International Journal of Nursing Studies Advances 7 (2024) 100251

Contents lists available at ScienceDirect

International Journal of Nursing Studies Advances

journal homepage: www.sciencedirect.com/journal/international-journal-of-nursing-studies-advances

How can family members of patients in the intensive care unit be supported? A systematic review of qualitative reviews, meta-synthesis, and novel recommendations for nursing care

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ARTICLE INFO

Keywords:
Intensive care units
ICU
Critical care unit
Family nursing
Family centered care
Family members
Relatives
Experience
Meta-synthesis

ABSTRACT

Background: Families are an important part of the intensive care unit (ICU) team. Being a family member in the ICU can be distressing due to interacting factors, such as the critical condition of the patient, the responsibility of acting as the patient's advocate, and partaking in decision-making related to treatment. Nurses need to be aware of the family's well-being throughout the patient's ICU stay.

Objective: To synthesize reviews of family members' experiences and needs during patients' ICU admission and develop recommendations to support nurses in strengthening their relationships with families.

Design: Systematic review of qualitative and mixed method reviews.

Data sources: Extensive searches without time limits identified systematic reviews published until June 27, 2024 in CINAHL, PubMed, Scopus, and Web of Science. Reviews were eligible if they provided knowledge required to inform high-quality on-site family care during the patient's ICU admission.

Review methods: Quality appraisal adhered to the Joanna Briggs Institute checklist for systematic reviews and research syntheses. Themes were generated by integrating review results and narratively summarizing the main contents. Finally, findings were translated into clinical practice recommendations by using the four-component GRADE-CERQual assessment (low to high recommendation grades). Recommendations were backtracked to primary research studies for validation. All recommendations were critically reflected upon with an expert panel of ICU nurses.

Results: The nine included reviews were built on 124 original studies published between 1995 and 2021. One central theme, "Emotional limbo and extreme moments", mirrored the core of families'

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https://doi.org/10.1016/j.ijnsa.2024.100251
Received 23 July 2024; Received in revised form 16 September 2024; Accepted 21 October 2024
Available online 24 October 2024
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experiences characterized by waiting time, i.e., for the patient to get better or worse, and overwhelming emotions and confusion brought about by the patient's critical illness. Three subthemes reflected actions to counterbalance emotional challenges: a) Responding to family members' existential needs, b) Establishing optimal grounds for reciprocal communication, and c) Enhancing a humanizing approach and atmosphere in the ICU. The meta-synthesis resulted in 11 aggregated recommendations. The findings highlighted that nurses should proactively address emotional issues to help preserve families' ability to keep going, allow families to be present and function as a part of the team, and inform families of the patient's situation and how they can practically help.

Conclusions: Nurses should use multiple adjustable approaches to alleviate family's burden during an ICU stay. Findings help nurses to prioritize care and make physical and emotional space for family caregivers. Results emphasize the need to facilitate the agency of family caregivers and reinforce their strengths through nurse-family dialogues.

Tweetable abstract: Novel recommendations to enhance nursing care of family members to patients admitted to the Intensive Care Unit.

What is already known

- Family members of patients admitted to the ICU encounter emotional repercussions during their loved one's admission.
- Family members provide essential information, for instance, regarding the patient's wishes for treatment and care, when patients cannot communicate their preferences, likes, and dislikes.
- Family members help to ascertain that healthcare professionals provide person-centered care; nevertheless, more emphasis needs to be placed on the care of family members in clinical guidelines for ICU nurses.

What this paper adds

- In addition to three subthemes reflecting the experiences of families of patients admitted to the ICU, the findings add 11 recommendations that translate into clinical care and thereby extend evidence that nurses can use to respond to the needs of family members in the ICU.
- Critical elements of the 11 recommendations involve multicomponent strategies to enhance agency within the families; for instance, inviting family involvement in the care process and proactively addressing emotional issues—all to help preserve families' ability to keep going and reduce their burden.
- The review helps nurses prioritize the care of families and make physical and emotional space for them during their loved one's ICU stay, while knowledge obtained from an expert group of ICU nurses simultaneously provides pragmatic ideas for incorporating recommendations into clinical care.

1. Introduction

The Intensive Care Unit (ICU) provides the most complex and devoted care available in modern medical society. Patients admitted to the ICU are characterized as being critically ill yet have the potential to improve (Williams et al., 2021). Their care is founded upon multidisciplinary teamwork to provide person-centered care nested within a highly technological environment. In ICU care, there is a logical predisposition towards maintaining and improving essential bodily organ function and preventing detrimental side effects from disease or injury using cutting-edge technology (Marshall et al., 2017). Due to the severity of patients´physical condition, sedation, and breathing tubes, many patients in the ICU cannot communicate their care preferences. Thus, they cannot be active in life-altering decision-making (Scott et al., 2019). Moreover, complications of ICU treatment, such as confusion and delirium, also inhibit patients from managing their situation independently (Scott et al., 2019).

To ascertain that patients' wishes are sufficiently governed, family members often act as patients´advocates, which can sometimes be a considerable weight to bear (Halain et al., 2022; Collet et al., 2024; Schwartz et al., 2022). Family members are not merely confined to individuals sharing genetic bonds but include individuals who have a close, meaningful relationship with the patient and can provide personal support, such as a close friend or a relative (Davidson et al., 2017). Family members are important because they provide essential information concerning patients´medical and personal history, which is difficult for the ICU staff to obtain otherwise. Moreover, they are often involved in complex decision-making, such as whether a treatment should be continued (Davidson et al., 2017; Mishkin et al., 2024). It is, therefore, hardly surprising that family members are considered an integral part of the ICU team in many settings (Schwartz et al., 2022).

Having a close relative admitted to the ICU is a difficult experience. Beyond the existential impacts, such as the perception of having their entire lives and routines turned upside down, family members frequently report experiencing a range of psychological responses, including anxiety, acute stress, doubt, fear, helplessness, worry, and anguish. Recently, many of these effects have been encapsulated in the concept of Post-Intensive Care Syndrome - Family (PICS-F) (Dijkstra et al., 2022; Hayes et al., 2024).

The role of the ICU nurse is vital in meeting the needs of family members; the provision of information and establishment of a trusting relationship are required for fulfilling family memberś need for security (Ito et al., 2023). Communication-based family support provided by ICU nurses and doctors has demonstrated reduced anxiety, depression, and post-traumatic stress disorders among family members who are recipients of targeted care strategies (Kentish-Barnes et al., 2022). A large, state-of-the-art qualitative study by Hetland et al. (2018) used five open-ended questions on social media that overviewed factors influencing family engagement in critically ill patients. The respondents comprised 374 nurses. Based on findings, the researchers underscored that nurses can improve family members' experiences just by motivating them to ask questions and reach comprehension, and by encouraging participation in daily care activities; for instance, mouth cleaning, applying cream to body parts, and assisting with light exercises/movement. Suggestions akin to those have gained wider momentum and substantiate the need for ICU nurses to establish ways to support family members emotionally and develop clinically valuable methods to better assess and meet their needs (Kynoch et al., 2019; Kydonaki et al., 2021; Schwartz et al., 2022).

An array of qualitative studies and reviews have gauged family members' experiences of having a close relative in ICU care (Eggenberger and Nelms, 2007; Kang et al., 2020; Nolen and Warren, 2014; Verhaeghe et al., 2005). Most recently, Sui et al. (2023) orchestrated a data synthesis of 23 original studies showing multi-level aspects of surrogate decision-making, elucidating how such responsibility adversely influences family members' experiences and functioning within their larger family system. The authors pledge that optimization of family care is warranted and that the topic should be addressed to eliminate unevenness in the patient-clinician relationships. Considering the extant number of qualitative studies and reviews, it is striking that no review of reviews has hitherto been performed to merge knowledge of family members' experiences during patients' ICU stay. The appropriateness of exploring and integrating existing knowledge to inform evidence-based recommendations to guide ICU nurses in caring for family members seems obvious. Consequently, we aim to bridge this divide by synthesizing qualitative data from systematic reviews. Our guiding research questions were: "What are the experiences, needs, and perceptions of family members of ICU patients throughout the care in the ICU, and are there facilitating aspects that may improve family members' experience?" and "What recommendations can be extracted to guide the care of family members in the ICU?"

2. Methods

2.1. Study design

A thematic synthesis of qualitative systematic reviews, a summation of results, and generation of recommendations were executed to bring results into practical use (Smith et al., 2011). We used the Grading of Recommendation Assessment, Development, and Evaluation-Confidence in Evidence from Reviews of Qualitative Research, GRADE-CERQual process, to transfer findings into clinical practice recommendations (Colvin et al., 2018).

2.2. Search strategy

Initial explorative searches helped to identify key articles, including free text combinations of words corresponding to PICOT, the acronym for population, issue of interest, context, outcome, and time. These free-text searches were executed in several electronic databases, including PubMed, CINAHL, JBI electronic database, Web of Science and Scopus, and renowned housings dedicated to preparing systematic reviews, such as the National Institute of Clinical Health and Excellence (NICE), the Scottish International Guideline Network, and the Cochrane collaboration—they were imperative to find sensitive keywords, map the field, generate effective inclusion/exclusion criteria, and decide upon databases to include in the final search strategy. Two authors (TG, MEK) tested and developed search strings that fit the MeSH terms of 10 key articles chosen from the free searches that subsequently were approved and tested by a healthcare librarian. Extensive searches without time limits identified systematic reviews published until June 27, 2024 in CINAHL, PubMed, Scopus, and Web of Science. Reviews were eligible if they provided knowledge required to inform high-quality on-site family care during the patient's ICU admission. For detailed inclusion criteria according to PICOT and database searches, see supplementary file a.

2.3. Study selection

Study inclusion transpired in distinct phases. Initially, we evaluated whether the titles within all databases were eligible according to the predetermined inclusion criteria (TG,KB,MEK). Then, the abstracts were screened, whereafter potentially suitable reviews were read in totality and mirrored against the inclusion criteria (TG,KB); this process was replicated by another team of authors (MEK,RJJ) blinded to the first team's assessment. Finally, if there was any doubt, all authors met to resolve questions of compatibility. Forward citation tracking of included articles was executed on Google Scholar. New records underwent the same screening process as the database searches; see online supplementary file b for an overview of the screening process and reasons for exclusion of records.

2.4. Appraisal of quality and risk of bias of the included reviews

The 11-item critical appraisal checklist for systematic reviews and research syntheses from the Joanna Briggs Institute (JBI) was used to gauge aspects of importance related to the quality of the included reviews. Each "Yes" indicated acceptable item coverage and was awarded one point, whereas "No" and "Unclear" were given zero points. This provided a maximum of 11 points. A higher score

indicated higher certainty in the body of evidence (Aromataris et al., 2015). Two teams of authors, blinded to the other team's assessment, appraised the quality (Team 1: TG,KB; Team 2: RJJ,MEK). Any disagreement was resolved through discussion, and the assessment was presented as a single score. A score of six provided an artificial cut-off point for low quality. A score between seven and nine indicated medium quality and 10 and 11 were for high quality. Reviews receiving low-quality scores (≤6) were excluded because they could jeopardize the synthesis quality. Combining studies of qualitative reviews with poor quality does not have the foundational strength to elicit trustworthy results (Lewin et al., 2018). All reviews with scores in the grey area of 6–8 underwent additional appraisal from all authors. A main concern of bias was synthesizing reviews that potentially had used results from the same primary research studies. To obtain an overview of this risk, we scrutinized the crossover of included reviews in an Excel spreadsheet, thoroughly read all articles more than once, and assessed their use to ensure that the finding were accurate and not overinterpreted. See supplementary file c.

2.5. Data extraction and synthesis

The first author (TG) read all the articles and preliminarily extracted data into matrixes according to Smith et al.,' approach (2011). This procedure was repeated by MEK and checked by RJJ and went in circles for three rounds, until consensus was reached about significant statements. The hallmark of this method relies on extracting and presenting the data intelligibly to improve the integration, interpretation, and validity of results. The first table covered the main study characteristics: information about: author(s), year, type of review type, target area, method for qualitative synthesis, and total number of participants. The latter columns presented extracted themes about family members' experiences; see Table 1.

More "thick" topical descriptions, divided into themes, sub-themes, and main contents reflecting family members' experiences, were extracted from each article; see supplementary file d, and then united across the reviews. To accomplish this latter step, information was tabulated according to significant statements, condensed statements, and abstract synthesized thematic content (MEK, RJJ, TG), which made thematic synthesis and in-depth analysis and interpretation possible; see Table 2.

Throughout the synthesis, we foregrounded families' perspectives and extracted themes from individual articles that corresponded to this focus. Healthcare professionals and the ICU environment were only considered in the way they influenced the experience of the families. Following this data extraction, we inductively coded recurrent themes and key concepts across included articles into descriptive, aggregating, or explanatory names and summarized them narratively (Thomas and Harden, 2008).

2.6. Grading confidence of recommendations and methodological rigor

GRADE-CERQual was used to interpret and summarize findings and formulate recommendations to help clinical decision-making (Lewin et al., 2018). Throughout the GRADE-CERQual, we evaluated four critical components: methodological limitations of the review, coherence of presentation, adequacy of data, and relevance across included articles (Lewin et al., 2018). The level of confidence ascribed to each recommendation ranged from high to moderate, low, and very low confidence (Lewin et al., 2018). The GRADE-CERQual process was completed as a concerted effort through several discussion rounds where we paid close attention to the origin and quality of evidence and contradictory findings. The discussions benefited from the authors' different experiences; three were seasoned researchers accustomed to qualitative methodology (MEK, KB, RJJ), and three were clinicians with various experiences with ICU care (TG, RJJ, MEK). All provided perspectives that fed into the final formulation of recommendations. As a final step, we backtracked five random recommendation clusters to their corresponding primary research studies to ascertain that the findings were interpreted in line with the context of the primary research studies. To evaluate the usefulness of the recommendations, we involved four experienced ICU nurses from two ICUs. We asked them to reflect on the clinical applicability and relevance of the recommendations, i.e., the need for education, resources, and ideas for use.

3. Results

3.1. Search results

The search yielded 892 hits; 67 abstracts were eligible and evaluated against the inclusion criteria. In this process, 34 records were excluded. Twenty-four records of the remaining 33 were excluded; ultimately, nine reviews fulfilled the inclusion criteria. Citation tracking of the included articles did not elicit further eligible reviews. For a modified PRISMA flow chart displaying an overview of the search process, methodology, and the main reasons for exclusion, see Fig. 1.

