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# Facilitators and barriers to parental involvement in neonatal pain management in the NICU: a scoping review



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# Facilitators and barriers to parental involvement in neonatal pain management in the NICU: a scoping review

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## ABSTRACT

**Objectives** Neonatal pain prevention is not only a humanistic but also an ethical imperative. Fitting with the principles of family-centered care, parental involvement in neonatal pain management plays an active role in infant development and parental well-being. However, the process of parental involvement faces constant challenges. To help structure and implement a family engagement program in neonatal pain management in the NICU, we conducted a scoping review to identify facilitators and barriers to parental involvement in neonatal pain management.

**Methods** We conducted the scoping review using the Arksey and O'Malley framework. PubMed, Cochrane Library, Web of science, CINAHL, Scopus, Wanfang database (Chinese), CNKI (Chinese), VIP database(Chinese), and SinoMed (Chinese) were searched systematically for relevant studies published in English and Chinese from inception up to October 2023. We categorized the facilitators and barriers based on the socio-ecological model and analyzed the results thematically in each category.

**Results** Eleven studies were included for the final analysis, of which ten English studies were qualitative and one Chinese study was a literature review. The 36 facilitators and 46 barriers extracted were grouped into four domains of the socio-ecological model framework. Of the ten facilitator themes, the most critical theme was informational and emotional support. Of the ten barrier themes, the most frequently reported themes included lack of knowledge and support and restricted policies and resources.

**Conclusion** Our review highlights the essential roles of intrapersonal and interpersonal factors in parental involvement in pain management while suggesting the interconnectedness of factors in various domains within the context of the socio-ecological model. It implies that most interventions require development and administration at both intra- and interpersonal levels. Regarding the macro level, a broad program with clear regulatory approaches and targeted guidelines could be developed in the future to drive innovations in NICU pain management mode.

**Strengths and limitations of this study**

- This is the first scoping review to comprehensively identify and summarize facilitators and barriers to parental involvement in neonatal pain management in the NICU.
- Our findings went through three reviewers screening the literature, two reviewers extracting and cross-checking the data, and the entire research team discussing to minimize bias.
- We used the socio-ecological model as a theoretical framework to categorize and analyze the results.
- In addition to excluding gray literature, we did not assess the quality of the included studies.

## INTRODUCTION

Globally, nearly 30 million babies need to be hospitalized each year for reasons such as being born too early, being underweight, or suffering from illnesses.[1] It means that babies will unavoidably be subjected to a great deal of painful stimuli associated with their care and treatment. According to a systematic review, each newborn in the NICU undergoes 7.5–17.3 painful maneuvers on average each day.[2] Painful stimuli can cause a variety of neurophysiological reactions and behavioral changes in infants.[3] In the short term, it may lead to wound dehiscence, apnea, and feeding difficulties. Long-term effects may even impact the neurodevelopment, behavioral patterns, and future responses of the infant to pain in childhood and adulthood.[4]

Neonatal pain management has gradually gained widespread international focus and attention in recent years, with non-pharmacologic pain management now serving as the primary focus of care. Non-pharmacologic interventions such as parent-led breastfeeding and kangaroo care have made parents a strong potential supportive force in neonatal pain management and play an active role. Evidence indicates that parent participation in managing their infants' suffering not only helps to relieve pain[5]-[8]

but also lessens parental stress[9] and promotes attachment between parents and infants,[10] as well as parental role attainment.[11] Furthermore, this management mode aligns with the patient- and family-centered care paradigm advocated by international organizations, which somewhat advances high-quality healthcare.[12] However, parental engagement in pain management is a complex, multidetermined, and interactive process. Parents' individual characteristics interact with environmental features to influence individual behaviors.[13] Consequently, a range of individual, interpersonal, organizational, and societal issues may have an impact on parental involvement in this behavior, leading to a low level of actual involvement and a challenging implementation process.[14] Previous studies have focused on the effectiveness of pain management by parents,[5],[15]-[17] as well as the attitudes, perceptions, and experiences of parents and medical professionals in this area.[18]-[20] Several studies have explored influencing factors but have focused on different factors, leading to divergent conclusions.

To better develop the practice of parental involvement in pain management in the NICU, it is essential to understand the knowledge related to the practice process. Clarifying the influencing factors of parental involvement in neonatal pain management will help the development of relevant strategies and programs in healthcare organizations, which may bring many benefits and convenience to infants, parents, and healthcare professionals. To the best of our knowledge, no previous review has systematically sorted out the facilitators and barriers influencing parental involvement in neonatal pain management at the individual, organizational, and societal levels. Therefore, a scoping review was conducted using the socio-ecological model (SEM) as a theoretical framework,[21] aiming to provide a comprehensive overview of facilitators and barriers to implementation and to identify knowledge gaps in the literature to inform clinical practice.

## METHODS

Scoping reviews are used to describe the scope of knowledge and core concepts in a particular field of study. They have extremely broadly defined research questions.

Therefore, a scoping review was chosen reasonably to explore what is known about the facilitators and barriers to parental involvement in neonatal pain management in the NICU. We followed the methodological framework developed by Arksey and O'Malley[22] for the scoping review and reported according to the PRISMA-ScR checklist.[23] The methodological framework consists of five stages: (1) identifying the research questions, (2) identifying relevant studies, (3) study selection, (4) charting the data and (5) collating, summarising and reporting the results. The review protocol was registered on the Open Science Framework (https://doi.org/10.17605/OSF.IO/95NBY).

**Stage 1: identifying the research questions**

The following are the specific research questions that this review poses:

1. What are the factors that impact the level of parental involvement in the NICU when it comes to managing the pain of newborns?
2. What factors serve as facilitators for parental engagement in the management of neonatal pain in the NICU? What factors serve as obstacles?

**Stage 2: identifying relevant studies**

A five-person research team was first assembled, and two of them (LF and MS) searched PubMed and CNKI in advance to find pertinent MESH terms, keywords, and synonyms. Following group deliberation, the ultimate search strategy was honed and a thorough, systematic search of the PubMed, Cochrane Library, Web of Science, CINAHL,Scopus,Wanfangdatabase(Chinese),CNKI(Chinese),VIPdatabase(Chinese), and SinoMed (Chinese) was conducted. We searched the databases using the main concepts such as parental involvement, newborn, and pain for articles published from inception to October 2023. The specific search terms are shown in Table 1, and the complete PubMed search strategy is presented in Table 2. Lastly, a manual retrieval of the included literature references was conducted by two independent reviewers (LF and MS).

**TABLE 1** Concept groups and search terms

| Concept groups | Search terms |
|---|---|
| Parental involvement | Parent*/parents/family/parental involvement/parental participation/family involvement/family participation/family integrated care/family centered care/family centred care |
| Newborn | Newborn*/neonat*/preterm*/prematur*/infant*/neonatal intensive care unit/NICU |
| Pain | Pain*/pain management/heel/needles/needle puncture/injection/vaccines/breastfeeding/kangaroo care/skin to skin |

**TABLE 2** PubMed search strategy

| Search | Query |
|---|---|
| #1 | "parents"[MeSH Terms] OR "family"[MeSH Terms] OR "parent*"[Title/Abstract] OR "parental involvement"[Title/Abstract] OR "parental participation"[Title/Abstract] OR "family involvement"[Title/Abstract] OR "family participation"[Title/Abstract] OR "family integrated care"[Title/Abstract] OR "family centered care"[Title/Abstract] OR "family centred care"[Title/Abstract] |
| #2 | " newborn*"[Title/Abstract] OR " neonat*"[Title/Abstract] OR " preterm*"[Title/Abstract] OR " prematur*"[Title/Abstract] OR " infant "[MeSH Terms] OR "neonatal intensive care unit"[Title/Abstract] OR "NICU"[Title/Abstract] |
| #3 | "pain"[MeSH Terms] OR "pain management"[MeSH Terms] OR "heel"[MeSH Terms] OR "needles"[MeSH Terms] OR "needle puncture"[Title/Abstract] OR "injection"[Title/Abstract] OR "vaccines"[MeSH Terms] OR "breastfeeding"[Title/Abstract] OR "kangaroo care"[Title/Abstract] OR "skin to skin"[Title/Abstract] |
| #4 | #1 AND #2 AND #3 |

**Stage 3: study selection**

Based on the particular research questions, the PCC (Population, Concept, and Context)[24] framework was used to determine the inclusion criteria: (1) Population: Parents of newborns and NICU healthcare workers; (2) Concept: studies on the perceptions, attitudes, behaviors, experiences, current status, and factors influencing the management of pain in newborns by parents and healthcare professionals; (3) Context: pain management in the NICU. We included quantitative studies, qualitative studies, mixed studies, and literature reviews. Studies had to be full texts and published by October 2023 in English or Chinese. We excluded conference abstracts, case reports, commentaries, guidelines, consensuses, and study protocols. In addition, studies that

focused on the effectiveness of neonatal pain interventions and did not occur in NICUs were excluded as well.

After removing duplicates using NoteExpress software and closely adhering to the inclusion and exclusion criteria, three researchers (LF, MS, LX) with training in evidence-based nursing independently screened the literature. Another researcher (JJ) made decisions regarding studies that were in disagreement during the screening process.

**Stage 4: charting the data**

After reading the included literature several times, two researchers (LF and MS) extracted the data, cross-checked it, and then combined, summarized, and descriptively assessed its content. A visual table was used to display the final results. Authors, publication year, country, study design, study population, study topic, and factors influencing parental involvement (facilitators and barriers) were among the data extracted. Since the scoping review did not mandate it, we did not assess the quality of the included literature.

**Stage 5: collating, summarising and reporting the results**

To ensure the consistency and reliability of the results, two researchers (LF and MS) independently generalized and categorized the extracted factors using the socio-ecological model (SEM). The SEM emphasizes that individuals are influenced by their surroundings and that they interact with each other to form a complete ecosystem. The advantage of this model is that it allows existing research to focus not only on the individuals themselves but also on family, organizational, socio-cultural, and other factors that influence the individuals, making the research more systematic and comprehensive. In this study, two reviewers first categorized and coded the facilitators and barriers to parental involvement in neonatal pain management at each of the four levels of the SEM framework: intrapersonal, interpersonal, institutional, community and public policy. Next, we synthesized factors with similar themes at the same level and ultimately identified the name of each theme. All the team members reviewed and

discussed the categorization of each factor during this process. The collated data was presented visually in diagrams, and the findings were reported narratively.

**Patient and public involvement**

None

**RESULTS**

**Literature search results**

We began by retrieving a total of 28267 Chinese and English literature; after importing NoteExpress software to remove duplicates, 14,457 of these were still available, and 23 were left after reading the titles and abstracts of the literature. Of these, we concentrated on studies that examined the perceptions, attitudes, behaviors, experiences, current status, and influencing factors of parents and healthcare professionals during the process of managing neonatal pain. After reviewing the entire text again, 12 were eliminated, leaving 11 papers included in the end.[9],[10],[18],[19],[25]-[31] No additional literature was included after manually searching the references of the included literature. Figure 1 depicts the process of screening literature.

**Characteristics of included literature**

Ten of the eleven relevant studies, published between 2004 and 2023, were in English, and one was in Chinese. Ten studies were qualitative, including focus groups, open-ended questionnaire surveys, individual interviews, and focused ethnography; the Chinese study was a literature review. Parents of newborns in NICUs, neonatologists, nurses, and assistant nurses were among the study participants. Ten qualitative investigations were carried out, with the majority taking place in Europe (the United Kingdom, Finland, Switzerland, and Sweden), with the remaining ones conducted in Iran, Australia, and the United States. Table 3 displays the characteristics of the included literature.

