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Navigating Family Involvement in Scandinavian Intensive Care Units—An Integrative Review

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ABSTRACT

Background: Family involvement in the intensive care unit (ICU) is recognized as important, yet its implementation is complex and varies across contexts, including Scandinavian settings.

Aim: This integrative review aimed to synthesize and integrate the evidence on family involvement in Scandinavian ICUs across the perspectives of family members, patients, and healthcare professionals. Findings are presented thematically rather than by perspective to capture shared and contrasting dimensions within overarching concepts.

Design: An integrative review was conducted following Whittemore and Knafl's framework.

Methods: A systematic search was conducted in five databases (PubMed, PsycINFO, and CINAHL) covering January 2010–October 2023, with an update in January 2025. A systematic search strategy was applied, and reporting adhered to PRISMA guidelines. Peer-reviewed studies published between 2013 and 2024 in English, Danish, Swedish, or Norwegian were included.

Findings: Fourteen studies met the inclusion criteria: nine qualitative (including one case-oriented) and five cross-sectional surveys. The review highlights the critical role of family involvement in the ICU, emphasizing its positive impact on patient care and family wellbeing. Active participation by family members provides both practical assistance and emotional support, fostering a patient-centred approach that improves patient outcomes. However, integrating families into care also presents significant challenges. Healthcare professionals' attitudes and behaviours, along with institutional policies and resource limitations, strongly influence the experience of family involvement. Families often face emotional stress and uncertainty, which can affect their engagement and lead to varying levels of participation. These findings underscore the need for strategies that balance collaboration with sensitivity to contextual and individual factors.

Conclusions: Family involvement in Scandinavian ICUs is a complex, context-dependent phenomenon shaped by relational, emotional, and organizational factors. It requires healthcare teams to balance challenges with the benefits for patients and families.

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1 | Background

The engagement and impact of patients have become a priority in Scandinavian healthcare, emphasizing participatory healthcare [1–6]. However, patient involvement in settings like the Intensive Care Unit (ICU) is challenging due to patients' complex conditions and sedative medications, which limit their participation in care decisions. This elevates the role of family members, making them crucial in the patient's care process. As a result, the care model for ICU patients has shifted from a Person-centred approach to a Patient and Family Centred Care (PFCC) model, emphasizing the engagement of patient and family [7]. This model promotes a collaborative relationship between healthcare providers, patients, and families to enhance healthcare delivery, health outcomes, safety and quality [8]. However, there is a lack of a comprehensive overview and synthesis of how family involvement is practiced within Scandinavian ICUs.

1.1 | Cultural and Legal Foundations of Family Involvement in Scandinavian ICUs

The organization and delivery of intensive care in Scandinavian countries are shaped by unique cultural, social, and healthcare system characteristics. Since the 1950s, care for the elderly and healthcare services have been regarded as a societal responsibility in Scandinavia. Within this welfare-state framework, the provision of care and support for elderly and ill individuals is organized to ensure equity and to relieve families of the primary caregiving obligation, reflecting its construction as a societal responsibility. Scandinavian countries have relatively few private ICUs, fewer restrictions on visits [9], and relatively high staffing levels [10]. Furthermore, in the Scandinavian context, the family assumes an advisory role when the patient is unable to express their wishes. In situations where the patient's wishes cannot be ascertained (e.g., due to unconsciousness), healthcare professionals (HCPs) are responsible for providing the necessary treatment to prevent imminent and serious threats to the patient's life or health [11]. Given these structural and contextual factors, there is a clear need to explore how family involvement is expressed, implemented, and evaluated within the region. A focused review of Scandinavian literature can provide valuable insights into current practices, challenges, and possibilities, and help identify areas for future research and improvement.

1.2 | Defining and Understanding Family Involvement in Healthcare and ICU

Involvement is commonly defined in European and Nordic dictionaries as the act or process of taking part in something [12] bringing someone in [13], engaging or including someone [14], or actively participating in something [15]. In other contexts, involvement has been described as knowing what's going on or looking after someone [16]. However, Olding et al. (2016) [17] argue that involvement is more complex than a single definition and should be understood as a dynamic process, particularly in the ICU [17].

Family involvement includes both the support relatives provide to the patient and the support they receive in their caregiving

roles [18]. In Scandinavian health legislation, family is defined as those individuals whom the patient regards as family, regardless of legal or biological ties [5, 19–20]. This broad definition reflects the person-centred approach that characterizes Scandinavian healthcare. Despite its frequent use, key concepts related to family involvement have often been applied interchangeably in research, which contributes to conceptual ambiguity. Clarifying what constitutes family involvement in the ICU context is therefore essential for both clinical practice and research.

Family involvement can occur at various levels within the healthcare system. At an organizational level, family involvement can create organizational learning, drive care improvements, and enhance development processes [5]. At the point-of-care level, the focus of this review, patients and families provide valuable insights into preferences and needs, which, when systematically integrated into care, enable care to best meet individual needs [2, 21]. HCPs, and especially ICU nurses, play a pivotal role in facilitating family involvement in patient care. Their responsibilities extend beyond clinical tasks to include creating an environment that supports family presence and engagement [22]. To our knowledge, studies on patient outcomes related to family involvement report varied effects, including reduced need for pain relief, shorter duration on the ventilator, and improved physiological parameters [23–26]. Family involvement's impact on relatives' mental health, such as dissatisfaction, psychological distress, depression, and PTSD; needs, expectations, communication gaps, and training, however, remains unclear as studies show varying results [27–29]. Finally, it is also worth noting that recent advancements in ICU treatment, such as reduced sedation, less invasive ventilation, and early mobilization, have facilitated greater patient and family involvement [30]. Despite these developments, few reviews have synthesized how families, patients, and HCPs perceive family involvement within Scandinavian intensive care settings. Integrating existing evidence across Denmark, Norway, and Sweden can identify both converging and diverging patterns, highlight best practices, and uncover gaps in knowledge that warrant further research. Moreover, a review can inform clinical guidelines and policy development by offering insights into strategies that enhance collaboration between families and HCPs, ultimately improving patient outcomes and family well-being. An integrative review approach was selected for this study because it enables a comprehensive synthesis of empirical evidence—both quantitative and qualitative—alongside theoretical perspectives. This methodology is particularly suited to exploring family involvement in ICUs across Scandinavian countries, as it allows for a nuanced understanding of complex interactions and contextual factors. These findings are expected to inform the development of tailored strategies that enhance family engagement in intensive care settings and ultimately contribute to improved patient and family outcomes.

2 | Method

This study used an integrative review design with a systematic search strategy, reported according to Whittemore and Knafl [31] and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines [32, 33]. An integrative review approach was adopted to capture diverse methodological,

empirical, and theoretical perspectives on family involvement in the ICU, incorporating critical appraisal to enhance overall understanding.