3.2. Methodological quality of the reviews

The nine included reviews were of medium to high quality with a median score of nine. For a summary of quality scores; see supplementary file e. Only one review provided sufficient detail on excluded studies (Kynoch et al., 2021).

The mapping of crossover references between primary studies showed that the reviews were based on 124 primary research studies. Eleven primary studies were used in more than one review. There was crossover in seven reviews with a maximum percentage of crossover of 25 % in two reviews (Kynoch et al., 2021; Scott et al., 2019); see supplementary file c, for details of crossover.

Table 1
Characteristics of included reviews and main themes reflecting family members' experiences.

Authors Year Country	Review type Qualitative synthesis	Target area	Method of qual. synthesis	Total studies in the review	Studies in synthesis Participants	Publication range of studies in the reviews	Themes/categories reflecting family members' experiences*
Boehm et al., 2021 USA	Systematic review and qualitative meta-synthesis	Patients and family members' experience with delirium in the ICU	Deductive synthesis of issues related to delirium, then inductive coding of remaining data	$N = 14$ qualitative. studies	**$N = 5$ studies** $n = 5$ qualitative studies $n = 48$ family members	1996–2020	**Two of four themes reflected families' experiences:** 1. Family members felt compassion, uncertainty, and anxiety during ICU delirium, as well as apprehension about the future 2. During ICU delirium, family members valued communication with the team, being involved in the patient's care, and signs of their recovery
Chen et al., 2020 USA	Mixed-method review	Family members' experience of end-of-life-care in ICU	Inductive synthesis according to emerging key concepts, use of CERQual for confidence in findings	$N = 50$ studies $n = 15$ qualitative $n = 33$ quantitative $n = 2$ mixed method	**$N = 17$ studies** $n = 15$ qualitative $n = 2$ mixed method $N = 522$ family members	2013–2018	1. Distressing emotions 2. Shared end-of-life decision-making 3. Proactive communication 4. Personalized end-of-life care 5. Valuing nursing care
Coombs et al., 2020 UK	Mixed method review	Factors influencing family members' perceptions of safety in the adult ICU	Narrative synthesis	$N = 20$ $n = 16$ qualitative $n = 4$ quantitative.	**$N = 16$ studies** $n = 16$ qualitative studies $N = 384$ family members	1996–2007	1. Family visiting: feeling safe by being close to the patient 2. Information and communication: feeling safe through knowledge and understanding 3. Caring: feeling safe when witnessing and receiving care 4. Professional competence: feeling safe with capable and skilful staff
Imanipour et al., 2019 Iran	Systematic review and qualitative meta synthesis	Experiences of family members of patients admitted in adult ICUs	Inductive coding and thematic synthesis	$N = 28$ $n = 26$ qualitative studies. studies $n = 2$ mixed method	**$N = 28$ studies** $n = 26$ qualitative studies $n = 2$ mixed method $N = 717$ family members Of those, 30 were families but only counted as 1 family member	2007–2018	**Two of three themes reflected families experiences during ICU admission** 1. Floating a. Shock and disorientation b. Uncommon ICU environment c. Emotional response d. Feeling of vulnerability e. Fear of having a family member dying f. Alteration in family dynamic 2. Probing a. Family members need to know. b. An opportunity to describe their loved one c. Doubts and ambivalence d. Information seeking e. Interpreting f. Hearing and recalling

(*continued on next page*)

Table 1 (*continued*)

Authors Year Country	Review type Qualitative synthesis	Target area	Method of qual. synthesis	Total studies in the review	Studies in synthesis Participants	Publication range of studies in the reviews	Themes/categories reflecting family members' experiences*
							g. Communication-related difficulties h. h. Experiencing the gravity of the patient's illness.
Kydonaki et al. (2021) UK	Integrative review	Implementation of family rounds in the ICU, including issues that affect family involvement and exploring how family members perceive family rounds	Inductive thematic analysis and narrative synthesis	*N* = 15 3=qualitative 1=mixed method 11=quantitative	***N* = 4 studies** 3= =qualitative 1=mixed method *N* = 39 family members *n* = 56 (mixed participants incl. family members) Observation of 300 individual rounds involving family members.	2003–2018	All three themes reflected families' experiences of rounds in critical care: 1. Interactions and communication 2. Organization of rounds 3. Intensive Care Unit culture
Kynoch et al. (2021) Australia	Systematic review and meta-aggregation	Needs and experiences of families with a relative in the ICU	JBI meta-aggregation	*N* = 20 qual. studies Total participants *n* = 236 family members	***N* = 20 studies** *n* = 20 qualitative studies *N* = 236 family members	2010–2019	Four themes reflected the experiences and needs of families with a relative admitted to ICU 1. Family member's altered psychosocial health a. Cultural and religious needs b. Emotional, psychological, and physical impact on FM c. Family dysfunction as a result of crisis d. Hope e. Impact on financial security f. Uncertainty and unpredictability 2. Family member proximity and involvement a. Involvement in care b. Proximity matters 3. Information and communication a. Information needs b. Information delivery 4. The ICU environment a. ICU physical environment b. b. Relationship with and support from staff influence the perception of care.
Nielsen et al. (2023) Denmark	Systematic review and qualitative meta-synthesis	Factors contributing to patients' and relatives' experience of intensive care as humanized or dehumanized	Qualitative meta synthesis – inductive coding and theme generation. Interpretation built on Ricoeur's hermeneutic phenomenology	*N* = 15 studies *n* = 14 qualitative *n* = 1 mixed method Total participants *N* = 572 *n* = 315 patients	***N* = 15 studies** *n* = 14 qualitative *n* = 1 mixed method *N* = 144 family members	2004–2020	Three of six themes reflected factors that contributed to experience of families of ICU as humanized or dehumanized: 1. Seeing the patient as safe, and cared for as a unique human being, comforted relatives

(*continued on next page*)

Table 1 (*continued*)

Authors Year Country	Review type Qualitative synthesis	Target area	Method of qual. synthesis	Total studies in the review	Studies in synthesis Participants	Publication range of studies in the reviews	Themes/categories reflecting family members' experiences*
				$n = 113$ health care workers $n = 144$ family members			2. Experiencing connectedness with the patient and maintaining bonds 3. Feeling cared for helped relatives endure the critical situation in the ICU
Scott et al. 2019* UK	Scoping review	Needs and experiences of family members of adults admitted to ICU and interventions to improve family satisfaction and psychological well-being and health	Key themes developed and results described narratively	$N = 43$ articles $n = 3$ reviews $n = 26$ quantitative $n = 8$ qualitative $n = 6$ mixed method Total participants approx. $n = 749$	***N* = 8 studies**** $n = 7$ qualitative $n = 1$ mixed method $N = 163$ family members	2018–2021	Two of four subthemes reflected factors that contributed to experience of families of ICU as humanized or dehumanized: 1. Family members' perception of their needs 2. 2. Uncertainty
Sui et al. (2023) China	Systematic review and thematic synthesis	Family members' perceptions of surrogate decision-making in the ICU	Thematic synthesis inductive analysis CERQual	$N = 23$ $n = 21$ qualitative $n = 2$ mixed method	***N* = 23 studies** $n = 21$ qualitative $n = 2$ mixed method $N = 749$ family members	1995–2021	1. Individual systems: the nature of surrogate decision-making experiences a. Suffering from the emotional and psychological burden b. Emergence of different cognitive styles c. Reshaping a new life order in disruption 2. Family systems: the mutual effects of surrogate decision-making and family dynamics a. The family as a whole closely connecting with each other 3. Medical systems: surrogate decision-making serves as a prism to reflect social perceptions a. Reflecting social perception of the medical system

* Only themes pertaining to family's experience reported and where it is possible to separate qualitative and quantitative results to allow a qualitative synthesis.

** Scott et al., 2019: The five studies used in qualitative synthesis were Bond et al.; Fry & Warren, Keenan and Joseph; Agard & Harder; Burr; Iversen; Jameson; Johanessen. However, a reference also exists to Hinding and Fridlund in the text of the result section, but this study was not presented in the table of included studies and reference list.

3.3. Characteristics of included studies

The majority of articles were systematic reviews in the form of either meta-aggregation or qualitative synthesis ($n = 5$) (Boehm et al., 2021; Imanipour et al., 2019; Kynoch et al., 2021; Nielsen et al., 2023; Sui et al., 2023). Other designs were a scoping review ($n = 1$) (Scott et al., 2019), a mixed method ($n = 2$) (Chen et al., 2020; Coombs et al., 2020), and an integrative review ($n = 1$) (Kydonaki et al., 2021). Five reviews focused solely on family members (56 %) (Chen et al., 2020; Coombs et al., 2020; Imanipour et al., 2019; Kynoch et al., 2021; Sui et al., 2023) whereas four included family members, patients, and/or healthcare professionals (44 %) (Boehm et al., 2021; Kydonaki et al., 2021; Nielsen et al., 2023; Scott et al., 2019). Families' general experience in the ICU was emphasized in five articles (56 %) (Coombs et al., 2020; Imanipour et al., 2019; Kynoch et al., 2021; Nielsen et al., 2023; Sui et al., 2023) and end-of-life care in one review (11 %) (Chen et al., 2020). Two reviews focused on interventions (22 %) (Kydonaki et al., 2021; Scott et al., 2019). Intervention types, amongst others, encompassed participation in ward rounds and physical care provision, environmental change within the ICU, support via the web, and discussions with healthcare professionals. One review reported the families' experiences of delirious ICU patients (11 %) (Boehm et al., 2021). Participating family members numbered 3002 if adding numbers from each review or 2804 when correcting for crossover; see Table 2. All reviews were published between 2017 and 2023 but the original studies on which they built were published between 1995 and 2021.

3.4. Thematic synthesis and overview of findings

A total of 210 significant statements were extracted across the reviews, see Table 2.

One central theme, "Emotional limbo and extreme moments" mirrored the core of families' experiences. It was characterized by overwhelming emotions, such as uncertainty, helplessness, and confusion. Observing their loved ones' critical illness created waiting time regarding what would happen next—a state between hope and despair—not knowing how things would turn out. The three overlapping subthemes present variations of family members experiences and helpful issues that nurses could endorse, namely: a) Responding to family members' existential needs ($n = 82$ significant statements), b) Establishing optimal grounds for reciprocal communication ($n = 74$ significant statements), and c) Enhancing a humanizing approach and atmosphere in the ICU ($n = 54$ statements). See Fig. 2 for a crude overview of themes, subthemes, and main contents. Each sub-theme and contents are presented as a coherent narrative with corresponding recommendations.

3.4.1. a. Responding to family memberś existential needs

The families' strong emotional responses included shock, anxiety, and fear in connection to the ICU admission. The whole situation "sucked". Feelings of sadness, vulnerability, hopelessness, and helplessness while their family member was in the ICU were also prominent, especially if their relative was deteriorating quickly. Adverse feelings were, among others, fueled by an intrinsic uncertainty about whether the patient would suffer permanent disability or survive. Being constantly alert physically and psychologically drained family members. Not all feelings, however, were negative and strength-depriving. Thus, the families mobilized energy and the ability to "keep going" by staying hopeful. Creating and supporting a haven of hope and trust was emphasized as a critical issue that provided families with strength and the ability to cope with emotional ups and downs. This, in some instances, also included faith and spirituality. Mixed emotions were noted concerning apprehensiveness about the future and prognosis, and feeling overwhelming compassion and helplessness if they were unable to assist their loved one through fear, pain, and agitation. Similarly, the sudden critical illness was frustrating and evoked anxiety, depression, fear, and remorse. Bearing witness to the fragile physical appearance of the patient in the ICU environment and their utter dependence on others made the families feel particularly estranged from a person they otherwise knew so well. Family members' emotions needed recognition through, for instance, receiving empathetic statements, attention, and updates from healthcare professionals. Otherwise, they would feel alone and emotionally isolated.

Recommendation 1: Nurses should address the turbulence of emotions (sadness, vulnerability, helplessness, hopelessness) that family members encounter and support them in preserving hope and keeping going (high confidence).

Many family members endured physical ramifications provoked by the emotional limbo. These included altered sleep, fatigue, difficulties concentrating, nausea, lack of appetite, headaches, and more. They often neglected their own needs, such as eating and drinking, in the midst of their concerns. However, if nurses proactively attended to those needs, they could prevent a negative loop, enhancing the family members' energy, endurance, and psychological well-being.

Recommendation 2: Nurses should ask family members about physical symptoms, such as difficulties sleeping and headache, and inquire whether they have attended to their own bodily needs, such as nutrition, and help them to fulfill their needs (low confidence).

Allowing family members to be physically present at the bedside fostered feelings that healthcare professionals cared for them and the patients as unique persons. When families were present and observed that healthcare professionals paid attention to the patient's needs, it also increased their confidence in the quality of care and helped to build trust. The need for physical proximity reflected a need to be present. It simultaneously helped families to make realistic assumptions about the patient's condition. Moreover, being at the bedside and seeing the patient with their own eyes furnished meaningful and familiar ways to engage. For instance, family members could bring items that were a part of patients' everyday lives before the ICU admission, such as music and books, newspapers, or other written material that they would read to them. Easing family uncertainty was spearheaded by making them feel important and appreciated in the eyes of healthcare professionals. Nevertheless, families suffered emotional distress if they received inadequate attention, support for their own suffering, or updates on the patient's condition.

The role of an advocate was sedimented by sharing information about the patient's wishes and personal characteristics, thus making healthcare professionals aware of their uniqueness. Simultaneously, information exchange and interaction between healthcare

Table 2
Significant statements, condensed statements, and synthesized thematic content under each subtheme related to the experiences of family members of patients admitted to the ICU.

