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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), Denmark/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 whereas 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 ($\alpha=0.89$) 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

| Family Members | Feeling | Safety | Intensive Care Unit |
|-----------------------|----------------|----------------|----------------------------|
| Family member* | Feel* | Safe* | Intensive Care Unit* |
| Famil* | Emotion* | Vulnerab* | ICU |
| Relative* | Experienc* | Risk | Critical Care Unit* |
| Parent* | Perception* | Patient Safety | CCU |
| Mother* | View* | Competen* | Critical Care |
| Father* | attitude | Satisf* | Intensive Therapy Unit* |
| Sibling * | | harm | ITU |
| Brother* | | | Intensive Care |
| Sister* | | | |
| Husband | | | |
| Wife | | | |
| Partner | | | |
| Loved one* | | | |
| Child* | | | |
| Next of kin | | | |
| Relation* | | | |

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| Care* | | | |
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Table 2: Checklist for assessing the quality of qualitative studies

| Criteria | | YES (2) | PARTIAL (1) | NO (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? | | | |
| SCORE = Total all columns and calculate marks out of 20 e.g. 20/20 = 1. If <0.60 then exclude. | | | | |

Table 3: Checklist for assessing the quality of quantitative studies

| Criteria | | YES (2) | PARTIAL (1) | NO (0) | N/A |
|----------|---|------------|----------------|-----------|-----|
| 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? | | | | |

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| 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? | | | | |
| SCORE =Total of (“yes” and “partial” columns) / 28 – (total number of “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 |
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| Blom et al. [21] Sweden 2013 | Explore participation and support as experienced by close relatives. | 7 close relatives of patients cared for in an ICU. | Phenomenological study with semi-structured interviews. Data analysed phenomenologically with a focus on meanings (Dahlberg et al 2008). | Being allowed to participate in the patient's care is important for relatives. Aspects of experiences included: participation in the care of and being close to the patient; confidence in the care; support needed for involvement; vulnerability. | Support is important to improve relatives' well-being and their ability to contribute to the patients' care. An open and flexible attitude from health-care professionals is necessary. Family need confidence in the care the patient receives in the ICU. |
| Chaboyer et al. [22] Australia 2005 | Examine perceptions of ICU transfer held by patients and family members with focus on difficult and helpful situations. | 7 patients and 6 family members in general ICU of one large regional Australian teaching hospital. | Descriptive qualitative case study. Two focus groups (patients and families separate) were carried out to address three specific | Four main themes: sense of sudden abandonment; pervasive feelings of vulnerability and helplessness; loss of | ICU nurses, ward nurses and affiliated healthcare professionals need to provide emotional support throughout ICU transfer. Strategies to provide this support must be |

