

Scoping Review of the Needs and Roles of Grandparents of Infants in the NICU

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ABSTRACT

Objective: To map existing evidence on the needs and roles of grandparents of infants in the NICU.

Data Sources: We searched five databases: CINAHL, MEDLINE, Scopus, APA PsycNet, and ProQuest Dissertations and Theses Global. We also reviewed reference lists and explored unpublished studies and gray literature. We included sources in which the authors described the needs and roles of grandparents of infants in the NICU as described by grandparents, parents, and health care professionals.

Study Selection: Two independent reviewers screened titles and abstracts and then assessed full texts using pre-defined inclusion and exclusion criteria. We resolved disagreements through discussion or adjudication by the first author. We selected 22 publications, including quantitative, qualitative, and mixed-methods studies; a meta-review; and opinion papers.

Data Extraction and Synthesis: We extracted the following data: authors, publication year, country, aims, study design, methods, sample, data collection tools, and key findings. We created a summary table and wrote a narrative synthesis to connect findings with our objective.

Conclusion: Through the scoping review, we found that grandparents needed to be involved in the care of their grandchildren and to understand the NICU environment. As they sought to bond with their grandchildren, grandparents also provided key emotional and practical support for parents. To meet the needs of grandparents, health care professionals in the NICU should answer their questions within the bounds of privacy limitations and offer tailored interventions. Because recent research on this topic remains limited, we recommend further studies to address this gap and strengthen family-centered care in NICUs.

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Parents experience significant challenges when their infants are hospitalized in the NICU. In a qualitative study by Nelson et al. (2022), mothers reported feeling like outsiders and feeling unheard by the care team, needing to travel long distances, coping with limited space at the NICU, and managing competing family responsibilities. Consistently, Bertonecchi et al. (2025) reported that parents experienced intense emotions, including anxiety, fear, fatigue, and guilt, during the hospitalization of their infants at the NICU, all occurring simultaneously with their transition into the parental role. In this context, their parents—that is, the grandparents of the hospitalized infants—often provide substantial support. For example, Brødsgaard et al. (2017) conducted a study involving nine grandparents and highlighted the supportive role grandparents played for parents who had infants

hospitalized in the NICU. According to Brødsgaard et al., this support took various forms, including practical assistance, emotional support, advocacy, and protecting the parents from additional stressors (e.g., to share information regarding the NICU and the premature newborn with other family members). Similarly, in a randomized controlled trial involving 84 mothers whose infants were hospitalized in the NICU, Tavasolnia et al. (2017) found that support provided by grandmothers significantly reduced maternal depression symptoms and strengthened maternal role development.

However, certain factors limit grandparents' involvement with the parents and the preterm or medically compromised infants. In studies by Hawthorne et al. (2021) and Huang et al. (2024), grandparents reported that the restrictions within

Grandparents encounter numerous challenges when their grandchildren are hospitalized in the NICU that can hinder their ability to fulfill the traditional role of grandparents.

the NICU significantly limited their ability to be present with their preterm or medically compromised grandchildren, which can affect their role as grandparents. In a phenomenological study conducted with 13 grandparents, Priel et al. (2022) concluded that grandparents may perceive the NICU visitation restrictions and the workload burden of health care providers as barriers to developing a relationship with their grandchildren and to supporting their adult children. Moreover, the seven grandmothers who participated in a qualitative study conducted by Hawthorne et al. (2021) reported that they often felt unwelcome because health care professionals ignored them, avoided eye contact, or failed to answer their questions. It should also be emphasized that grandparents may struggle to fulfill their role in this unique situation because their experience differs from what they imagined or encountered with other healthy, full-term grandchildren (Brødsgaard et al., 2017).

Grandparents might not know how to best support the parents if they receive little information and assistance regarding the hospitalization of their grandchildren. For example, Hawthorne et al. (2021) reported the substantial lack of information perceived by the grandmothers who participated in their study. Moreover, Priel et al. (2022) found that when grandparents had limited access to the NICU and their grandchildren, it was difficult for them to understand the situation. Adult children cannot always inform their parents about an infant's condition because parents lack time and energy. According to Brødsgaard et al. (2017), this context further contributed to the information deficit experienced by grandparents. This lack of information, combined with concerns about infants' health and development, often led to the need for reassurance of grandparents remaining unmet (Huang et al., 2024). As concluded by Huang et al. (2024), who conducted a cross-sectional quantitative study with 280 grandparents, the most pressing needs of grandparents were to receive reassurance and to be adequately informed about the NICU and their preterm or medically compromised grandchildren. Unfortunately, this uncertainty, lack of information, and restricted access may undermine the development of a

relationship between the grandparents and their grandchildren (Priel et al., 2022).

It is important to better understand the needs and roles of grandparents of infants in the NICU so that health care professionals can provide them with effective information and support. Such clarity could reduce stress and anxiety and could promote the development of the grandparent-grandchild relationship (Brødsgaard et al., 2017; Hawthorne et al., 2021; Huang et al., 2024). It would also allow grandparents to offer their adult children more effective and appropriate support. Support from close relatives, including grandparents, has been associated with reduced parental depression symptoms, posttraumatic stress, and anxiety among parents of infants in the NICU. For example, through a descriptive quantitative study that included 300 parents, Soghier et al. (2020) demonstrated that increased parental social support after a preterm birth was associated with a significant reduction in symptoms of depression. Similarly, following the completion of a systematic review encompassing 49 studies to identify factors associated with posttraumatic stress and anxiety among parents whose newborns were admitted to the NICU, Malouf et al. (2024) concluded that adequate social support served as a protective factor against posttraumatic stress and anxiety in these parents. Therefore, grandparents' support can be characterized as essential.

Most researchers who explored the need and roles of grandparents of infants in the NICU conducted qualitative studies (Brødsgaard et al., 2017; Hawthorne et al., 2021; Priel et al., 2022), and an assessment or measurement tool specifically designed for this purpose is not actually available. Therefore, health care professionals may struggle to find evidence on which to tailor appropriate interventions (Huang et al., 2024). To address this gap, we conducted a scoping review to summarize existing evidence on the needs and roles of grandparents of infants in the NICU.

Methods

A scoping review is a type of evidence synthesis designed to systematically identify and map the breadth of available data on a given topic (Munn et al., 2022). We deemed this methodological approach suitable for considering the review question. We conducted this scoping review according to the Joanna Briggs Institute (JBI) methodology for scoping reviews (Peters et al., 2020).