**TABLE 3** Literature characteristics

| First author (year) | Country | Study design | Participants | Study topic | Facilitators | Barriers |
|---|---|---|---|---|---|---|
| Neshat (2023)[25] | Iran | Qualitative (individual interviews and focus group discussions) | Nurses (n=21) Neonatologists (n=2) Assistant nurse (n=1) | Care providers' experiences regarding barriers to maternal participation in neonatal pain management | NA | ▸ Maternal inadequate emotional readiness<br>▸ Maternal unfamiliarity with role<br>▸ Care providers' time pressure<br>▸ Fear of family-care provider tension<br>▸ Care providers' insufficient knowledge<br>▸ Neglected joint decision-making<br>▸ Restricted organizational participative policies |
| Palomaa (2016)[26] | Finland | Qualitative (open-ended questionnaires) | Parents (n=140) | Factors influencing parental participation in neonatal pain alleviation | ▸ Parental counseling by staff<br>▸ Parents' awareness of their own role<br>▸ Parents' motivation<br>▸ Family-friendly facilities<br>▸ Good communication | ▸ Restrictive environment<br>▸ Lack of knowledge<br>▸ Everyday life requirements<br>▸ Underestimation of parents<br>▸ The nature of medical procedures<br>▸ Procedure- and pain-related emotions<br>▸ Deteriorated health status of the child and mother<br>▸ Uncertainty of parenting |

Continued

**TABLE 3** Continued

| First author (year) | Country | Study design | Participants | Study topic | Facilitators | Barriers |
|---|---|---|---|---|---|---|
| Axelin (2010)[9] | Finland | Qualitative (semistructured interviews) | Mothers (n=23) | Mothers' different styles of involvement in preterm infant pain care | ▸ Nurses' support<br>▸ Strong maternal attachment<br>▸ Mothers' empathy and rationalization of their infants' pain | ▸ Mothers' stressful emotions regarding their infants' pain and the NICU environment |
| Axelin (2015)[27] | Finland/ Sweden/ USA | Qualitative (focus-group interviews) | Nurses (n=87) | Neonatal intensive care nurses' perceptions of parental participation in infant pain management | ▸ Welcome for parents<br>▸ Parent education<br>▸ Nurses' awareness of the importance of collaboration with the parents<br>▸ Nurses' empowerment of parents<br>▸ Respect for parenthood | ▸ Nurses' advocate for the infant<br>▸ Nurses' protection of parents from infant pain<br>▸ Passive or absent parent |
| Skene (2012)[10] | UK | Qualitative (focused ethnography) | Mothers (n=10) Fathers (n=8) | How parents interact with their infants and with nurses regarding the provision of comfort care in a Neonatal Intensive Care Unit | ▸ Parents' focus and observation of infants<br>▸ Written information provided by nurses<br>▸ Nurses' encouragement, support, and guide<br>▸ Increased parents' confidence<br>▸ Transfer of responsibility<br>▸ Parents' unique knowledge of their infants | NA |

Continued

**TABLE 3** Continued

| First author (year) | Country | Study design | Participants | Study topic | Facilitators | Barriers |
|---|---|---|---|---|---|---|
| Franck (2012)[28] | UK | Qualitative (visits and open-ended questionnaires) | Parents (n=169) | An empirical and conceptual update of parental involvement in neonatal pain management | ▸ Strong sense of attachment<br>▸ Values parental involvement in comforting<br>▸ Strong sense of parental role<br>▸ Staff provide instruction on how parent can comfort<br>▸ Parent able to be present during painful procedures | ▸ Parent emotional difficulties<br>▸ Not wanting to "be in the way"<br>▸ Parental lack of knowledge<br>▸ Complications of equipment or health status of the infant<br>▸ Staff passive attitudes and behaviors |
| Gale (2004)[18] | UK | Qualitative (focus groups and individual interviews) | Parents (n=12) | Parents' views of their experiences observing and coping with their infant's pain in the neonatal intensive care unit | ▸ Staff support<br>▸ Involvement in parenting in the NICU<br>▸ Information resources | ▸ Inability to protect infant<br>▸ Mismatch between parent and staff perceptions of infant pain<br>▸ Barriers to parental role attainment<br>▸ Impact of painful procedures<br>▸ Unpreparedness for infant pain |
| Jyoti (2023)[29] | Australia | Qualitative (open-ended questionnaires) | Parents (n=52) | Parents' perspectives on their baby's pain management and comfort postoperatively | ▸ Information resources<br>▸ Communication practices | ▸ Acute and fragile babies' condition<br>▸ Mothers' poor condition<br>▸ Lack of facilities available to parents<br>▸ COVID-19 restrictions |

Continued

**TABLE 3** Continued

| First author (year) | Country | Study design | Participants | Study topic | Facilitators | Barriers |
|---|---|---|---|---|---|---|
| Marfurt (2016)[19] | Switzerland | Qualitative (focus group interviews) | Nurses (n=17)<br>Neonatologists (n=6) | The experiences of professionals regarding involvement of parents in neonatal pain management | ▲ Professional know-how and sound communication skills<br>▲ Reflective and collaborative practice among professionals<br>▲ Parents' stable emotions<br>▲ Adequate organizational resources (time, staffing, or space) | ▲ Limited know-how and communication skills<br>▲ Nonreflective and noncollaborative pain care practices<br>▲ Professionals' control and paternalistic attitudes<br>▲ Limited organizational resources (time, space, and infrastructure)<br>▲ Organizational course of action |
| Hassankhani (2020)[30] | Iran | Qualitative (focused ethnography) | Nurses (n=15)<br>Mothers (n=18) | Nurses and mothers experiences of their role during painful procedures on neonates in neonatal intensive care unit | ▲ Maternal tolerance and presence during the painful procedures | ▲ Maternal anxiety or protest<br>▲ Lack of the tolerance for painful procedures<br>▲ Mother's trust in the nurse's skills |
| Zhou JX (2019)[31] | China | Literature review | NA | The methods, advantages needs and factors of parents participating in neonatal pain management | ▲ Affirmation from healthcare professionals<br>▲ Information support and emotional support provided by nurses | ▲ Lack of knowledge and time for pain management among nurses<br>▲ Underestimation of parental competence<br>▲ Lack of valid pain assessment<br>▲ Lack of knowledge about pain among parents<br>▲ Perceptual differences and information asymmetries between nurses and parents |

## Levels and themes

A total of 82 factors were analyzed from all included studies, and we categorized facilitators and barriers separately according to the SEM framework. 36 facilitators were grouped into three levels: intrapersonal level, interpersonal level, and institutional level. These facilitators covered ten themes in all, but they did not touch on the community and public policy levels of the framework. The theme of informational and emotional support at the interpersonal level was the most often mentioned facilitator. 46 barriers covered all domains found in the SEM framework. We categorized them into four levels and ten themes. The most frequently reported barriers included the theme of lack of knowledge and support at the intrapersonal level and the theme of restricted policies and resources at the institutional level. Facilitators and barriers were grouped into different themes and categorized at various levels within the context of the SEM, as shown in Figure 2.

## Facilitators

### Intrapersonal level

Twelve facilitators from seven studies were categorized at this level and synthesized into five themes: (1) strong sense of parental role, (2) parents' motivation, (3) parent-infant attachment, (4) learning to parent and (5) stable emotions. Parents' perceived importance of their role as caregivers of their infants and their perceived responsibility to protect their infants from harm promoted parental participation in pain relief.[26],[28] Parents expressed their desire to alleviate their infants' pain, and they hoped to be present to help their infants during the painful procedures. As their participation increased, so did the infants' positive response, which in turn increased the parents' motivation to participate.[18],[26] Two studies emphasized the significance of parent-infant attachment.[9],[28] The stronger the sense of attachment, the greater the opportunity for parental involvement,[28] and in turn, participation also increased attachment.[9] A focused ethnography conducted by Skene et al. described the process of parents moving from an initial fear of touching their infants to increased confidence in their ability to comfort their infants as they approached discharge. It was also a

process whereby parents gradually acquired comforting and parenting skills as well as engagement.[10] Two other studies suggested that parents' emotional stability was a contributing factor.[19],[30] If parents were calm and accepting of painful procedures, they were allowed to be present and participate more often by nurses.

**Interpersonal level**

Twenty facilitators from nine studies were categorized at this level and synthesized into three themes: (1) informational and emotional support, (2) good communication and (3) respect and empowerment. With eight studies referring to it, the theme of informational and emotional support was the most commonly reported of all the facilitators.[9],[10],[18],[26]-[29],[31] Parents often relied on nurses for support and guidance in their involvement in infant pain relief.[10] They found it helpful to receive pain-related information from healthcare professionals, such as the reasons, times, and methods for their involvement in pain management.[26]-[28] Parents referred to different ways of accessing verbal and written information, such as verbal guidance, counseling, advice, visualization, practical demonstrations, brochures, videos, and online.[26],[29] They also suggested that counseling and support be tailored to the individual's needs.[10],[26] In addition to informational support, emotional support was also relevant in promoting parental involvement. The nurses' welcome and invitation made the parents part of the infant's pain management,[27] and their encouragement and affirmation allowed the parents to become confident in comforting their infants.[10],[31] Another study conducted in the UK mentioned that the support of other parents with similar experiences on the internet helped relieve the stress related to their information needs about the management of infant pain.[18] Good communication between nurses and between nurses and parents promoted parental involvement in pain relief. Maintaining a flow and consistency of information between nurses helped understand babies' pain cues and parents' current condition, leading to better explanations and agreement with the parents regarding pain issues.[19],[26],[29] In addition, respecting and valuing parents and assigning responsibility to them made their participation more proactive.[10],[27]

### Institutional level

At the institutional level, four facilitators fell into two categories: (1) adequate organizational resources and (2) organizational environment and regulations. Organizational resources included facilities, time, staffing, and space. Parents indicated that family-friendly facilities, a pleasant care environment, and enough space promoted their involvement.[26] Another study suggested ample time was a prerequisite for parental involvement, and additional staff was considered an asset.[19] In a NICU in Switzerland, the reflective and collaborative practices established among the professionals created a supportive environment and ultimately led to greater parent involvement.[19] A survey conducted in four NICUs in the UK mentioned that if the hospital did not limit parental visits, then parents would be able to be present during painful procedures.[28]

## Barriers

### Intrapersonal level

Twenty-one barriers were identified across eight studies at this level, described as four themes: (1) parental emotional stress, (2) lack of knowledge and support, (3) poor condition of infants or mothers and (4) everyday life requirements. Many studies reported that parents' emotional problems created barriers to their participation and that these emotional stresses were associated with illness and painful procedures in infants.[9],[18],[25],[26],[28],[30] A study conducted in Finland also indicated that the NICU environment was stressful for the mothers.[9] Nurses had to keep them out of the NICU when parents were anxious and fearful. Lack of knowledge and support was identified as the most frequently reported barrier at this level, with five studies mentioning it.[18],[25],[26],[28],[31] Specifically, parents lacked knowledge about the reason, timing, content, and relief of pain procedures, and they did not know how to comfort their infants during pain procedures.[18],[25],[26],[28] Parents' uncertainty about their own caregiving abilities led to their reluctance to be involved in pain procedures and became a hindrance.[18],[26],[28] They wanted to seek support from healthcare professionals for pain information and skills.[18],[25] Another theme of

identified barriers was the poor condition of infants or mothers. For example, the acute and deteriorated health status of infants made pain procedures more numerous and complex, and they required more instrumental monitoring, which prevented parental involvement.[18],[26],[28],[29] On the other hand, the pain, contractions, and weakness of mothers after cesarean section limited their activities, making it a challenge to stay with their hospitalized infants.[26],[29] Moreover, one of the studies also showed that everyday life requirements formed another barrier.[26] Care for the baby's siblings, long distances between home and hospital, daily chores, and work reduced the opportunity for parents to participate in pain relief.