Subtheme a: Responding to family members' existential needs			
Studies contributing to review findings*	Significant statements extracted from reviews (n = 82)	Condensed statements - interpretations	Synthesized thematic content
Boehm et al., 2021 Chen et al., 2020 Coombs et al., 2020 Imanipour et al., 2019 Kydonaki et al., 2021 Kynoch et al., 2021 Nielsen et al., 2023 Scott et al., 2019 Sui et al., 2023	Shock in connection with the ICU stay. 1. The thought of death and finality caused anguish. 2. Situation described by using analogies such as "brutal hell" and "paralysing". 3. The sudden critical illness in the patient was frustrating and evoked anxiety, depression, distress, and sorrow. 4. Feeling the impact and severeness of their relative's critical illness. 5. Cycles of emotions – limbo due to the unpredictability of the situation. 6. Fluctuating between despair and optimism. 7. Constant fear of "new" complications. 8. An array of intense worries such as shock, disorientation, vulnerability, and fearing mortality. 9. Emotional turmoil or roller-coaster of emotions due to the ICU admission and instability of their family member's condition. 10. Feeling sadness, vulnerability, hopelessness, and helplessness. 11. Emotions such as helplessness and despair, being scared and feeling ambushed – "the whole situation sucked". Anxious about the future, wondering if the patient will fully recover. 1. Lack of agency, feeling totally dependent on the HCP care-giving abilities. 2. Feeling alone, difficult to express feelings. Waiting for information away from the patient without sufficient explanation evoked anxiety and fearfulness. Helpful when physicians and nurses explicitly addressed suffering and concerns. 1. Emotional recognition from nurses helped family members to feel supported, also in decision-making. 2. Tedious waiting time, not knowing the outcome. 3. Feeling overwhelmed, not knowing how to navigate the unknown situation. 4. Uncertainties of outcomes and unpredictability highly distressing. 5. The ICU was a terrifying place signifying uncertainty. 6. Helpful when given the opportunity to express feelings and experiences.	1. Anguish and helplessness to witness their loved one's critical illness. 2. Existential threat when fearing death or permanent disability. 3. Emotional limbo – unpredictability fluctuating between despair and optimism. 4. Intense worries – the whole situation sucks. 5. Feeling alone with one's emotions. 6. Lacking agency and feeling dependent on staff. 7. Tedious waiting time.	**Emotional responses and psychological impact** (n = 23)
Imanipour et al., 2019 Kynoch et al., 2021 Sui et al., 2023	1. Physical symptoms such as altered sleep patterns. 2. Physical and mental consequences (e.g., depression, guilt, difficulties concentrating, forgetting own needs such as eating, drinking, sleeping, daily routines – resulting in symptoms such as nausea, headaches, tachycardia. 3. Physical symptoms such as sobbing, heart pounding, (psychological) fatigue.	1. Physical symptoms such as altered sleep patterns, difficulties concentrating, heart pounding, headaches, fatigue, nausea. 2. Psychological consequences such as depression and guilt. 3. Forgetting own existential needs such as eating and drinking.	**Physical impact** (n = 3)
Boehm et al., 2021 Chen et al., 2020 Kynoch et al., 2021 Nielsen et al., 2023 Scott et al., 2019 Sui et al., 2023	Feeling compassion for the patient, nervous, scared, and anxious on their behalf.Acutely aware of the patient's fear and agitation.Difficult if their relative was in pain. Observing deterioration (or dying) without being able to help resulted in helplessness and suffering. 1. Difficult to observe the suffering that their relative had to endure. 2. Concerned what would happen if the patient survived, i.e., mental and physical disability and dependency. 3. Uncertainty and anxiety regarding their relative's survival and whether they would suffer permanent disability. 4. Fear of losing the patient either dying or that they would be different.	1. Scared and nervous on the patient's behalf. 2. Suffer if the patient suffers. 3. Fearing for the patient's future i.e., concerning survival, and permanent disability.	**Empathizing with the patient's situation** (n = 11)

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Subtheme a: Responding to family members' existential needs			
	5. Difficult to see limits between life and death and accepting advanced therapies to rescue the patient's life albeit being unacceptable in other situations. 6. Family members envisioned how the patient would feel such as loss of dignity and not being able to decide things for themselves. 7. Encountering a state of constant "empathic suffering".		
Kynoch et al., 2021 Scott et al., 2019 Sui et al., 2023	1. Staying close to the patient, helped the family members to act as an advocate. 2. Afraid of making the wrong decisions when acting as the patient's advocate. 3. Aware that surrogate decisions sometimes would have consequences that they would need to live with – a huge burden to take life-altering decisions and be sufficiently convinced that the decision was right. 4. Difficult to make decisions without collaboration with healthcare professionals - insecurity about what was needed in the ICU and feeling responsibility that "wrong" decisions could lead to their loved one's continuance of life with low life quality or death. 5. Difficult for family members when finding themselves in a situation where their wishes differed from the patient's wishes. 6. Difficult to make decisions and feel responsible for the well-being of their loved one. 7. Being entrusted with their relative's decisions was both a burden and a privilege. 8. When acting as the patient's advocate it is important that the staff respects the voice of the patient through the family members. 9. Important that family members are invited to participate in decision-making and that healthcare professionals use common meeting points to consider the patient's uniqueness.	1. Important to be physically close and observing the patient and treatment up close when acting as an advocate. 2. Scared of making the "wrong" decisions. 3. Difficult to make decisions that might not match patient's wishes 4. Important to make the decisions in close collaboration with knowledgeable healthcare professionals. 5. A privilege to make certain that the patient's voice is heard although the patient cannot speak for themself. 6. Important to feel accepted and invited to act as an advocate by the healthcare professionals.	**The role as an advocate** ($n = 9$)
Boehm et al., 2021 Chen et al., 2020 Kynoch et al., 2021 Nielsen et al., 2023 Sui et al., 2023	1. Puzzled by the patient's odd behavior (i.e., during delirium or when disoriented). 2. Want to "be there" for their sick relative but find it difficult when their relative acts strange, such as pulling the lines, screaming, etc. 3. Feeling that the patient in the bed is not the person they know. 4. Difficult to recognize the patient; they might appear unfamiliar in the ICU environment. 5. Difficulties recognizing their relative in the ICU attached to tubes/medical equipment. 6. It could be difficult to recognize one's sick relative in the ICU environment, might seem foreign and not look like the person they love. 7. Hard to witness that the patient no longer looked like the person they knew. 8. Difficult for family members to observe that their relative looked sick and changed due to illness and lying amid medical equipment.	1. Feeling that the patient looks different, not entirely as the person they recognize and love. 2. Difficult to recognize the patient amid tubes and medical equipment. 3. Puzzling when patients behave strangely, i.e., when delirious or when disoriented.	**Perceiving the patient as estranged** ($n = 8$)
Boehm et al., 2021 Chen et al., 2020 Coombs et al., 2020 Imanipour et al., 2019 Kydonaki et al., 2021 Kynoch et al., 2021 Nielsen et al., 2023 Sui et al., 2023	1. Being physically present in the ICU helped family members to stay emotionally connected. 2. Bringing items and getting ideas from healthcare professionals to help family members engage in meaningful/familiar ways, such as bringing books, cards, and other things that are a part of the patient's routine and what they are used to doing/like doing. 3. Helping to ground the patient and connecting to the patient made relatives feel a sense of purpose. 4. Wish to be engaged and included in efforts to orient the patient. When their presence helped to calm patients and (re)orient them, they felt a sense of purpose. 5. Emotional distress (i.e., during end-of-life care) was triggered by inadequate attention, support, and updates.	1. Physical presence a helpful way to stay emotionally connected and grounded. 2. Important to feel useful and have a sense of purpose. a. Some by partaking in direct care. b. Some by providing other kinds of personalized support i.e., by reading or bringing familiar things to the ICU. c. Some by assuring that patients wishes in care provision were fulfilled. 3. Important with updates on the patient's situation. 4. Fear what would happen if not being present at the ICU– important to trust the healthcare professionals.	**Maintaining emotional connection and optimism** ($n = 28$)

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Subtheme a: Responding to family members' existential needs			
	6. Ascertaining that their relative received personalized care. 7. Participating in direct patient care and being involved in parts of care. 8. Participating in direct patient care helped. 9. Provided comfort in being close to their relatives and observing the care/treatment. 10. Fear that adverse events would happen if they went away. 11. Reluctant to leave the patient if feeling uncertain about their condition or mistrusting the care. 12. Need for information and for a venue where they could describe their sick relative as a person. 13. Desire to be included in treatment decisions and caregiving, and obtain some kind of role. 14. Respecting the patient's voice 15. Important to trust the care provided by HCP. 16. Faith and spirituality helped some. 17. Important for FM to find ways to be involved. 18. Hope was the crux of coping and fuelled the ability to keep going. 19. Being allowed to stay at the bedside provided reassurance and emotional comfort. 20. Some found comfort in being involved in care, both due to cultural reasons and providing meaningfulness and agency (i.e., applying lotion, talking to their relative, holding hands). 21. Involvement in care should be individualized. 22. Important for FM that HCPs are sensitive to spiritual beliefs and provide culturally sensitive support 23. Helping FM to experience closeness was imperative to restore a bond between the patient and the FM Seeing the patient safe and cared for as a unique human and being present at patient's bedside comforted relatives and gave hope. 24. Paying attention to the patient's needs and wishes, including their spiritual needs, helped FM to trust that HCPs sincerely cared for patients. 25. Experiencing connectedness and averting separation supported FM. 26. Good to be encouraged to talk with, touch and feel their relative and establish closeness. 27. Maintaining hope was important but sometimes FM were unrealistically optimistic. 28. Faith and spirituality became more important for many than during usual daily life	5. Sensitive support respecting faith, spirituality, hope and cultural needs. 6. Important to that the patient is treated as a unique person, helps the family members to maintain closeness with the person.	
Subtheme b: Establishing optimal grounds for reciprocal communication			
References*	Significant statements extracted from reviews ($n = 74$)	Condensed statements - interpretations	Synthesized thematic content
Boehm et al., 2021 Chen et al., 2020 Imanipour et al., 2019 Kydonaki et al., 2021 Kynoch et al., 2021 Nielsen et al., 2023 Scott et al., 2019 Sui et al., 2023	1. Could see small warning signs overseen by staff. Reciprocal trust was important so relatives felt that they could inform staff about their gut feelings/ unique insights. 2. Felt responsible for care and longed to be involved in decision-making. 3. Involvement fostered a sense of agency, feeling more familiar with the situation, and eased uncertainty. 4. Staying alert and being updated helped family members to provide information that again helped healthcare professionals to adequately address patients' needs at the end of life. 5. Helping to adjust and gain knowledge and understanding. 6. Interaction between family members and healthcare professionals improved understanding of both the family members' and patient's needs.	1. Reciprocal trust important to allow family members to react to their "gut" feeling about the patient. 2. Involvement and gaining knowledge and understanding is helpful for agency. 3. Continuous information-sharing and updates conducive for providing meaningful care and making the family members feel involved. 4. Important to create equal relationship that respects what everyone brings to the table to help the patient's condition and a shared understanding of the patient's condition. 5. Use of helping aids such as diaries to enhance information-sharing.	**Mutual information-sharing** ($n = 13$)

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Subtheme b: Establishing optimal grounds for reciprocal communication			
References*	Significant statements extracted from reviews ($n = 74$)	Condensed statements - interpretations	Synthesized thematic content
	7. Interactions enabled sharing of valuable information. 8. Reciprocal benefits. Healthcare professionals learned important aspects about the patient that informed their care provision and family members about the patient's condition and ICU environment. 9. The interaction between family and healthcare professionals improved clinicians´ understanding of the patient and their family. 10. Continuous information-sharing between patients and ICU staff creates an important structure for meaningful care that ensures that care is provided as close as possible to the patient's wishes. 11. Use of a diary could serve as a communication tool between HCPs and relatives, it comforted the relatives to see what the HCP had written in the diary i.e., if they had been away from the patient. 12. FM needs to create a form for alliance between them and the HCPs to help them to cope; this alliance is built on trust. 13. Unequal relationship and lack of familiarity with the ICU could make the FM feel abandoned by the HCP if they lacked explanation.		
Boehm et al., 2021 Coombs et al., 2020 Kydonaki et al., 2021 Kynoch et al., 2021 Nielsen et al., 2023 Scott et al., 2019 Sui et al., 2023	1. Communication with the ICU team helps family members to make sense of the situation. 2. Being asked to wait outside the ICU was difficult, especially if staff constantly entered and left the unit. Then they sometimes wondered if something terrible had suddenly happened to their relative 3. Ward rounds helped family members to gain insight into the patient's situation, physical condition. 4. Ward rounds was a venue for family education, a place to gain consent and share updates. 5. Family members reluctant to participate in rounds if they feared that they might interrupt the work of the ICU staff. 6. Family members participation in structured rounds helped involvement in patient's ICU process and eased their way into the ICU atmosphere. 7. Ward rounds opened possibility for sharing uncertainty, goals and care priorities, and created clarity about the goals of care. 8. Ward rounds had a strong focus on improving foundation for better care delivery, increased family members´ and healthcare professionals´ awareness of uncertain clinical situations and helped to inform steps in care provision. 9. Allowing presence of family members is a precondition for optimal communication process. 10. Involvement of family members in different levels of care or even just their presence empowered family members to take part in decision-making – when they comprehended the treatment better. 11. Inviting questions after rounds and encouraging questions during rounds. 12. Helped communication and trust if family members were welcomed as a part of the ICU team. 13. Being a part of the ICU team helped family members to better comprehend the patient's situation and help them to understand what was going on. 14. Important for families to know that a team was pursuing establishing what was best for the patient.	1. Attendance during ward rounds or other forms for close planned communication helps family members. 2. Ward rounds was a venue for family education, a place to gain consent and share updates. 3. Ward rounds a way to get updated with goals of care. 4. Ward rounds can create a better focus for care delivery. 5. Ward rounds can be a place where relevant questions are raised, contemplated, and answered. 6. Important to invite questions from family members. 7. Ascertain that everything is comprehended correctly by the relative. 8. Being invited as a part of the team helps the family members to comprehend the patient's situation.	**Inclusion in the ICU Team – active role in rounds** ($n = 14$)
Chen et al., 2020 Coombs et al., 2020	1. Continuous up-to-date information was a prominent fundamental need. 2. Proactive information given on the initiative of HCPs.	1. Up-to-date and proactive information a fundamental need of family members. Not knowing is the worst thing. 2. Vulnerability, insecurity, stress, and difficulties coping when information is inadequate.	**Accessibility and comprehension of information** ($n = 26$)

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Table 2 (*continued*)