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We used the Preferred Reporting Items of Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) to report our findings (Tricco et al., 2018). We registered the protocol in Open Science Framework Registries (Lebel et al., 2023).

Review Question

Our review question was as follows: What is known about the needs and roles of grandparents of infants in the NICU?

Inclusion Criteria

Following the JBI methodology for scoping reviews, we defined the population, concept, and context to inform the development of the search strategy, the selection of relevant reports, and the systematic extraction of data (Peters et al., 2020). For the population, we considered reports that included grandparents, parents, and health care professionals. Including the perspectives of parents and health care professionals allowed us to capture complementary viewpoints because these individuals interact with grandparents during the NICU hospitalization and can provide valuable insights. For the concept, we examined research exploring these needs and roles within the context of neonatal hospitalization; we excluded those focused on the post-discharge period. We defined “needs” as necessities expressed by grandparents or any requirements for grandparents, as determined by parents or health care professionals. We defined “roles” as positions assumed or desired by the grandparents, as perceived by themselves, parents, or health care professionals. Regarding the context, we considered reports from all geographic regions without restrictions.

We applied the following inclusion criteria: included grandparents and parents or health care providers and focused on grandparents' needs or roles during their grandchildren's NICU hospitalizations. All infants hospitalized in the NICU were included, not only those born preterm. We included all types of published reports and gray literature such as reports of quantitative, qualitative, or mixed-methods studies; literature reviews; and opinion papers. We excluded studies focusing on the loss of a newborn or infant because grief is a distinct experience. We did not apply time restrictions to publication dates to include all relevant literature.

Search Strategy

We applied a search strategy consistent with the JBI methodology for conducting scoping reviews (Peters et al., 2020). We selected relevant keywords and index terms (e.g., medical subject headings) for all databases. For example, we used key terms such as grandparent, grandmother, and grandfather for the population. For the outcome, key terms related to the concept (e.g., needs, role) and context (e.g., NICU, neonat*) were included for greater precision. An expert health care librarian validated the search strategy developed by the research team. Subsequently, we executed the search strategy in the following databases: CINAHL (EBSCO), MEDLINE (EBSCO), Scopus (Elsevier), APA PsycNet (American Psychological Association), and ProQuest Dissertations and Theses Global (Clarivate). In addition, we searched reference lists of the included studies to identify more relevant articles. We also carried out searches for unpublished studies and gray literature in Google and Google Scholar with relevant keywords (e.g., grandparents, NICU). We conducted the literature search in February 2024, and we updated the search in February 2025 to include the most recent reports. See [Supplementary Table S1](#) for the search strategy used in selected databases.

Study Selection

After conducting the search strategy across all databases, we uploaded all records to Covidence systematic review software. We initially removed duplicate records automatically using Covidence. Remaining duplicate records were then identified and eliminated manually within Covidence. Following this step, a total of 558 records remained. Before proceeding with the full screening process, we (two independent reviewers, P.H.H. and A.B-P., and the first author, V.L.) conducted a pilot exercise with 15 records to ensure consistency in the screening process. Following this, two independent reviewers (P.H.H. and A.B-P.) screened the titles and abstracts of all identified records according to the inclusion and exclusion criteria. Following the title and abstract evaluation, we retained 53 reports for full-text evaluation. The corresponding author of one report was contacted to obtain the complete text; however, the author was unable to provide it because access to the full version was not available. Thus, it could not be retrieved to be assessed in the full-text evaluation phase. We also included one full report from citation searching. Therefore, the independent reviewers

The context of uncertainty, unfamiliarity, and restricted access to the hospitalized infant may negatively affect the development and maintenance of the grandparent–grandchild relationship.

(P.H.H. and A.B-P.) proceeded to the full-text screening of 53 reports. According to the inclusion and exclusion criteria, we included 22 reports in the review. Disagreements were resolved through discussion (P.H.H. and A.B-P.) or by the first author (V.L.). We created a flow diagram (Page et al., 2021) about the selection process (Figure 1).

Data Extraction

Two independent reviewers (P.H.H. and A.B-P.) extracted data from the selected reports using a data extraction template developed according to the JBI data extraction template. We performed a pilot test of the data extraction tool with two reports and then revised the tool for accuracy and clarity. Extracted data included authors, publication year, country, aims, study design, methods, sample, data collection tools, and key findings related to the needs and roles of grandparents of infants in the NICU. We resolved any disagreements regarding data extraction through discussion (P.H.H. and A.B-P.) or by the first author (V.L.). In addition, the first author (V.L.) assessed the accuracy of the final extracted data after reading the full text of the selected reports.

Data Analysis and Presentation

We analyzed the results following the recommendations of Pollock et al. (2023). The first author (V.L.) conducted frequency analyses to describe the main characteristics of the reports included in this scoping review (e.g., country of origin, study design). The first author (V.L.) applied basic descriptive analyses to summarize the findings of the selected reports, ensuring a clear and comprehensive presentation aligned with the scoping review question. The independent reviewers (P.H.H. and A.B-P.) then validated the summarized findings to ensure methodological rigor. Based on these results, we developed a narrative synthesis to connect the findings to the objective of the scoping review.

Results

Characteristics of Included Reports

We included 22 reports in this scoping review, including those of 14 qualitative studies, (Brødsgaard et al., 2017; Buarque et al., 2006; Frisman et al., 2012; Hall, 2004a, 2004b; Hawthorne et al., 2021; Magowan et al., 2020; Mondkar et al., 2018; Nyondo-Mipando et al., 2020; Priel et al., 2022; Prudhoe & Peters, 1995; Rempusheski, 1990; Sarapat et al., 2017; Yue et al., 2020), 4 quantitative studies (Blackburn & Lowen, 1986; Huang et al., 2024; McHaffie, 1991, 1992), 1 mixed-methods study (Nyondo-Mipando et al., 2021), 1 meta-review (van Wyk et al., 2024), and 2 opinion articles (Discenza,

