detail? | | | |
| 14 | Conclusions supported by the results? | | | |
| | RE =Total of ("yes" and "partial" columns) / 28 – (total number | | | |
| | N/A") e.g. 28/28 - 0 = 1. | | | |
| If < | 0.60 then exclude. | | | |

Table 4: Studies included in review

| Author | _ | _ | | | |
|----------------------|------------------------|-----------------------|------------------------------|--------------------------------|----------------------------------|
| Country & Year | Aim | Sample | Study design | Main findings | Implications |
| , | | | | | |
| Blom et al. [21] | Explore participation | 7 close relatives of | Phenomenological study | Being allowed to participate | Support is important to improve |
| Sweden | and support as | patients cared for in | with semi-structured | in the patient's care is | relatives' well-being and their |
| 2013 | experienced by close | an ICU. | interviews. Data analysed | important for relatives. | ability to contribute to the |
| | relatives. | | phenomenologically with a | Aspects of experiences | patients' care. An open and |
| | | | focus on meanings | included: participation in the | flexible attitude from health- |
| | | | (Dahlberg et al 2008). | care of and being close to the | care professionals is necessary. |
| | | | | patient; confidence in the | Family need confidence in the |
| | | | | care; support needed for | care the patient receives in the |
| | | | | involvement; vulnerability. | ICU. |
| Chaboyer et al. [22] | Examine perceptions | 7 patients and 6 | Descriptive qualitative case | Four main themes: sense of | ICU nurses, ward nurses and |
| Australia | of ICU transfer held | family members in | study. Two focus groups | sudden abandonment; | affiliated healthcare |
| 2005 | by patients and | general ICU of one | (patients and families | pervasive feelings of | professionals need to provide |
| | family members with | large regional | separate) were carried out | vulnerability and | emotional support throughout |
| | focus on difficult and | Australian teaching | to address three specific | helplessness; loss of | ICU transfer. Strategies to |
| | helpful situations. | hospital. | | | provide this support must be |

| | | | questions about the | importance; ambivalence | developed, implemented and |
|-------------------|----------------------|-----------------------|----------------------------|-------------------------------|----------------------------------|
| | | | transfer experience. | about experience. | evaluated. |
| | | | Thematic analysis | | |
| | | | conducted. | | |
| | | | | | |
| Egerod et al.[23] | Examine experience | Qualitative content | Qualitative descriptive | Three main categories | Family caregivers need |
| Denmark & Sweden | of family caregivers | analysis to | binational design. Dairies | emerged: trajectory; | information, proximity to the |
| 2017 | of patients with | explore diaries | recorded family response | treatment; and Patient and | patient, and a social network to |
| | necrotising soft | written by close | to questions about | Family. Four themes central | take over home responsibilities. |
| | tissue infection | family members (n = | interactions with | to the family caregiver | Information and reassurance are |
| | during the acute | 15) from university | healthcare providers. | experience developed: | important to the family during |
| | stage of disease. | hospitals in Denmark | Diaries analysed using | craving information, needing | the acute stage of necrotising |
| | | and Sweden that | NVivo version 11. | to be near, suffering | soft tissue infection. Family |
| | | included an intensive | Supplemental | separation and network | members need to see for |
| | | care stay. | demographic data | taking over. | themselves that everything is |
| | | | generated from the | Family caregivers feared poor | being done to save the patient. |
| | | | hospital chart. Content | outcomes or neglect if they | |
| | | | analysis undertaken. | were unable to be present. | |

| Fisher et al. [24] | Examine surrogate | 7 ICUs in 2 tertiary | Qualitative study. Patients | 46% of participants identified | An in-depth understanding of |
|---------------------|----------------------|------------------------|-----------------------------|--------------------------------|-----------------------------------|
| USA | decision makers' | care academic | screened and contacted 6 | at least one preventable | the types of events SDMs find |
| 2016 | (SDM) perspectives | hospitals in USA. | weeks after ICU discharge. | breakdown in care. Types of | problematic and the associated |
| | on preventable | From 129 SDMs | In-depth telephone | breakdowns involved medical | harms is an important step |
| | breakdowns in care | eligible and available | interviews with SDMs who | care (n=52), communication | towards improving the safety |
| | among critically ill | for participation, | identified a preventable | (n=59), and both (n=40). | and patient-centeredness of |
| | patients with acute | complete follow up | breakdown in care. SDMs | Adverse consequences of | healthcare. |
| | respiratory failure. | available on 70 | asked to describe the | breakdowns included physical | |
| | | SDMs. | preventable breakdown in | and psychological impact and | |
| | | | care in detail. Directed | impaired decision making. 28 | |
| | | | content analysis used with | of 32 SMDs raised concerns | |
| | | | frequency counts, and | with clinicians; only 25% were | |
| | | | descriptive statistics. | satisfactorily addressed. | |
| Freitas et al. [25] | Understand the | 14 family members | Exploratory qualitative | Seven categories were | Family are important in |
| Brazil | meaning of comfort | in a general adult ICU | study using semi- | identified that gave comfort | healthcare. For the family |
| 2012 | for the families of | of a large public | structured interviews | to family members: safety; | members, comfort meant that |
| | people experiencing | teaching hospital. | exploring situations of | receptiveness; information; | the relative was well-treated by |
| | a critical health | | comfort or discomfort | social and spiritual support; | skilful and expert professionals, |