Subtheme b: Establishing optimal grounds for reciprocal communication			
References*	Significant statements extracted from reviews ($n = 74$)	Condensed statements - interpretations	Synthesized thematic content
Imanipour et al., 2019 Kydonaki et al., 2021 Kynoch et al., 2021 Nielsen et al., 2023 Scott et al., 2019 Sui et al., 2023	3. Family members longed for proactive, regular, and sensitive communication endeavors with HCPs 4. Adequate information was a prerequisite for reducing stress and coping with the situation. 5. Feeling vulnerable and insecure if information was incomprehensible. 6. Difficult to process a lot of information at once. 7. Information on what had been done and what to expect provided feelings of overview and control. 8. Important to be able to reach information and communicating optimally with HCPs. 9. Lack of continuity, information flow, and involvement evoked anxiety and increased burden. 10. Predictability in provision of information helped FM to adjust to the uncertain situation/condition. 11. Negative effects if information needs were unmet. 12. Checklists could be used during rounds. 13. Important that family members always knew who to approach for information. 14. Ensure continuity between staff turnovers. 15. Important that HCPs used language that was easy to understand without medical jargon. 16. Nurses were often mediators for information and explaining information. 17. Family members needed to understand patient's condition to endure the difficult and emotional situation associated with the patient's critical illness. 18. When information needs were satisfied and FMs distressful situation recognized, it alleviated some of the relatives' suffering. 19. There should be an atmosphere that allows for questioning. 20. Not knowing is the worst part – important to have easy access to information. 21. Important to understand information accurately i.e., related to the treatment and care plan 22. Important to interact frequently with staff to discuss the patient's wishes and to ascertain that they were executed. 23. Difficult if HCPs appeared too busy and not sufficient time for FM questions and concerns. 24. Important to have time for proper information. 25. Medical jargon should be circumvented. 26. Importance of accessibility.	3. Difficulties processing much information at the same time. 4. Continuity of information helpful for relieving anxiety. 5. Important to ensure continuity with the care of patients and family members at staff turn-overs. 6. Creating an atmosphere and time that invites questions and repetition of information as often as needed. 7. Contemplate the language used for information provision, i.e., circumvent use of medical jargon.	
Boehm et al., 2021 Chen et al., 2020 Coombs et al., 2020 Imanipour et al., 2019 Kydonaki et al., 2021 Kynoch et al., 2021 Nielsen et al., 2023 Scott et al., 2019 Sui et al., 2023	1. Required "to the point information" i.e., regarding delirium, not just being told that the patient is a bit tired and confused. 2. Many wanted to be prepared for the risk of delirium early on. 3. Important that information and presence from HCP was infused with kindness and that eye contact was established. 4. Adequate, structured, and honest information from HCPs was important. 5. If perceiving that information was withheld it evoked suspicion, mistrust, and fear for patient's safety. 6. Updates needed to be in a timely manner and communicated clearly and honestly. 7. Important to be assured that the best level of care was provided for the patient. 8. Some felt the need to surveillance the care to protect their relative from errors in care 9. Help from HCPs to interpret of what is going on and get an overview of the situation.	1. Honest information where family members are prepared for difficult situation/anticipated difficult reaction from the patient, i.e., confusion or delirium. No sugar-coating. 2. Showing kindness, politeness, compassion, professionalism, and knowledge when providing family members with information. 3. Making the family members feel cared for. 4. Information should go beyond information about vital signs and provide a fuller analysis of the situation. 5. Tailoring information to each family member's needs. 6. Easier to trust when sometimes allowed to be present during difficult situations or caregiving situations.	**Honesty and trust** ($n = 21$)

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Subtheme b: Establishing optimal grounds for reciprocal communication			
References*	Significant statements extracted from reviews ($n = 74$)	Condensed statements - interpretations	Synthesized thematic content
	10. Information important to relieve doubts and ambivalence. 11. Positive communication endeavors and continuity in communication between HCPs and family members helped to build trust and positive relationships. 12. Information needs to be honest and frequent and is one of the main issues FM associates with quality care. 13. Information should be provided to FM in a polite, empathic, and consistent way 14. Kindness, professionalism, knowledgeable, and highly-skilled HCPs were valued. 15. Information delivery approaches should be tailored to individual FM needs. 16. Confidence in HCPs' quality of care provided reassurance. 17. Important to be allowed to be present to observe the HCP while they provided care (at least in some situations) for the patients. 18. Feeling cared for helped family members endure the critical situation in the ICU. 19. Difficult to leave the patient's side and constantly searching for clues, i.e., in the HCPs' attitude, of whether the patient improving or deteriorating. 20. Information should go beyond information about vital signs and provide a fuller analysis of the situation. 21. Honesty and truthful information without sugar-coating.		
Subtheme c: Enhancing a humanizing approach and atmosphere in the ICU			
References*	Significant statements extracted from reviews ($n = 54$)	Condensed statements - interpretations	Synthesized themes
Chen et al., 2020 Coombs et al., 2020 Sui et al., 2023	1. Nurses were perceived as the frontliners of caregiving; they gathered necessary information from family members which helped them to structure care to respond to patients' and families' needs. 2. Nurses played a large role in provision of information and helping transitions to different treatment levels, i.e., transition from active to end-of-life care. 3. Nurses played a large role in provision of information and helping transitions to different treatment levels, i.e., transition from one ICU to another or from ICU to general ward. 4. Nurses often acted as navigators. 5. Would be great with a designated resource that have time to help the family members during the ICU admission.	1. Nurses are frontline caregivers, closest to the patient's bedside and to providing support according to the patient's/family member's needs. 2. Acting as navigators for family members and the patients at admission, different levels of care and transitions between different states of needs during the ICU stay, and during discharge to general wards.	**Nurse navigators to alleviate family experiences** ($n = 5$)
Chen et al., 2020 Coombs et al., 2020 Kynoch et al., 2021 Nielsen et al., 2023 Scott et al., 2019 Sui et al., 2023	1. Needs for personalized end-of-life care were underrecognized by healthcare professionals. 2. Healthcare professionals showing genuine interest in patients' care, and keeping them clean and comfortable, enhanced a sense of serenity and security. 3. Created staff if the patient was well taken care of, clean, and seemed physically comfortable. 4. Kindness, smiles, and comforting touch provided by healthcare professionals to patients, and that went beyond tasks that were absolutely required, created connectedness and trust.	1. Showing genuine interest in the patient's and family's well-being, not treating the patient as an "object". 2. Important to observe that the patient is well-cared for and kept clean and physically comfortable. 3. Important that personal preferences are respected. 4. Kindness, smiles, and comforting touch provided by healthcare professionals to both patients and family members, and that went beyond tasks that were absolutely required, created connectedness and trust.	**Caring for the person, not just the body** ($n = 11$)

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Subtheme c: Enhancing a humanizing approach and atmosphere in the ICU			
References*	Significant statements extracted from reviews (n = 54)	Condensed statements - interpretations	Synthesized themes
	5. Showing genuine interest in the patient's and family's well-being, not treating the patient as an "object". 6. A humanized environment was perceived when FM encountered that the patient was being approached as a unique human being. 7. Important that personal preferences are respected. 8. Dehumanizing when staff failed to acknowledge distress and discomfort that family members observed in the patients. 9. Trusting healthcare professionals helped family members to feel secure enough to leave the hospital, i.e., during nighttime, and to take care of their own needs and their family needs at home. 10. Important that the patient is treated with humanity as a person, not just as a body. 11. Important to feel that the healthcare professionals genuinely cared for the patient.		
Chen et al., 2020 Imanipour et al., 2019Kydonaki et al., 2021Kynoch et al., 2021 Nielsen et al., 2023	Opening visitation hours 1. The family room becomes a kind of home away from home. 2. More presence of family members and allowing their presence within the ICU fostered better familiarity with the surroundings and the use of medical jargon which in its turn also increased trust in care. 3. Sometimes helpful to be allowed space within the hospital to physically be present and where family members/friends/relatives can physically be there and support each other. 4. ICU family room 5. Social workers often helpful with issues of concern. 6. Good facilities, allowing for privacy such as family rooms, reduced stress . 7. Family rooms a good place to meet with others, even relatives of other patients, and share stories and concerns. 8. Open visiting hours were important to allow being nearby the patient. 9. Family rooms helped FM to withdraw from the overwhelming and stressful ICU environment while still being close by. 10. Open visitation policies important	1. Open visitation policies important. 2. Good facilities allowing for privacy, such as family rooms, reduced stress. 3. Family rooms a good place to meet with others, even relatives of other patients, and share stories and concerns. 4. Family rooms helped to get away from the overwhelming and stressful ICU environment while still being close by.	**Allowing open visitation policies** (n = 12)
Coombs et al., 2020 Imanipour et al., 2019 Kydonaki et al., 2021 Kynoch et al., 2021	1. It was comforting to know about the equipment and technology. 2. Strange environment that is artificial and unfamiliar, overwhelmed by the equipment. 3. The physical surroundings in the ICU were overwhelming to family members. 4. Difficult to see their relative connected to tubes, and attached to and reliant on medical equipment. 5. Could be difficult and cause feelings of insignificance when not having a role by the patient and seeing everything being managed by the HCPs. 6. Support from staff influenced family members' experience of the technical ICU environment and perception of care.	1. Information about the ICU surroundings; equipment and technology – what everything attached to the patient does and what the peeps mean. 2. Difficult to see the dependency on technology to keep their loved one alive.	**Help to adjust to the overwhelming ICU environment** (n = 6)
Coombs et al., 2020 Kynoch et al., 2021 Sui et al., 2023	1. Positive interactions, increased feelings of safety. 2. Wish for personal connections with the staff, feeling disconnected increased distress.	1. Establishing connections with the ICU staff increased feelings of safety. 2. Help from professional counselors or other health practitioners, such as psychologists,	**Establishing personal connections with staff** (n = 4)

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Table 2 (*continued*)

Subtheme c: Enhancing a humanizing approach and atmosphere in the ICU			
References*	Significant statements extracted from reviews (n = 54)	Condensed statements - interpretations	Synthesized themes
	3. Sometimes help from professional counselors or other health practitioners, such as psychologists, helped to share concerns and alleviate worries. 4. Sometimes involvement of other professionals, such as chaplains and social workers, was helpful.	helped to share concerns and alleviate worries. 3. Involvement of other professionals, such as chaplains and social workers, as needed.	
Imanipour et al., 2019 Kydonaki et al., 2021 Kynoch et al., 2021 Nielsen et al., 2023 Sui et al., 2023	1. Family members' attention is divided; sick relative, home life, and adjusting to the hospital's routines. 2. Disruption of habitual organization of life and personal life. 3. The hospital admission disrupts personal life and usual family routines. 4. Logistical consideration that needed to be taken into account is the travel time for FM to the ICU, work obligations, and other obligations within the family. 5. If participating and inviting FM in rounds it should be flexible to allow them to attend without it interrupting other obligations as well. 6. Feeling alone in the ICU with one's own life in imbalance and lacking normality. 7. Waiting time on many levels; waiting for the patient to improve, waiting in the waiting room, waiting to be at the bedside etc. 8. Can cause guilt to leave the patient's bedside, especially important to be near the patient when they regain consciousness or show anxiousness or distress. 9. Daily life routines are turned upside down. 10. New roles in family dynamics and responsibilities, i.e., caused by changes at home, childcare, transportation to and from the hospital. 11. Family members who are nurses (HCPs) are particularly vulnerable and might be subject to expectation that they cannot fulfil, i.e., bearing the emotional turmoil better and supporting their family. 12. Financial ramifications i.e., due to medical costs, loss of income. For some, this was the greatest root of exogeneous stress/concerns. 13. Relatives missed the patient; home felt empty. 14. Disruption of daily life. 15. New challenges, going between hospital and home; sometime long-distance traveling, financial consequences when not being able to go to work, conflicts within the family. 16. Need to feel as a family unity, discuss and share feelings with relatives and friends in person or over phone i.e., in relation to surrogate decision-making.	1. Family members feel divided; sick relative, home life, and adjusting to the hospital's routines. 2. Disruption of own life, new challenges between hospital and home. 3. Logistical consideration that needed to be taken into is the travel time for family member to the ICU, work obligations, and other obligations within the family. 4. Financial ramifications i.e., due to medical costs, loss of income. For some this was the greatest root of exogeneous stress/concerns. 5. Need to feel as a family unit, discuss and share feelings with relatives and friends in person or over phone i.e., in relation to surrogate decision-making.	**Fissure in family members personal life** (n = 16)

* For significant statements in each included article, see online supplementary file.

professionals and family members required nurses to invite families to participate in decision-making and articulate their opinions. This also provided room to inform about deterioration, share less encouraging information, and contain complicated feelings and feedback. Healthcare professionals, in a quest for family-relatedness, proactively motivated family members to communicate their experiences, which in turn widened possibilities for relevant support strategies. Ascertaining that families were an inherent part of the ICU team helped nurses provide better care. Also, it helped establish how the family members could be more active around the patient.

Recommendation 3: Supporting family members to be present in the ICU by promoting their role as an advocate and participation in the ICU team are important elements of nursing (high confidence).