**Interpersonal level**

Barriers categorized at this level were grouped into three themes: (1) staff's authoritarianism and passivity, (2) communication and trust and (3) perception differences between parents and staff. Staff's underestimation of parental competence led to their control over infant pain management. They did not allow parents to be present because they considered that it protected both babies and parents.[19],[26],[27],[31]

Parents expressed that staff were dismissive and indifferent to them. Besides, staff did not take parents into account in pain relief as well.[26],[28] Three studies referred to issues of communication and trust.[19],[25],[30] Limited communication skills increased insecurity and unease about parental presence. Language barriers, too, impeded effective communication.[19] Lack of trust between staff and mothers raised their tensions, thus preventing mothers from observing the intervention.[25] Yet another study noted that mothers' trust in nurses' skills affected their inclusion during pain procedures.[30] Mismatch in perceptions of infant pain and information asymmetries between parents and staff were identified as another category of barrier factors.[18],[31]

**Institutional level**

Twelve barriers at the institutional level included two themes: (1) restricted policies and resources and (2) lack of training and time. Several studies emphasized the

importance of organizational policies and resources in parental involvement. [19],[25],[26],[29] For instance, one study conducted in Switzerland revealed that nonreflective and noncollaborative pain care practices, limited organizational resources, and the organizational course of action in the NICUs were mentioned as factors hindering parent involvement.[19] The mother's desire to participate in pain relief was ignored because it was not included in the hospital's strategic plan. The hospital did not even have specific organizational guidelines or additional parking.[25],[29] The restrictive environment of the NICU, such as limited space, complex equipment, insufficient facilities, limited visiting hours, inappropriate procedure timing, and professionally demanding procedures, greatly limited parental participation.[26],[29] Furthermore, the lack of organizational human resources resulted in a high workload for the nurses, and time pressures made them reluctant to involve mothers. Nurses also expressed that the lack of training opportunities led to insufficient knowledge about the importance of parental involvement in pain management as well as neonatal pain, thus making the implementation of pain management challenging.[25],[31]

**Community and public policy levels**

Data from a study conducted in Australia were collected from June through November 2020, and as such, parental access to the NICU has been limited by restrictions related to the COVID-19 pandemic.[29]

**DISCUSSION**

Nowadays, parental involvement in neonatal pain management practice is still an emerging field in many countries, even though it has been considered to be beneficial for multiple stakeholders.[27] This field faces many difficulties and challenges; therefore, policymakers, hospital administrators, and healthcare professionals need evidence to help make decisions in the implementation process. This scoping review identified facilitators and barriers to parental involvement in the management of neonatal pain in the NICU at multiple levels within the context of the SEM. The interactions that may occur between the various levels need to be taken into account when developing implementation strategies. For example, parents' emotions at the

intrapersonal level could influence healthcare professionals' attitudes and support for them. In turn, the relationships and interactions between healthcare workers and parents at the interpersonal level could affect parents' emotions, behaviors, and knowledge levels. Similarly, restrictive environments and policies at the institutional level might have an impact on parents at both the intrapersonal and interpersonal levels. For instance, a lack of staff training left both staff and parents with a lack of pain knowledge, leading to tensions and poor communication between them, as well as parents' negative attitudes. This is precisely why we chose the SEM as the theoretical framework to summarize the factors that influence parental involvement. This framework provided us with a new way of thinking and perspective. In this way, strategies for improvement based on influencing factors at one level may have a positive impact on other levels, which can inform our improvement measures and thus facilitate the implementation of pain management clinical practice.

Our findings showed significant differences in the number of facilitators and barriers at various levels. One and the same factor might be a facilitator in one situation and a barrier in another. Intrapersonal factors such as parental role, parents' motivation, parental emotional stress, and parents' knowledge had a significant impact on parental involvement behavior, which was consistent with previous metasynthesis results.[32] However, our review suggested additional intrapersonal factors, including mother-infant attachment, condition of infants or mothers, and everyday life requirements. Regarding taking an active role in pain management, parents' opinions were consistent. They were eager to help with their infant's pain relief and conveyed concerns about their pain and therapy.[11],[26],[33]-[35] Self-determination theory suggests that an individual's motivation and willingness may be associated with three basic psychological needs: autonomy, competence, and relatedness.[36] This concept can be spanned across interpersonal and institutional domains. Parents' motivation and willingness to participate in pain management may become stronger if they have a sense of control over the NICU environment and are cared for by the staff. A strong sense of parental role was identified as a factor contributing to participation.[28] Evidence

suggests that mother-infant attachment is linked to the creation of parental roles and that nurse support can enhance mother-infant connection.[9],[37],[38] Parental emotions and knowledge were the most frequently reported intrapersonal factors in the current scoping review, with support from healthcare professionals playing an equally crucial role. It again exemplifies the influence of interpersonal relationships on individual factors within the framework. Instead of excluding parents from the NICU, healthcare professionals can calm them by building trust with them through good communication and explanations as well as positive encouragement and invitations. In addition, healthcare professionals should provide parents with pain-related information to give them the knowledge and skills that will help them establish their role as caregivers, strengthen their confidence, and promote participation. Poor condition of infants or mothers and everyday life requirements were barriers to parental involvement. It was in line with the findings of two systematic reviews.[39],[40] Encouraging other family members to assist with some of the family responsibilities can help reduce the stress in the lives of mothers, while other improvements need further study.

In our scoping review, interpersonal factors primarily refer to interpersonal relationships and interactions between parents and healthcare professionals, with only one study mentioning peer support on the Internet.[18] Informational and emotional support from staff has already been mentioned in the previous discussion, as it plays the most prominent role in facilitating parental involvement in pain management and spans almost all domains of the SEM. Specifically, in terms of the information content, first, staff should emphasize to parents the importance of participating in pain management and increase the awareness of their roles and responsibilities as caregivers; then, staff need to inform parents about the pain procedures that their infants may have to go through, the timing of the procedures, and the parent's tasks during the process; and lastly, how to participate and cooperate is of paramount importance, and the pain relief employed by the specific methods are to be provided. In terms of the information form, in addition to verbal instructions and written pamphlets, live demonstrations, visualization, the parents' personal needs, and the infant's characteristics are all worth

considering. Nowadays, parents' access to health information from the Internet and smartphones is becoming an increasingly popular means and gaining more parental preference.[41] Hence, it is recommended that professionals, organizations, communities, and governments progressively enhance their attention, development, and utilization of social media. There may be value in developing a learning toolkit that contains information in a variety of formats. Furthermore, parents with similar caregiving experiences in the NICU are another valuable resource, and peer-to-peer support from them could be considered an effective psychoeducational intervention.[42] However, there are few studies related to parental involvement in education and training for pain management, either in the construction of instructional programs or the evaluation of training effectiveness, which could be an area for future research. Parental involvement in the pain relief process is also a continuous learning process of parenting, which is not without the emotional encouragement and affirmation of the clinical staff. The positive feedback from the staff and the infant will promote continued parental involvement. Staff's authoritarianism and passivity was a major barrier, consistent with the findings of another study.[32] This partially overlaps with the institutional domain of the model. The organizational policies and regulations influence, to some extent, the decision-making of the professionals who are the gatekeepers of the NICU. Professionals should value collaboration with parents and consider and respect their feelings when conducting any procedure, trusting their unique knowledge of their infant rather than questioning the parent's competence.[10] Trust is built on good communication. Nurse-to-nurse, nurse-to-physician, and nurse-to-parent communication all have an impact on parental involvement.[19],[25],[26],[29] Organizations can promote good communication through training, staffing, and the physical health care environment.[43] Perception differences between parents and staff are an additional barrier identified in this scoping review that can be addressed by good communication. Studies showed that parents in the NICU had specific expertise about their own infants' pain and comfort needs, and nurses could gain new information directly from them.[10] Nurses need to be aware of the parents' unique strengths in this

area, encourage their participation, and gradually work through the transfer of responsibility and authority in the process. The comforting experience and confidence of the empowered parent increase, which in turn promotes participation.

Organizational resources and regulations played a key role in affecting parental involvement at the institutional level, which echoed multiple studies on kangaroo care and breastfeeding.[39],[40],[44] Parents generally expressed dissatisfaction with the limited space, inadequate facilities, and restrictive policies of the NICUs. To our knowledge, many healthcare organizations employed various strategies, policies, and resources when it came to providing healthcare; some even did not incorporate parental engagement into their strategic plans at all.[25],[29] The development of specific and realistic guidelines and policies is a pressing issue for the organization. For example, consulting with parents about each other's roles and responsibilities to enhance shared decision-making, securing unlimited visitation hours to ensure that parents can be present at any time, and setting up friendly facilities such as private family rooms, screens, lockers, and collapsible recliners to increase parents' convenience and comfort. This may cross the model's community and public policy domains and may require stronger public policy support and funding from social organizations such as charities. Moreover, the timing of some routine pain procedures and doctor rounds may be reasonably adjusted to the needs of the parents, as parents may provide more detailed information about their babies directly to healthcare professionals.[10] Of course, joint consultation and agreement among multiple parties are necessary. Interprofessional collaboration has been cited as an enabling factor in facilitating pain management practice;[19],[45] however, such collaborative practice is often lacking within organizations. Evidence suggests that power imbalances in clinical practice hinder interprofessional joint decision-making.[46] Interprofessional communication channels, interprofessional educational programs, and evidence-based strategies can reduce power imbalances, improve interdisciplinary communication,[47]-[49] and create supportive organizational cultures and climates to promote parental involvement. Additionally, nurses cited workload and time pressures as leading them to prioritize

infant survival over pain management, a finding supported by other studies.[48],[50] These studies similarly identified high workload as a barrier to optimal management of patient pain, in part due to the shortage of nurses in the institution. The nursing shortage is a globalized issue that can be addressed through the development of a country-specific data-informed model of supply and demand routes, evidence-based policies and resource allocation, improved working and employment conditions, and the implementation of wage management mechanisms.[51],[52] Finally, the lack of organizational training programs in neonatal pain management leads to a lack of knowledge among healthcare professionals about neonatal pain and a similar lack of appreciation of the benefits of parental involvement in pain relief. There are continuing education programs, such as training forums and seminars,[48] where healthcare professionals can enhance their learning of standard procedures and guidelines while bridging the gap between knowledge and practice in the clinical setting. However, specific training programs, including content and format, require further research.