2.1 | Problem Identification and Review Aim

Family involvement in the ICU is widely recognized as beneficial for both patients and their relatives, yet its implementation remains complex and inconsistent. It is also well established that family members of patients admitted to ICUs represent a vulnerable group, as they are at risk of developing post-intensive care syndrome–family (PICS-F) [28]. Evidence indicates that between 11.1% and 45.8% of ICU families experience PICS-F, manifested through anxiety, depression, post-traumatic stress disorder, and physical impairments [34]. PICS-F arises from a combination of psychological vulnerability, traumatic events related to the patient's condition, and the stressful ICU environment [35, 36]. Recognizing the international consensus on the importance and effectiveness of family-centred care (FCC), this review aimed to synthesize and integrate the evidence on family involvement in Scandinavian ICUs across the perspectives of family members, patients, and HCPs. The integrated findings are presented thematically rather than by perspective, to capture shared and contrasting dimensions within overarching concepts.

2.2 | Literature Search

A systematic search was conducted in four databases (PubMed, PsycINFO, Central and CINAHL) covering January 2010 to October 2023, with an update in January 2025 (see Appendix S1). The keyword strategy was developed from an initial search of the literature in collaboration with four librarians, using MeSH mapped terms for Population (Intensive Care Units, Critical care), Interest (Patient, Family, caregivers), Context (Scandinavian Countries), and Outcome (Professional-Family Relation*, Involvement, Participation, Presence*, Engagement, Empowerment, Communication; See Appendix S1). EndNote was used for reference management (EndNote Program). The searches included reference and citation tracking, as well as hand-searching two additional journals (Scandinavian Journal of Caring Sciences and Intensive and Critical Care Nursing).

2.2.1 | Inclusion and Exclusion Criteria

Criteria were defined based on the problem formulation and aim. We included peer-reviewed empirical qualitative, quantitative, and mixed-method studies published in English, Danish, Swedish, or Norwegian from 2013 onwards, when family involvement became a political vision [2, 37]. Eligible studies explored the perspectives on family involvement among adult ICU patients in a Scandinavian context. Exclusion criteria were non-empirical studies (reviews, grey literature, theoretical papers), studies involving paediatric patients or palliative care populations, studies related to organ donation, COVID19-related studies, post-ICU studies, and those outside the Scandinavian ICU context.

2.3 | Data Evaluation and Extraction

Data extraction was conducted following Whittemore and Knaf's (2005) five-step integrative review model [31], which is based on Cooper's (1998) framework [38]. The PICO model was used to guide problem identification and structure the search strategy (Appendix S1). Step 2 involved conducting the systematic search. In Step 3, all retrieved studies were read and appraised for quality using the approach described by Aromataris [39]. After appraisal, eligible studies were organized into a study matrix (Table 1). In Step 4, two authors (first and last) independently extracted relevant text segments, identified key findings, and interpreted the findings. Finally, in Step 5, the extracted data were synthesized and presented according to Whittemore and Knaf's guidelines [31].

2.3.1 | Quality Appraisal

The Joanna Briggs Institute (JBI) methodology was applied for quality assessment [39], using the appropriate checklists for qualitative and quantitative studies [40, 41]. Two reviewers independently appraised each study, and any discrepancies were resolved through discussion. The appraisal results are summarized in tables (Appendix S2). In line with JBI recommendations, no cut-off scores were used; therefore, no studies were excluded based on appraisal outcomes [39].

2.4 | Data Analysis and Synthesis

Analysis followed Popenoe et al. [42]. Qualitative data were coded into meaningful units, condensed into codes, subcategories, and a main category. Quantitative findings (sentences/statistics relevant to the aim) were extracted, condensed, and similarly organized. Studies were read in full, summarized, and analyzed iteratively across methodologies. Data were synthesized into integrated categories addressing the review aim and questions. Reporting followed PRISMA-ScR guidelines [43].

An Artificial intelligence tool (copilot) was utilized to support grammar correction, spelling checks, and language editing throughout the manuscript preparation.

3 | Findings

3.1 | Search Outcomes

The systematic search identified 3011 studies, and an additional 3 through reference and citation searches (Figure 1). After duplicate removal, 2551 were excluded, leaving 463 for title/abstract screening. Of these, 401 were excluded and 62 were assessed at full text level. Following full-text screening, 48 were excluded, resulting in 14 included studies. All authors independently screened studies at the title, abstract, and full-text levels; disagreements were resolved by consensus among three authors (Figure 1).

3.2 | Critical Appraisal

Overall, all studies were rated as high quality, except for Frivold et al. [45], which showed minor limitations. For qualitative

TABLE 1 | Characteristics of included studies including critical appraisal.

Authors (year), country	Setting	Sample	Aim	Design/data collection/ analysis	Key findings	JBI critical appraisal summary (See Appendix S2)
1. Akroute, A.R. & Bondas, T., 2016, Norway	One cardiac ICU	Experienced critical care nurses (CCN; <i>n</i> = 6)	To explore the experiences of CCNs in relation to families of elderly ICU patients (≥ 80 years)	<ul style="list-style-type: none"> - Interpretative qualitative study - Individual semi-structured interviews - Content analysis 	<p>The overall theme:</p> <ul style="list-style-type: none"> - CCNs's ambivalent interactive struggle with the relatives of elderly patients <p>Two themes covered the overall theme:</p> <ul style="list-style-type: none"> - Relatives are a resource for CCNs and the patient - Relatives are seen as a challenge 	Yes: 8 No: 2
2. Alexandersen, et al., 2021, Norway	One general ICU	Long-term critically ill patients (<i>n</i> = 17)	To explore how the presence of family and health care professionals influences long-term critically ill patients' inner strength and willpower as an incitement to keep fighting for recover	<ul style="list-style-type: none"> - Descriptive qualitative study with a hermeneutic-phenomenological approach - Individual interviews, 6–18 months after ICU discharge - Analysed by a hermeneutic-phenomenological approach 	<p>Four main themes identified how family and staff promoted and challenged the patient's inner strength and willpower:</p> <ul style="list-style-type: none"> - Importance of family and friends - Staff contributions - Challenges to inner strength and willpower in relation to family - Loneliness and indifferent care 	Yes: 10
3. Blom, H., et al., 2013, Sweden	One general ICU	Close family members (<i>n</i> = 7) of ICU patients	To explore the phenomena of participation and support as experienced by close families of patients in an ICU	<ul style="list-style-type: none"> - Descriptive qualitative study with a phenomenological approach - Individual interviews - Analysed with a focus on meanings 	<p>Being allowed to participate in the care of critically ill ICU patients is important for close family members. Their experiences can be described as having four constituents:</p> <ul style="list-style-type: none"> - Participation in the care of and being close to the patient - Confidence in the care the patient receives - Support needed for involvement in caregiving - Vulnerability 	Yes: 10

(Continues)

TABLE 1 | (Continued)