Family members expressed a need to build up perceptions of safety through the ICU journey. A precondition for feeling safe was a trustful relationship with the healthcare professionals responsible for caring for their family member. One way of alleviating difficult emotions and building foundations for trust was to activate family members in the decision-making of patient care, informing about

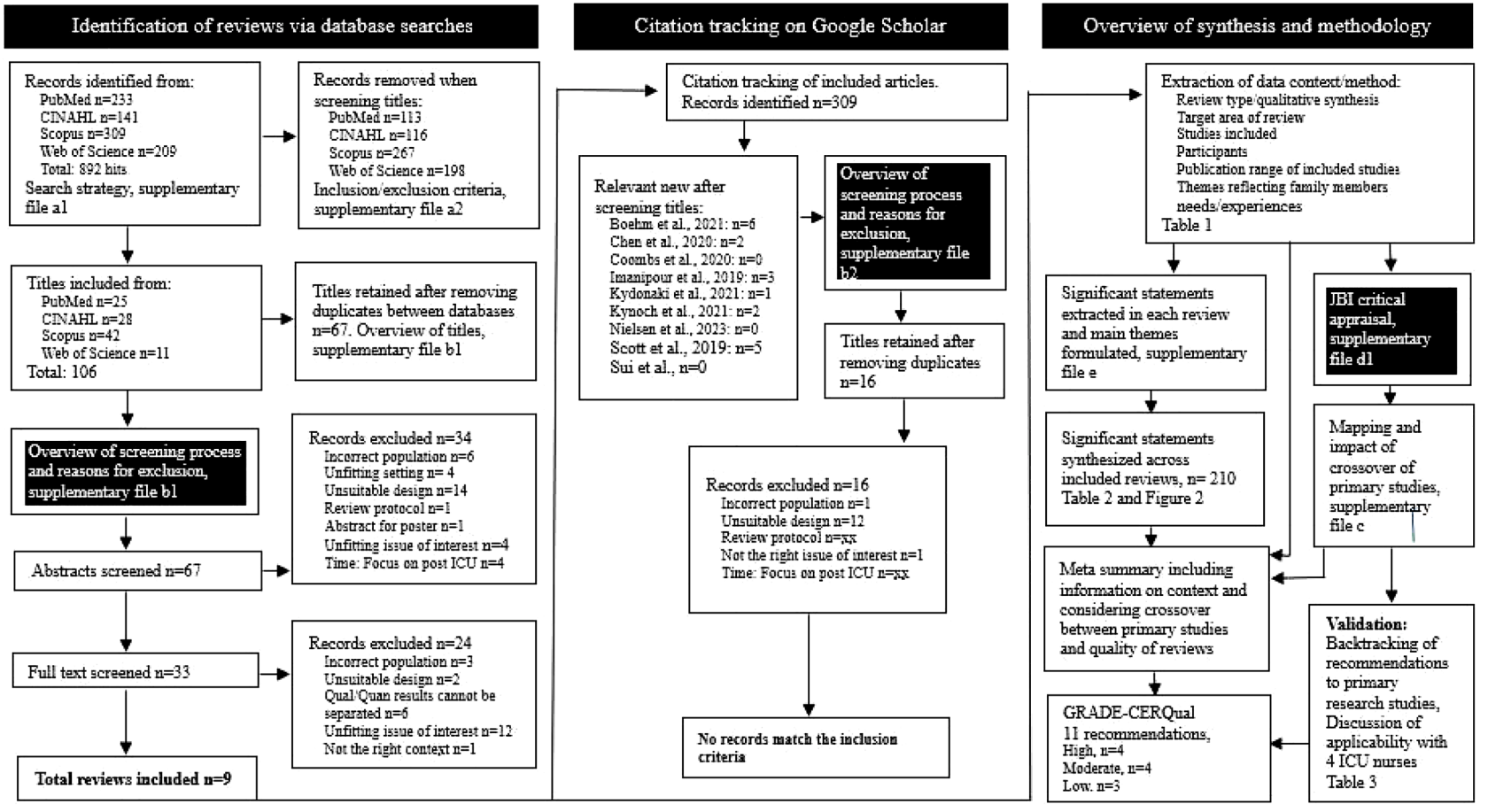

Fig. 1. Extended PRISMA flow chart including overview literature search methodology
The reporting in the flow chart aligns with the PRISMA statement's recommendations (Page et al., 2021).

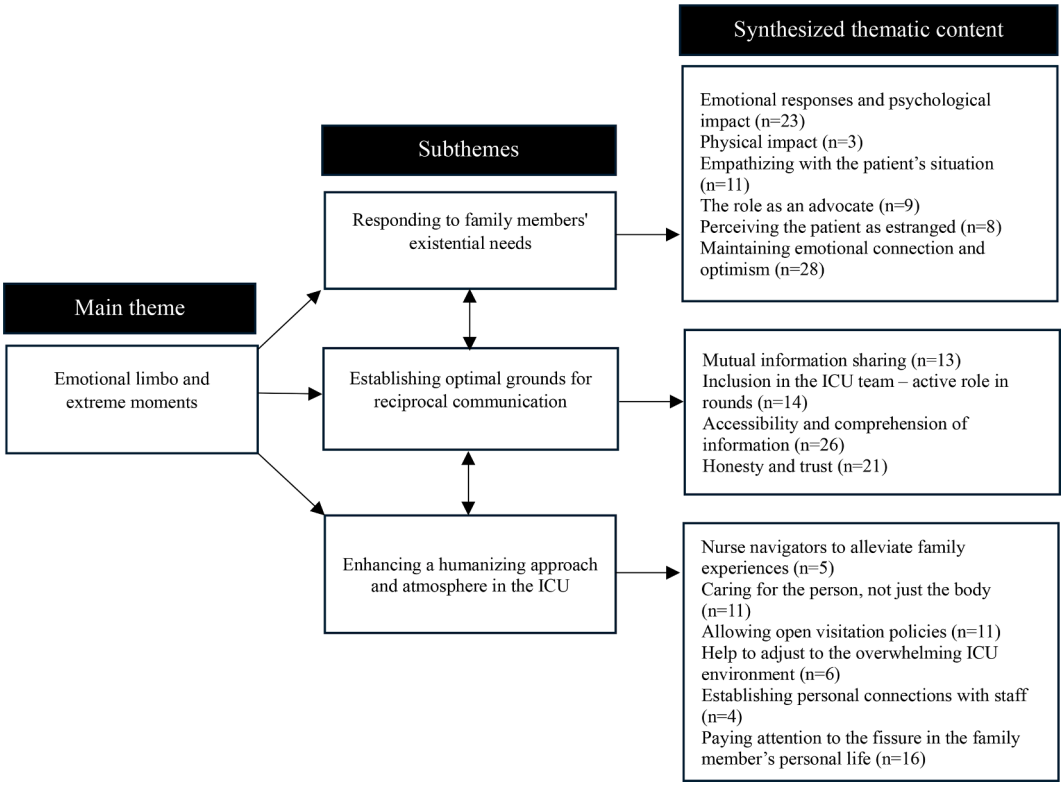

Fig. 2. Overview of main theme, subthemes, and thematic content built on significant statements.

treatment response and prognosis, and explaining the care. Sensitive support respecting faith, spirituality, hope, and cultural need was imperative.

When healthcare professionals succeeded in supporting family members so they helped to make the patient feel more calm or comfortable, it created at least some feeling of control in an otherwise chaotic situation. Information needs was one of the most prominent needs expressed by the families. By gaining more realistic information about the patient's condition, families were able to express how they experienced the severity of the condition and, in turn, created a common ground for understanding between them and the nursing staff.

Recommendation 4: Nurses should facilitate actions that create feelings of safety and family agency in the care continuum. This is mainly accomplished by building trust between nurses and family members through information-sharing and decision-making processes, and finding ways to increase person-centered care and closeness between the family member and patient (high confidence).

3.4.2. b. Establishing optimal grounds for reciprocal communication

High-level communication interchange and mutual information-sharing were important for families' perceptions of quality care. Notably, family members emphasized adequate regular information and honesty. Prompt information about anticipated care, complications, and ICU treatment was effective and helped them comprehend what was going on at any time. To exemplify a situation of care complications, family members found that if they had received timely information, they would have been able to prepare for the prospects of delirium early on during the ICU stay.

Recommendation 5: Nurses should create an atmosphere that allows for mutual expression and information-sharing to support understanding and make families aware of different aspects of the patient's situation and ways they can help (high confidence).

Feeling like an important member of the ICU team and minimizing extant waiting time, such as when waiting for answers, being present at the bedside, and being able to do something for the patient helped secure a sense of belonging and agency. An active role in ICU rounds fostered a productive relationship with the interdisciplinary team and helped communication exchange. Family members often viewed nurses as mediators for making information from physicians comprehensible. Families sometimes questioned information if they did not entirely understand the content in the immediacy of daily rounds or family meetings but later used invitations from nurses to ask questions and gain comprehension. During rounds, nurses could play a pivotal role in bridging communication gaps by encouraging discussions, for instance, by providing a summary at the end of rounds, inviting questions, and explicitly inviting family members to take an active role. It was highlighted that implementing communication tools, checklists, or a "goal sheet" during rounds or diaries could improve goal setting and daily documentation of updates. A way for family members to become accustomed to ICU rounds was, for instance, if they were allowed to stay as they wanted by the bedside. In some instances, family members felt like outsiders on the rounds and expressed concerns that their presence during rounds might interrupt the work of the ICU staff.

Recommendation 6: Family members' participation in daily rounds should be encouraged to help build trust towards the ICU team and gain information on the patient's treatment and condition. Nurses should actively invite families to ask questions and challenge their understanding of the provided information (moderate confidence).

Many family members expressed a desire for the physicians and nurses to be "more than just a white coat", which underscores the importance of healthcare professionals connecting on a more personal level and showing genuine interest in the patient's well-being. Additionally, encouraging family members to express themselves during family meetings increased their satisfaction and perceptions of being heard.

Daily information was highly appreciated. It helped family members reach realistic expectations, i.e., preparing for deterioration or improvement, and assured them that the best level of care was provided. On the contrary, if family members perceived that information was withheld, it evoked suspicion, lack of trust, and even fear for the patient's safety, which was distressful. Staff needed to ascertain that the provided information had been processed and understood adequately. ICU nurses had a frontline role by gathering information from family members about the patient's wishes and personal life. Doing so provided a foundation on which to adapt nursing care to patients' and their families' needs, and develop meaningful care plans that respected the patient's voices.

Recommendation 7: Nurses should be sensitive to families' needs, provide honest information, and ensure that families understand information (i.e., circumvent medical jargon). Also, families should be encouraged to share issues related to the patient's medical history, personal life, and unique needs that are important for caregiving (moderate confidence).

It is crucial to highlight the value of family members' input during the ICU stay and initial admission. Their sharing of essential information about the patient not only benefited the reciprocal relationship but also played a significant role in trust building. This collaborative approach fostered a sense of involvement in the patient's care. Additionally, the ICU staff's timely and regular updates on the patient's condition throughout the ICU stay were equally important to family members.

Recommendation 8: A venue for information-sharing should begin as soon as possible after admission in the form of a formal meeting between nurses and families and other healthcare professionals as needed (moderate confidence).

3.4.3. c. Enhancing a humanizing approach and atmosphere in the ICU

Family members described nurses as navigators within an unknown environment. Nurses were important in identifying unique needs, were gatekeepers for their presence, played a role in their comprehension of care, and found optimal ways to interact and be with the patient. These different nursing tasks were crucial to humanizing the ICU experience and supporting the perception of the ICU as a safe place. Family members cherished friendliness, compassion, and the nurses' ability to communicate complicated and sensitive information about the patient's condition. Likewise, they appreciated it if nurses' insight went beyond mere understanding of the patient's condition, i.e., if they addressed the emotional distress inevitably experienced by the family members.

Recommendation 9: Nurses need to function as navigators within the ICU to humanize the ICU experience (low confidence).

Family members sought respect and dignity from nurses and wished for personal connections. Moreover, they valued compassionate, knowledgeable, personalized, professional, and honest relationships and felt supported if that was realized. The kindness and comfort provided by nurses who exceeded the absolutely-required tasks created trust and feelings of connectedness. If family members, in lieu of trust, felt unsafe and obliged to watch over the patient to circumvent errors in care, such as when the nurses did not recognize the patient's discomfort or stress, it was perceived as dehumanizing. It was important for family members to perceive genuine interest and kindness from nurses towards the care and comfort of the patients as persons and provide a personal touch to the care, not merely treat the patient as a failing, sick body. Relatives also needed a personal connection with nurses; smiles, inquiring about them and the patient as individuals, and providing care beyond tasks that were absolutely needed. In line with this, participating in personal care and allowing flexible visiting hours provided closeness. This closeness could entail just being there while nursing staff performed personal care or being invited to participate more directly in isolated, safe tasks such as applying moisturizer to hands. Restrictive visitation policies were problematic because they prevented the family from directly supporting the patient. In certain situations, relatives found it particularly important to be present; for example, when patients were extubated, when they regained consciousness, if they were transferred to another department, or if they showed signs of anxiousness or other distress.

The ICU family room was recalled positively and negatively in the minds of family members. For some, dwelling in the room was associated with difficult situations that triggered anxiety and fear. Family rooms were important, and when they were considered comfortable and relaxing and had good facilities, they were used to calm down between bedside visits and reduce stress. Some family members described the family room as central to the ICU stay because it somehow, with time, felt like a second home. Loneliness also needs to be dealt with by many family members. Here, the family room was also, by some, considered a venue to meet others, even relatives of other patients, and share stories and concerns.

Recommendation 10: Participating in personal care and allowing flexible visiting hours provides an anchor for proximity. This proximity could be just being close while the nurse performed personal care or being invited to apply moisturizer to hands. It is important that family members feel that nurses care for the patient as a person, not just as a body. The family room at the ICU needs to be a comfortable and welcoming place for family members (moderate confidence).

The foreign ICU environment impacted the overall ICU experience, which yet again interacted with perceived higher stress levels. The ICU environment was overwhelming because of the technology and monitoring. That made the ICU experience terrifying for some family members, especially if they had witnessed fear-evoking events such as acute, life-threatening situations. Therefore, it was important for family members to receive information about the equipment and technology surrounding the patient, such as what the numbers and sounds meant, to ease their minds. Staying at the ICU created a fissure in many family members' personal lives and daily routines, and their needs were on hold. They were isolated within the ICU with only limited contact with their family and friends, and spent much time waiting at the patient's bedside. If family members received inadequate attention during their loved one's ICU stay

and negative emotions such as uncertainty, concerns, and fear were allowed to escalate, it was dehumanizing. Several instances could trigger insecurity or anxiety; for example, if family members felt they had made the "wrong" decisions when acting on the patient's behalf. Therefore, healthcare professionals need to provide information thoughtfully and intelligibly—i.e., without medical jargon. Several logistical challenges often occurred, such as usual work obligations, other obligations within the family, difficulties with transportation, economic ramifications, and a family dynamic turned upside down.

Recommendation 11: Nurses need to inform family members about the equipment, such as monitors attached to the patient and other foreign issues in the ICU environment. Nurses should ask families about their well-being, need for support, and concerns about "usual daily life" (moderate confidence).

3.5. Overview of recommendation, their evidence profile and critical reflection from ICU nurses

The recommendations built on the evidence according to GRADE-CERQual comprise: four high-grade recommendations, five moderate, and two low-grade recommendations. The primary reasons for low evidence profiles were a lack of description of context and more "thick" descriptions. Clinical points discussed with seasoned ICU nurses about the proposed recommendations are presented alongside the CERQual evidence profile in Table 3.