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

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

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

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

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

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

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

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

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| <p>Plakas et al. [34] Greece 2014</p> | <p>This study explored the experience of vigilant attendance for the relatives of patients in Greek critical care units.</p> | <p>25 family members from adult general ICUs of three general public hospitals.</p> | <p>Qualitative study adopting social constructionist grounded theory. Open-ended interviews and observations undertaken. Observations were carried out in the waiting rooms. Coding data line by line was the first step of the analysis, followed by the selective or focused coding. Constant comparative analysis and memo writing used. Data saturation achieved.</p> | <p>Vigilant attendance a main coping mechanism for relatives. This comprised of: being as close as possible to feel relief; being there to find out what is going on; monitoring changes in the loved one and making own diagnosis; interacting with the ICU professional. Relatives felt satisfaction from being close as the best alternative for not actually being inside the ICU and they tried to learn what was going on by alternative methods.</p> | <p>Changes in visiting policies in Greece are needed to meet the needs of relatives adequately. By seeing patients, relatives were also able to make their own diagnoses and could therefore avoid relying solely on information given to them. However, a prerequisite for successful vigilant attendance was to get on well with doctors and nurses. Nurse staffing levels can impact on how families feel safe in ICU.</p> |
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| <p>Potinkara and Paunonen [35] Finland 1996</p> | <p>To address which factors in everyday nursing situations strengthen the feeling of security in the significant others of critically ill patients.</p> <p>To explore how age and gender, duration of intensive care and patient's named nurse affect the views of significant others on factors that act to strengthen their sense of security.</p> | <p>Fourteen significant others of critically ill patients in two ICUs at a Finnish university hospital.</p> | <p>Qualitative study with focused interviews that included exploration of encounters with the nursing staff and ways in which nursing can help to alleviate anxiety. The classification scheme was formed out of the raw data. Some quantitative examination conducted comparing main categories to age and gender of the patient's significant other, the patient's named nurse and patient's number of treatment days in an ICU.</p> | <p>Four main themes: interaction, confidence, nurse characteristics, and professional competence.</p> <p>Significant others considered it important to have close contact with the nursing staff.</p> <p>Each patient's named nurse had an important role to play in improving the quality of nursing care.</p> <p>Factors which had to do with attitudes (subjectively evaluated and not objectively discernible) were the most important determinants of safe, quality nursing care.</p> | <p>The significant others in this study attached most importance to factors which had to do with attitudes. Good technical skills on the part of the nurse are not sufficient; an understanding is also required in nurses of the foundations of their job and its objectives. The ability to do things in such a manner that they are experienced by significant others as increasing security was also important.</p> <p>Short treatment periods and non-systematic meetings with the nurse can be especially problematic.</p> |
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| <p>Riley et al. [36]</p> <p>USA</p> <p>2014</p> | <p>To examine perceptions related to traditional/restricted ICU visitation among patients' families, nurses, and physicians, to understand barriers and issues, and to gauge the generalizability of others' work.</p> | <p>Eight female family members, three physicians, and seven nurses from across five ICUs with a traditional/restrictive visitation policy at an academic, tertiary care hospital.</p> | <p>Three family focus group meetings were held and preceded two focus groups for nurses and one focus group for physicians. All sessions were voice recorded.</p> | <p>Patients' families identified facilitators of patient-centeredness as nurses' and physicians' communication, concern, compassion, closeness, and flexibility. However, competing roles of control over the patient's health care served as barriers to a patient-centred paradigm.</p> | <p>Patient-centred care is an expectation among patients, patients' families, and health quality advocates. These exploratory methods increased understanding of the powerful perceptions of family members, physicians, and nurses involved with patient care and provided direction to plan interventions to implement patient-centred, family-supportive ICU services.</p> |
| <p>Urizzi and Correa [37]</p> <p>Brazil</p> <p>2007</p> | <p>Understand the experiences of ICU patients' relatives, in order to contribute to health care</p> | <p>17 with relatives of ICU patients hospitalized at a single ICU in a single site.</p> | <p>Qualitative study using phenomenology. Open-ended audio-taped interviews conducted exploring experiences of</p> | <p>Six themes developed: difficult, painful, speechless experience; experiencing and recognizing somebody's life; break-up of the family's daily</p> | <p>Family members notice the care the staff provides to their relative and want to stay close to their relatives. Meeting specific needs including: getting</p> |