| | condition who are | | experienced in the ICU. | proximity; convenience; and | that the team acted immediately |
|---------------------|-----------------------|-----------------------|----------------------------|------------------------------|----------------------------------|
| | condition who are | | experienced in the reo. | proximely, convenience, and | that the team detea minediately |
| | hospitalized in an | | Data saturation reached. | integration. | in order to meet the care and |
| | ICU. | | Constant comparison | | treatment needs of the relative, |
| | | | method of analysis. | | with attention and |
| | | | | | responsibility. |
| Freitas et al. [26] | Validation of the | Sample of 274 family | Two instruments were | The validated scale had 55 | The comfort scale presented |
| Brazil | Comfort Scale for | members in six ICUs | used. The first collected | items distributed in four | satisfactory psychometric |
| 2015 | Family Members of | in three large public | patient and family | factors: safety, support, | parameters, and was therefore |
| | Persons in a Critical | hospitals. | sociodemographic data. | family member-relative | the first valid instrument for |
| | State of Health | | The second was the | interaction; and integration | evaluating the comfort of family |
| | (ECONF). | | preliminary version of the | with oneself and the | members of people in a critical |
| | | | ECONF, 62 items over | everyday. The comfort scale | state of health. This paper was |
| | | | seven dimensions, one of | presented satisfactory | included as the validated scale |
| | | | which was safety (14 | psychometric parameters | explored many aspects of safety |
| | | | items). Descriptive | using the tests applied. | and advanced understanding |
| | | | statistics and principal | | through its theoretical |
| | | | component analysis used. | | framework. |

| Hunziker et al. [27] | To identify factors | 449 participants | Prospectively collected | Clinical interventions and | There are specific factors at ICU |
|----------------------|-----------------------|-----------------------|-----------------------------|----------------------------------|-------------------------------------|
| USA | independently | across nine ICUs at a | observational cohort study | outcomes had relatively little | admission that can identify |
| 2012 | associated with | tertiary care | using the FS-ICU and | impact on family member | families at high risk of |
| | dissatisfaction with | university hospital. | unadjusted and | satisfaction. Family-reported | dissatisfaction with care. Other |
| | critical care. | | multivariable analyses. | dissatisfaction was | aspects of the patient/family |
| | | | | independently associated | experience during the ICU stay |
| | | | | with: perceived competence | are also strongly associated with |
| | | | | of nurses; concern and caring | dissatisfaction. These results can |
| | | | | by ICU staff; completeness of | inform future evidence-based |
| | | | | information, dissatisfaction | strategies to improve |
| | | | | with decision-making | satisfaction with the ICU |
| | | | | processes. | experience. |
| Jacelon & Henneman | To examine the | Five family members | Qualitative, descriptive | Three major themes | Insight into the concerns of |
| [28] | meaning and relative | of older patients in | approach using | identified: the older patient's | family members related to the |
| USA | importance that | the ICU at a small | unstructured interviews | health status and ICU; family | dignity of the older critically ill |
| 2014 | family members of | rural, community | was used. Data consisted | roles, relationships, and goals; | patient can guide nurses as they |
| | older patients in the | hospital and a large, | of audio taped interviews | and staff interactions with | provide care. Importance of |
| | | | of study participants. Data | family members. Pain and | empathy, emotional support, |