Authors (year), country	Setting	Sample	Aim	Design/data collection/analysis	Key findings	JBIC critical appraisal summary (See Appendix S2)
4. Bohart S., et al., 2023, Denmark	Six general ICUs	Patients ($n = 8$) and family members ($n = 15$)	To explore perspectives and wishes for PFCC among adult patients and family-members with recent experience of admission to an adult ICU	<ul style="list-style-type: none"> - Explorative descriptive study - Dyad interviews with patients and familymembers, or individual interviews - Analysed using inductive thematic analysis 	<p>Three main themes were identified:</p> <ul style="list-style-type: none"> - Ongoing dialogue is fundamental - Humanizing the family to navigate 	<p>Yes: 9 Unclear: 1</p>
5. Frivold, G., et al., 2015, Norway	Three general ICUs	Family members ($n = 13$)	To illuminate the meaning of being taken care of by nurses and physicians for families in Norwegian ICUs	<ul style="list-style-type: none"> - Descriptive qualitative study with a phenomenological hermeneutical approach - Individual interviews 2–12 months after patients ICU discharge - Analysed by a phenomenological hermeneutical method 	<p>Two main themes were identified:</p> <ul style="list-style-type: none"> - Being in a receiving role - Being in a participating role 	<p>Yes: 10</p>
6. Frivold G., et al., 2018, Norway	Nine general ICUs	Family members of former ICU patients ($n = 261$)	To explore family members' satisfaction with care and decision-making during the ICU stays and their follow-up needs after the patient's discharge or death	<ul style="list-style-type: none"> - Cross-sectional survey study - Questionnaire: the instrument Family Satisfaction in ICU (FS-ICU 24) and questions about follow-up needs - Descriptive and statistical analyses were performed 	<ul style="list-style-type: none"> - Respondents $n = 123$ (response rate 47%) - Satisfaction with care received higher scores than satisfaction with decision-making - Family members were satisfied with the treatment and care for the patient, but less satisfied with the care of the family members and the ICU staff's communication skills 	<p>Yes: 7 No: 2</p>

(Continues)

TABLE 1 | (Continued)

Authors (year), country	Setting	Sample	Aim	Design/data collection/ analysis	Key findings	JBIC critical appraisal summary (See Appendix S2)
7. Frivold, G., et al., 2022, Nordic countries: Norway, Denmark, Sweden and Finland	158 General ICUs	ICU staff (n = 196)	To describe family involvement, communication practices and visiting policies in adult ICUs	<ul style="list-style-type: none"> - Cross-sectional survey - Specially designed survey based on literature covering 11 sections: Type of ICU, visiting policies, admission to the ICU, information and conferences with family members about the patient, general guidelines for family members, treatment of children under 18 as family members, facilities for family members, care initiatives targeting family members, follow-up initiatives in the ICU, ICU personnel and additional comments - Quantitative data were analysed by descriptive and statistical analyses - Qualitative data were analysed using content analysis 	<ul style="list-style-type: none"> - Respondents n = 158 (response rate 81%) - Family involvement: Family participation in patient care, including involvement in ward rounds and presence during cardiopulmonary resuscitation, varied between the countries, whereas most families in all countries were involved in decision-making (> 80% involved) - Communication practices: Family conferences were generally initiated by staff or family members. Children < 18 years did not always receive information directly from the staff, and parents were not advised about how to inform their children. - Written information about patient treatment and being a family member of an ICU patient were rarely or never mentioned (65% and 47%), respectively - Visiting policies and practices: Most respondents described open visiting and restrictions were also mentioned in the qualitative component 	Yes: 7 No: 2

(Continues)

TABLE 1 | (Continued)

Authors (year), country	Setting	Sample	Aim	Design/data collection/ analysis	Key findings	JBIC critical appraisal summary (See Appendix S2)
8. Haave, R. et al., 2021, Norway	Two general ICUs	Family members of ICU patients ($n = 165$)	To describe how family members assessed their satisfaction with the ICU stay using Family Satisfaction in the Intensive Care Unit 24 (FS-ICU 24) items instrument. Another aim was to identify which demographic variables were associated with differences in family satisfaction	<ul style="list-style-type: none"> - Cross-sectional design - The FS-ICU 24 questionnaire - Statistical analysis was conducted 	<ul style="list-style-type: none"> - Respondents $n = 57$ (response rate 34%) - Family members were generally satisfied with the care that was received in the ICU. - Family members were equally satisfied with the nursing care and with the overall treatment (FS-Care), for both the hospitalized patient and for the family itself. - The degree of satisfaction was somewhat lower in relation to the information given by ICU staff, and family members' participation in the decision-making process (FS-DM) 	Yes 9
9. Haugdahl, H. S., et al., 2018, Norway	One general ICU	Family members ($n = 13$)	To explore family members' experiences of long-term intensive care unit patients' pathways towards survival and to highlight family members' efforts to promote the patient's health during the ICU stay.	<ul style="list-style-type: none"> - Descriptive qualitative study with a hermeneutic phenomenological approach - Semistructured interviews with family members once and at 6–18 months after ICU discharge - Analysed thematically within the context of Antonovsky's salutogenic theory and Merleau-Ponty's phenomenology of the body 	<ul style="list-style-type: none"> - Three themes were identified: <ul style="list-style-type: none"> - A body at a breaking point - Family members' presence - Breaking through. - Inner strength was central to promote patient's health based on family members' knowledge about the patient 	Yes 10

(Continues)

TABLE 1 | (Continued)

Authors (year), country	Setting	Sample	Aim	Design/data collection/ analysis	Key findings	JBI critical appraisal summary (See Appendix S2)
10. Jensen, H.I., et al. 2017, Denmark & Netherlands	21 ICUs (11 from DK and 10 from NL)	Family members ($n = 1496$)	To examine satisfaction with care assessments in a large cohort of Danish and Dutch family members, and the measurement characteristics of the euroFS-ICU	<ul style="list-style-type: none"> - Crosssectional survey - The euroFS-ICU questionnaire - Statistical analysis 	<ul style="list-style-type: none"> - Respondents $n = 573$ from Denmark and $n = 504$ from the Netherlands, representing 920 ICU patients (response rate 72%) - Overall, family members rated the ICU care moderately highly - Respondents from Denmark typically provided higher ratings than respondents from the Netherlands. - Danish respondents gave higher ratings, on average, than respondents from the Netherlands - Items with the highest ratings were concern towards patients, ICU atmosphere, opportunities to be present at the bedside, and ease of getting information - Items with lower ratings were management of patient agitation, emotional support of the family, consistency of information, and inclusion in and support during decision-making processes 	Yes: 7 Unclear: 2

(Continues)

TABLE 1 | (Continued)