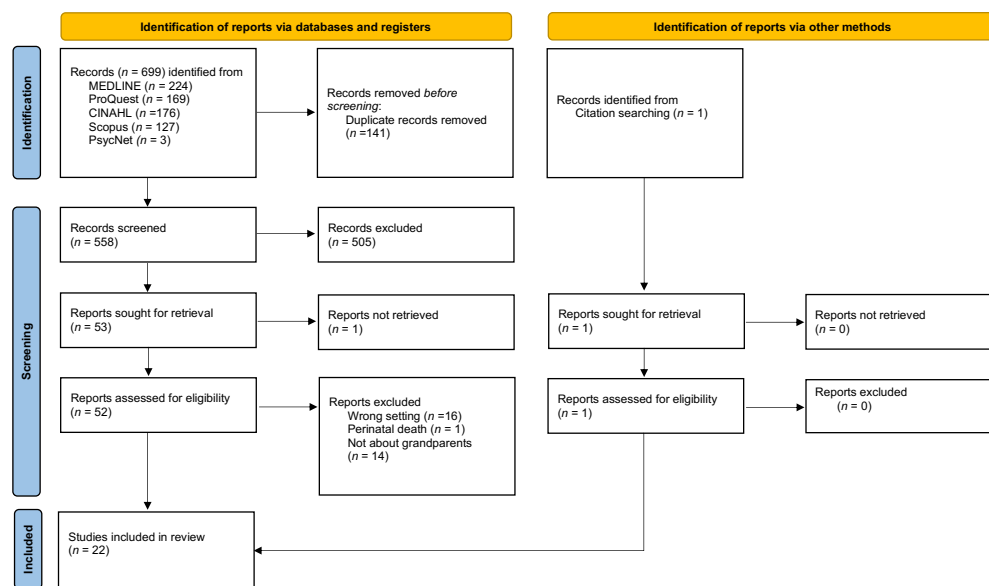


Figure 1. Flow diagram of study selection process.

2013; Spitzer, 2003). The research studies ($n = 20$) were conducted in a wide range of countries, including Brazil ($n = 1$), China ($n = 2$), Denmark ($n = 3$), India ($n = 1$), Israel ($n = 1$), Malawi ($n = 2$), South Africa ($n = 1$), Sweden ($n = 1$), Thailand ($n = 1$), Uganda ($n = 1$), the United Kingdom ($n = 2$), and the United States ($n = 4$). The opinion articles ($n = 2$) were published in the United States. Of the 22 selected reports, 12 were published more than a decade ago between 1986 and 2013 (see [Supplementary Table S2](#) for full details about the characteristics of included reports).

In all selected reports, researchers focused on the needs or roles of grandparents of infants in the NICU. The authors of 8 reports examined grandparents exclusively, whereas the authors of 14 reports included parents and health care professionals, primarily nurses and physicians. When researchers addressed needs and roles from multiple perspectives, we prioritized reporting the viewpoint of each group: grandparents, parents, and health care professionals. Researchers in 1 study explored grandparents' experiences without including them directly (Yue et al., 2020), whereas the authors of 11 reports included grandfathers (Blackburn & Lowen, 1986; Brødsgaard et al., 2017; Hall, 2004b; Huang et al., 2024; McHaffie, 1991, 1992; Nyondo-Mipando et al., 2020; Priel et al., 2022; Prudhoe & Peters, 1995; Rempusheski, 1990; Spitzer, 2003). We narratively summarize the literature on needs and roles of grandparents of infants in the NICU and provide a summary table of these results ([Supplementary Table S3](#)).

Grandparents' Needs

In 13 reports, researchers discussed the needs of grandparents (Blackburn & Lowen, 1986; Brødsgaard et al., 2017; Frisman et al., 2012; Hall, 2004a, 2004b; Hawthorne et al., 2021; Huang et al., 2024; Magowan et al., 2020; McHaffie, 1991, 1992; Prudhoe & Peters, 1995; Rempusheski, 1990; Spitzer, 2003). From their perspective, grandparents required emotional support to cope with the preterm birth and hospitalization of their grandchildren (Blackburn & Lowen, 1986; Prudhoe & Peters, 1995). They also needed information and answers to their inquiries about the NICU and their preterm or medically compromised grandchildren's health status and development because they experienced fear and uncertainties about those elements (Blackburn & Lowen, 1986; Brødsgaard et al., 2017; Hall, 2004a; Hawthorne et al., 2021; Huang et al., 2024; Magowan et al.,

2020; Prudhoe & Peters, 1995; Rempusheski, 1990). In addition, they sought to participate in the NICU as valued family members, wanting to feel included in the inner circle, allowing them to be with the infants and support the parents (Brødsgaard et al., 2017; Frisman et al., 2012; Hall, 2004a, 2004b; Hawthorne et al., 2021; McHaffie, 1991).

Parents, for their part, felt that grandparents needed emotional support to adjust to the preterm birth; this support could come through their presence in the NICU, receiving information about prematurity and the NICU, and talking with friends and family (Prudhoe & Peters, 1995). Regarding health care professionals' views on grandparents' needs, some believed that restrictions, such as limited visiting hours and access to their grandchildren, prevented grandparents from being as involved as they wished (McHaffie, 1991). In contrast, other health care professionals in the same unit felt that grandparents' needs were generally met despite these limitations (McHaffie, 1991). Health care professionals also observed that grandparents required a better understanding of the stress experienced by parents to provide effective support (McHaffie, 1992). These professionals considered grandparents' needs to be secondary to those of the parents. However, they acknowledged the importance of grandparents' desire to be active participants (McHaffie, 1992) and to receive compassionate care from health care providers (Spitzer, 2003).

In summary, according to grandparents, parents, and health care professionals, grandparents had two essential needs: to be involved in the NICU as important family members and to be informed about the NICU and the preterm or medically compromised infant's health condition and specifics. These needs were intrinsically linked to their role as grandparents, which they needed to embrace sooner than expected because of preterm birth.

Grandparents' Roles

Among the 22 reports selected for this scoping review, 14 were focused on the role of grandparents from their perspectives (Brødsgaard et al., 2017; Frisman et al., 2012; Hall, 2004a, 2004b; Hawthorne et al., 2021; McHaffie, 1991, 1992; Nyondo-Mipando et al., 2020; Priel et al., 2022; Prudhoe & Peters, 1995; Rempusheski, 1990; Sarapat et al., 2017; Spitzer, 2003; van Wyk et al., 2024), 5 were focused on the parents' perspectives (Blackburn & Lowen, 1986;

McHaffie, 1991, 1992; Nyondo-Mipando et al., 2020; Prudhoe & Peters, 1995), and 5 were focused on the perspectives of health care professionals (Discenza, 2013; Hawthorne et al., 2021; McHaffie, 1991, 1992; Nyondo-Mipando et al., 2021).