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

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| <p>Weyant et al. [39]</p> <p>USA</p> <p>2017</p> | <p>Explore perceptions of nurses' caring behaviours among intubated patients and their family members.</p> | <p>Eight family members of 14 patients in a single acute cardiovascular intensive care unit.</p> | <p>Phenomenological study. A semi-structured interview guide was used. Intubation and restraint use was explored. Data analysed by inductive method. Computer assisted data analysis software used.</p> | <p>Key themes were providing information, providing reassurance, demonstrating proficiency, and being present. Other caring behaviours were nurses giving guidance and using a soothing tone of voice. Timeliness and attention appear to contribute to the perception that the nurse was present for patients and family members.</p> | <p>When patients and family members are asked directly about their experience, valuable insight is gained into what they perceive as caring and what contributes to recovery as perceived by those in crisis and in high-intensity medical settings.</p> |
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| <p>Wong et al. [40] Australia 2017</p> | <p>Discuss families' experiences of their interactions when a relative is admitted unexpectedly to an Australian ICU. Findings reported part of a broader study that explored families' experiences of their interactions in ICU. Reports only on the subcategory 'Living with uncertainty'.</p> | <p>25 family members of 21 patients admitted unexpectedly to an ICU in a single metropolitan, tertiary level ICU.</p> | <p>Constructivist grounded theory with in-depth audio-taped interviews. Each interview reviewed and coded before next participant interviewed. Theoretical saturation achieved. Constant comparative method. Computer assisted qualitative data analysis software – NVIVO.</p> | <p>Three components of living with uncertainty: being kept in the dark; being in a state of emotional turmoil; and confronting a foreign environment. The ICU environment is a direct source of uncertainty and anxiety for families coming to ICU. Events leading up to the families' arrival in ICU are an additional source of emotional turmoil and may influence the nature and extent of their uncertainty. Platitudes and unhelpful words/phrases were seen as</p> | <p>ICU staff need to focus clinical interventions on reducing factors that heighten family uncertainty e.g. explain environment and technology, while optimising strategies that help alleviate it. Staff need to understand events prior to ICU and the impact of this on families' emotional state. Families, when facilitated to move beyond feeling helplessness and loss of control, cope better with their situation.</p> |
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| | | | | barriers to control leading to distrust of staff. | |
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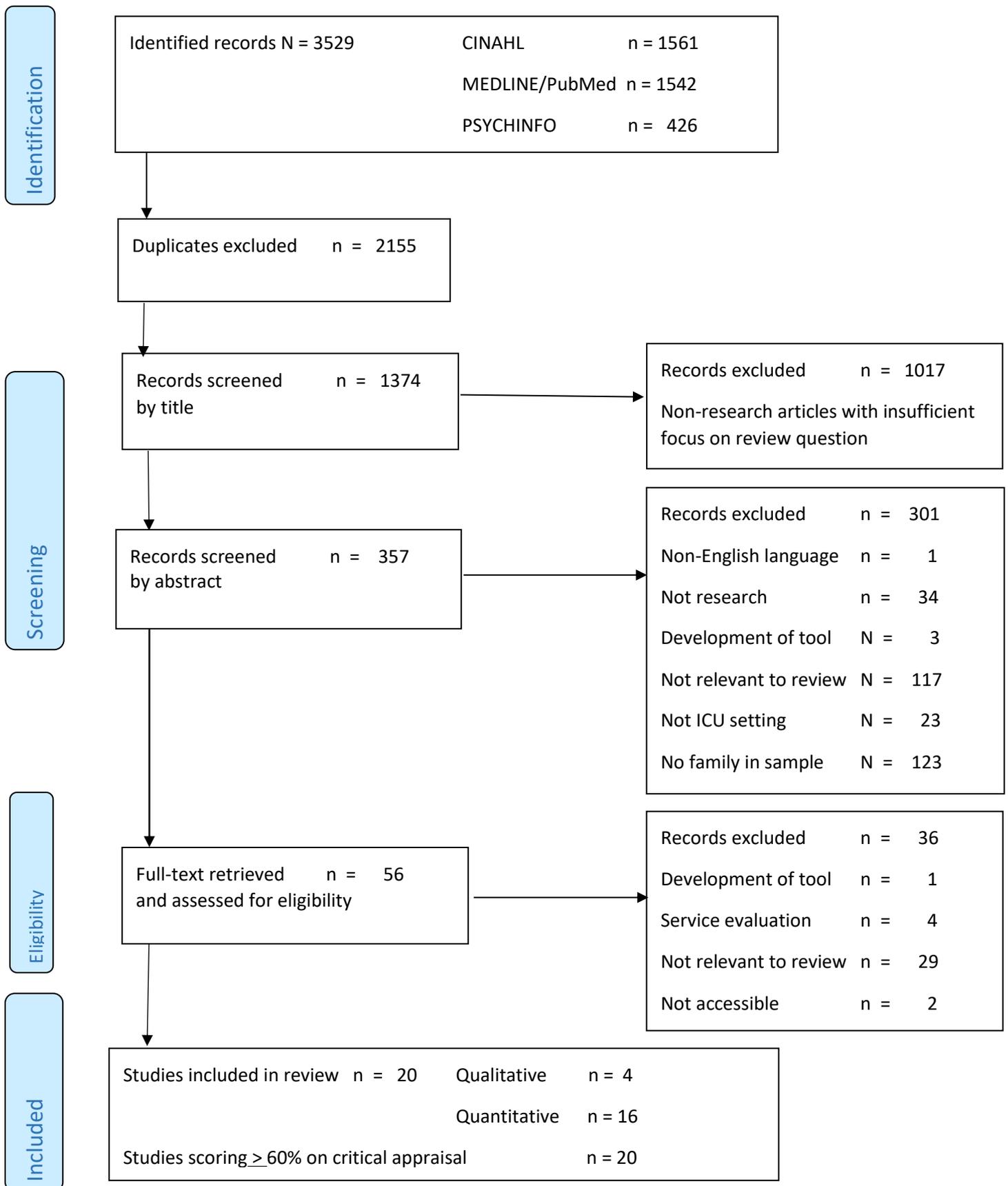