Authors (year), country	Setting	Sample	Aim	Design/data collection/analysis	Key findings	JBI critical appraisal summary (See Appendix S2)
11. Nygaard, A. M., et al., 2022, Norway	Four general ICUs	Participants ($n = 32$)	To explore ICU nurses' and physicians' bedside interaction with ICU patients' families and discuss this in light of the ethics of care.	<ul style="list-style-type: none"> - A descriptive, qualitative study - Data were (1) Participant observation (11–14 shifts) and (2) focus group interviews ($n = 7$) - Analysed using a thematic narrative analysis 	<ul style="list-style-type: none"> - Three themes were identified: <ul style="list-style-type: none"> - Being attentive - An active approach - Degree of tolerance - The narratives presented under each theme reveal contrasts in clinicians' interactions with families 	Yes: 9 Unclear: 1
12. Nyhagen, R., et al., 2023, Norway	Two general ICUs	Patients ($n = 6$), family members ($n = 6$), nurses ($n = 7$), and physical therapists ($n = 2$)	To explore communication between patients, family members, and nurses and to investigate previously unidentified communication challenges.	<ul style="list-style-type: none"> - Case-oriented design with multiple triangulations - Participants' observations ($n = 9$ patients and families communicating with healthcare professionals) - Interviews: Patients ($n = 6$), family members ($n = 6$), and clinicians ($n = 9$) - Analysed using an inductive, open approach based on the theoretical framework of communication 	<ul style="list-style-type: none"> - Communication often seemed uncomplicated at the time of observations, but information from the interviews revealed another picture <ul style="list-style-type: none"> - Participants emphasized different things when they discussed their experiences, revealing a discrepancy in perceived importance in the situation - Family members had an important role in interpreting signs from the patient, uncovering challenges that would have been unknown to the nurses otherwise 	Yes: 10

(Continues)

TABLE 1 | (Continued)

Authors (year), country	Setting	Sample	Aim	Design/data collection/ analysis	Key findings	JBIC critical appraisal summary (See Appendix S2)
13. Nyhagen, R., et al., 2024, Norway	Two general ICUs	ICU patients ($n = 6$), family members ($n = 6$), and clinicians ($n = 9$)	To explore family members' engagement in symptom communication in the ICU.	<ul style="list-style-type: none"> - Descriptive qualitative study - Interviews: Patients ($n = 6$), family members ($n = 6$), and clinicians ($n = 9$) - Participant observation with interviewed participants ($n = 9$) - Analysed using thematic analysis 	<p>Three main themes were identified:</p> <ul style="list-style-type: none"> - Intermediary role (recognize and report symptoms, provide patient information, and assist in communication) - Independent role (provide familiarity, manage symptoms, and promote patient communication) - Conditions for family engagement (intensive care unit environment, relationship with the patient, and patient preferences) 	Yes 10
14. Oxenbøll Collet, M., et al., 2023, Denmark	32 ICUs	Critical Care Nurses ($n = 32$) all held a master's degree in health or nursing science from the 32 included ICUs	To describe current practice and experiences of contemporary patient and family engagement in ICU at the individual level, the organizational level and in the research process according to critical care nurses.	<ul style="list-style-type: none"> - National qualitative survey - A web-based survey developed by the research team consisting of open-ended questions to describe current practice and the experience of patient and family engagement in ICU - Analysed using descriptive statistics and qualitative content analysis 	<ul style="list-style-type: none"> - Respondents $n = 24$ complete, $n = 8$ partially completed (response rate 78%) - At the individual level, 27 respondents stated that they involved patients and 25 said they involved family in daily treatment and care - At the organizational level, 28 intensive care units had an overall strategy or guideline for patient and family engagement, and 4 units had established a PFE panel - In the research process, 11 units engaged patients and families 	Yes: 5 Unclear: 1 No: 1 NA: 2

Note: Critical Appraisal Summary: Yes: Criterion met; No: Criterion not met; Unclear: Insufficient information to judge; NA: Not applicable. Numbers indicate how many checklist items received each rating (e.g., Yes = 8, No = 2). Full item-level appraisal is available in Appendix S2.

Abbreviations: CCN, Critical care nurse; FS-DM, Family satisfaction decision-making; FS-ICU, Family Satisfaction in ICU; ICU, intensive care unit; PFCC, Patient and Family Centred Care; PFE, Patient and family engagement.

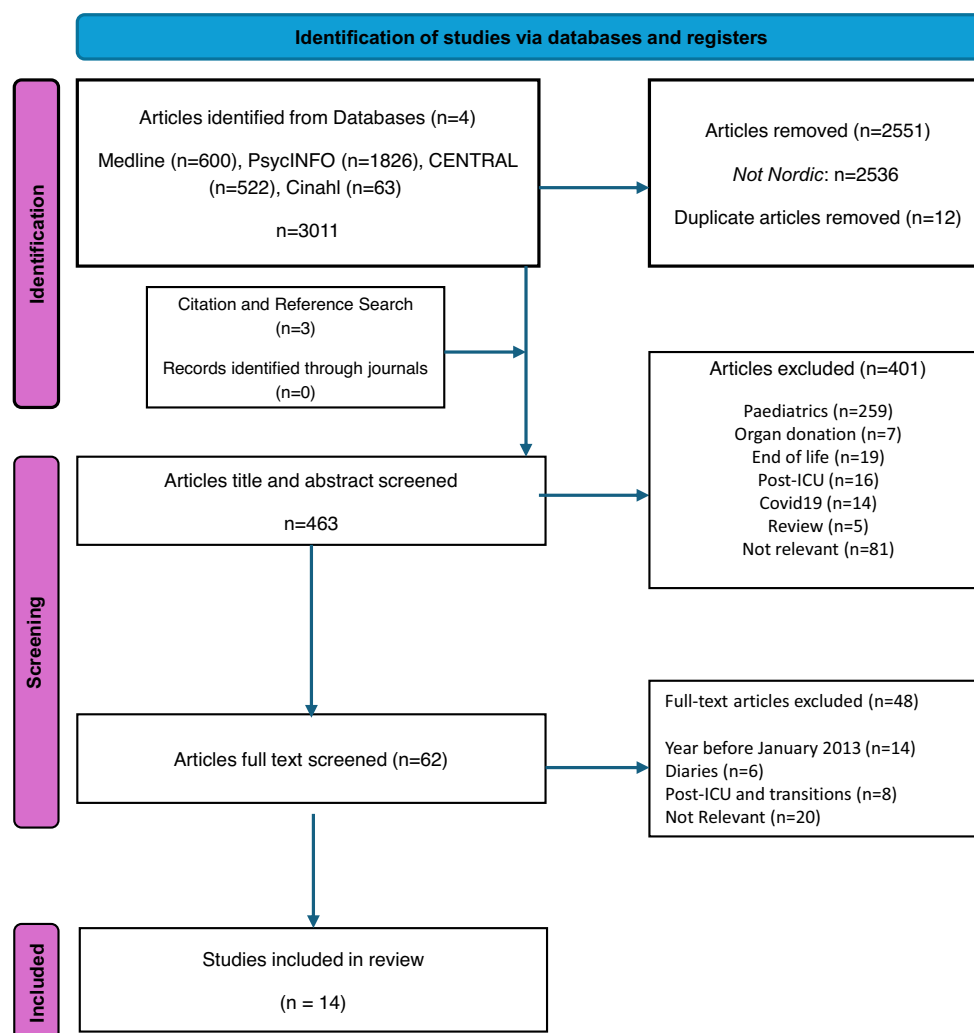


FIGURE 1 | PRISMA flow diagram for integrative review on family involvement (adapted from [44]).

studies, concerns were noted regarding reflexivity and researcher positionality [46]. For quantitative studies, common issues included lack of sample size justification and frequent confounding factors [40]. These observations are reflected in the cells under the JBI Critical Appraisal Summary in Table 1 where each cell summarizes key strengths and limitations identified during the appraisal process. A full item-level appraisal is available in Appendix S2.