Based on the included studies, our review only found relevant restrictions imposed by the COVID-19 pandemic at the community and public policy levels of the model. It indicates even more that comparable public health events could serve as obstacles to parental access to the NICU. In the context of the SEM framework, specific policies of the United Nations, the World Health Organization, and individual countries affect the behaviors of various populations at the institutional, interpersonal, and intrapersonal levels, yet parents may not be able to change this fact. Several other studies of family involvement in neonatal care reported financial issues such as transportation subsidies, food, lodging, and hospitalization costs; socio-cultural norms such as local customs and beliefs, preterm stigma, stigmatization of male involvement in child care, and the Chinese cultural tradition of'sitting the month'; and public policies such as maternal-infant separation policy, paid leave, and paternity leave.[39],[40],[44],[53],[54] Although our review did not reach similar conclusions, it has to be recognized that these factors are real and equally likely to have an impact on parental involvement in pain management. As such, more extensive research is needed to reveal additional

influencing factors in the future.

**Strengths and limitations**

This scoping review identified specific facilitators and barriers to parental involvement in NICU pain management within the context of the SEM. This theoretical framework gives us a more valuable and comprehensive perspective that enables us to consider not only the parental intrapersonal factors but also the external environmental factors and their interactions, providing more insightful information for future studies, clinical implementations, and interventions. We searched a total of nine databases in both English and Chinese, and the screening process was conducted independently by three reviewers. The extraction of facilitators and barriers might be somewhat subjective, but a double cross-check was performed, and all results were decided through discussion in the research team to minimize bias. Although we included as many study designs as possible, it had to be acknowledged that there was a lack of overall evidence, especially for quantitative studies. It may have led us to miss some influencing factors in various domains of the model. This is a direction for future research and may require the development of relevant scales or other tools to collect reliable data. Another limitation is that we did not perform a methodological quality assessment of the included studies, as the focus of our study was to map the available literature on the topic. Finally, the exclusion of gray literature may have resulted in the omission of some studies.

## CONCLUSION

Neonatal pain prevention is an ethical requirement, as well as a medical mandate, and parental access to the NICU to participate in neonatal care is a challenging innovation. Successful innovation requires an in-depth understanding of the factors influencing implementation. This review identified gaps in the evidence, synthesized existing facilitators and barriers, and emphasized the impact of intrapersonal and interpersonal factors, particularly informational and emotional support, on parental engagement behaviors. Institutional policies and resources were likewise critical and deserved the attention of the health system. Limited evidence was found at the

community and public policy levels, but we suggested some potential areas for future research. A broad program of nationally or regionally coordinated management mode is key, requiring clear regulatory approaches and targeted guidelines. The interconnectedness and complexity of facilitators and barriers across the SEM highlight that multifaceted interventions show promise in promoting parental engagement behaviors and pain management practices. More research exploring multiple factors in the socio-ecological domains will help to better understand their impact on parental involvement behaviors, promote more effective interventions and implementation, and facilitate innovations in management mode.

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**Legend**

**Figure 1** Flowchart of the literature search and study selection process.

**Figure 2** Facilitators and barriers to parental involvement in neonatal pain management in the NICU within the levels of the socio-ecological model.

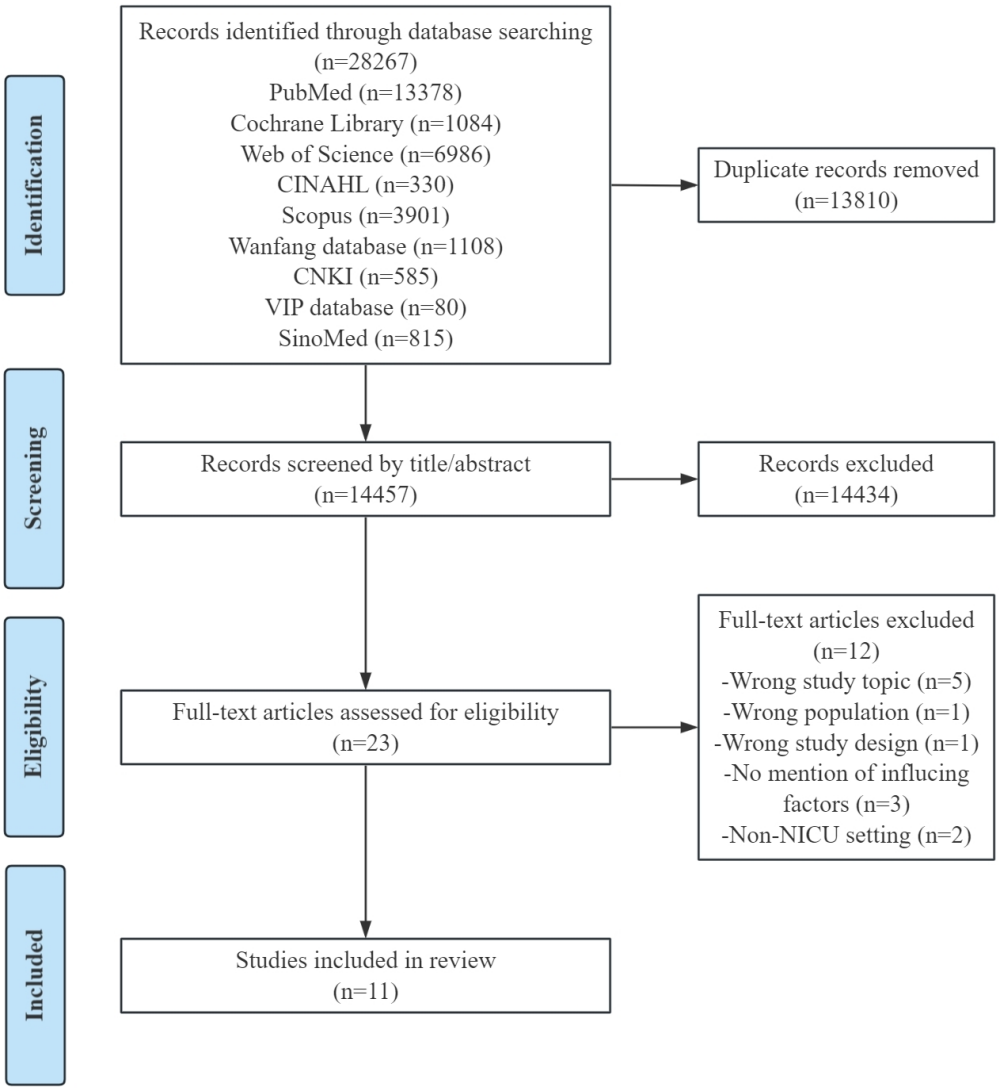


Figure 1 Flowchart of the literature search and study selection process.

445x484mm (72 x 72 DPI)

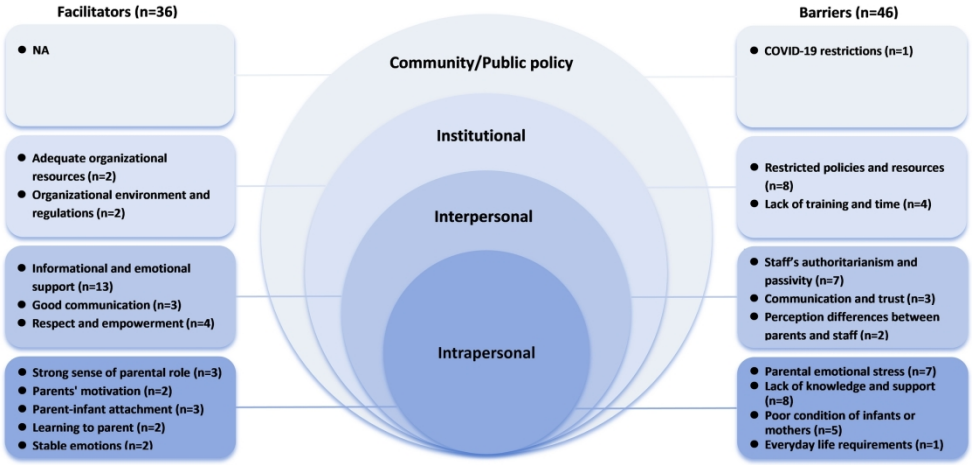


Figure 2 Facilitators and barriers to parental involvement in neonatal pain management in the NICU within the levels of the socio-ecological model.

224x108mm (300 x 300 DPI)

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# Facilitators and barriers to parental involvement in neonatal pain management in the NICU: a scoping review



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# Facilitators and barriers to parental involvement in neonatal pain management in the NICU: a scoping review


## ABSTRACT

**Objectives** Neonatal pain prevention is not only a humanistic but also an ethical imperative. Fitting with the principles of family-centered care, parental involvement in neonatal pain management plays an active role in infant development and parental well-being. However, the process of parental involvement faces constant challenges. To help structure and implement a family engagement program in neonatal pain management in the NICU, we conducted a scoping review to identify facilitators and barriers to parental involvement in neonatal pain management.

**Methods** We conducted the scoping review using the Arksey and O'Malley framework. PubMed, Cochrane Library, Web of science, CINAHL, Scopus, Wanfang database (Chinese), CNKI (Chinese), VIP database(Chinese), and SinoMed (Chinese) were searched systematically for relevant studies published in English and Chinese from inception up to October 2023. We categorized the facilitators and barriers based on the socio-ecological model and analyzed the results thematically in each category.

**Results** Ten English qualitative studies were included in the final analysis. The 34 facilitators and 41 barriers extracted were grouped into four domains of the socio-ecological model framework. Of the ten facilitator themes, the most critical theme was informational and emotional support. Of the ten barrier themes, the most frequently reported theme was restricted policies and resources.

**Conclusions** Our review highlights the essential roles of intrapersonal and interpersonal factors in parental involvement in pain management while suggesting the interconnectedness of factors in various domains within the context of the socio-ecological model. It implies that most interventions require development and administration at both intra- and interpersonal levels. Regarding the macro level, a broad program with clear regulatory approaches and targeted guidelines could be developed in the future to drive innovations in NICU pain management mode.


**Keywords** family, neonatal intensive & critical care, nursing care, pain management,

review

**Strengths and limitations of this study**

- This is the first scoping review to comprehensively identify and summarize facilitators and barriers to parental involvement in neonatal pain management in the NICU.
- Our findings went through three reviewers screening the literature, two reviewers extracting and cross-checking the data, and the entire research team discussing to minimize bias.
- We used the socio-ecological model as a theoretical framework to categorize and analyze the results.
- In addition to excluding gray literature, we did not assess the quality of the included studies.

## INTRODUCTION

Globally, nearly 30 million babies need to be hospitalized each year for reasons such as being born too early, being underweight, or suffering from illnesses.[1] It means that babies will unavoidably be subjected to a great deal of painful stimuli associated with their care and treatment. According to a systematic review, each newborn in the NICU undergoes 7.5–17.3 painful maneuvers on average each day.[2] Painful stimuli can cause a variety of neurophysiological reactions and behavioral changes in infants.[3] In the short term, it may lead to wound dehiscence, apnea, and feeding difficulties. Long-term effects may even impact the neurodevelopment, behavioral patterns, and future responses of the infant to pain in childhood and adulthood.[4]

Neonatal pain management has gradually gained widespread international focus and attention in recent years, with non-pharmacologic pain management now serving as the primary focus of care. Non-pharmacologic interventions such as breastfeeding and kangaroo care have made parents a strong potential supportive force in neonatal pain management. Evidence indicates that parent participation in managing their infants' suffering not only helps to relieve pain[5]-[8] but also lessens parental stress[9] and promotes attachment between parents and infants,[10] as well as parental role

attainment.[11] This management mode aligns with the patient- and family-centered care paradigm advocated by international organizations and will play a crucial role in improving the well-being of infants and families, enhancing the ability of families to provide care, and successfully integrating preterm infants into their family units.[12] It could, in part, advance high-quality healthcare.[13] However, parental engagement in pain management is a complex, multidetermined, and interactive process. Parents' individual characteristics interact with environmental features to influence individual behaviors.[14] Consequently, a range of individual, interpersonal, organizational, and societal issues may have an impact on parental involvement in this behavior, leading to a low level of actual involvement and a challenging implementation process.[15] Numerous barriers and limitations will negatively impact families, increasing their anxiety and desire for information, as well as their insecurity and distrust of the care provided by healthcare professionals.[16] Previous studies have focused on the effectiveness of pain management by parents,[5],[17]-[19] as well as the attitudes, perceptions, and experiences of parents and medical professionals in this area.[20]-[22] Several studies have explored the influencing factors, but these have focused on different aspects and perspectives and have reached divergent conclusions.