Grandparents viewed their role alongside the parents and their preterm or medically compromised grandchildren as multifaceted, encompassing emotional support (e.g., listening, comforting, instilling hope, being patient, being available for consolation, acknowledging the unique circumstances, aiding parents in recognizing their own needs), providing practical assistance (e.g., preparing meals, caring for other children), advocating for the parents and grandchildren (e.g., ensuring quality care by monitoring the infants' treatment, monitoring the parents' well-being), shielding parents from additional stressors (e.g., problems, negative feelings), sharing information with other family members about the infants' health condition, and engaging with the grandchildren while respecting the parent-infant bond and avoiding intrusiveness (Brødsgaard et al., 2017; Frisman et al., 2012; Hall, 2004b; Hawthorne et al., 2021; McHaffie, 1991).

Unfortunately, health issues, geographical distance, and financial constraints limited grandparents' involvement during the infants' hospitalization, and they wished they could provide more help to the parents (McHaffie, 1992). They also felt constrained by the guidelines governing their actions and presence in the NICU and often felt unwelcome (Blackburn & Lowen, 1986; Priel et al., 2022). They sometimes hesitated to ask staff questions (Hawthorne et al., 2021), and they experienced a sense of detachment from their grandchildren (Priel et al., 2022). However, some grandparents appreciated being recognized by the staff as integral members of the family (Brødsgaard et al., 2017). They needed to adapt their role as grandparents to the unique environment of the NICU, where it can be challenging to feel like a grandparent when the infant differs from the expected newborn and is connected to tubes and monitors (Hall, 2004a). In addition, restrictions such as visiting hours and no-touch policies affected their ability to establish their grandparent identities (McHaffie, 1991).

Furthermore, grandparents needed to assume their new role in a context where their psychological readiness for grandparenting was disrupted by preterm birth (Rempusheski, 1990).

Their grandparenting role was complicated by their dual identity as grandparents and parents of children experiencing premature birth (Hall, 2004a). They worried about their children's potential challenges in adapting to the situation and coping with emotional issues (e.g., anxiety, fear), physical burdens (e.g., sleep deprivation, well-being), and financial changes (Blackburn & Lowen, 1986; Hall, 2004b). Their concerns also extended to the infants' survival, development, and related challenges (Blackburn & Lowen, 1986; Frisman et al., 2012; Hall, 2004a; Spitzer, 2003). Receiving guidance from health care professionals was beneficial in enhancing their involvement and role as grandparents (Buarque et al., 2006; Frisman et al., 2012; Hall, 2004b; Prudhoe & Peters, 1995).

Parents did not regard grandparents as reliable sources of information regarding the preterm infants (Blackburn & Lowen, 1986; McHaffie, 1992). Nevertheless, they expected grandparents to provide emotional support by fostering hope, providing a listening ear, and protecting them from difficulties in adapting to the situation (McHaffie, 1992; Nyondo-Mipando et al., 2020; Prudhoe & Peters, 1995). Parents also expected grandparents to offer practical support such as caring for siblings, assisting with household chores, and providing transportation for parents and others (McHaffie, 1991, 1992). They should remain ready to assist when parents seek help (McHaffie, 1991). Furthermore, parents believed that grandparents' role involved being present in the NICU with their grandchildren to begin building a relationship and demonstrating that their grandchildren and the parents were their top priorities (McHaffie, 1991, 1992). Conversely, parents felt that grandparents might face challenges in attending the NICU because of work, health, or financial constraints (McHaffie, 1991).

For health care providers, grandparents needed to remain strong to support parents emotionally and practically (Discenza, 2013; Magowan et al., 2020; McHaffie, 1991, 1992; Nyondo-Mipando et al., 2021). They were expected to take pride in their grandchildren and parents by praising their efforts to boost confidence, supporting mothers who breastfeed or express milk, being present during discharge preparations to help retain information, and showing affection toward their grandchildren and the parents. Health care professionals also emphasized the need for grandparents to cultivate relationships with their grandchildren, shield

parents from potential problems, and educate themselves about their grandchildren because many lacked a clear understanding of what was happening in the NICU, which made them hesitant to engage in certain care practices (McHaffie, 1991; Yue et al., 2020). Health care providers highlighted the importance of balancing the presence of grandparents with the parents' new role as caregivers (McHaffie, 1991).

In sum, according to grandparents, parents, and health care professionals, a key element of the grandparents' role was the support they provided to parents in various forms. They also agreed that building a relationship with their grandchildren was another important aspect of their role.

Cultural Aspects in Selected Studies

Although the researchers whose work is included in this scoping review generally reported consistent findings, those who conducted research in Asia and Africa described context-dependent variations and highlighted the role of cultural factors in caregiving practices. For instance, researchers in India emphasized grandmothers' need for reassurance regarding the use of milk from human milk banks and breast milk donation practices (Mondkar et al., 2018). In a study in Malawi, grandparents played a pivotal role in providing food and essentials to mothers during postpartum hospitalization and in assisting or performing kangaroo mother care (KMC) with the newborns when the mothers were unable to do so (Nyondo-Mipando et al., 2020). Similarly, in a study conducted in China, researchers highlighted the substantial influence of grandparents on KMC practices; health care professionals reported that grandparents' resistance, rooted in cultural beliefs, hindered the promotion and implementation of KMC among parents (Yue et al., 2020). These researchers revealed context-dependent determinants of the involvement of grandparents that were not evident in studies conducted in North America, South America, or Europe (Blackburn & Lowen, 1986; Brødsgaard et al., 2017; Discenza, 2013; Frisman et al., 2012; Hall, 2004a, 2004b; Hawthorne et al., 2021; McHaffie, 1991, 1992; 1992; Prudhoe & Peters, 1995; Rempusheski, 1990; Spitzer, 2003).

Discussion

In our scoping review, we illuminated the current state of knowledge about the needs and roles of grandparents of infants in the NICU. By summarizing the literature, we found that two primary

Our review contributes to the existing body of knowledge by summarizing the literature on the needs and roles of grandparents of infants in the NICU.

needs were expressed by the grandparents: to receive information and to be actively involved. Furthermore, based on the evidence, we found that the principal role of grandparents was to provide multifaceted support to their adult children, the parents of the infants in the NICU, while they also worked to establish meaningful relationships with their new grandchildren.

Grandparents' need for information is not a new concept. Kynoch et al. (2021) reported that family members whose loved ones were receiving critical care required information to fully understand the hospitalized person's situation and condition. Similarly, Davidson et al. (2017) offered recommendations for family-centered approaches in neonatal, pediatric, and adult critical care settings and recommended the implementation of an educational intervention aimed at family members to promote improvements in their psychological well-being and overall satisfaction. However, according to the results of a systematic review that included 20 articles, many educational programs exist in the NICU, but none was aimed at grandparents; instead, these programs focused on parents (Springer et al., 2023). Similarly, van Wyk et al. (2024) conducted a meta-review of 54 studies to examine psychological distress among all family members of newborns hospitalized in the NICU and interventions to prevent or mitigate such distress. Among their findings, they concluded that no interventions specifically targeting grandparents had been previously studied.