Figure 1: Flow diagram of study selection process based on PRISMA [15] 26 July 2020

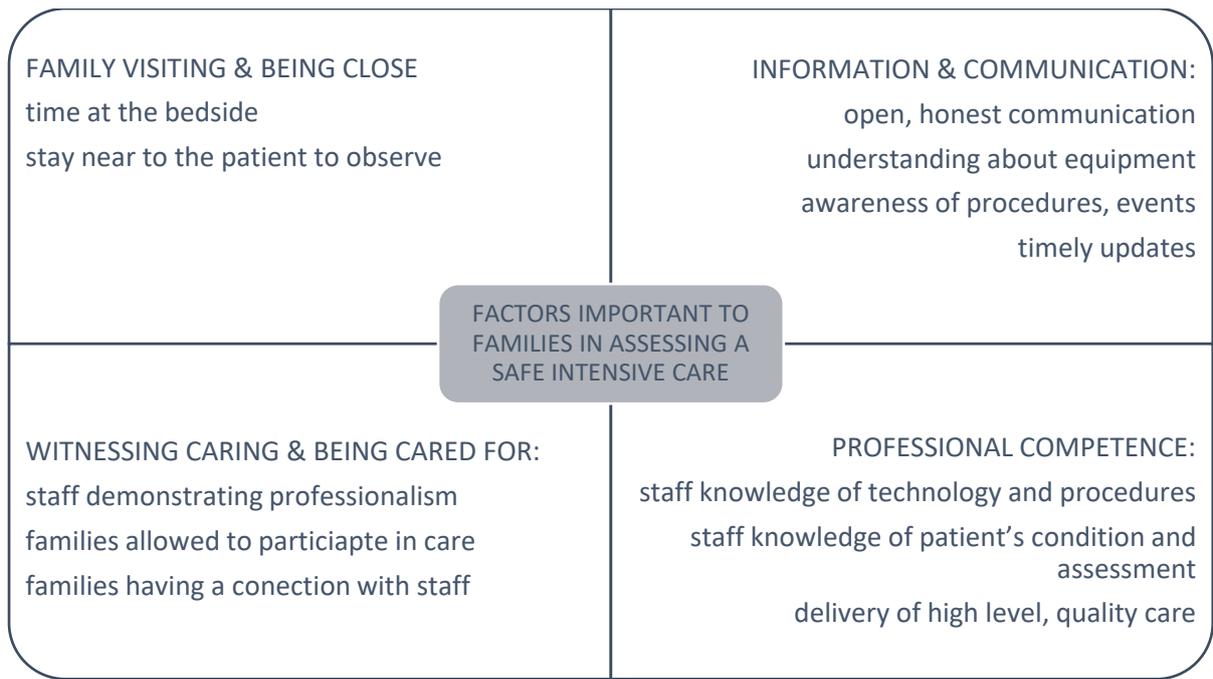


Figure 2: Key factors influencing family member perspectives on safety in the intensive care unit