To better develop the practice of parental involvement in pain management in the NICU, it is essential to understand the knowledge related to the practice process. To the best of our knowledge, no previous review has systematically sorted out the facilitators and barriers influencing parental involvement in neonatal pain management at the individual, organizational, and societal levels. Clarifying the influencing factors of parental involvement in neonatal pain management will help the development of relevant strategies and programs in healthcare organizations to provide targeted policy and environmental support at different levels, which may bring benefits and convenience to infants, parents, and healthcare professionals. Therefore, a scoping review was conducted using the socio-ecological model (SEM) as a theoretical framework,[23] aiming to provide a comprehensive overview of facilitators and barriers to implementation and to identify knowledge gaps in the literature to inform clinical

practice.

## METHODS

Scoping reviews are used to describe the scope of knowledge and core concepts in a particular field of study. They have extremely broadly defined research questions. Therefore, a scoping review was chosen reasonably to explore what is known about the facilitators and barriers to parental involvement in neonatal pain management in the NICU. We followed the methodological framework developed by Arksey and O'Malley[24] for the scoping review and reported according to the PRISMA-ScR checklist.[25] The methodological framework consists of five stages: (1) identifying the research questions, (2) identifying relevant studies, (3) study selection, (4) charting the data and (5) collating, summarising and reporting the results. The review protocol was registered on the Open Science Framework (https://doi.org/10.17605/OSF.IO/95NBY).

### Stage 1: identifying the research questions

The following are the specific research questions that this review poses:

1. What are the factors that impact the level of parental involvement in the NICU when it comes to managing the pain of newborns?
2. What factors serve as facilitators for parental engagement in the management of neonatal pain in the NICU? What factors serve as obstacles?

### Stage 2: identifying relevant studies

A five-person research team was first assembled, and two of them (LF and MS) searched PubMed and CNKI in advance to find pertinent MeSH terms, keywords, and synonyms. Following group deliberation, the ultimate search strategy was honed and a thorough, systematic search of the PubMed, Cochrane Library, Web of Science, CINAHL, Scopus, Wanfangdatabase (Chinese), CNKI (Chinese), VIPdatabase (Chinese), and SinoMed (Chinese) was conducted. We searched the databases using the main concepts such as parental involvement, newborn, and pain for articles published from inception to October 2023. The specific search terms are shown in Table 1, and the complete PubMed search strategy is presented in Table 2. Table S1 shows the

precise and full search strategies for all English and Chinese databases. Lastly, a manual retrieval of the included literature references was conducted by two independent reviewers (LF and MS).

**TABLE 1** Concept groups and search terms

| Concept groups | Search terms |
|---|---|
| Parental involvement | Parent*/parents/family/parental involvement/parental participation/family involvement/family participation/family integrated care/family centered care/family centred care |
| Newborn | Newborn*/neonat*/preterm*/prematur*/infant*/neonatal intensive care unit/NICU |
| Pain | Pain*/pain management/heel/needles/needle puncture/injection/vaccines/breastfeeding/kangaroo care/skin to skin |

**TABLE 2** PubMed search strategy

| Search | Query |
|---|---|
| #1 | (((((((((parents[MeSH Terms]) OR (family[MeSH Terms])) OR (parent*[Title/Abstract])) OR (parental involvement[Title/Abstract])) OR (parental participation[Title/Abstract])) OR (family involvement[Title/Abstract])) OR (family participation[Title/Abstract])) OR (family integrated care[Title/Abstract])) OR (family centered care[Title/Abstract])) OR (family centred care[Title/Abstract]) |
| #2 | ((((((infant[MeSH Terms]) OR (newborn*[Title/Abstract])) OR (neonat*[Title/Abstract])) OR (preterm*[Title/Abstract])) OR (prematur*[Title/Abstract])) OR (neonatal intensive care unit[Title/Abstract])) OR (NICU[Title/Abstract]) |
| #3 | (((((((((pain[MeSH Terms]) OR (pain management[MeSH Terms])) OR (heel[MeSH Terms])) OR (needles[MeSH Terms])) OR (needle puncture[Title/Abstract])) OR (injection[Title/Abstract])) OR (vaccines[MeSH Terms])) OR (breastfeeding[Title/Abstract])) OR (kangaroo care[Title/Abstract])) OR (skin to skin[Title/Abstract]) |
| #4 | #1 AND #2 AND #3 |

**Stage 3: study selection**

Based on the particular research questions, the PCC (Population, Concept, and Context)[26] framework was used to determine the inclusion criteria: (1) Population: Parents of newborns and NICU healthcare workers; (2) Concept: all studies on factors influencing parental involvement in neonatal pain management in the NICU, including perceptions, attitudes, behaviors, experiences, and current status, etc. of parents and healthcare professionals who mention influencing factors; (3) Context: pain management in the NICU. We included quantitative studies, qualitative studies, and

mixed studies. Studies had to be full texts and published by October 2023 in English or Chinese. We excluded conference abstracts, case reports, commentaries, guidelines, consensuses, study protocols, and literature reviews. In addition, studies that focused on the effectiveness of neonatal pain interventions and did not occur in NICUs were excluded as well.

After removing duplicates using NoteExpress software and closely adhering to the inclusion and exclusion criteria, three researchers (LF, MS, LX) with training in evidence-based nursing independently screened the literature. Another researcher (JJ) made decisions regarding studies that were in disagreement during the screening process.

**Stage 4: charting the data**

After reading the included literature several times, two researchers (LF and MS) extracted the data, cross-checked it, and then combined, summarized, and descriptively assessed its content. A visual table was used to display the final results. Authors, publication year, country, study design, study population, study topic, and factors influencing parental involvement (facilitators and barriers) were among the data extracted. Since the scoping review did not mandate it, we did not assess the quality of the included literature.

**Stage 5: collating, summarising and reporting the results**

To ensure the consistency and reliability of the results, two researchers (LF and MS) independently summarized and categorized the extracted factors using the socio-ecological model (SEM). The SEM emphasizes that individuals are influenced by their surroundings and that they interact with each other to form a complete ecosystem. The advantage of this model is that it allows existing research to focus not only on the individuals themselves but also on family, organizational, socio-cultural, and other factors that influence the individuals, making the research more systematic and comprehensive. In this study, two reviewers first categorized and coded the facilitators and barriers to parental involvement in neonatal pain management at each of the four levels of the SEM framework: intrapersonal, interpersonal, institutional, community

and public policy. Next, we synthesized factors with similar themes at the same level and ultimately identified the name of each theme. All the team members reviewed and discussed the categorization of each factor during this process. The collated data was presented visually in diagrams, and the findings were reported narratively.

**Patient and public involvement**

None.

## RESULTS

### Literature search results

We began by retrieving a total of 28267 Chinese and English literature; after importing NoteExpress software to remove duplicates, 14457 of these were still available, and 22 were left after reading the titles and abstracts of the literature. Of these, we focused on studies that refer to the perceptions, attitudes, behaviors, experiences, and current status of parents and healthcare professionals that mention influencing factors. After reviewing the entire text again, 12 were eliminated, leaving 10 papers included in the end.[9],[10],[20],[21],[27]-[32] No additional literature was included after manually searching the references of the included literature. Figure 1 depicts the process of screening literature.

### Characteristics of included literature

A total of 10 relevant studies were included, published between 2004 and 2023, all in English. All ten studies were qualitative, including focus groups, open-ended questionnaire surveys, individual interviews, and focused ethnography. Parents of newborns in NICUs, neonatologists, nurses, and assistant nurses were among the study participants. Most of the included studies were conducted in Europe (the United Kingdom, Finland, Switzerland, and Sweden), while the rest were conducted in Iran, Australia, and the United States. Table 3 displays the characteristics of the included literature.

**TABLE 3** Literature characteristics

| First author (year) | Country | Study design | Participants | Study topic | Facilitators | Barriers |
|---|---|---|---|---|---|---|
| Neshat (2023)[27] | Iran | Qualitative (individual interviews and focus group discussions) | Nurses (n=21) Neonatologists (n=2) Assistant nurse (n=1) | Care providers' experiences regarding barriers to maternal participation in neonatal pain management | NA | ▸ Maternal inadequate emotional readiness<br>▸ Maternal unfamiliarity with role<br>▸ Care providers' time pressure<br>▸ Fear of family-care provider tension<br>▸ Care providers' insufficient knowledge<br>▸ Neglected joint decision-making<br>▸ Restricted organizational participative policies |
| Palomaa (2016)[28] | Finland | Qualitative (open-ended questionnaires) | Parents (n=140) | Factors influencing parental participation in neonatal pain alleviation | ▸ Parental counseling by staff<br>▸ Parents' awareness of their own<br>▸ Parents' motivation<br>▸ Family-friendly facilities<br>▸ Good communication | ▸ Restrictive environment<br>▸ Lack of knowledge<br>▸ Everyday life requirements<br>▸ Underestimation of parents<br>▸ The nature of medical procedures<br>▸ Procedure- and pain-related emotions<br>▸ Deteriorated health status of the child and mother<br>▸ Uncertainty of parenting |
| Axelin (2010)[9] | Finland | Qualitative (semistructured interviews) | Mothers (n=23) | Mothers' different styles of involvement in preterm infant pain care | ▸ Nurses' support<br>▸ Strong maternal attachment<br>▸ Mothers' empathy and rationalisation of their infants' pain | ▸ Mothers' stressful emotions regarding their infants' pain and the NICU environment |
| Axelin (2015)[29] | Finland/ Sweden/ USA | Qualitative (focus-group interviews) | Nurses (n=87) | Neonatal intensive care nurses' perceptions of parental participation in infant pain management | ▸ Welcome for parents<br>▸ Parent education<br>▸ Nurses' awareness of the importance of collaboration with the parents<br>▸ Nurses' empowerment of parents<br>▸ Respect for parenthood | ▸ Nurses' advocate for the infant<br>▸ Nurses' protection of parents from infant pain<br>▸ Passive or absent parent |
| Skene (2012)[10] | UK | Qualitative (focused ethnography) | Mothers (n=10) Fathers (n=8) | How parents interact with their infants and with nurses regarding the provision of comfort care in a Neonatal Intensive Care Unit | ▸ Parents' focus and observations of infants<br>▸ Written information provided by nurses<br>▸ Nurses' encouragement, support, and guide<br>▸ Increased parents' confidence | NA |

| | | | | | | |
|---|---|---|---|---|---|---|
| | | | | | ▸ Transfer of responsibility<br>▸ Parents' unique knowledge of their infants | |