The need for involvement in neonatal care is also not surprising. Larocque et al. (2021) reported that this principle underpins the family-centered care approach, which aims to address the needs of parents and families. However, because grandparents are often still regarded as visitors in NICUs, it can be challenging for them to participate in the care of their preterm or medically compromised grandchildren and to be perceived as important family members (Brødsgaard et al., 2017; Frisman et al., 2012; Hall, 2004a, 2004b; Hawthorne et al., 2021; McHaffie, 1991; Nyondo-Mipando et al., 2020). Following the completion of a scoping review on the barriers and facilitators of the family-centered approach in pediatric and

neonatal critical care that included 17 articles, Aljawad et al. (2025) concluded that the effective implementation of this approach relies on thorough planning as well as the assessment of family needs. Larocque et al. (2021) also discussed the importance of supporting and caring for all family members during hospitalization in the NICU to implement an appropriate family-centered approach aimed at enhancing families' overall well-being. Evaluating and implementing interventions to address the need for grandparents' involvement by health care professionals is a key element in improving their experience during their grandchildren's hospitalization.

Grandparents' supportive role aligns with societal expectations for parents welcoming a new child into their family. Indeed, grandparents are expected to provide emotional and practical support to new parents as they navigate parenthood (Scelza & Hinde, 2019). Researchers who conducted a meta-analysis of 11 studies found that grandparents' support during the postpartum period was linked to improved psychological well-being in mothers of full-term infants (Riem et al., 2023). However, to our knowledge, only Tavasolnia et al. (2017) reported the positive effect of the support provided by grandmothers on the psychological well-being of mothers of infants hospitalized in the NICU. Considering that parents of premature or medically compromised infants face a higher risk of experiencing changes in their psychological well-being (Deshwali et al., 2023), it is essential to examine this aspect in greater depth in future research. Grandparents of preterm or medically compromised infants operate in a context where their preparation for grandparenthood has been disrupted by the early birth or the infant's hospitalization. These grandparents established relationships with their grandchildren in a specialized care environment (i.e., the NICU) when their own roles as parents required significant support of their adult children (Brødsgaard et al., 2017).

It is essential to recognize that parental authority primarily mediates grandparents' involvement in neonatal care. In high-income countries such as Canada (Government of Canada, 2022) and the United States ("Grandparent Visitation & Custody Laws," 2023), grandparents lack automatic legal rights regarding their grandchildren. Nevertheless, existing legislation accounts for the social and developmental significance of grandparental roles and stipulates that restrictions on grandparent contact must be justified by serious

reasons (Government of Canada, 2022). Consequently, parents act as key gatekeepers in determining the conditions under which inter-generational bonds are maintained. This dynamic manifests in clinical practice given that parents must provide consent for grandparents to have access to their hospitalized grandchildren (Flacking et al., 2022).

We included studies that reflected the perspectives of grandparents, parents, and health professionals in this scoping review, and findings about the needs and roles of grandparents of infants in the NICU were consistent across these studies. However, we found one specific difference. Grandparents specifically described a dual role: as grandparents and as parents (Blackburn & Lowen, 1986; Spitzer, 2003). This difference may stem from the methodologies used for data collection because in several studies involving parents and health care professionals, researchers relied on quantitative methods such as surveys, which limited grandparents' ability to elaborate on their experiences. In addition, some unique aspects were revealed in studies from African and Asian countries, as highlighted previously. These variations may be linked to cultural differences that influence care practices and family dynamics across different countries or continents. In an integrative review on cultural influences in neonatal care that included 19 articles, Nyaloko et al. (2023) highlighted that cultural beliefs play a crucial role in shaping family practices with preterm infants. According to the results of this review, in certain cultural contexts senior family members occupied a dominant position within the family hierarchy and exerted authority and shaped household decisions, including those related to child-rearing practices. This may affect how parents and grandparents conceptualized their role with their grandchildren. We did not locate studies in which researchers specifically investigated the relationships between cultural influences and the needs and roles of grandparents. Consequently, it is not possible to determine how cultural norms and practices may have influenced the findings of the reports included in this scoping review.

Even though nine reports included in this scoping review were published 15 or more years ago, their results do not differ from those published more recently (Blackburn & Lowen, 1986; Buarque et al., 2006; Hall, 2004a, 2004b; McHaffie, 1991, 1992; Prudhoe & Peters, 1995; Rempusheski, 1990; Spitzer, 2003). This finding is interesting

because it suggests that the needs and roles of grandparents have remained consistent over time despite significant changes in care practices and technology in recent years. The adoption of family-focused care, such as family-centered care (Gooding et al., 2011) and family integrated care (Waddington et al., 2021), does not appear to have influenced the needs and roles of grandparents of infants in the NICU. This may partly result from the failure to involve grandparents in the family-centered approach in clinical practice. In addition, the use of social media or other technological tools such as websites to improve information access for grandparents, similar to parents, also seems to have had little effect on their needs and roles (Colette et al., 2023; Lebel et al., 2021; Orr et al., 2017). This could be related to the quality of certain sources. Researchers who evaluated nearly 200 websites focused on prematurity found that most were of average to poor quality depending on the information provided (Dol et al., 2019).

Limitations

We acknowledge several limitations in our scoping review. Because we excluded studies conducted after discharge from the NICU, our findings pertain exclusively to the period of NICU hospitalization. Consequently, we cannot generalize the results beyond the hospitalization period. In addition, our findings offer limited representation of grandfathers' perspectives given that researchers in only 11 of the included studies had grandfathers as participants (Blackburn & Lowen, 1986; Brødsgaard et al., 2017; Hall, 2004b; Huang et al., 2024; McHaffie, 1991, 1992; Nyondo-Mipando et al., 2020; Priel et al., 2022; Prudhoe & Peters, 1995; Rempusheski, 1990; Spitzer, 2003). Furthermore, the inclusion of perspectives from parents and health care professionals regarding the needs and roles of grandparents of infants in the NICU constitutes a methodological limitation of this scoping review given that it may dilute the direct representation of grandparents' own experiences and viewpoints. Identifying grandparents' perspectives was occasionally challenging, particularly in studies where their views were not clearly distinguished from those of other participants. In such cases, the narratives of grandparents were interwoven with those of parents and/or health care professionals, which made it difficult to isolate and analyze their specific viewpoints (Magowan et al., 2020; Sarapat et al., 2017; Spitzer, 2003).