4. Discussion

This systematic review identified and synthesized qualitative evidence about family members' needs, experiences, and perceptions during a loved one's ICU stay and is the first to produce graded recommendations for nursing practice. The results obtained by merging nine good-quality qualitative or mixed-method systematic reviews, which collectively incorporated 124 primary qualitative studies, affirm the importance of establishing an explicit and structured nursing assessment of families' needs during the ICU stay. In addition to previous reviews, we formulated 11 recommendations based on aggregate findings and meta-summary statements. Recommendations and policies on family nursing in ICU care are currently understated. Nevertheless, there is consensus that family nursing is an inherent and essential part of ICU nursing (Kleinpell et al., 2018).

The overarching theme " Emotional limbo and extreme moments" contained three subthemes reflecting nursing approaches to alleviate challenging ICU experiences for family members, namely responding to their existential needs, establishing grounds for communication, and creating a humanizing approach and atmosphere. In line with the results of many other primary studies and reviews—and quite unsurprisingly—our synthesis underscores that the ICU stay significantly intrudes into families' lives (i.e., Flinterud et al., 2023; Halain et al., 2022). Many fluctuations and opposite emotional experiences surface, ranging from sadness, vulnerability, powerlessness, anxiousness, and uncertainty to intense hope, positivity, and feeling needed. Notably, nurses can tilt the family's experience positively and stimulate participation and agency which is known to have a therapeutic effect on their experiences (Young et al., 2017).

The novel recommendations we put forth address strategies to diminish the emotional repercussions of having a relative with a critical illness admitted to the ICU. In a review and meta-analysis of 46 studies on patient- and family-centered care interventions in the ICU by Goldfarb et al. (2017), the authors identify emotional support as one of the main domains in family ICU care. However, only two of the included review studies addressed this topic somewhat but without measuring clear-cut emotional support outcomes (Goldfarb et al., 2017). The emphasis on emotions expressed by families must carry over to actual incorporation in family interventions and ways to assess emotional distress and trajectories during ICU admission. For instance, it would be possible to redesign a new version of the "distress thermometer" currently used for cancer patients (Ownby, 2019) into a family distress thermometer in the ICU and incorporate meaningful issues into a problem assessment list as revealed in this review to explain high distress levels. Items in the problem list could mirror the main topics on the problems list of the original thermometer: practical problems, family problems, emotional problems, spiritual/religious concerns, and physical issues. An attractive feature of the distress thermometer is an "others" feature inviting families to utter concerns that may not be on the list. In contrast to the distress thermometer that describes the degree of distress within the past week, distress would be within the previous day until *now* for the ICU assessment. Though other family ICU burden instruments exist, such as the 21-item Critical Care Family Satisfaction Survey instrument (Kentish-Barnes et al., 2009), they do not explicitly take the temperature of immediate distress/emotional un-equilibrium that family members may encounter. Identifying the emotional symptoms of family members during the ICU stay is necessary when planning proper support and call for structured and regular assessments (Zante et al., 2020).

Though our findings encourage active participation in care, nurses must assess the family's preferences and customize solutions. Reasons for not wanting to participate in direct care, according to clinical staff we consulted as a part of the validation approach of interventions, indirectly related to the patient's critical illness, attachment to monitors, not being able to touch the patient without direct guidance from the staff, and fear of doing damage–which has recurrently been emphasized in studies in the past two decades (i.e., Azoulay et al., 2003; Garrouste-Oregas et al., 2010; Wong et al., 2020). It seems reasonable to encourage more indirect caregiving participation and psychosocial and emotional care that calls for the family's intimate knowledge of the patients–for instance, by bringing preferred music and pictures from home, being present, reading out loud to patients, and providing comfort and assurance. Involving family members in indirect caregiving procedures counts as more than just finding a task for them to do. It is involvement in non-pharmacological interventions to help the patient—and they should be promoted for their effectiveness in, for instance, stimulating and soothing patients. Music therapy is an excellent example of a non-pharmacological intervention requiring knowledge of patients. Functional MRI studies have shown that familiar or well-liked music stimulates the emotional and reward circuits of the brain better than unfamiliar music (Pereira et al., 2011). Playing patients' preferred style of music or favorite songs may also help to stabilize

Table 3
Recommendations, CERQual evidence profile, and critical reflection and clinical points from ICU nurses about the use of the 11 recommendations.

Subtheme 1: Responding to family members´ existential needs		
Recommendations	Assessment of coherence, adequacy and relevance	Critical reflections and clinical points
1: Nurses should address the turbulence of emotions (sadness, vulnerability, helplessness, hopelessness) that family members encounter and support them in preserving hope and keeping going. **High confidence**	Minor methodological limitations throughout the nine reviews contributing to the findings: Boehm et al., 2021; Chen et al., 2020; Coombs et al., 2020; Imanipour et al., 2019; Kydonaki et al., 2021; Kynoch et al., 2021; Nielsen et al., 2023; Scott et al., 2019; Sui et al., 2023. Data from primary studies included in the reviews originate from Western/Westernized countries. Very minor concerns about coherence. No concerns about adequacy.	Familiarity with, and comprehension of, emotional issues that family members go through. Though emotional responses vary within and between families, nurses should be trained and educated to provide emotional support. It is important to design a tool for ICU nurses to approach family members´ emotions. This could, for instance, be trained in simulation training alongside other nursing skills, such as caring for a patient on a mechanical ventilator merged with ICU family nursing care, i.e., explaining the use of the ventilator to family members.
2: Nurses should ask family members about physical symptoms, such as difficulties sleeping and headache, and inquire whether they have attended to their own bodily needs, such as nutrition, and help them to fulfil their needs. **Low confidence**	Minor methodological limitations in the three reviews contributing to the findings: Imanipour et al., 2019; Kynoch et al., 2021; Sui et al., 2023. Data from primary studies included in the reviews originate from Western/Westernized countries.No concerns about coherence.Considerable concerns about adequacy, no explicit attention to physical symptoms, lack of explicit consideration and description of context of physical symptoms within the reviews. Very limited data available.	ICU nurses often encourage family members to eat, sleep, drink, and walk outside. However, it is learnt through experience rather than explicitly taught when starting to work in the ICU. Asking family members about their physical well-being has excellent potential as an opening for conversation and building a trusting relationship between ICU nurses and family members. An idea might be to create a daily checklist that nurses could ask family members to use to ascertain that their basic physical needs are attended to, containing aspects related to exercise, nutrition and fluid intake, showering, and social relations and responsibility. According to the nurses, this recommendation has high clinical importance, although it is not being addressed much in the included literature
3: Supporting family members to be present in the ICU by promoting their role as an advocate, and fostering their participation in the ICU team, are important elements of nursing. **High confidence**	Minor methodological limitations throughout the six reviews contributing to the findings: Boehm et al., 2021; Chen et al., 2020; Kynoch et al., 2021 Nielsen et al., 2023; Scott et al., 2019; Sui et al., 2023. Data from primary studies included in the reviews originate from Western/Westernized countries. Very minor concerns about coherence. No concerns about adequacy.	Supporting family members can be considered the backbone of ICU nursing. However, family members are sometimes not as close as ICU nurses think, and difficulties may exist within the family unit. Nurses need to obtain an overview of family patterns and resources. The group discussed that family members should be encouraged to take a break from the ICU occasionally and ask other family members or close friends to take over for a while. Consensus was strong in favor of allowing family members to be present and absent as they preferred. There are scarce descriptions in guidelines and available research results regarding the support of family members who are absent from the ICU or family members who are reluctant to be there. Implementing a structured framework for information seeking, such as the Calgary family nursing framework, could prove highly beneficial. For instance, creating a family tree and a list of family members or close friends who can support the family and otherwise be involved in the patient's ICU stay. This could help to streamline the support. This framework is already used at our university hospital but has yet to be fully adapted for the ICU setting
4: Nurses should perform actions that create feelings of safety and family agency in the care continuum. This is mainly accomplished by building trust between nurses and family members through information-sharing and decision-making processes and finding ways to increase person-centered care and closeness between the family member and patient. **High confidence**	Minor methodological limitations throughout the eight reviews contributing to the findings: Boehm et al., 2021; Chen et al., 2020 Coombs et al., 2020; Imanipour et al., 2019; Kydonaki et al., 2021; Kynoch et al., 2021; Nielsen et al., 2023; Sui et al., 2023. Data from primary studies originate from Western/Westernized countries. Very minor concerns about coherence. No concerns about adequacy.	Interrogate the family about the patient's personality and preferences and invite discussions about what the patient would have preferred in the current circumstances. When nurses and family members talk, it helps family members explain the patient's wishes while they, in turn, gain knowledge about the patient's treatment. Sometimes, family members feel burdened by the responsibility of acting as an advocate. Still, they must be assured that they can discuss their decisions with healthcare professionals and, at all times, are provided with professional advice and

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Table 3 (*continued*)

Subtheme 1: Responding to family members´ existential needs		
Recommendations	Assessment of coherence, adequacy and relevance	Critical reflections and clinical points
		knowledge. They are not solely responsible for any decision. Their feelings about making decisions on behalf of their loved ones should be brought out in the open. Asking about the patient and functioning before ICU admission also helps health professionals provide proper medical advice. Family members should be explicitly invited to contribute to the patient's personalized information. These preferences could be communicated by having a little book at the patient's bedside with recorded preferences
Subtheme 2 Establishing optimal grounds for reciprocal communication		
Recommendations		Critical reflections and clinical points
5: Nurses should create an atmosphere that allows for mutual expression and information sharing to support understanding and make the family aware of different aspects of the patient's situation and ways they can help. **High confidence**	Minor methodological limitations throughout the eight reviews contributing to the findings: Boehm et al., 2021; Chen et al., 2020 Imanipour et al., 2019; Kydonaki et al., 2021; Kynoch et al., 2021; Nielsen et al., 2023; Scott et al., 2019; Sui et al., 2023. Data from primary studies originate from Western/Westernized countries. Very minor concerns about coherence. No concerns about adequacy.	ICU nurses should be proactive in initiating and maintaining contact with family members. Face-to-face communication should occur without the ICU nurse sitting behind a computer screen that functions as a shield between them and the family members. ICU nurses should sit down, create eye contact, and use a light touch to ensure that the ICU nurse is fully there for them and the family has their undistracted attention. There are both formal and informal encounters with family members. Although ICU nurses often meet family members throughout the day and provide frequent updates, they must have formal, regular meetings with families. For family members who live in a rural area and thus may not be physically present at all times, electronic solutions, i.e., face time, pose a feasible solution for information sharing and support. The same aspects are important here as in face-to-face meetings, namely that the nurse has to be in surroundings that support undisturbed conversations. It is important to emphasize to the family members that their presence and knowledge contribution are a massive part of the patient's treatment and a catalyst for making meaningful decisions.
6: Family members' participation in daily rounds should be encouraged to help build trust towards the ICU team and share information on the patient's treatment and condition. Nurses should actively invite families to ask questions and challenge their understanding of the provided information. **Moderate confidence**	Minor methodological limitations throughout the eight reviews contributing to the findings: Boehm et al., 2021; Coombs et al., 2020; Kydonaki et al., 2021; Kynoch et al., 2021; Nielsen et al., 2023; Scott et al., 2019; Sui et al., 2023. Data from primary studies originate from Western/Westernized countries. Some concerns about coherence. Concerns about adequacy, data rather thin in description of the context of "daily rounds".	Daily rounds currently need to be better defined, and it is unclear exactly what people talk about when they refer to daily rounds in the literature, i.e., related to context and structure. Daily rounds may be quite different between different ICUs. Family members should be encouraged to participate in daily rounds at the bedside. However, it is important to note that discussions of patients´ treatment should be addressed in a professional manner before involving family members, i.e. by professional pre-rounds. This is to ensure that any uncertainties are minimized. It is also important to follow up after daily rounds to confirm that the family members have a clear understanding of the discussed content. To facilitate this, family members could be encouraged to write down any questions that arise before the daily rounds.
7: Nurses should be sensitive to families' needs, provide honest information, and ensure that families understand information (i.e., circumvent medical jargon). Also, families should be encouraged to share issues related to the patient's medical history, personal life, and unique needs that are important for caregiving. **Moderate confidence**	Minor methodological limitations throughout the nine reviews contributing to the findings: Boehm et al., 2021; Chen et al., 2020; Coombs et al., 2020; Imanipour et al., 2019; Kydonaki et al., 2021; Kynoch et al., 2021; Nielsen et al., 2023; Scott et al., 2019; Sui et al., 2023. Data from primary studies originate from Western/Westernized countries. Some concerns about coherence. Concerns about adequacy, data rather thin in	Important issues about this recommendation are explained further under recommendation four.