**TABLE 3** Continue

| First author (year) | Country | Study design | Participants | Study topic | Facilitators | Barriers |
|---|---|---|---|---|---|---|
| Franck (2012)[30] | UK | Qualitative (visits and open-ended questionnaires) | Parents (n=169) | An empirical and conceptual update of parental involvement in neonatal pain management | ▸ Strong sense of attachment<br>▸ Values parental involvement in comforting<br>▸ Strong sense of parental role<br>▸ Staff provide instruction on how parent can comfort<br>▸ Parent able to be present during painful procedures | ▸ Parent emotional difficulties<br>▸ Not wanting to "be in the way"<br>▸ Parental lack of knowledge<br>▸ Complications of equipment or health status of the infant<br>▸ Staff passive attitudes and behaviors |
| Gale (2004)[20] | UK | Qualitative (focus groups and individual interviews) | Parents (n=12) | Parents' views of their experiences observing and coping with their infant's pain in the neonatal intensive care unit | ▸ Staff support<br>▸ Involvement in parenting in the NICU<br>▸ Information resources | ▸ Inability to protect infant<br>▸ Mismatch between parent and staff perceptions of infant pain<br>▸ Barriers to parental role attainment<br>▸ Impact of painful procedures<br>▸ Unpreparedness for infant pain |
| Jyoti (2023)[31] | Australia | Qualitative (open-ended questionnaires) | Parents (n=52) | Parents' perspectives on their baby's pain management and comfort postoperatively | ▸ Information resources<br>▸ Communication practices | ▸ Acute and fragile babies' condition<br>▸ Mothers' poor condition<br>▸ Lack of facilities available to parents<br>▸ COVID-19 restrictions |
| Marfurt-Russenberger (2016)[21] | Switzerland | Qualitative (focus group interviews) | Nurses (n=17)<br>Neonatologists (n=6) | The experiences of professionals regarding involvement of parents in neonatal pain management | ▸ Professional know-how and sound communication skills<br>▸ Reflective and collaborative practice among professionals<br>▸ Parents' stable emotions<br>▸ Adequate organizational resources (time, staffing, or space) | ▸ Limited know-how and communication skills<br>▸ Nonreflective and noncollaborative pain care practices<br>▸ Professionals' control and paternalistic attitudes<br>▸ Limited organizational resources (time, space, and infrastructure)<br>▸ Organizational course of action |
| Hassankhani (2020)[32] | Iran | Qualitative (focused ethnography) | Nurses (n=15)<br>Mothers (n=18) | Nurses and mothers experiences of their role during painful procedures on neonates in neonatal intensive care unit | ▸ Maternal tolerance and presence during the painful procedures | ▸ Maternal anxiety or protest<br>▸ Lack of the tolerance for painful procedures<br>▸ Mother's trust in the nurse's skills |

## Levels and themes

A total of 75 factors were analyzed from all included studies, and we categorized facilitators and barriers separately according to the SEM framework. 34 facilitators were grouped into three levels: intrapersonal level, interpersonal level, and institutional level. These facilitators covered ten themes in all, but they did not touch on the community and public policy levels of the framework. The theme of informational and emotional support at the interpersonal level was the most often mentioned facilitator. 41 barriers covered all domains found in the SEM framework. We categorized them into four levels and ten themes. The most frequently reported barrier was the theme of restricted policies and resources at the institutional level. Facilitators and barriers were grouped into different themes and categorized at various levels within the context of the SEM, as shown in Figure 2.

## Facilitators

### Intrapersonal level

Twelve facilitators from seven studies were categorized at this level and synthesized into five themes: (1) strong sense of parental role, (2) parents' motivation, (3) parent-infant attachment, (4) learning to parent and (5) stable emotions. Parents' perceived importance of their role as caregivers of their infants and their perceived responsibility to protect their infants from harm promoted parental participation in pain relief.[28],[30] Parents expressed their desire to alleviate their infants' pain, and they hoped to be present to help their infants during the painful procedures. As their participation increased, so did the infants' positive response, which in turn increased the parents' motivation to participate.[20],[28] Two studies emphasized the significance of parent-infant attachment.[9],[30] The stronger the sense of attachment, the greater the opportunity for parental involvement,[30] and in turn, participation also increased attachment.[9] A focused ethnography conducted by Skene et al. described the process of parents moving from an initial fear of touching their infants to increased confidence in their ability to comfort their infants as they approached discharge. It was also a process whereby parents gradually acquired comforting and parenting skills as

well as engagement.[10] Two other studies suggested that parents' emotional stability was a contributing factor.[21],[32] If parents were calm and accepting of painful procedures, they were allowed to be present and participate more often by nurses.

**Interpersonal level**

Eighteen facilitators from eight studies were categorized at this level and synthesized into three themes: (1) informational and emotional support, (2) good communication and (3) respect and empowerment. With seven studies referring to it, the theme of informational and emotional support was the most commonly reported of all the facilitators.[9],[10],[20],[28]-[31] Parents often relied on nurses for support and guidance in their involvement in infant pain relief.[10] They found it helpful to receive pain-related information from healthcare professionals, such as the reasons, times, and methods for their involvement in pain management.[28]-[30] Parents referred to different ways of accessing verbal and written information, such as verbal guidance, counseling, advice, visualization, practical demonstrations, brochures, videos, and online.[28],[31] They also suggested that counseling and support be tailored to the individual's needs.[10],[28] In addition to informational support, emotional support was also relevant in promoting parental involvement. The nurses' welcome and invitation made the parents part of the infant's pain management,[29] and their encouragement and affirmation allowed the parents to become confident in comforting their infants.[10] Another study conducted in the UK mentioned that the support of other parents with similar experiences on the internet helped relieve the stress related to their information needs about the management of infant pain.[20] Good communication between nurses and between nurses and parents promoted parental involvement in pain relief. Maintaining a flow and consistency of information between nurses helped understand babies' pain cues and parents' current condition, leading to better explanations and agreement with the parents regarding pain issues.[21],[28],[31] In addition, respecting and valuing parents and assigning responsibility to them made their participation more proactive.[10],[29]

**Institutional level**

At the institutional level, four facilitators fell into two categories: (1) adequate organizational resources and (2) organizational environment and regulations. Organizational resources included facilities, time, staffing, and space. Parents indicated that family-friendly facilities, a pleasant care environment, and enough space promoted their involvement.[28] Another study suggested ample time was a prerequisite for parental involvement, and additional staff was considered an asset.[21] In a NICU in Switzerland, the reflective and collaborative practices established among the professionals created a supportive environment and ultimately led to greater parent involvement.[21] A survey conducted in four NICUs in the UK mentioned that if the hospital did not limit parental visits, then parents would be able to be present during painful procedures.[30]

**Barriers**

**Intrapersonal level**

Twenty barriers were identified across seven studies at this level, described as four themes: (1) parental emotional stress, (2) lack of knowledge and support, (3) poor condition of infants or mothers and (4) everyday life requirements. Many studies reported that parents' emotional problems created barriers to their participation and that these emotional stresses were associated with illness and painful procedures in infants.[9],[20],[27],[28],[30],[32] A study conducted in Finland also indicated that the NICU environment was stressful for the mothers.[9] Nurses had to keep them out of the NICU when parents were anxious and fearful. Lack of knowledge and support was a frequently reported barrier at this level, with four studies mentioning it.[20],[27],[28],[30] Specifically, parents lacked knowledge about the reason, timing, content, and relief of pain procedures, and they did not know how to comfort their infants during pain procedures.[20],[27],[28],[30] Parents' uncertainty about their own caregiving abilities led to their reluctance to be involved in pain procedures and became a hindrance.[20],[28],[30] They wanted to seek support from healthcare professionals for pain information and skills.[20],[27] Another theme of identified barriers was the poor condition of infants or mothers. For example, the acute and deteriorated health

status of infants made pain procedures more numerous and complex, and they required more instrumental monitoring, which prevented parental involvement.[20],[28],[30],[31] On the other hand, the pain, contractions, and weakness of mothers after cesarean section limited their activities, making it a challenge to stay with their hospitalized infants.[28],[31] Moreover, one of the studies also showed that everyday life requirements formed another barrier.[28] Care for the baby's siblings, long distances between home and hospital, daily chores, and work reduced the opportunity for parents to participate in pain relief.

**Interpersonal level**

Ten barriers categorized at this level were grouped into three themes: (1) staff's authoritarianism and passivity, (2) communication and trust and (3) perception differences between parents and staff. Staff's underestimation of parental competence led to their control over infant pain management. They did not allow parents to be present because they considered that it protected both babies and parents.[21],[28],[29] Parents expressed that staff were dismissive and indifferent to them. Besides, staff did not take parents into account in pain relief as well.[28],[30] Three studies referred to issues of communication and trust.[21],[27],[32] Limited communication skills increased insecurity and unease about parental presence. Language barriers, too, impeded effective communication.[21] Lack of trust between staff and mothers raised their tensions, thus preventing mothers from observing the intervention.[27] Yet another study noted that mothers' trust in nurses' skills affected their inclusion during pain procedures.[32] Mismatch in perceptions of infant pain and information asymmetries between parents and staff were identified as another category of barrier factors.[20]

**Institutional level**

Ten barriers at the institutional level included two themes: (1) restricted policies and resources and (2) lack of training and time. Several studies emphasized the importance of organizational policies and resources in parental involvement.[21],[27],[28],[31] For instance, one study conducted in Switzerland

revealed that nonreflective and noncollaborative pain care practices, limited organizational resources, and the organizational course of action in the NICUs were mentioned as factors hindering parent involvement.[21] The mother's desire to participate in pain relief was ignored because it was not included in the hospital's strategic plan. The hospital did not even have specific organizational guidelines or additional parking.[27],[31] The restrictive environment of the NICU, such as limited space, complex equipment, insufficient facilities, limited visiting hours, inappropriate procedure timing, and professionally demanding procedures, greatly limited parental participation.[28],[31] Furthermore, the lack of organizational human resources resulted in a high workload for the nurses, and time pressures made them reluctant to involve mothers. Nurses also expressed that the lack of training opportunities led to insufficient knowledge about the importance of parental involvement in pain management as well as neonatal pain, thus making the implementation of pain management challenging.[27]

**Community and public policy levels**

Data from a study conducted in Australia were collected from June through November 2020, and as such, parental access to the NICU has been limited by restrictions related to the COVID-19 pandemic.[31]

## DISCUSSION

Nowadays, parental involvement in neonatal pain management practice is still an emerging field in many countries, even though it has been considered to be beneficial for multiple stakeholders.[29] This field faces many difficulties and challenges; therefore, policymakers, hospital administrators, and healthcare professionals need evidence to help make decisions in the implementation process. This scoping review identified facilitators and barriers to parental involvement in the management of neonatal pain in the NICU at multiple levels within the context of the SEM. The interactions that may occur between the various levels need to be taken into account when developing implementation strategies. For example, parents' emotions at the intrapersonal level could influence healthcare professionals' attitudes and support for

them. In turn, the relationships and interactions between healthcare workers and parents at the interpersonal level could affect parents' emotions, behaviors, and knowledge levels. Similarly, restrictive environments and policies at the institutional level might have an impact on parents at both the intrapersonal and interpersonal levels. For instance, a lack of staff training left both staff and parents with a lack of pain knowledge, leading to tensions and poor communication between them, as well as parents' negative attitudes. This is precisely why we chose the SEM as the theoretical framework to summarize the factors that influence parental involvement. This framework provided us with a new way of thinking and perspective. In this way, strategies for improvement based on influencing factors at one level may have a positive impact on other levels, which can inform our improvement measures and thus facilitate the implementation of pain management clinical practice.