In addition, certain contextual factors that could significantly influence the needs and roles of grandparents of infants in the NICU were not addressed or extracted from the selected studies and, as such, were not reflected in the findings of this scoping review. Notably, the family structure (nuclear family, single parent, or other) and the nature of the relationship between the grandparents and the parents of preterm or medically compromised infants were largely overlooked. This omission may lead readers to assume, whether accurately or not, that only nuclear families were represented or that the parent-grandparent relationship was generally positive. However, in cases where grandparents exhibit abusive behaviors, ties have been severed by the parents, or other complex relational dynamics are present, perceptions of the needs and roles of grandparents may be substantially affected for all parties. Unfortunately, we did not take these factors into account during data extraction because they were not within the scope of our study.

Implications for Research

In future studies, researchers should systematically capture grandparents' perspectives rather than conflating them with those of parents or other stakeholders. Comparative studies involving parents and health care professionals are needed to allow researchers to examine convergences and divergences in reported needs and expectations. Researchers must also address the underrepresentation of grandfathers through gender-sensitive analyses and explore potential differences between paternal and maternal grandparents. Further investigation should focus on strategies that enable health care professionals to respond effectively to grandparents' needs and support their involvement during NICU hospitalization, informing the development of individualized, evidence-based interventions. Educational needs of grandparents warrant dedicated attention to guide tailored programs, and cross-cultural studies are essential to clarify how cultural norms shape the roles and needs of grandparents to ensure that interventions remain contextually relevant and culturally responsive.

Implications for Practice

Health care professionals can address grandparents' needs during NICU hospitalization by actively integrating them into family-centered care. This involves engaging grandparents in discussions with parents and systematically

assessing their needs to implement individualized, evidence-informed interventions. Because no validated tools currently exist to evaluate grandparents' needs, initiating structured professional–grandparent dialogues is a critical first step. Given that information and involvement emerged as the most frequent needs in this scoping review, targeted, low-resource strategies can help to meet them. Facilitating grandparents' presence at the bedside, enabling appropriate physical contact, and encouraging participation in care-related discussions are feasible approaches that may enhance both grandparent and parental well-being. Recognizing and valuing grandparents' supportive role within the family network is essential. Neonatal teams should acknowledge their emotional complexity and provide psychosocial support. By addressing grandparents' needs and reinforcing their contributions, professionals can strengthen family resilience. Therefore, integrating grandparents into family-centered care is pivotal for optimizing holistic neonatal care and promoting positive outcomes for the entire family system.

Conclusion

In this scoping review, we highlighted that grandparents face distinct needs and encounter significant challenges in fulfilling their needs and roles when their grandchildren are hospitalized in the NICU. These findings revealed critical gaps in the literature and emphasize the need for targeted research to develop evidence-based interventions that improve grandparents' experiences and engagement. Further synthesis of the available evidence on the needs and roles of grandparents of infants in the NICU may allow researchers to formulate actionable recommendations that inform clinical practice and guide policy development in neonatal care settings.

SUPPLEMENTARY MATERIALS

Note: To access the supplementary materials that accompany this article, visit the online version of the *Journal of Obstetric, Gynecologic, & Neonatal Nursing* at <http://jognn.org> and at <https://doi.org/10.1016/j.jogn.2026.02.001>.

CONFLICT OF INTEREST

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Supplementary Table S1: Search Strategy

APA PsycNet	Search Strategy: Any Field	Results
1 (population)	Index Terms: {Grandparents} OR Any Field: Grandparent* OR Any Field: grandmother* OR Any Field: grandfather*	5 588 887
2 (concept)	{Needs} OR {Needs Assessment} OR {Roles} OR Any Field: "information need"	28 872
3 (context)	Any Field: nicu OR Any Field: prematur* OR Any Field: neonat* OR Index Terms: {Neonatal Intensive Care}	61 455
Combination	1 AND 2 AND 3: 0	0
Combination	1 AND 2: 0	0
Combination	1 AND 3: Controlled vocabulary only. *Selected combination.	3
Combination	1 AND 3: Controlled vocabulary only. *Update 02/2025.	3
CINAHL	Selected Field: Any Field	Results
1 (population)	(Grandparent* OR grandmother* OR grandfather*) OR (MH "Grandparents")	4 967
2 (concept)	(Need* OR Role*) OR ((MH "Information needs") OR (MH "Human needs (psychology)") OR (MH "Role") OR (MH "Needs assessment"))	1 402 630
3 (context)	(NICU OR neonat* OR prematur*) OR ((MH "Infant, premature") OR (MH "Infant, hospitalized") OR (MH "Intensive care units, neonatal"))	151 039
Combination	1 AND 2 AND 3: Relevant, but less targeted results on the first page	70
Combination	1 AND 2: Very broad, untargeted results	1 805
Combination	1 AND 3: Highly relevant results. *Selected combination	172
Combination	1 AND 3: Highly relevant results. *Update 02/2025.	176
MEDLINE	Search Strategy: All Fields	Results
1 (population)	((Grandparent* OR grandmother* OR grandfather*) OR (MH "Grandparents"))	8 363
2 (concept)	((Need* OR role*) OR (MH "Role") OR (MH "Conflict, psychological") OR (MH "Needs assessment") OR (MH "psychology, social"))	5 953 512
3 (context)	((NICU OR neonat* OR prematur*) OR (MH "Infant, premature") OR (MH "Infant, newborn") OR (MH "Intensive care units, neonatal"))	1 002 614
Combination	1 AND 2 AND 3: Relevant, but less targeted results	261
Combination	1 AND 2: Very broad, results not very targeted	2 205
Combination	1 AND 3: Highly targeted and relevant results. *Selected combination	210
Combination	1 AND 3: Highly targeted and relevant results. *Update 02/2025.	224
ProQuest	Search Strategy: In All Fields	Results
1 (population)	MAINSUBJECT.EXACT("Grandparents") OR grandmother* OR grandfather* OR grandparent*	1 640 075
2 (concept)	Need* OR role* OR MAINSUBJECT.EXACT("Needs") OR MAINSUBJECT.EXACT("Roles")	74 015 156
3 (context)	NICU OR neonat* OR prematur* OR MAINSUBJECT.EXACT("Premature babies") OR MAINSUBJECT.EXACT("Neonatal nursing")	1 725 186
Combination	1 AND 2 AND 3: Irrelevant results	148 897
Combination	1 AND 2: Very broad, untargeted results	1 130 225
Combination	1 AND 3: Relevant results when free vocabulary is removed. *Selected combination	169
Combination	1 AND 3: Relevant results when free vocabulary is removed. *Update 02/2025.	169