3.3 | Study Characteristics

The 14 studies were published between 2013 and 2024, and eight (57%) were published in 2020 or later [45, 47–53]. In total, three countries were represented. Ten studies were performed in Norway [45, 47, 49, 50, 52–57] one in Sweden [58], one in Finland [45] and three in Denmark [48, 51, 59]. Nine studies had a qualitative design [47–50, 52, 54, 55, 57–58], of which one had a case–case-oriented study design [51], and five studies had a cross-sectional survey design [45, 51, 53, 56, 59], see Table 1. The two studies [51] and [52] originate from the same overarching fieldwork dataset but are reported as separate analyses addressing different research questions.

The studies highlighted the roles of family involvement from multiple perspectives. In the qualitative studies, a total of 60 family members [48, 50, 52, 55, 57–58], 56 HCPs [49, 50, 52, 54], and 37 patients [47, 48, 50, 52] were interviewed. Seven studies collected data through individual in-depth interviews [47, 50, 52, 54, 55, 57–58], one used dyadic interview with patients and family members [48], and one conducted focus group interviews with nurses and physicians [49].

In the five quantitative, cross-sectional studies, six different questionnaires were used. Four of them were aimed at family members: Family Satisfaction in the Intensive Care Unit (FS-ICU 24) [53, 56], a self-made questionnaire focusing on family members' follow-up needs [56], the euroQ2 questionnaire, and the euroFS-ICU [59]. Two cross-sectional studies focused on general ICU routines [45, 51] and their questionnaires were answered by ICU representatives (ICU nurse, research nurse or nurse coordinator) [45, 51]. These studies examined ICU procedures affecting family involvement, including visitation policies and how HCPs facilitate or limit such involvement [45, 51]. In total, 753 family members responded to questionnaires [53, 56, 59].

3.4 | Family Involvement in Scandinavian ICUs

One main category: “Navigating family involvement in Scandinavian ICU” and two subcategories emerged from the synthesis: “The power of family involvement in ICU” and “Balancing the challenges of family involvement in ICU” (Figure 2). The subcategories integrate codes reflecting experiences from all perspectives. When HCPs describe relatives’ experiences, these descriptions are based on their interpretations rather than direct accounts.

3.4.1 | The Power of Family Involvement in ICU

Thirteen of the 14 articles described beneficial impacts of family involvement in ICU [45, 47–49, 51–59]. Three codes emerged: *Family members’ direct, practical contributions to care and support*, *A way to safeguard the patient’s interests*, and *Meeting Family Members’ Needs*.

In summary, this subcategory is about how navigating family involvement in the ICU is vital for patient care, significantly impacting the wellbeing of both patients and their families. When family members actively participate, they provide practical help and emotional support, ensuring that patients’ needs and preferences are met. This involvement also benefits family members, giving them a sense of purpose and connection. By fostering a collaborative environment, the ICU team can support a holistic, patient-centred approach to care, ultimately enhancing outcomes for both patients and family members.

3.4.1.1 | Family Members’ Direct, Practical Contributions to Care and Support.

From the HCPs’ perspective,

many family members described finding strength and meaning in contributing directly to the care of their loved ones. Their involvement included practical tasks such as assisting with patient care, accompanying patients on wheelchair walks, participating in medical rounds, supporting communication through aids, and helping with breathing techniques for dyspnoea [48, 52]. Furthermore, HCPs acknowledged that families played a crucial role in providing comfort and safety, especially for patients experiencing delirium [51] and were described as valuable resources for understanding the patient and individualizing care [51, 52]. Families also emphasized the importance of providing emotional support and reassurance [48, 52, 58]. Some family members expressed that their contribution was crucial not only for the patient but also for their own sense of purpose, actively engaging in daily routines and feeling satisfied when their presence helped distinguish between habitual behaviour and delirium or provided comfort during distress [48]. Families valued being acknowledged as individuals rather than merely extensions of the patient [48, 58]. According to families, practical involvement extended beyond bedside care to tasks such as managing household responsibilities or communicating with the patient’s workplace [48]. Some family members documented daily events to process their experiences and preserve memories [48]. Family members reported that meaningful involvement was facilitated when they received support and recognition from HCPs [58]. This was important for families of both survivors and non-survivors, as active participation provided a sense of purpose and alleviated emotional distress during a challenging time [58]. However, some family members expressed surprise when their knowledge about the patient was not sought [55]. From the patients’ perspective, family presence was described as encouraging and motivating