Our findings showed significant differences in the number of facilitators and barriers at various levels. One and the same factor might be a facilitator in one situation and a barrier in another. Intrapersonal factors such as parental role, parents' motivation, parental emotional stress, and parents' knowledge had a significant impact on parental involvement behavior, which was consistent with previous metasynthesis results.[33] However, our review suggested additional intrapersonal factors, including mother-infant attachment, condition of infants or mothers, and everyday life requirements. Regarding taking an active role in pain management, parents' opinions were consistent. They were eager to help with their infant's pain relief and conveyed concerns about their pain and therapy.[11],[28],[34]-[36] Self-determination theory suggests that an individual's motivation and willingness may be associated with three basic psychological needs: autonomy, competence, and relatedness.[37] This concept can be spanned across interpersonal and institutional domains. Parents' motivation and willingness to participate in pain management may become stronger if they have a sense of control over the NICU environment and are cared for by the staff. A strong sense of parental role was identified as a factor contributing to participation.[30] Evidence suggests that mother-infant attachment is linked to the creation of parental roles and

that nurse support can enhance mother-infant connection.[9],[38],[39] Parental emotions and knowledge were the most frequently reported intrapersonal factors in the current scoping review, with support from healthcare professionals playing an equally crucial role. It again exemplifies the influence of interpersonal relationships on individual factors within the framework. It is the responsibility of neonatal healthcare providers to screen and assess parents for emotional problems that may be affecting their children's moods,[40] but this is not a reason to exclude them from the NICU. Instead, healthcare professionals can calm them by building trust with them through good communication and explanations as well as positive encouragement and invitations. In addition, healthcare professionals should provide parents with pain-related information to give them the knowledge and skills that will help them establish their role as caregivers, strengthen their confidence, and promote participation. Poor condition of infants or mothers and everyday life requirements were barriers to parental involvement. It was in line with the findings of two systematic reviews.[41],[42] Encouraging other family members to assist with some of the family responsibilities can help reduce the stress in the lives of mothers, while other improvements need further study.

In our scoping review, interpersonal factors primarily refer to interpersonal relationships and interactions between parents and healthcare professionals, with only one study mentioning peer support on the Internet.[20] Informational and emotional support from staff has already been mentioned in the previous discussion, as it plays the most prominent role in facilitating parental involvement in pain management and spans almost all domains of the SEM. Specifically, in terms of the information content, first, staff should emphasize to parents the importance of participating in pain management and increase the awareness of their roles and responsibilities as caregivers; then, staff need to inform parents about the pain procedures that their infants may have to go through, the timing of the procedures, and the parent's tasks during the process; and lastly, how to participate and cooperate is of paramount importance, and the pain relief employed by the specific methods are to be provided. In terms of the information

form, in addition to verbal instructions and written pamphlets, live demonstrations, visualization, the parents' personal needs, and the infant's characteristics are all worth considering. Nowadays, parents' access to health information from the Internet and smartphones is becoming an increasingly popular means and gaining more parental preference.[43] Hence, it is recommended that professionals, organizations, communities, and governments progressively enhance their attention, development, and utilization of social media. There may be value in developing a learning toolkit that contains information in a variety of formats. Furthermore, parents with similar caregiving experiences in the NICU are another valuable resource, and peer-to-peer support from them could be considered an effective psychoeducational intervention.[44] However, there are few studies related to parental involvement in education and training for pain management, either in the construction of instructional programs or the evaluation of training effectiveness, which could be an area for future research. Parental involvement in the pain relief process is also a continuous learning process of parenting, which is not without the emotional encouragement and affirmation of the clinical staff. The positive feedback from the staff and the infant will promote continued parental involvement. Staff's authoritarianism and passivity was also a barrier, consistent with the findings of another study.[33] This partially overlaps with the institutional domain of the model. Although listening and respect are among the core principles of patient- and family-centered care,[40] evidence suggested that more than one-third of ICUs had a poor "climate of mutual respect".[45] This may further jeopardize the clinician-patient relationships and discourage family engagement. The organizational policies and regulations influence, to some extent, the decision-making of the professionals who are the gatekeepers of the NICU. Professionals should value collaboration with parents and consider and respect their feelings when conducting any procedure, trusting their unique knowledge of their infant rather than questioning the parent's competence.[10] Trust is built on good communication. Nurse-to-nurse, nurse-to-physician, and nurse-to-parent communication all have an impact on parental involvement.[21],[27],[28],[31] Organizations can promote good communication through training, staffing, and the

physical health care environment.[46] Additionally, healthcare institutions should be aware of communication issues that arise from language and culture. Providing evidence-based racial and cultural sensitivity training and implicit and explicit bias training for healthcare professionals may mitigate disparities caused by communication issues,[47] but further research is urgently needed to identify best practices. Perception differences between parents and staff are an additional barrier identified in this scoping review that can be addressed by good communication. Studies showed that parents in the NICU had specific expertise about their own infants' pain and comfort needs, and nurses could gain new information directly from them.[10] Nurses need to be aware of the parents' unique strengths in this area, encourage their participation, and gradually work through the transfer of responsibility and authority in the process. The comforting experience and confidence of the empowered parent increase, which in turn promotes participation.

Organizational resources and regulations played a key role in affecting parental involvement at the institutional level, which echoed multiple studies on kangaroo care and breastfeeding.[41],[42],[48] Parents generally expressed dissatisfaction with the limited space, inadequate facilities, and restrictive policies of the NICUs. To our knowledge, many healthcare organizations employed various strategies, policies, and resources when it came to providing healthcare; some even did not incorporate parental engagement into their strategic plans at all.[27],[31] The development of specific and realistic guidelines and policies is a pressing issue for the organization. For example, consulting with parents about each other's roles and responsibilities to enhance shared decision-making, securing unlimited visitation hours to ensure that parents can be present at any time, and setting up friendly facilities such as private family rooms, screens, lockers, and collapsible recliners to increase parents' convenience and comfort. This may cross the model's community and public policy domains and may require stronger public policy support and funding from social organizations such as charities. Moreover, the timing of some routine pain procedures and doctor rounds may be reasonably adjusted to the needs of the parents, as parents may provide more detailed

information about their babies directly to healthcare professionals.[10] Of course, joint consultation and agreement among multiple parties are necessary. Interprofessional collaboration has been cited as an enabling factor in facilitating pain management practice;[21],[49] however, such collaborative practice is often lacking within organizations. Evidence suggests that power imbalances in clinical practice hinder interprofessional joint decision-making.[50] Interprofessional communication channels, interprofessional educational programs, and evidence-based strategies can reduce power imbalances, improve interdisciplinary communication,[51]-[53] and create supportive organizational cultures and climates to promote parental involvement. Additionally, nurses cited workload and time pressures as leading them to prioritize infant survival over pain management, a finding supported by other studies.[52],[54] These studies similarly identified high workload as a barrier to optimal management of patient pain, in part due to the shortage of nurses in the institution. The nursing shortage is a globalized issue that can be addressed through the development of a country-specific data-informed model of supply and demand routes, evidence-based policies and resource allocation, improved working and employment conditions, and the implementation of wage management mechanisms.[55],[56] Finally, the lack of organizational training programs in neonatal pain management leads to a lack of knowledge among healthcare professionals about neonatal pain and a similar lack of appreciation of the benefits of parental involvement in pain relief. There are continuing education programs, such as training forums and seminars,[52] where healthcare professionals can enhance their learning of standard procedures and guidelines while bridging the gap between knowledge and practice in the clinical setting. However, specific training programs, including content and format, require further research.

Based on the included studies, our review only found relevant restrictions imposed by the COVID-19 pandemic at the community and public policy levels of the model. It indicates even more that comparable public health events could serve as obstacles to parental access to the NICU. In the context of the SEM framework, specific policies of the United Nations, the World Health Organization, and individual countries affect the

behaviors of various populations at the institutional, interpersonal, and intrapersonal levels, yet parents may not be able to change this fact. Several other studies of family involvement in neonatal care reported financial issues such as transportation subsidies, food, lodging, and hospitalization costs; socio-cultural norms such as local customs and beliefs, preterm stigma, stigmatization of male involvement in child care, and the Chinese cultural tradition of "sitting the month"; and public policies such as maternal-infant separation policy, paid leave, and paternity leave.[41],[42],[48],[57],[58] Although our review did not reach similar conclusions, it has to be recognized that these factors are real and equally likely to have an impact on parental involvement in pain management. As such, more extensive research is needed to reveal additional influencing factors in the future.

**Strengths and limitations**

This scoping review identified specific facilitators and barriers to parental involvement in NICU pain management within the context of the SEM. This theoretical framework gives us a more valuable and comprehensive perspective that enables us to consider not only the parental intrapersonal factors but also the external environmental factors and their interactions, providing more insightful information for future studies, clinical implementations, and interventions. We searched a total of nine databases in both English and Chinese, and the screening process was conducted independently by three reviewers. The extraction of facilitators and barriers might be somewhat subjective, but a double cross-check was performed, and all results were decided through discussion in the research team to minimize bias. Although we included as many study designs as possible, it had to be acknowledged that there was a lack of overall evidence, especially for quantitative studies. It may have led us to miss some influencing factors in various domains of the model. This is a direction for future research and may require the development of relevant scales or other tools to collect reliable data. Another limitation is that we did not perform a methodological quality assessment of the included studies, as the focus of our study was to map the available literature on the topic. Finally, the exclusion of gray literature may have resulted in the

omission of some studies.

## CONCLUSION

Neonatal pain prevention is an ethical requirement as well as a medical mandate. Parental access to the NICU to participate in neonatal pain management reflects a family-centered and humanistic philosophy of care and is an imperative strategy. However, it is an equally challenging and innovative change. Successful change requires an in-depth understanding of the factors influencing implementation. This review identified gaps in the evidence, synthesized existing facilitators and barriers, and emphasized the impact of intrapersonal and interpersonal factors, particularly informational and emotional support, on parental engagement behaviors. Institutional policies and resources were likewise critical and deserved the attention of the health system. Limited evidence was found at the community and public policy levels, but we suggested some potential areas for future research. A broad program of nationally or regionally coordinated management mode is key, requiring clear regulatory approaches and targeted guidelines. The interconnectedness and complexity of facilitators and barriers across the SEM highlight that multifaceted interventions show promise in promoting parental engagement behaviors and pain management practices. More research exploring multiple factors in the socio-ecological domains will help to better understand their impact on parental involvement behaviors, promote more effective interventions and implementation, and facilitate innovations in management mode.

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**Contributors** JJ is the corresponding author and the guarantor; she has designed the study, contributed to the writing of the manuscript, and oversees graduate student responsibilities to complete this work. LF has taken the primary responsibility for communication with the journal during the manuscript submission, peer review, and publication process and has ensured that all the journal's administrative requirements, such as providing details of authorship and gathering conflict of interest forms and statements, are properly completed. LF and MS conducted the scoping review, participated in data extraction and synthesis, and wrote the first draft of the paper for submission. LF, MS, BT, and LX contributed to the study design, search strategy, interpretation of study results, and review of the manuscript. All five authors reviewed the accuracy and integrity of the work. All five authors provided specific content and clinical expertise to inform the discussion and

implications of the study results.

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**Competing interests** None declared.