Scopus	Search Strategy: All Fields/Title, Abstract, Keywords/Keywords	Results
1 (population)	(Grandparents OR grandmother* OR grandfather*)	56 567
2 (concept)	(Need* OR Role*)	26 648 539
3 (context)	(NICU OR prematur* OR neonat*)	2 177 767
Combination	1 AND 2 AND 3: Relevant, but less targeted results on the first page	3 766 in "all fields" 139 in "abstract, keywords and title" 3 in "keywords"
Combination	1 AND 2: Very broad, untargeted results	36 160 in "all fields" 5 078 in "title, abstract, keywords" 219 in "keywords"
Combination	1 AND 3 : Highly relevant results with search in keywords. *Selected combination.	110 in "keywords"
Combination	1 AND 3 : Highly relevant results with search in keywords. *Update 02/2025.	127 in "keywords"

Supplementary Table S2: Characteristics of Included Reports

Authors, Year / Country	Aims	Study Design / Methods / Sample	Data Collection Tool
Blackburn & Lowen, 1986 / USA	To determine the feelings, perceptions, and experiences of grandmothers and grandfathers during their premature grandchildren's hospitalization in the NICU. To identify similarities and differences in the parents' and grandparents' feelings and perceptions.	Retrospective exploratory survey / 83 grandparents (57 grandmothers and 26 grandfathers) and 50 parents (36 mothers and 14 fathers)	A questionnaire with open-ended and fixed-response items
Brødsgaard et al., 2017 / Denmark	To describe the effect of premature infants' extended families participating in Family-Centered Care groups in the NICU.	Descriptive qualitative study using content analysis / 16 grandparents (grandmothers and grandfathers—detailed numbers not specified)	Focus groups
Buarque et al., 2006 / Brazil	To investigate the influence of support groups on the family of risk newborn infants and on neonatal unit workers.	Qualitative study / 13 mothers, 6 fathers, 2 grandmothers, and 16 health care workers	Observations of participants and through tape-recorded interviews
Discenza, 2013 / USA	To give some tips to pass along to the grandparents.	Opinion article / NA	No data collection
Frisman et al., 2012 / Sweden	To explore and describe the experience of becoming a grandmother to a premature infant.	Qualitative study using content analysis / 11 grandmothers	Interviews
Hall, 2004a / Denmark	To identify the grandfathers' experiences when a newborn or small grandchild is critically ill.	Hermeneutic phenomenological study / 7 grandfathers	Retrospective semistructured interviews
Hall, 2004b / Denmark	To identify Danish grandmothers' experiences when a small grandchild is undergoing intensive care and thus add to a broader body of nursing knowledge about this phenomenon.	Hermeneutic phenomenological study / 7 grandmothers	One interview per participant with an interview guide
Hawthorne et al., 2021 / USA	To explore the experiences of mothers, fathers, and grandmothers whose premature infants were cared for in an NICU by nurses whose practice was grounded in Watson's Caritas Processes.	Descriptive qualitative study using content analysis / 17 parents and grandmothers (6 mothers, 4 fathers, and 7 grandmothers)	Semistructured interviews
Huang et al., 2024 / China	To assess the grandparents' needs of preterm infants in the NICU, exploring the impact of demographic elements on these	Quantitative, cross-sectional study / 280 grandparents (142 grandmothers and 138 grandfathers)	The NICU-Family Need Inventory

(Continued)

Supplementary Table S2: Continued

Authors, Year / Country	Aims	Study Design / Methods / Sample	Data Collection Tool
	needs to offer guidance for clinical care practices.		
Magowan et al., 2020 / Uganda	To determine the barriers and facilitators to the acceptability of donated human milk for vulnerable infants in this low-income setting from the perspective of caregivers (mothers, fathers, and grandparents) as well as health care workers.	Qualitative study using thematic analysis / 28 participants in the focus groups (21 mothers, 6 grandmothers, and 1 father). Four in-depth interviews were conducted with health care providers (one clinical officer and three staff nurses).	Six focus group discussions and four in-depth interviews
McHaffie, 1991 / UK	To investigate the support these families received and the effectiveness of current visiting policies.	Quantitative study / 198 nurses, 33 doctors, and 93 families (89 parents and 182 grandparents (grandmothers and grandfathers; detailed numbers not specified)	Survey with open-ended questions
McHaffie, 1992 / UK	To provide information to help nurses and midwives to improve the service they give in helping families to cope and adjust both in the hospital and following the infants' discharge home.	Quantitative descriptive study / 198 nurses, 33 doctors, and 93 families (181 parents and 242 grandparents; detailed numbers not specified)	Postal questionnaires
Mondkar et al., 2018 / India	To understand mothers' and key influencers' and service providers' perceptions and practices on donor human milk and human milk banks.	Qualitative study / In-depth interviews were conducted with nine service providers, and seven focus group discussions were conducted with 56 service recipients (17 potential human milk donors, 18 fathers, 7 human milk donors, 8 mothers, and 6 grandmothers)	Nine in-depth interviews and seven focus groups
Nyondo-Mipando et al., 2020 / Malawi	To explore the experiences of caregivers in the implementation of KMC.	Descriptive qualitative study in the phenomenological tradition / 14 mothers, 6 fathers, 3 grandmothers, and 1 grandfather	10 non-participatory observations and 24 face-to-face interviews
Nyondo-Mipando et al., 2021 / Malawi	To triangulate the perspectives of health care workers, mothers, grandmothers, aunts, and fathers with facility assessments to identify gaps that can be addressed to improve breastfeeding support in Malawi.	Convergent mixed-methods study drawing from a cross-sectional quantitative study and a descriptive qualitative study / 31 health care workers (20 nurses, 7 clinical officers, and 4 Medical doctors), 30 postnatal mothers, grandmothers, aunts, and	Adaptation of the World Health Organization's Integrated Maternal, Neonatal, and Child Quality of Care Assessment and Improvement Tool and semistructured interviews with health care workers, postnatal

(Continued)