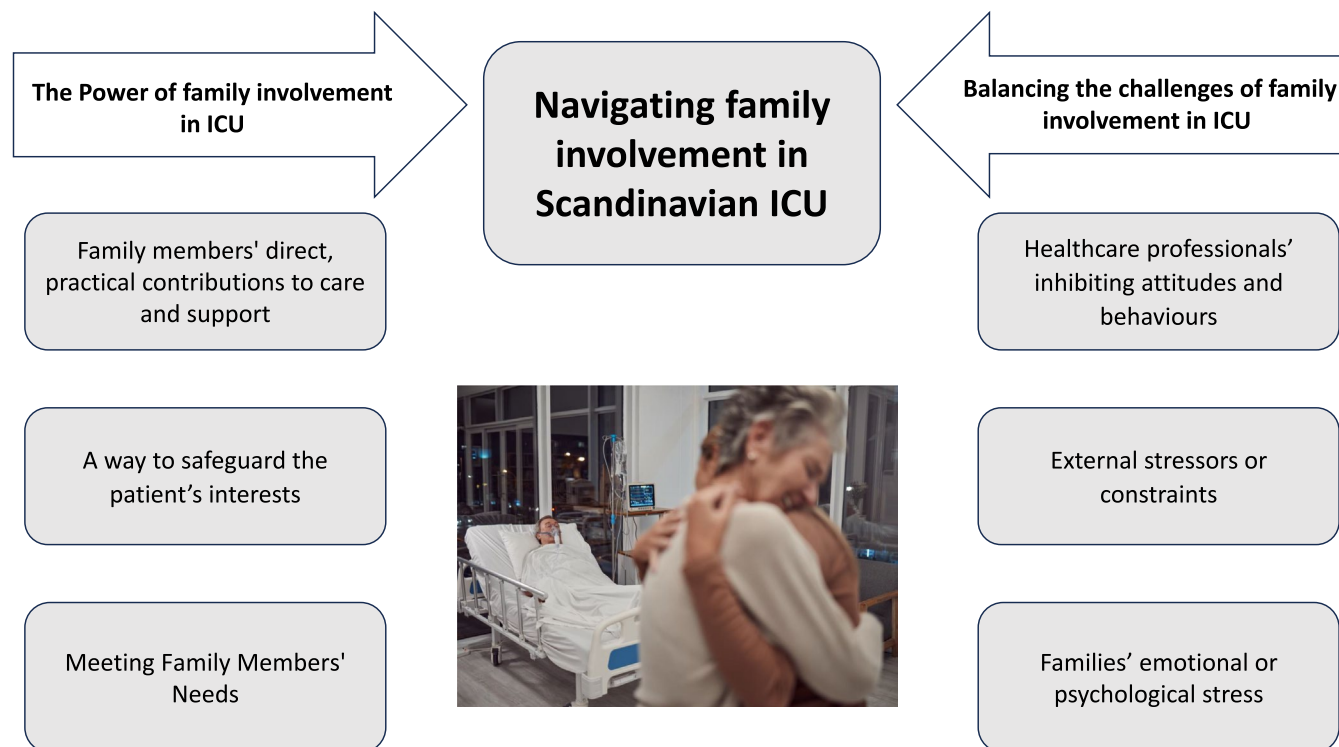


FIGURE 2 | A summary of the main category, the two subcategories, and their six codes. (Picture from colourbox <https://www.colourbox.com/>).

during recovery [47]. Visits from family members were perceived as important breaks from daily distress and reinforced patients' sense of significance to loved ones, strengthening their determination to recover and maintain their roles within the family [47]. Patients' primary memories of their ICU stay were often related to family interactions, underscoring their central importance in the ICU experience [47, 52, 54].

3.4.1.2 | A Way to Safeguard the Patient's Interests. Across all three perspectives, safeguarding the patient's interests was described as a key responsibility for families, achieved through presence, communication, structured information exchange, involvement in panels, and access through generous visitation policies. In studies describing HCPs' perspectives, physical presence was the most frequently mentioned form of involvement [45, 48, 51, 52, 55, 57, 59]. However, families also emphasized that being present—whether physically or symbolically—was essential for the patient's well-being, representing a lifeline and hope in the alienating ICU environment [48, 52]. Physical presence included actions such as holding the patient's hand and offering comfort [48], while symbolic presence involved emotional closeness or reminders, such as photographs [58]. Families reported high satisfaction with opportunities to be at the bedside, both in a questionnaire study (88.5%, $n = 572$) [59] and interviews [45, 55]. They described their presence as meaningful regardless of the patient's level of consciousness [48] and viewed it as an essential contribution to recovery [57]. Family members referred to decision-making processes ranging from routine daily treatment choices to more critical matters, such as determining limitations on life-prolonging interventions [55]. For some, being present provided comfort and a way to express love and care during difficult times [57]. Presence could also be maintained virtually through video calls, tablets, or phone communication [45, 51, 54, 58]. Families valued observing care from a distance, participating in daily routines, and joining ward rounds or decision-making processes [45, 55, 57]. Observing individualized care reinforced trust and confidence in nursing care [50, 57]. Communication and information sharing served two distinct functions in the included studies: (1) meeting families' needs for clarity, continuity, and support, and (2) enabling families to safeguard the patient's interests by sharing essential knowledge about symptoms and preferences. From the HCPs' perspective, family involvement was facilitated through effective communication and information sharing [45, 49, 50, 52, 54]. From a family perspective, continuous updates and support were also considered essential for enhancing participation and satisfaction [48, 58]. Communication methods included verbal updates, written materials, phone calls, and informal conversations during visits [48, 58]. Families expressed that telecommunication was particularly helpful when visiting was restricted [48]. Families contributed valuable information about patients' pain or discomfort, helping clinicians personalize care [52]. However, information-sharing was often described by HCPs as spontaneous and dependent on individual nurses [45, 49–51, 54]. Families reported that waiting for updates was stressful, especially when scheduled calls were delayed or contacting busy ICU staff was difficult [48, 49]. Structured information exchange was rarely implemented, though families recommended systematic procedures and valued formal consultations with HCPs for detailed updates [48].

Patients, family members, and HCPs all reported that families played a critical role by sharing medical history, preferences, and signs of discomfort [47, 50, 51, 54, 55, 57]. Family members also emphasized the importance of clarity, honesty, and consistency in communication [59] and suggested additional measures such as counselling resources, involvement during care transitions, and mandatory discharge meetings [48].

Other facilitating factors included public involvement (PPI) panels and visitation policies. PPI panels were described as opportunities for dialogue, feedback, and collaboration, ranging from informal conversations to structured meetings and conferences [48, 51]. These panels were considered effective for improving family involvement, though participation was limited (reported by only 25% of nurses in one study) [51]. Visitation policies also shaped involvement: open visiting hours were standard in most Scandinavian ICUs [45, 51], though some units restricted visits to two people or made individual agreements with families [45]. Families appreciated flexible visiting times, with some reporting being welcome to stay as long as they wished [52].

3.4.1.3 | Meeting Family Members' Needs. Both families and HCPs perceived that it was HCPs who possessed the capacity to facilitate and create conditions conducive to family involvement [45, 49, 51, 55, 58]. Examples of meeting families' needs encompassed adopting an inviting and open approach, building trust through ongoing conversations, engaging in inclusive and collaborative dialogues, and, when appropriate, involving families in shared decision-making. Although family members were not always able or expected to contribute to medical decisions, they emphasized the importance of being asked for their opinions and having the opportunity to voice them [55]. Families generally understood the complexity and stressfulness of the ICU environment and recognized the severity of their loved ones' illnesses, which shaped their expectations of decision-making processes [54]. In situations where treatment-level decisions were required, HCPs often relied on family members to provide information about patient preferences, particularly when patients were unable to participate themselves [51]. Several studies showed that families accepted decisions made by HCPs and expressed respect for these decisions, even in cases with unfavorable outcomes [54]. Many family members also appreciated that HCPs ultimately assumed responsibility for final decisions, especially in highly complex medical situations [55]. Moreover, two studies evaluating family satisfaction reported that a majority felt included in the decision-making process and supported by HCPs throughout these discussions [53, 59].