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data sharing statement** None.

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**Legend**

**Figure 1** Flowchart of the literature search and study selection process.

**Figure 2** Facilitators and barriers to parental involvement in neonatal pain management in the NICU within the levels of the socio-ecological model.

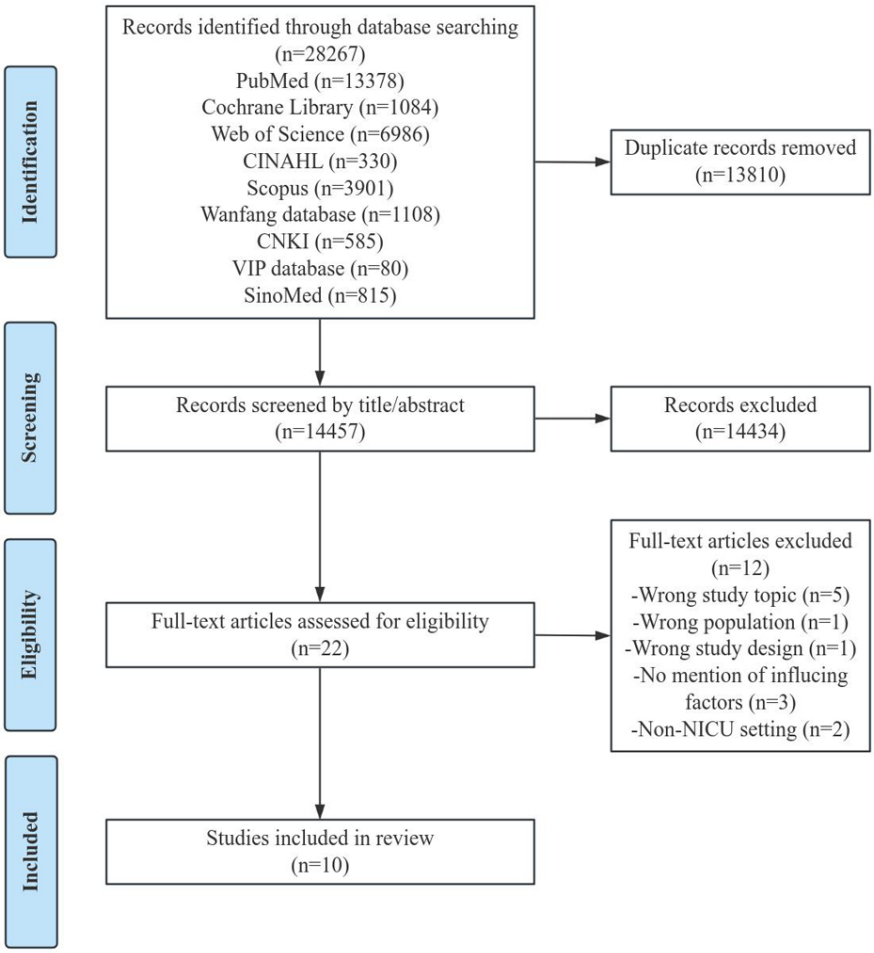


Figure 1 Flowchart of the literature search and study selection process.

90x90mm (300 x 300 DPI)

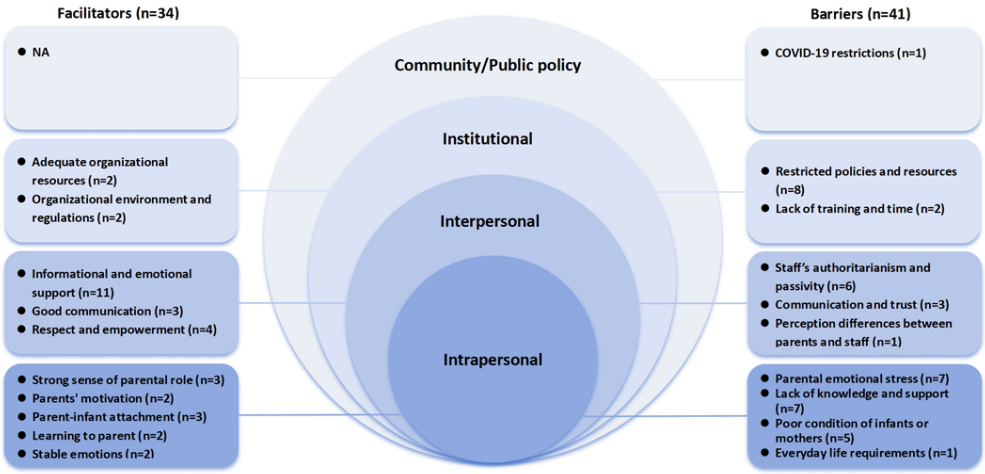


Figure 2 Facilitators and barriers to parental involvement in neonatal pain management in the NICU within the levels of the socio-ecological model.

90x90mm (300 x 300 DPI)

## Supplementary file

Search terms (English):

1. Parent*/parents/family/parental involvement/parental participation/family involvement/family participation/family integrated care/family centered care/family centred care
2. Newborn*/neonat*/preterm*/prematur*/infant*/neonatal intensive care unit/NICU
3. Pain*/pain management/heel/needles/needle puncture/injection/vaccines/breastfeeding/kangaroo care/skin to skin

Search terms (Chinese):

1. “父母/家庭/父母参与/家庭参与/家庭为中心”
2. “新生儿/早产儿/新生儿监护室/新生儿监护病房/NICU”
3. “疼痛/疼痛管理/足跟采血/足底采血/穿刺/母乳喂养/袋鼠式护理”

Table S1 Search strategies for all databases

| Database | Search strategies |
|---|---|
| PubMed | #1: (((((((((parents[MeSH Terms]) OR (family[MeSH Terms])) OR (parent*[Title/Abstract])) OR (parental involvement[Title/Abstract])) OR (parental participation[Title/Abstract])) OR (family involvement[Title/Abstract])) OR (family participation[Title/Abstract])) OR (family integrated care[Title/Abstract])) OR (family centered care[Title/Abstract])) OR (family centred care[Title/Abstract])<br>#2: ((((((infant[MeSH Terms]) OR (newborn*[Title/Abstract])) OR (neonat*[Title/Abstract])) OR (preterm*[Title/Abstract])) OR (prematur*[Title/Abstract])) OR (neonatal intensive care unit[Title/Abstract])) OR (NICU[Title/Abstract])<br>#3: (((((((((pain[MeSH Terms]) OR (pain management[MeSH Terms])) OR (heel[MeSH Terms])) OR (needles[MeSH Terms])) OR (needle puncture[Title/Abstract])) OR (injection[Title/Abstract])) OR (vaccines[MeSH Terms])) OR (breastfeeding[Title/Abstract])) OR (kangaroo care[Title/Abstract])) OR (skin to skin[Title/Abstract])<br>#4: #1 AND #2 AND #3 |
| Cochrane library | #1: MeSH descriptor: [Parents] explode all trees<br>#2: MeSH descriptor: [Family] explode all trees<br>#3: (parent* or parental involvement or parental participation or family involvement or family participation or family integrated care or family centered care or family centred care):ti,ab.kw<br>#4: #1 or #2 or #3<br>#5: (neonat* or preterm infants or neonatal intensive care unit or NICU):ti,ab,kw<br>#6: MeSH descriptor: [Pain] explode al trees<br>#7: MeSH descriptor:[Pain Management] explode all trees<br>#8: MeSH descriptor: [Needles] explode all trees<br>#9: MeSH descriptor: [Heel] explode all trees<br>#10: MeSH descriptor: [Vaccines] explode all trees |

| | |
|---|---|
| | #11: (needle puncture or injection or breastfeeding or kangaroo care or skin to skin):ti.ab.kw<br>#12: #6 or #7 or #8 or #9 or #10 or #11<br>#13: #4 and #5 and #12 |
| Web of Science | #1: TS=(parent* OR parents OR family OR parental involvement OR parental participation OR family involvement OR family participation OR family integrated care OR family centered care OR family centred care) and Preprint Citation Index<br>#2: TS=(neonat* OR preterm infants OR neonatal intensive care unit OR NICU) and Preprint Citation Index<br>#3: TS=(pain OR pain management OR heel OR needles OR needle puncture OR injection OR vaccines OR breastfeeding OR kangaroo care OR skin to skin) and Preprint Citation Index<br>#4: #1 AND #2 AND #3 and Preprint Citation Index |
| CINAHL | S1: SU parent* OR SU parents OR SU family OR SU parental involvement OR SU parental participation OR SU family involvement OR SU family participation OR SU family integrated care OR SU family centered care<br>S2: SU neonat* OR SU preterm infants OR SU neonatal intensive care unit OR SU NICU<br>S3: SU pain OR SU pain management OR SU heel OR SU needles OR SU needle puncture OR SU injection OR SU vaccines OR SU breastfeeding OR SU kangaroo care OR SU skin to skin<br>S4: S1 AND S2 AND S3 |
| Scopus | (TITLE-ABS-KEY (parent* OR parents OR family OR parental involvement OR parental participation OR family involvement OR family participation OR family integrated care OR family centered care) AND TITLE-ABS-KEY (neonat* OR preterm infants OR neonatal intensive care unit OR nicu) AND TITLE-ABS-KEY (pain OR pain management OR heel OR needles OR needle puncture OR injection OR vaccines OR breastfeeding OR kangaroo care OR skin to skin)) |
| Wanfangdatabase (Chinese) | 主题:("父母" OR "家庭" OR "父母参与" OR "家庭参与" OR "家庭为中心") and 主题:("新生儿" OR "早产儿" OR "新生儿监护室" OR "新生儿监护病房" OR "NICU") and 主题:("疼痛" OR "疼痛管理" OR "足跟采血" OR "足底采血" OR "穿刺" OR "母乳喂养" OR "袋鼠式护理") |
| CNKI (Chinese) | (主题：父母+家庭+父母参与+家庭参与+家庭为中心(精确)) AND (主题：新生儿+早产儿+新生儿监护室+新生儿监护病房+NICU(精确)) AND (主题：疼痛+疼痛管理+足跟采血+足底采血+穿刺+母乳喂养+袋鼠式护理(精确)) |
| VIPdatabase (Chinese) | (M=父母 OR M=家庭 OR M=父母参与 OR M=家庭参与 OR M=家庭为中心) AND (M=新生儿 OR M=早产儿 OR M=新生儿监护室 OR M=新生儿监护病房 OR M=NICU) AND (M=疼痛 OR M=疼痛管理 OR M=足跟采血 OR M=足底采血 OR M=穿刺 OR M=母乳喂养 OR M=袋鼠式护理) |
| SinoMed | ( "父母"[常用字段:智能] OR "家庭"[常用字段:智能] OR "父母参与"[常 |

| | |
|---|---|
| (Chinese) | 用字段:智能] OR "家庭参与"[常用字段:智能] OR "家庭为中心"[常用字段:智能]) AND( "新生儿"[常用字段:智能] OR "早产儿"[常用字段:智能] OR "新生儿监护室"[常用字段:智能] OR "新生儿监护病房"[常用字段:智能] OR "NICU"[常用字段:智能]) AND( "疼痛"[常用字段:智能] OR "疼痛管理"[常用字段:智能] OR "足跟采血"[常用字段:智能] OR "足底采血"[常用字段:智能] OR "穿刺"[常用字段:智能] OR "母乳喂养"[常用字段:智能] OR "袋鼠式护理"[常用字段:智能]) |