| | ICU ascribed to | urban teaching | were analysed using the | intubation concerned | communication, being informed |
|-----------------------|----------------------|-----------------------|---------------------------|---------------------------------|-------------------------------------|
| | dignity. | hospital. | constant comparative | families. | and being involved was |
| | | | method. | | identified in the staff interaction |
| | | | | | theme. |
| | | | | | |
| Johansson et al. [29] | To generate a | 29 adult relatives of | Secondary analysis of two | Relatives need to be | Healthcare professionals must |
| Sweden | theoretical | adult ICU patients in | previous studies about | empowered and supported to | understand how relatives can be |
| 2005 | understanding of | southwest Sweden. | relatives of ICU patients | use both internal and external | helped to have control over their |
| | what relatives | | using grounded theory | resources to cope with critical | vulnerable situation. |
| | experience as | | methodology. | care. Relatives need to | Relatives need to be given |
| | supportive when | | Theoretical sampling | encounter professionalism | opportunity to participate e.g. |
| | faced with having an | | undertaken and | and feel secure. Being | invited to share information |
| | adult next-of-kin | | open coding, axial coding | acknowledged and | and thoughts about the patient's |
| | admitted to critical | | and selective coding | participating in care was | condition and encounter |
| | care. | | conducted. | important. | security. |

| Leith [30] | To describe patients' | 53 patients and 35 | Qualitative component of a | Patients and family members | Patients and family members |
|---------------------|-----------------------|-------------------------|------------------------------|-------------------------------|----------------------------------|
| Canada | and family members' | family members | descriptive, cross-sectional | were positive, neutral or | perceived the transfer from the |
| 1999 | perceptions of | across two | survey. The 3 open-ended | ambivalent, and negative | ICU as a significant and |
| | transfer from an ICU. | university-affiliated | questions were asked | about transfer. Some patients | sometimes negative event. |
| | | tertiary care centres. | related to transfer from | and family members | The reduction in staffing and |
| | | | the ICU. Paraphrased | perceived transfer from ICU | intensity of care was stressful |
| | | | summaries developed | as a sign of progress, many | and worrying to patients and |
| | | | immediately after. | expressed concern about the | family members. |
| | | | Content analysis was | dramatic change in the level | |
| | | | conducted. | of care after transfer. | |
| Maxwell et al. [31] | The focus of this | 30 critical care | A descriptive, exploratory | Statistically significant | The most important needs |
| USA | study was to | nurses and 20 family | design. A survey tool was | differences (P < 0.05) were | family members have can be |
| 2007 | compare intensive | members of critically | used to collect data using | demonstrated for nine items | met with assurance, proximity, |
| | care nursing | ill patients from a | the 30-item version of the | on the Critical Care Family | and informational nursing |
| | perspectives on the | 375-bed community | adapted Critical Care | Needs Inventory and for 22 | interventions. Family needs can |
| | needs of families | hospital with a 16- | Family Needs Inventory | items on the Needs Met | be met by increasing family |
| | with those identified | bed critical care unit. | and the adapted 30-item | Inventory. Family members | access to the patient, improving |
| | by families and | | version of the Needs Met | rated all items as being of | communication with the |

| | explore nursing and | | Inventory. Two open- | greater importance than did | physician and the health care |
|---------------|-----------------------|-------------------------|------------------------------|-------------------------------|-----------------------------------|
| | family perspectives | | ended questions were also | the registered nurses. | team, and creating a family- |
| | of what has been | | included. Data analysed | Answers to the open-ended | friendly environment. |
| | done or could be | | using descriptive and | questions were grouped into: | |
| | done to meet family | | inferential statistics. | (1) support, (2) comfort, (3) | |
| | needs. | | | proximity, (4) information, | |
| | | | | and (5) assurance. | |
| McKiernan and | To describe the lived | Six family members | A phenomenological | Four main themes emerged: | Nurses must interact with, and |
| McCarthy [32] | experience of family | in a single ICU site in | method with in-depth, | the need to know; making | care for, family members of |
| Ireland | members in the ICU. | Ireland. | unstructured interviews. | sense of it all; being there | patients. Development of a |
| 2010 | | | The interviews were tape | with them and caring and | family centred care is necessary. |
| | | | recorded. Field notes in the | support. Nursing knowledge | Caring reassurance, the |
| | | | form of memos were also | and competence was also | presence of the nurse at the |
| | | | kept as was a reflective | acknowledged as essential for | beside and honest information |
| | | | journal. Thematic analysis | confidence in care. | sharing provided by the nurses |
| | | | undertaken. | | enabled a sense of security. |
| | | | | | Support was needed by family |