Supplementary Table S2: Continued

Authors, Year / Country	Aims	Study Design / Methods / Sample	Data Collection Tool
		fathers (20 were women, including 2 grandmothers and 1 aunt, and 10 were fathers)	mothers, grandmothers, aunts, and fathers
Priel et al., 2022 / Israel	To examine the experience of grandparenting a preterm grandchild up to the first year after the birth in the Israeli context.	Interpretative phenomenological analytic method / 9 grandmothers and 4 grandfathers	In-depth semistructured interviews
Prudhoe & Peters, 1995 / USA	To explore the experience of preterm birth from the perspectives of both parents and grandparents.	Exploratory qualitative study / 12 families (23 parents and 32 grandparents; detailed numbers not specified)	Focused interviews with the parents and mailed questionnaires for the grandparents
Rempusheski, 1990 / USA	To elicit from grandparents who had grandchildren in the NICU information about their expectations or anticipations as well as the current status of the following: <ul style="list-style-type: none"> — the role they have assumed or are assuming; — the new grandchild; — relationships within a three-generation family; — the kinds of interactions with nurses in the NICU. 	Grounded theory / 15 grandparents (11 grandmothers and 4 grandfathers)	Open-ended interviews
Sarapat et al., 2017 / Thailand	To explore perceptions and caregiving practices of parents regarding involvement in caring for their hospitalized preterm infants and the sociocultural influences involved in this.	Descriptive qualitative study / 22 parents (19 mothers and 3 fathers), 2 grandmothers, and 3 nurses	In-depth interviews, participant observation, field notes, and clinical document reviews
Spitzer, 2003 / USA	No specified aim.	Commentary paper / 1 grandfather who is also a neonatologist	No data collection
van Wyk et al., 2024 / South Africa	To provide a comprehensive summary of the incidence of psychological distress in all family members with an infant admitted to the NICU.	Meta-review / 54 studies were included (systematic reviews)	No specific data collection tool
Yue et al., 2020 / China	To (1) establish a conceptual framework to analyze the barriers and facilitators to KMC scale-up and (2) provide recommendations for KMC adoption in Chinese hospitals to ensure sustainability and scale-up.	Qualitative study / 18 nurses and 10 doctors and 10 parents	Clinical observations and semistructured interviews

Note. KMC = kangaroo mother care; NA = not applicable.

Supplementary Table S3: Needs and Roles of Grandparents of Infants in the NICU as Identified by Grandparents, Parents, and Health Care Providers

Participants	Needs	Roles
According to Grandparents	<ul style="list-style-type: none"> Emotional support because they are concerned about the parents (their coping ability, physical and emotional strain, and financial situation) and the infant (survival and development).¹⁻³ To be informed early about the preterm infant and the NICU from health care providers or the parents to better understand the situation and facilitate communication.^{1,4-13} To be present at the NICU for their child and grandchild.^{4,7-9} To be included in the NICU / To be recognized as essential family members.^{4-6,8,11,14,15} To have the ability to cope with the emotional strain of the situation.¹ To have affection, attention, caring, and respect.¹² Being able to speak, share, and ask questions.^{5,12,13} Their own need to be involved became secondary; the most important things were the family's well-being, health, and condition.⁴ Reassurance about the quality of care received by the baby.^{4,9} To have more time for their psychological preparation to be grandparents and to deal with negative feelings.⁷ 	<ul style="list-style-type: none"> Providing emotional support to the parents.^{2-4,6-8,10,11,14} Providing practical support to the parents.^{2-4, 6,7,10,11,14-17} To be present at the NICU to develop a relationship with their grandchild.^{5,10,14} Advocating for the parents and the grandchild.⁶ Protecting the parents from additional stressors.^{6,7} Informing other family members about the situation / To be available for the immediate family.^{4,6,7,15} To compose with their role duality such as being parents and grandparents.^{3,8} To accept the grandchild as a unique human / The prematurity is a part of the grandchild's history.⁶⁻⁸ To help the parents understand their own needs (i.e., to leave the ward for a while for their psychological health).^{4,11} To be involved without disrupting.^{2,4,8,14,18} To be available for the parents / To prioritize helping and being there for them.^{5,7,11,17} To worry about other grandchildren and their parents in the NICU (e.g., did they get enough sleep? will they get emotional trauma?).^{3,11,17} To pray for their child and grandchild / To be hopeful.^{5,10,11} To be grandparents despite constraints (e.g., health issues, distance, finances, work).^{4,10,14}

(Continued)

Supplementary Table S3: Continued

Participants	Needs	Roles
According to Parents	<ul style="list-style-type: none"> Emotional support.² Information about the NICU and the preterm infant.² To be an active participant in the NICU.² 	<ul style="list-style-type: none"> Providing emotional support to the parents.^{2,10,14,15} Providing practical support to the parents.^{2,10,14,15} Being present at the NICU to develop a relationship with their grandchild.^{10,14} They are not a reliable source of information about the preterm infant.^{1,10} To maintain a sense of hope.^{10,14} To show that the infant and parents are a priority in their lives.^{10,14} To protect the parents from problems.^{10,14}
According to Health Care Providers	<ul style="list-style-type: none"> To understand the stress experienced by parents to support them better.¹⁰ To be an active participant in the NICU.¹⁰ To have compassionate insights from the health care providers.³ 	<ul style="list-style-type: none"> Providing emotional support to the parents.^{3,10,14,19} Providing practical support to the parents.^{3,10,14,19,20} Being present at the NICU to support the parents and develop a relationship with their grandchild.^{5,14,19,20} Showing affection to the parents and their grandchild.¹⁹ To educate themselves about the NICU and prematurity.¹⁴ To be strong for their child and spouse.¹⁹ To be involved without disrupting.^{10,14} To advocate within the household for the infant's best care.^{21,22}

¹Blackburn & Lowen (1986); ²Prudhoe & Peters (1995); ³Spitzer (2003); ⁴Frisman et al. (2012); ⁵Hawthorne et al. (2021); ⁶Brødsgaard et al. (2017); ⁷Rempusheski (1990); ⁸Hall (2004a); ⁹Huang et al. (2024); ¹⁰McHaffie (1992); ¹¹Hall (2004b); ¹²Buarque et al. (2006); ¹³Mondkar et al., (2018); ¹⁴McHaffie (1991); ¹⁵Nyondo-Mipando et al. (2020); ¹⁶Sarapat et al. (2017); ¹⁷van Wyk et al. (2024); ¹⁸Priel et al. (2022); ¹⁹Discenza (2013); ²⁰Magowan et al. (2020); ²¹Yue et al. (2020); ²²Nyondo-Mipando et al. (2021).