From a HCP perspective, meeting families' needs began with an inviting approach, characterized by active and welcoming behaviors such as making eye contact, positioning themselves beside caregivers and patients during conversations, maintaining a friendly and accessible presence, and explicitly inviting families into the ICU [49]. This initial openness created the foundation for trust-building, which was further facilitated through inclusive, professionally guided conversations.

Once an inviting atmosphere had been established, HCPs worked to build trust by prioritizing transparent

communication about the patient's condition, offering timely updates on clinical progress and planned interventions, including actively encouraging family participation in care and decision-making [49]. Proactively sharing information, before families requested it, was highlighted as an important strategy for fostering both involvement and trust. Examples included informing families when diagnostic procedures (e.g., X-rays) were completed or offering to arrange consultations with the attending physician [49]. When communication from one HCP was unclear, clarification from another helped families feel more included [55].

A large Danish study showed that 63% ($n=1077$) of family members reported insufficient involvement, identifying this as the most common reason for dissatisfaction with ICU care [59]. According to both families and HCPs, involvement was facilitated when staff softened the presentation of difficult information [58], took time for conversations [58], used simple and understandable language, and listened attentively while still providing guidance [49]. HCPs also supported involvement by facilitating consultations with social workers, priests, or psychologists [51]. Finally, discussing typical thoughts and feelings experienced by family members was described as helpful for promoting their engagement [49].

3.4.2 | Balancing the Challenges of Family Involvement in ICU

In total, nine of the fourteen articles [45, 47–49, 51, 52, 54, 55, 58] described challenges of family involvement in the ICU. These factors were categorized into three codes: *Healthcare professionals' inhibiting attitudes and behaviours*, *Families' emotional or psychological stress*, and *Family members' view of their role*.

In summary, this subcategory explores how navigating family involvement in the ICU presents unique challenges that require careful balance. The behavior and characteristics of ICU HCP play a significant role in shaping the experiences of both patients and their families. External factors, such as hospital policies and limited resources, can further complicate family involvement. Families often face emotional and psychological stress, which can affect their ability to support patients. Additionally, families may have varying perspectives on their role, ranging from active participation to hesitation or reluctance to engage in care.

3.4.2.1 | Healthcare Professionals' Inhibiting Attitudes and Behaviours. According to HCPs, their own approaches, conversations, and decision-making could create barriers to family involvement [49, 50, 54]. Some clinicians described adopting a passive communication style, in which discussions focused narrowly on immediate clinical parameters, such as temperature or blood test results, and additional information was provided only when families explicitly asked for it. Observational data supported this, showing behaviors such as avoiding eye contact, refraining from asking questions, and offering minimal or no information; these actions were collectively described as a "passive" approach [49].

Families were highly sensitive to such demeanour and communication patterns. Two studies reported that when information

was delivered using medical jargon or without sufficient explanation, families found it difficult to understand and participate [55, 58]. When patients or families felt objectified or dehumanized, this contributed to additional suffering [58].

HCPs also reflected on how prolonged exposure to critically ill patients could alter their perception of severity, developing what one ICU physician termed "speed blindness", resulting in a higher threshold for recognizing and communicating seriousness [49]. In addition, clinicians noted that insecurity about managing both patient care and family needs simultaneously, as well as low tolerance linked to workload, resilience, and experience, could further hinder effective engagement [49].

3.4.2.2 | External Stressors or Constraints. According to HCPs, several external circumstances could hinder family involvement. These included institutional routines and physical constraints (e.g., visiting hours, shift changes, room layout), the complexity of advanced care, and patient-related factors such as clinical condition, fatigue, and the need for rest [45, 47, 49, 51, 54]. Patient activities, such as rest periods, medical rounds, and procedures for neighbouring patients, were viewed as unavoidable yet reduced opportunities for family presence [45].

Communication-related barriers were also common. HCPs described how linguistic challenges and cultural diversity sometimes complicated interactions, leading to misunderstandings [54]. Families similarly reported difficulties understanding medical language and decision-making processes, which limited their ability to participate [48, 54]. When practical support or guidance was lacking, families experienced additional uncertainty and complexity during communication [48].

Environmental and organizational constraints further restricted involvement. Long waiting periods away from the patient, limited privacy in multi-bedrooms, and restrictions on visitor numbers due to simultaneous care for other patients contributed to frustration [45].

3.4.2.3 | Families' Emotional or Psychological Stress. HCPs reported that families' expectations could sometimes clash with the clinical reality, creating challenges in communication and involvement [49, 54]. Family members with healthcare backgrounds or higher education were occasionally perceived as more demanding, particularly when expressing unrealistic hopes for elderly or frail patients [54]. Stress among family members further contributed to difficulties; some families sought repeated clarification, required detailed explanations, or reacted with frustration, at times directing blame towards staff when outcomes were unfavorable [54]. In more severe situations, family members struggled to accept the seriousness of the patient's condition, questioned clinical decisions, or expressed mistrust, which added emotional strain for ICU staff [54].

From the family perspective, witnessing reduced responsiveness or uncertainty about the patient's condition evoked fear, despair, and helplessness [57]. Such emotional strain could hinder involvement and communication, especially during the early stages of the ICU stay when patients had difficulty expressing themselves

[48, 57]. The presence of delirium was described as frightening, yet families felt more capable and included when HCPs provided clear explanations that it was a common ICU occurrence [48].

Additional barriers to engagement included not recognizing the patient, facing language difficulties, or struggling with communication challenges related to mechanical ventilation [58]. Families also described feelings of being a nuisance, uncertainty about how to approach the patient, and concern that their presence might interrupt care, even though staff did not perceive this as problematic [52, 55, 58]. Patient perspectives added further nuance. Some worried that their altered physical appearance might distress family members, while others feared that HCPs might misinterpret their behavior, which could cause additional concern for their families [47, 58].

4 | Discussion

In this integrative review, we identified 14 studies published since 2013 addressing family involvement in Scandinavian ICUs. This review aimed to explore how family involvement in intensive care settings is characterized and described in the Scandinavian context. We identified aspects indicating that family involvement in the ICU is a complex and contextually shaped phenomenon, influenced by relational, emotional, and organizational factors. This aligns with findings from international studies outside Scandinavia [60–62]. Navigating family involvement requires balancing various challenges with the potential benefits such involvement can offer. This balancing act echoes findings from earlier international reviews showing that family-centred care interventions often require clinicians to negotiate tensions between relational, emotional, and organizational demands while protecting patient safety [63]. Challenges may include HCP attitudes and behaviours, institutional barriers, and the psychological burden placed on family members. In contrast, meaningful involvement may enhance care through families' practical support and their role in safeguarding patient interests—a dynamic also emphasized in recent reviews and a study of family participation and essential care [63–65]. Our findings are consistent with other studies that have shown that HCPs and ICU nurses play a crucial role in facilitating family involvement [22, 66]. They not only provide clinical care but also create conditions that allow families to be present at the bedside, participate in decision-making, and engage in patient care. This includes offering clear and honest information tailored to the family's level of stress and understanding, explaining the ICU environment, and assessing informational needs. By adopting a family-centred approach and demonstrating empathy and adaptability, nurses help families feel supported and included, which strengthens collaboration and improves the overall quality of care [22]. However, an important challenge identified in this review is that family presence can sometimes interfere with medical procedures or reduce care efficiency. Similar tensions, in which staff must balance protecting patient safety, dignity, and clinical needs while enabling family participation, have been explicitly described in prior studies and integrative reviews [63, 64, 67]. Managing these situations, therefore, requires a delicate balance between maintaining patient safety and honouring the principles of family-centred care. This responsibility places additional demands on ICU nurses, who must navigate