| | | | | | members to assist them in |
|------------------|-----------------------|------------------------|----------------------------|--------------------------------|---------------------------------|
| | | | | | coping. |
| | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |
| Nelms and | To explicate the | 11 families (41 family | Qualitative study using | Key themes explored: the | Caring interventions, such as |
| Eggenburger [33] | essence of the family | members) with a | phenomenology where | illness – the critical illness | honest and accurate information |
| USA | critical illness | family member in a | family members were | experience; the | and demonstrating a |
| 2010 | experience and the | large ICU. | interviewed (primary study | hospitalisation; family | commitment to care, can be |
| | family vision for the | | and secondary analysis) as | concern, vulnerability and | implemented by nurses to make |
| | kind of care they | | a group. Open-ended, | suffering; family-nurse | the critical care illness |
| | require and desire | | audiotaped interviews | interaction; family need for | experience more bearable for |
| | from nurses. | | were conducted. Van | connection with nurses. | families. These can support and |
| | | | Manen's interpretative | Families wanted and needed | comfort families thereby |
| | | | phenomenological method | a connection with nurses and | reducing their suffering and |
| | | | was used to analyse the | care for themselves in their | distress. |
| | | | data. | suffering on the ICU. | |

| Plakas et al. [34] | This study explored | 25 family members | Qualitative study adopting | Vigilant attendance a main | Changes in visiting policies in |
|--------------------|----------------------|-----------------------|----------------------------|----------------------------------|-----------------------------------|
| Greece | the experience of | from adult general | social constructionist | coping mechanism for | Greece are needed to meet the |
| 2014 | vigilant attendance | ICUs of three general | grounded theory. Open- | relatives. This comprised of: | needs of relatives adequately. By |
| | for the relatives of | public hospitals. | ended interviews and | being as close as possible to | seeing patients, relatives were |
| | patients in Greek | | observations undertaken. | feel relief; being there to find | also able to make their own |
| | critical care units. | | Observations were carried | out what is going on; | diagnoses and could therefore |
| | | | out in the waiting rooms. | monitoring changes in the | avoid relying solely on |
| | | | Coding data line by line | loved one and making own | information given to them. |
| | | | was the first step of the | diagnosis; interacting with the | However, a prerequisite for |
| | | | analysis, followed by the | ICU professional. | successful vigilant attendance |
| | | | selective or focused | Relatives felt satisfaction | was to get on well with doctors |
| | | | coding. Constant | from being close as the best | and nurses. Nurse staffing levels |
| | | | comparative analysis and | alternative for not actually | can impact on how families feel |
| | | | memo writing used. Data | being inside the ICU and they | safe in ICU. |
| | | | saturation achieved. | tried to learn what was going | |
| | | | | on by alternative methods. | |

| Potinkara and | To address | Fourteen significant | Qualitative study with | Four main themes: | The significant others in this |
|---------------|--------------------------|--------------------------|------------------------------|---------------------------------|----------------------------------|
| Paunonen [35] | which factors in | others of critically ill | focused interviews that | interaction, confidence, nurse | study attached most importance |
| Finland | everyday nursing | patients in two ICUs | included exploration of | characteristics, and | to factors which had to do with |
| 1996 | situations strengthen | at a Finnish | encounters with the | professional competence. | attitudes. Good technical skills |
| | the feeling of | university hospital. | nursing staff and ways in | Significant others considered | on the part of the nurse are not |
| | security in the | | which nursing can help to | it important to have close | sufficient; an understanding is |
| | significant others of | | alleviate anxiety. The | contact with the nursing staff. | also required in nurses of the |
| | critically ill patients. | | classification scheme was | Each patient's named | foundations of their job and its |
| | To explore how age | | formed out of the raw | nurse had an important role | objectives. The ability to do |
| | and gender, duration | | data. Some quantitative | to play in improving the | things in such a manner that |
| | of intensive care and | | examination conducted | quality of nursing care. | they are experienced by |
| | patient's named | | comparing main categories | Factors which had to do | significant others as increasing |
| | nurse affect the | | to age and gender of the | with attitudes (subjectively | security was also important. |
| | views of significant | | patient's significant other, | evaluated and not objectively | Short treatment periods and |
| | others on factors | | the patient's named nurse | discernible) were the most | non-systematic meetings with |
| | that act to | | and patient's number of | important determinants of | the nurse can be especially |
| | strengthen their | | treatment days in an ICU. | safe, quality nursing care. | problematic. |
| | sense of security. | | | | |