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Table 3 (*continued*)

Subtheme 2 Establishing optimal grounds for reciprocal communication		
Recommendations		Critical reflections and clinical points
8: A venue for information sharing should begin as soon as possible after admission in the form of a formal meeting between nurses, families, and other healthcare professionals as needed, **Moderate confidence**	description of the context of when and how a sensitive approach is realized, more thick descriptions. Minor methodological limitations in the three reviews contributing to the findings: Chen et al., 2020; Kydonacki et al., 2021; Kynoch et al., 2019. Data from primary studies included in the reviews originate from Western/Westernized countries. No concerns about coherence. Concerns about adequacy, superficial attention and lack of detail regarding first contact with families and how to obtain optimal conditions for information-sharing. Lacks explicit consideration and more description of context within the reviews. Limited depth of data.	It is important to involve family members, though there is much to do around the patient at the time of arrival when the patient is getting settled into the ICU. Often, relatives are invited to wait in the family room. However, the waiting time can be long and stressful. It is important that someone attends to the family and offers them the chance to see the patient for a short while. While waiting for the patient to be "set up", family members should be informed that they can contact the ICU staff if the waiting time is prolonged and/or their concerns arise. The first encounter is significant for the remaining ICU stay. Nurses should invite nurse-initiated family meetings to address patients' and family members' well-being in the ICU and establish tools to enhance information sharing. The generic hospital admission framework may serve as a structure for the initial meeting and care plan building.
Subtheme 3 Enhancing a humanizing approach and atmosphere in the ICU		
Recommendations		Critical reflections and clinical points
9: Nurses need to function as navigators within the ICU to humanize the ICU experience. **Low confidence**	Minor methodological limitations in the three reviews contributing to the findings: Chen et al., 2020; Coombs et al., 2020; Sui et al., 2023. Data from primary studies originate from Western/Westernized countries. Some concerns about coherence. Concerns about adequacy, data rather thin in description of the context of how the role as navigators are executed, more thick descriptions clearly warrented.	ICU nurses are active navigators for family members, where they, for instance, advise them on how to talk with and touch the patient and how they can help safely. The navigation also creates a space/spatiality and allows the family to act according to their preferences. That includes ICU nurses showing the family compassion and, among other things, avoiding the judgement of infrequent family memberś visits. The whole concept of humanizing the family's and patient́s ICU experience needs to be acted upon and integrated more clearly into the ICU nursing practice.
10: Participating in personal care and allowing flexible visiting hours provides an anchor for proximity. This proximity could be just being close while the nurse performed personal care or being invited to apply moisturizer on hands. It is important that family members feel that nurses care for the patient as a person, not just as a body. The family room at the ICU needs to be a comfortable and homey place for family members. **Moderate confidence**	Minor methodological limitations in the seven reviews contributing to the findings: Chen et al., 2020; Coombs et al., 2020; Kydonacki et al., 2021; Kynoch et al., 2021; Nielsen et al., 2023; Scott et al., 2019; Sui et al., 2023. Data from primary studies originate from Western/Westernized countries. Some concerns about coherence. Concerns about adequacy, data rather thin in description of the context of participating in daily care and surroundings in the family room – what does an adequate family room look like and contain?	The family room is an anchor for family members' well-being during their loved one's ICU stay. However, it must fulfil specific requirements to function optimally and feel like a home away from home. For instance, there needs to be a place to rest and have homey, welcoming surroundings. The family rooms should be strategically located close to the ICU, and there should be dedicated family areas (corresponding to the number of ICU patients). There is a lack of descriptions of the optimal family room (interiors, designs and more), but it is important that it is reflected upon at each unique ICU site and that one of the quality indicators of the ICU points towards the availability of a well-functioned family room.
11: Nurses need to inform family members about the equipment, such as monitors, attached to the patient and other foreign issues in the ICU environment. Nurses should ask families about their well-being, need for support, and concerns about "usual daily life". **Moderate confidence**	Minor methodological limitations in the four reviews contributing to the findings: Coombs et al., 2020; Imanipour et al., 2019; Kydonaki et al., 2021; Kynoch et al., 2021. Very minor concerns about coherence. Some concerns about adequacy, lack more thick description.	It cannot be emphasized enough how important it is to guide and explain to the family the equipment attached to the patient and the meaning of the numbers on the monitor. Regarding the family members' daily responsibilities outside the ICU, nurses should learn about children at home, work, school, and pets. Also, means of transportation and distance between home and hospital need to be determined and practical solutions found, if any problems are identified. It is important to collaborate here with social workers and other relevant members of the interdisciplinary teams to find solutions to social- and economic concerns and ramifications.

vital signs and diminish pain, anxiety, and delirium (Dalli et al., 2023; Golino et al., 2019). Music interventions beg for family involvement and can be implemented using both top-down (active) and bottom-up (passive) applications, which is a highly positive asset. An array of intervention studies has pointed towards the effectiveness of music playing for unconscious and even sedated ICU patients (Lorek et al., 2023; Rahgoi et al., 2021).

The importance of family members in the ICU is an issue that surfaces throughout our results and is a theme emphasized widely (Halain et al., 2022; Mitchell et al., 2016). Comments from clinical staff, however, also emphasized the importance of family members being helped or permitted "absence" from the bedside when needed; for instance, when their presence was needed at home or if they needed to get away from the ICU due to their health issues. Remarkably, discussion of absence was non-existent in the review results and it only seems to be addressed vaguely; for instance, in a qualitative study on critical illness, where family members "occasionally had to shield themselves (…), and highly appreciated their presence during visiting hours being voluntary and according to their own needs" (Flinterud et al., 2023, p. 7442).

In coherence with our results, the Guidelines for Family-Centered Care in ICUs suggests that family members should be involved in daily rounds (Davidson et al., 2017). However, due to the heterogeneous nature of patients in ICU, i.e., treatment diversity and intrinsic complexities, it can be difficult to pinpoint essential elements linked to family satisfaction with a round, which complicates pragmatic application (Bibas et al., 2019; Kerckhoffs et al., 2019). The structure of rounds should thus be carefully considered and their application well-described to enable comparison between studies. In line with clinical experts' groups discussion of recommendations, a professional pre-round prior to bedside rounds may be important to ascertain that healthcare professionals stand as a unit when talking to families. Otherwise, blatant disagreements, i.e., related to treatment possibilities, may fuel uncertainties.

The foreign ICU environment played a decisive role in family members' ICU experience. Thus, family members described the ICU environment as overwhelming and some even as terrifying. One important recommendation for nursing pertains to humanizing the ICU environment by, for instance, helping families to understand the technological surroundings. Although informing family members about the ICU's complicated equipment is rated "low confidence", it does not make it less important. It makes perfect sense at face value (cf. Halain et al., 2022; Table 3).

Family rooms are considered central for families to create privacy and freedom to withdraw from the patient while still remaining close by. However, both positive and negative aspects relate to family rooms. On the upside, family rooms afforded a social space where families could meet and share feelings with others encountering similar situations; it was a haven—or sort of a home away from home and a place allowing for rest. On the downside, family rooms correlated to feelings of loneliness and isolation, i.e., from one's own home and everyday life and, above all, reflected a hollow space in time entailing difficult waiting times—waiting for the patient to improve, waiting for information, waiting for freedom to go home and so forth. The literature states that family rooms should be private, comfortable, and designed to optimize family involvement (i.e., Hetland et al., 2018; Kynoch et al., 2021; Nin Vaeza et al., 2020). However, when scrutinizing primary research studies, descriptions of family rooms are superficial, using abstract requirements such as the need to be comfortable, clean, light, and friendly—and not being forgotten by ICU staff (Kutash and Northrop, 2007; McKiernan and McCarthy, 2010), which gives little direction for design. A recent scoping review included 44 original studies to map how the ICU design influences patients, families, and the ICU team (Saha et al., 2022). Only 11 studies reported issues related to families' perceptions of the environment, and a mere four studies emphasized the augmented presence of the family if the ICU design incorporated structures that allowed families to spend the night and had designated family spaces. However, accuracy and detail were warranted. Therefore, the family room must be aesthetically appealing and provide practical solutions, such as for cooking, sleeping, and activities like internet access and TV. Moreover, the inevitable difficult waiting time should be bridged with information and visits from the ICU staff to inform and comfort families (Björk et al., 2019; Nin Vaeza et al., 2020). Family members' need for flexibility in visiting hours is not only emphasized in our findings as a high-recommendation practice but is also incorporated in guidelines and consensus statements (Davidson et al., 2017; Kleinpell et al., 2018).

4.1. Implications for nursing practice

Family members' needs must be addressed during their loved ones ICU admission. The result helps nurses make professional, physical, and emotional space for families during their loved one's ICU stay. Huge varieties exist in ICUs across different countries and hospitals; therefore, implementation requires cultural adaptation, both at the department and organizational levels (McAndrew et al., 2020).

4.2. Strengths and limitations

The original research studies that the systematic reviews were based on ranged over an extensive period (1995–2017). Several quantitative studies have been conducted on family's well-being while their relative is admitted to the ICU. However, this review did not take quantitative data into the synthesis, so perhaps some data about these aspects are missing, although we discussed findings in the light of mainstream quantitative data. A considerable risk of bias is entailed when using qualitative data that other authors have already synthesized. Thus, a review of review calls for validity checks to ascertain that data reflects the actual findings from primary research studies and that recommendations are transferable to practical settings (cf. Lewin et al., 2018). To address these issues, we traced many recommendations back to the original studies and the context in which they were initially presented, and used reflexive interviews with expert clinicians to discuss the recommendations. We targeted important clinical issues that might had been lost during synthesis. To exemplify, there was a strong recommendation about encouraging family presence at the ICU, but the expert group emphasized that families, in some instances, should be supported in their absence at the ICU. To respond to this, we traced this

particular issue backwards within all included articles to be absolutely certain that it had not been mentioned previously.

5. Conclusion

A strong family focus is needed within the ICU and the novel 11 recommendations may be a launch-pad to enhance family-centered care and improve guidelines for nurses. The recommendations comprise multicomponent interventions that, when adjusted to individuals' needs, may effectively reduce family burden and broaden the scope of nursing care. Collectively, they emphasize the need to facilitate the agency of family caregivers and reinforce their strengths through nurse-family dialogues. The recommendations should gain headway into guidelines, and quality indicators should be utilized to ensure that family care adequately fit each ICU setting. Future research should emphasize more details of context by, for instance, describing family rooms in detail, so settings can be compared, and transferability of findings maximized.

Funding

No external funding.

CRediT authorship contribution statement

Thora Gunnlaugsdóttir: Writing – review & editing, Writing – original draft, Methodology, Formal analysis, Conceptualization. **Rannveig J. Jónasdóttir:** Writing – review & editing, Supervision, Methodology, Formal analysis, Conceptualization. **Kristín Björnsdóttir:** Writing – review & editing, Supervision, Methodology, Formal analysis, Conceptualization. **Marianne Elisabeth Klinke:** Writing – review & editing, Writing – original draft, Supervision, Methodology, Formal analysis, Conceptualization.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.ijnsa.2024.100251.

References

Aromataris, E., Fernandez, R., Godfrey, C.M., Holly, C., Khalil, H., Tungpunkom, P., 2015. Summarizing systematic review: methodological development, conduct and reporting of an umbrella review approach. Int. J. Evid. Based. Healthc. 13 (3), 132–140. https://doi.org/10.1097/XEB.0000000000000055.

Azoulay, É., Pochard, F., Chevret, S., Arich, C., Brivet, F., Brun, F., Charles, P.E., Desmettre, T., Dubois, D., Galliot, R., Garrouste-Orgeas, M., Goldgran-Toledano, D., Herbecq, P., Joly, L.M., Jourdain, M., Kaidomar, M., Lepape, A., Letellier, N., Marie, O., Page, B., Parrot, A., Rodie-Talbere, P.A., Sermet, A., Tenaillon, A., Thuong, M., Tulasne, P., Le Gall, J.R., Schlemmer, B., French Famirea Group, 2003. Family participation in care to the critically ill: opinions of families and staff. Intensive Care Med. 29, 1498–1504. https://doi.org/10.1007/s00134-003-1904-y.

Bibas, L., Peretz-Larochelle, M., Adhikari, N.K., Goldfarb, M.J., Luk, A., Englesakis, M., Detsky, M.E., Lawler, P.R., 2019. Association of surrogate decision-making interventions for critically ill adults with patient, family, and resource use outcomes: a systematic review and meta-analysis. JAMa Netw. Open. 2 (7), e197229. https://doi.org/10.1001/jamanetworkopen.2019.7229.

Björk, K., Lindahl, B., Fridh, I., 2019. Family members' experiences of waiting in intensive care: a concept analysis. Scand. J. Caring Sci. 33 (3), 522–539. https://doi.org/10.1111/scs.12660.

Boehm, L.M., Jones, A.C., Selim, A.A., Virdun, C., Garrard, C.F., Walden, R.L., Ely, E.W., Hosie, A., 2021. Delirium-related distress in the ICU: a qualitative meta-synthesis of patient and family perspectives and experiences. Int. J. Nurs. Stud. 122 (104030), 1–12. https://doi.org/10.1016/j.ijnurstu.2021.104030.

Chen, C., Michaels, J., Meeker, M.A., 2020. Family outcomes and perceptions of end-of-life-care in the intensive care unit: a mixed-methods review. J. Palliat. Care 35 (3), 143–153. https://doi.org/10.1177/0825859719874767.

Collet, Ö.M., Albertsen, H., Egerod, I., 2024. Patient and family engagement in Danish intensive care units: a national survey. Nurs. Crit. Care 29 (3), 614–621. https://doi.org/10.1111/nicc.12947.

Colvin, C.J., Garside, R., Wainwright, M., Munthe-Kaas, H., Glenton, C., Bohren, M.A., Carlsen, B., Tunçalp, Ö., Noyes, J., Booth, A., Rashidian, A., Flottorp, S., Lewin, S., 2018. Applying GRADE-CERQual to qualitative evidence synthesis findings—paper 4: how to assess coherence. Implement. Sci. 13 (1), 13. https://doi.org/10.1186/s13012-017-0691-8.

Coombs, M., Statton, S., Endacott, C.V., Endacott, R., 2020. Factors influencing family member perspectives on safety in the intensive care unit: a systematic review. Int. J. Qual. Health Care 32 (9), 625–638. https://doi.org/10.1093/intqhc/mzaa106.

Dalli, Ö.E., Yildirim, Y., Aykar, F.Ş., Kahveci, F., 2023. The effect of music on delirium, pain, sedation and anxiety in patients receiving mechanical ventilation in the intensive care unit. Intensive Crit. Care Nurs. 75, 103348. https://doi.org/10.1016/j.iccn.2022.103348.

Davidson, J.E., Aslakson, R.A., Long, A.C., Puntillo, K.A., Kross, E.K., Hart, J., Cox, C.E., Wunsch, H., Wickline, M.A., Nunnally, M.E., Netzer, G., Kentish-Barnes, N., Sprung, C.L., Hartog, C.S., Coombs, M., Gerritsen, R.T., Hopkins, R.O., Franck, L.S., Skrobik, Y., Kon, A.A., Scruth, E.A., Harvey, M.A., Lewis-Newby, M., White, D. B., Swoboda, S.M., Cooke, C.R., Levy, M.M., Azoulay, E., Curtis, J.R., 2017. Guidelines for family-centered care in the neonatal, pediatric, and adult ICU. Crit. Care Med. 45 (1), 103–128. https://doi.org/10.1097/CCM.0000000000002169.

Dijkstra, B.M., Felten-Barentsz, K.M., van der Valk, M.J.M., Pelgrim, T., van der Hoeven, H.G., Schoonhoven, L., Ebben, R.H.A., Vloet, L.C.M., 2022. Family participation in essential care activities: needs, perceptions, preferences, and capacities of intensive care unit patients, relatives and healthcare workers - an integrative review. Aust. Crit. Care 36 (3), 401–419. https://doi.org/10.1016/j.aucc.2022.02.003.