emotional complexity while ensuring clinical standards are upheld. Consequently, time, empathy, organizational support, clear guidelines, and targeted training for ICU HCPs are essential to enable nurses to fulfil this role effectively. Developing structured yet flexible strategies that empower nurses to manage these challenges is critical for promoting meaningful family involvement without compromising care quality.

A core prerequisite for family involvement is the possibility of physical presence at the bedside, as many forms of engagement—such as supporting patient communication, observing symptoms, and participating in conversations with HCPs cannot be fully achieved remotely. Consistent with international and Scandinavian studies [68, 69], families expressed a strong desire to be physically present and actively involved in the ICU. Scandinavian ICUs generally accommodate this through more flexible visiting practices [70–72].

However, the organization of visiting access remains a debated issue internationally, with studies reporting mixed views and no clear consensus [73–75]. While open or flexible visiting policies may enhance family connection and provide reassurance by allowing them to witness or participate in care, staff perspectives highlight potential challenges. ICU nurses have reported concerns about working under observation, workflow interruptions, and increased workload [73, 76]. One recent study further indicated that enhanced opportunities for family involvement did not necessarily translate into improved psychological outcomes for relatives [29].

Taken together, these findings suggest that visiting access is closely intertwined with the practical possibilities for family involvement, but that its implementation requires a context-sensitive balance between family needs, staff wellbeing, and the demands of ICU care. In our findings, as in other Scandinavian studies [77, 78], it was found that family expectations do not always align with the patient's condition or the healthcare system's capacity. In the Scandinavian region, extensive preventive healthcare has contributed to a generally healthy but aging population, in which many individuals experience illness primarily in old age, influencing perceptions about healthcare's curative abilities. Clear, compassionate communication and education about the possibilities and limitations of medical interventions are essential to bridge this gap and foster realistic expectations and cooperation.

Our findings emphasize that fostering a supportive environment and trusting communication between families and HCPs is fundamental to facilitating family involvement and ensuring effective collaboration. Furthermore, a recent systematic review highlights that ICU nurses must respond to families' existential needs, establish effective communication, and create a humanizing atmosphere to optimize care outcomes [79]. Beyond medical and demographic factors, the secularization of Scandinavian societies impacts the emotional and psychological support available to families. The decline of traditional communities or religious support places additional responsibility on HCPs to provide holistic care that addresses emotional and existential needs.

Training HCPs in these areas and creating safe spaces for families to express concerns are vital strategies for improving the ICU experience [80].

Cultural and systemic barriers may also influence family involvement in the ICU. Traditionally, the Scandinavian welfare model places primary responsibility for patient care on HCPs, with families expected to defer to clinical decisions [11]. This dynamic can leave family members feeling uncertain about how to engage, sometimes feeling like a burden or struggling to navigate and understand complex decision-making processes. However, newer care models such as person-centred care [81, 82] and family-centred care [83], supported by legislation in countries like Sweden, aim to redefine these roles by recognizing families as essential partners in patient well-being and recovery. Transitioning to these approaches requires a cultural shift involving improved communication, education, and organizational support that empowers families to participate actively in care decisions.

4.1 | Methodological Considerations

This review provides an overview of family involvement in Scandinavian ICUs. The strength of this study lies in its focus on family involvement, which has become a growing priority in healthcare policy. Moreover, we included studies with similar healthcare systems characterized by egalitarian values, transparency, and a strong emphasis on family-centred care. Cultural norms and practices related to family involvement differ from those in other countries, making it important to generate context-specific knowledge. However, limitations must be mentioned, such as excluding papers before 2013 and grey literature, which may have excluded relevant findings. Most of the studies included were qualitative, while the quantitative studies varied in sample size. The studies also differed in terms of study populations, including either patients or HCPs, which influenced the synthesis of findings and limited the ability to generalize findings. It should be noted that some of the quantitative studies raised concerns about risk of bias, particularly related to confounding variables and how these were addressed. Three qualitative studies did not sufficiently reflect on the researchers' influence on the findings, leaving alternative interpretations unexplored. However, the findings from these studies were generally consistent with those from higher-quality studies.

5 | Conclusion

Family involvement in Scandinavian ICUs is a complex and multifaceted phenomenon shaped by interacting clinical, relational, and organizational factors. Families contribute primarily through their presence at the bedside, which provides reassurance and emotional stability for both patients and relatives. They also offer emotional support, helping to reduce distress and strengthen patients' sense of safety. In addition, families support care by sharing personal knowledge about patient preferences, behaviors, and symptoms, which can enhance individualized care. Finally, families participate in care, ranging from assisting with basic comfort measures to supporting communication and decision-making.

Despite these contributions, families encounter barriers such as stress, uncertainty about their role, communication challenges, and organizational constraints. The degree to which involvement is successfully facilitated depends largely on HCPs' attitudes and practices, including trust-building dialogue, proactive

and clear information-sharing, and an inviting, inclusive approach. Structural conditions, particularly visitation policies, also shape opportunities for involvement and influence how involvement is enacted.

Overall, navigating family involvement requires balancing its inherent challenges with the substantial benefits it offers for patients, families, and HCPs. Effective, context-sensitive strategies that support presence, emotional support, knowledge-sharing, and participation are crucial for promoting meaningful and sustainable family involvement within Scandinavian ICUs.

6 | Clinical Implications

This review reveals the complex interplay between challenges and opportunities in family involvement within Scandinavian ICUs. The subcategory Balancing the challenges of family involvement in ICU highlights the need for ICU staff to manage emotional burdens, systemic constraints, and diverse family expectations with empathy and adaptability. Meanwhile, The Power of family involvement in ICU demonstrates how families can enhance care quality, advocate for patient interests, and experience meaningful engagement. These insights call for structured, yet flexible, family-inclusive practices that support both families and staff, ultimately strengthening family-centered care in high-acuity settings.

Author Contributions

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Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data that supports the findings of this study are available in the [Supporting Information](#) of this article.

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Supporting Information

Additional supporting information can be found online in the Supporting Information section. **Appendix S1:** Search strategy. **Appendix S2:** Quality appraisal of Quantitative and qualitative studies.