| Riley et al. [36] | To examine | Eight female | Three family focus group | Patients' families identified | Patient-centred care is an |
|-------------------|-------------------------|-------------------------|---------------------------|--------------------------------|-----------------------------------|
| USA | perceptions related | family members, | meetings were held and | facilitators of patient- | expectation among patients, |
| 2014 | to traditional/ | three physicians, | preceded two focus groups | centeredness as nurses' and | patients' families, and health |
| | restricted ICU | and | for nurses and one focus | physicians' communication, | quality advocates. These |
| | visitation among | and seven nurses | group for physicians. | concern, compassion, | exploratory methods increased |
| | patients' families, | from across five | All sessions were voice | closeness, and flexibility. | understanding of the powerful |
| | nurses, and | ICUs with a | recorded. | However, competing roles of | perceptions of family members, |
| | physicians, to | traditional/restrictive | | control over the patient's | physicians, and nurses involved |
| | understand barriers | visitation policy at an | | health care served as barriers | with patient care and provided |
| | and issues, and to | academic, tertiary | | to a patient-centred | direction to plan interventions |
| | gauge the | care hospital. | | paradigm. | to implement patient-centred, |
| | generalizability of | | | | family-supportive ICU services. |
| | others' work. | | | | |
| Urizzi and Correa | Understand the | 17 with relatives of | Qualitative study using | Six themes developed: | Family members notice the care |
| [37] | experiences of ICU | ICU patients | phenomenology. Open- | difficult, painful, speechless | the staff provides to their |
| Brazil | patients' relatives, in | hospitalized at a | ended audio-taped | experience; experiencing and | relative and want to stay close |
| 2007 | order to contribute | single ICU in a single | interviews conducted | recognizing somebody's life; | to their relatives. Meeting |
| | to health care | site. | exploring experiences of | break-up of the family's daily | specific needs including: getting |

| | humanization in this | | ICU relatives. Constant | routine; fear of having a | information, being present, |
|-------------|----------------------|-----------------------|----------------------------|--------------------------------|----------------------------------|
| | context. | | comparison undertaken | family member die; ICU: a | being listened to and being |
| | | | and thematic categories | fearsome scene, but | comforted are important. |
| | | | developed. | necessary; concern regarding | |
| | | | | the relative's care. | |
| Waters [38] | To compare African | 90 Family members | Non-experimental, | The types of professional | Family members' expectations |
| USA | American, Hispanic | from 3 suburban, | quantitative, between | nursing support most | of professional support from |
| 1999 | and White family | private hospitals and | group comparison study | preferred by a majority of the | critical care nurses were |
| | member's | one public city | (African American, | family members were | generally universal – suggesting |
| | perceptions of the | hospital. | Hispanic and White). The | consistent across cultural | equitable care, dignity and |
| | professional support | | professional support | groups. The recurrent 'theme' | respect should be universal |
| | they expect from | | questionnaire for critical | appears to be the ability of | values. |
| | critical care nurses | | care nurses working with | critical care nurses to keep | |
| | during a family | | family members (PSQ) was | family members connected, | |
| | member's critical | | administered to family | especially ethnic-minority | |
| | illness. | | members. ANOVA and post | family members. | |
| | | | hoc tests were computed. | | |

| Weyant et al. [39] | Explore perceptions | Eight family | Phenomenological study. A | Key themes were providing | When patients and family |
|--------------------|---------------------|----------------------|----------------------------|-------------------------------|----------------------------------|
| USA | of nurses' caring | members of 14 | semi-structured interview | information, providing | members are asked directly |
| 2017 | behaviours among | patients in a single | guide was used. Intubation | reassurance, demonstrating | about their experience, valuable |
| | intubated patients | acute cardiovascular | and restraint use was | proficiency, and being | insight is gained into what they |
| | and their family | intensive care unit. | explored. Data analysed | present. Other caring | perceive as caring and what |
| | members. | | by inductive method. | behaviours were nurses giving | contributes to recovery as |
| | | | Computer assisted data | guidance and using a soothing | perceived by those in crisis and |
| | | | analysis software used. | tone of voice. Timeliness and | in high-intensity medical |
| | | | | attention appear to | settings. |
| | | | | contribute to the perception | |
| | | | | that the nurse was present | |
| | | | | for patients and family | |
| | | | | members. | |