Eggenberger, S.K., Nelms, T.P., 2007. Being family: the family experience when an adult member is hospitalized with a critical illness. J. Clin. Nurs. 19 (9), 1618–1628. https://doi.org/10.1111/j.1365-2702.2007.01659.x.
Flinterud, S.I., Moi, A.L., Gjengedal, E., Ellingsen, S., 2023. Striving for a safe ground—a lifeworld approach of family members' experiences of the critical illness trajectory. J. Clin. Nurs. 32 (19–20), 7442–7453. https://doi.org/10.1111/jocn.16803.
Garrouste-Orgeas, M., Willems, V., Timsit, J.F., Diaw, F., Brochon, S., Vesin, A., Philippart, F., Tabah, A., Coquet, I., Bruel, C., Moulard, M.L., Carlet, J., Misset, B., 2010. Opinions of families, staff, and patients about family participation in care in intensive care units. J. Crit. Care 25 (4), 634–640. https://doi.org/10.1016/j.jcrc.2010.03.001.
Goldfarb, M.J., Bibas, L., Bartlett, V., Jones, H., Khan, N., 2017. Outcomes of patient-and family-centred care interventions in the ICU: a systematic review and meta-analysis. Crit. Care Med. 45 (10), 1751–1761. https://doi.org/10.1097/CCM.0000000000002624.
Golino, A.J., Leone, R., Gollenberg, A., Christopher, C., Stanger, D., Davis, T.M., Meadows, A., Zhang, Z., Friesen, M.A., 2019. Impact of an active music therapy intervention on intensive care patients. Am. J. Crit. Care 28 (1), 48–55. https://doi.org/10.4037/ajcc2019792.
Halain, A.A., Tang, L.Y., Chong, M.C., Ibrahim, N.A., Anaes, M., Abdullah, K.L., 2022. Psychological distress among the family members of intensive care unit (ICU) patients: a scoping review. J. Clin. Nurs. 31 (5–6), 497–507. https://doi.org/10.1111/jocn.15962.
Hayes, K., Harding, S., Blackwood, B., Latour, J.M., 2024. How and when post intensive care syndrome-family is measured: a scoping review. Intens. Crit. Care Nur. 84, 103768. https://doi.org/10.1016/j.iccn.2024.103768.
Hetland, B., McAndrew, N., Perazzo, J., Hickman, R., 2018. A qualitative study of factors that influence active family involvement with patient care in the ICU: survey of critical care nurses. Intens. Crit. Care Nur. 44, 67–75. https://doi.org/10.1016/j.iccn.2017.08.008.
Imanipour, M., Kiwanuka, F., Rad, S.A., Masaba, R., Alemayehu, Y.H., 2019. Family members' experiences in the adult intensive care units: a systematic review. Scand. J. Caring Sci. 33, 569–581. https://doi.org/10.1111/scs.12675.
Ito, Y., Tsubaki, M., Kobayashi, M., Yagome, S., Sakaguchi, Y., 2023. Effect size estimates of risk factors for post-intensive care syndrome-family: a systematic review and meta-analysis. Heart Lung 59, 1–7. https://doi.org/10.1016/j.hrtlng.2023.01.005.
Kang, J., Cho, Y.J., Choi, S., 2020. State anxiety, uncertainty in illness, and needs of family memberts of critically ill patients and their experiences with family-centered multidisciplinary rounds: a mixed model study. PLoS One 15 (6). https://doi.org/10.1371/journal.pone.0234296.
Kentish-Barnes, N., Lemiale, V., Chaize, M., Pochard, F., Azoulay, É., 2009. Assessing burden in families of critical care patients. Crit. Care Med. 37 (10), S448–S456. https://doi.org/10.1097/CCM.0b013e3181b6e145.
Kentish-Barnes, N., Chevret, S., Valade, S., Jaber, S., Kerhuel, L., Guisset, O., Martin, M., Mazaud, A., Papazian, L., Argaud, L., Demoule, A., Schnell, D., Lebas, E., Ethuin, F., Hammad, E., Merceron, S., Audibert, J., Blayau, C., Delannoy, P.Y., Lautrette, A., Lesieur, O., Renault, A., Reuter, D., Terzi, N., Philippon-Jouve, B., Fiancette, M., Ramakers, M., Rigaud, J.P., Souppart, V., Asehnoune, K., Champigneulle, B., Goldgran-Toledano, D., Dubost, J.L., Bollaert, P.E., Chouquer, R., Pochard, F., Cariou, A., Azoulay, E., 2022. A three-step support strategy for relatives of patients dying in the intensive care unit: a cluster randomised trial. Lancet 399 (10325), 656–664. https://doi.org/10.1016/s0140-6736(21)02176-0.
Kerckhoffs, M.C., Kant, M., van Delden, J.J.M., Hooft, L., Kesecioglu, J., van Dijk, D., 2019. Selecting and evaluating decision-making strategies in the intensive care unit: a systematic review. J. Crit. Care 51, 39–45. https://doi.org/10.1016/j.jcrc.2019.01.029.
Kleinpell, R., Heyland, D.K., Lipman, J., Sprung, C.L., Levy, M., Mer, M., Koh, Y., Davidson, J., Taha, A., Curtis, J.R., Council of the World Federation of Societies of Intensive and Critical Care Medicine, 2018. Patient and family engagement in the ICU: report from the task force of the World Federation of Societies of Intensive and Critical Care Medicine. J. Crit. Care 48, 251–256. https://doi.org/10.1016/j.jcrc.2018.006.
Kutash, M., Northrop, L., 2007. Family members' experiences of the intensive care unit waiting room. J. Adv. Nurs. 60 (4), 384–388. https://doi.org/10.1111/j.1365-2648.2007.04388.x.
Kydonaki, K., Takashima, M., Mitchell, M., 2021. Family ward rounds in intensive care: an integrative review of the literature. Int. J. Nurs. Stud. 113 (103771), 1–15. https://doi.org/10.1016/j.ijnurstu.2020.103771.
Kynoch, K., Chang, A., Coyer, F., McArdle, A., 2019. Developing a model of factors that influence meeting the needs of family with a relative in ICU. Int. J. Nurs. Pract. 25 (1), 1–9. https://doi.org/10.1111/ijn.12693.
Kynoch, K., Ramis, M.-A., McArdle, A., 2021. Experiences and needs of families with a relative admitted to an adult intensive care unit: a systematic review of qualitative studies. JBI Evid. Synthesis 19 (7), 1499–1554. https://doi.org/10.11124/JBIES-20-00136.
Lewin, S., Booth, A., Glenton, C., Munthe-Kaas, H., Rashidian, A., Wainwright, M., Bohren, M.A., Tunçalp, Ö., Colvin, C.J., Garside, R., Carlsen, B., Langlois, E.V, Noyes, J., 2018. Applying GRADE-CERQual to qualitative evidence synthesis findings: introduction to the series. Implement. Sci. 13 (1), 2. https://doi.org/10.1186/s13012-017-0688-3.
Lorek, M., Bąk, D., Kwiecień-Jaguś, K., Mędrzycka-Dąbrowska, W., 2023. The effect of music as a non-pharmacological intervention on the physiological, psychological, and social response of patients in an intensive care unit. Healthcare 11 (12), 1687. https://doi.org/10.3390/healthcare11121687.
Marshall, J.C., Bosco, L., Adhikari, N.K., Connolly, B., Diaz, J.V., Dorman, T., Fowler, R.A., Meyfroidt, G., Nakagawa, Pelosi, P., Vincent, J.L., Vollman, K., Zimmermann, J., 2017. What is an intensive care unit? a report of the task force of the World Federation of Societies of Intensive Care and Critical Care Medicine. J. Crit. Care 37, 270–276. http://doi.org/10.1016/j.jcrc.2016.07.015.
McAndrew, N.S., Schiffman, R., Leske, J., 2020. A theoretical lens through which to view the facilitators and disruptors of nurse-promoted engagement with families in the ICU. J. Fam. Nurs. 26 (3), 190–212. https://doi.org/10.1177/1074840720936736.
McKiernan, M., McCarthy, G., 2010. Family members' lived experience in the intensive care unit: a phenomenological study. Intens. Crit. Care Nur. 26 (5), 254–261. https://doi.org/10.1016/j.iccn.2010.06.004.
Mishkin, A.D., Allen, N.C., Cheung, S.G., Faccini, M.C., Flicker, L.S., Shalev, D., 2024. The stresses of surrogate decision-making: contributing factors and clinicians' role in mitigation. Am. J. Hosp. Palliat. Care 41 (8), 895–905. https://doi.org/10.1177/10499091231198750.
Mitchell, M.L., Coyer, F., Kean, S., Stone, R., Murfield, J., Dwan, T., 2016. Patient, family-centred care interventions within the adult ICU setting: an integrative review. Aust. Crit. Care 29 (4), 179–193. https://doi.org/10.1016/j.aucc.2016.08.002.
Nielsen, A.H., Kvande, M.E., Angel, S., 2023. Humanizing and dehumanizing intensive care: thematic syntesis (HumanIC). J. Adv. Nurs. 79 (1), 385–401. https://doi.org/10.1111/jan.15477.
Nin Vaeza, N., Martin Delgado, M.C., Heras La Calle, G., 2020. Humanizing intensive care: toward a human-centered care ICU model. Crit. Care Med. 48 (3), 385–390. https://doi.org/10.1097/ccm.0000000000004191.
Nolen, K.B., Warren, N.A., 2014. Meeting the needs of family members of ICU patients. Crit. Care Nurs. Q. 37 (4), 393–406. https://doi.org/10.1097/CNQ.0000000000000040.
Ownby, K.K., 2019. Use of the distress thermometer in clinical practice. J. Adv. Pract. Oncol. 10 (2), 175–179. https://doi.org/10.6004/jadpro.2019.10.2.7.
Page, M.J., McKenzie, J.E., Bossuyt, P.M., Boutron, I., Hoffmann, T.C., Mulrow, C.D., Shamseer, L., Tetzlaff, J.M, Akl, E.A., Brennan, S.E., Chou, R., Glanville, J., Grimshaw, J.M., Hróbjartsson, A., Lalu, M.M., Li, T., Loder, E.W., Mayo-Wilson, E., McDonald, S., McGuinness, L.A., Stewart, L.A., Thomas, J., Tricco, A.C., Welch, V.A., Whiting, P., Moher, D., 2021. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 372, 1–9. https://doi.org/10.1136/bmj.n71.
Pereira, C.S., Teixeira, J., Figueiredo, P., Xavier, J., Castro, S.L., Brattico, E., 2011. Music and emotions in the brain: familiarity matters. PLoS One 6 (11), 1–9. https://doi.org/10.1371/journal.pone.0027241.
Rahgoi, A., Mohammadzadeh Zarankesh, S., Kasaeizadeghan, S.S., Naghibeiranvand, M., 2021. Effect of classical music on physiological characteristics and observational and behavioral measures of pain in unconscious patients admitted to intensive care units. Compl. Med. J. 10 (4), 368–379. https://doi.org/10.32598/cmja.10.4.1016.1.
Saha, S., Noble, H., Xyrichis, A., Hadfield, D., Best, T., Hopkins, P., Rose, L., 2022. Mapping the impact of ICU design on patients, families and the ICU team: a scoping review. J. Crit. Care 67, 3–13. https://doi.org/10.1016/j.jcrc.2021.07.002.
Schwartz, A.C., Dunn, S.E., Simon, H.F.M., Velasquez, A., Garner, D., Tran Jr, D.Q., Kaslow, N.J., 2022. Making family-centered care for adults in the ICU a reality. Front. Psychiatry 13 (837708), 1–9. https://doi.org/10.3389/fpsyt.2022.837708.

Scott, P., Thomson, P., Sheperd, A., 2019. Families of patients in ICU: a scoping review of their needs and satisfaction with care. Nurs. Open 6 (3), 698–712. https://doi.org/10.1002/nop2.287.

Smith, V., Devane, D., Begley, C.M., Clarke, M., 2011. Methodology in conducting a systematic review of systematic reviews of healthcare interventions. BMC Med. Res. Methodol. 11 (15), 1–6. https://doi.org/10.1186/1471-2288-11-15.

Sui, W., Gong, X., Qiao, X., Zhang, L., Cheng, J., Dong, J., Zhuang, Y., 2023. Family members' perceptions of surrogate decision-making in the intensive care unit: a systematic review. Int. J. Nurs. Stud. 137 (104391), 1–16. https://doi.org/10.1016/j.ijnurstu.2022.104391.

Thomas, J., Harden, A., 2008. Methods for the thematic synthesis of qualitative research in systematic reviews. BMC Med. Res. Methodol. 8 (45), 1–10. https://doi.org/10.1186/1471-2288-8-45.

Verhaeghe, S., Defloor, R., Van Zuuren, F., Duijnstee, M., Grypdonck, M., 2005. The needs and experiences of family members of adult patients in an intensive care unit: a review of the literature. J. Clin. Nurs. 14 (4), 501–509. https://doi.org/10.1111/j.1365-2702.2004.01081.x.

Williams, H., Gow, J., Rana, R., Rouse, A., Chinthamuneedi, M., Beccaria, G., Ralph, N., 2021. Measuring the intensive care experience: a cross-sectional survey of patient and family experience of critical care. J. Clin. Nurs. 30 (23–24), 3623–3633. https://doi.org/10.1111/jocn.15884.

Wong, P., Redley, B., Digby, R., Correya, A., Bucknall, T., 2020. Familieś perspectives of participation in patient care in an adult intensive care unit: a qualitative study. Aust. Crit. Care 33 (4), 317–325. https://doi.org/10.1016/j.aucc.2019.06.002.

Young, A.J., Stephens, E., Goldsmith, J.V., 2017. Family caregiver communication in the ICU: toward a relational view of health literacy. J. Fam. Commun. 17 (2), 137–152. https://doi.org/10.1080/15267431.2016.1247845.

Zante, B., Camenisch, S.A., Schefold, J.C., 2020. Interventions in post-intensive care syndrome-family: a systematic literature review. Crit. Care Med. 48 (9), e835–e840. https://doi.org/10.1097/ccm.0000000000004450.