| Wong et al. [40] | Discuss families' | 25 family members | Constructivist grounded | Three components of living | ICU staff need to focus clinical |
|------------------|-----------------------|---------------------|---------------------------|----------------------------------|-----------------------------------|
| Australia | experiences of their | of 21 patients | theory with in-depth | with uncertainty: being kept | interventions on reducing |
| 2017 | interactions when a | admitted | audio-taped interviews. | in the dark; being in a state of | factors that heighten family |
| | relative is admitted | unexpectedly to an | Each interview reviewed | emotional turmoil; and | uncertainty e.g. explain |
| | unexpectedly to an | ICU in a single | and coded before next | confronting a foreign | environment and technology, |
| | Australian ICU. | metropolitan, | participant interviewed. | environment. The ICU | while optimising strategies that |
| | Findings reported | tertiary level ICU. | Theoretical saturation | environment is a direct | help alleviate it. Staff need to |
| | part of a broader | | achieved. Constant | source of uncertainty and | understand events prior to ICU |
| | study that explored | | comparative method. | anxiety for families coming to | and the impact of this on |
| | families' experiences | | Computer assisted | ICU. Events leading up to the | families' emotional state. |
| | of their interactions | | qualitative data analysis | families' arrival in ICU are an | Families, when facilitated to |
| | in ICU. Reports only | | software – NVIVO. | additional source of | move beyond feeling |
| | on the subcategory | | | emotional turmoil and may | helplessness and loss of control, |
| | 'Living with | | | influence the nature and | cope better with their situation. |
| | uncertainty'. | | | extent of their uncertainty. | |
| | | | | Platitudes and unhelpful | |
| | | | | words/phrases were seen as | |

| | | barriers to control leading to | |
|--|--|--------------------------------|--|
| | | distrust of staff. | |
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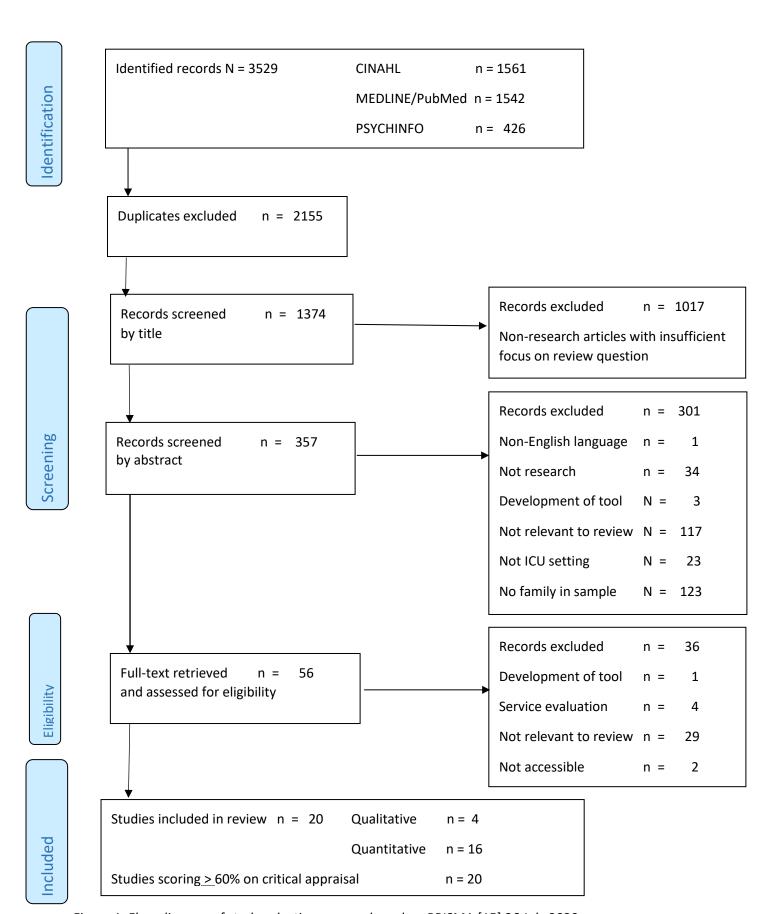


Figure 1: Flow diagram of study selection process based on PRISMA [15] 26 July 2020

FAMILY VISITING & BEING CLOSE time at the bedside stay near to the patient to observe

INFORMATION & COMMUNICATION:

open, honest communication
understanding about equipment
awareness of procedures, events
timely updates

FACTORS IMPORTANT TO FAMILIES IN ASSESSING A SAFE INTENSIVE CARE

WITNESSING CARING & BEING CARED FOR: staff demonstrating professionalism families allowed to particiapte in care families having a conection with staff

PROFESSIONAL COMPETENCE: staff knowledge of technology and procedures staff knowledge of patient's condition and assessment delivery of high level, quality care

Figure 2: Key factors influencing family member perspectives on safety in the intensive care unit