Parents' and nurses' experiences of partnership in neonatal intensive care units

a qualitative review and meta-synthesis

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What does this paper contribute to the wider global clinical community?

- Provides insight into parents' and nurses' experience of the partnership.

- Identification of factors that contribute to the partnership as facilitators and barriers, respectively.

- Co-creation of knowledge as well as development of competencies and negotiation of roles are essential to a successful partnership.

- Focus on nurses' important role as they are in a position where they can reduce and eliminate many of the barriers to the partnership.

Abstract

Aims and objectives: To explore how parents and nurses experience partnership in neonatal intensive care units (NICU) and to identify existing barriers and facilitators to a successful partnership.

Background: Family-centered care (FCC) is recommended as a frame of reference for treatment and care in NICUs. A key element in FCC is partnership. Such partnerships are characterised by complex interpersonal relationships and interactions between nurses and parents/families. Partnerships therefore appear to present a significant challenge.

Design: A qualitative review and meta-synthesis.

Methods: Comprehensive searching in ten databases: Cinahl, Pubmed (MEDLINE), Embase, PsycInfo, Scopus and Swemed+, Opengrey, MedNar, Google Scholar and ProQuest Dissertations & Thesis Global. A total of 1,644 studies (after removal of duplicates) were critically assessed and 21 studies fulfilled the inclusion criteria. A meta-aggregation was used to synthesise the findings from the studies. Methodically quality assessed with QUARI/SUMARI and PRISMA.

Findings: Through a meta-aggregative approach two synthesised findings were developed: 1) co-creation of mutual knowledge and 2) developing competencies and negotiating roles. The first synthesis embraced the categories: being respected and listened to, trust, sharing knowledge, and the second synthesis embraced the categories: space to learn with guidance, encouraging and enabling, being in control. In constructing the categories, findings were identified as characteristics, barriers and facilitators to application.

Conclusion: A successful relationship between parents and nurses can be achieved through co-creation of mutual knowledge as well as development of competencies and negotiation of roles. Neonatal Intensive Care Unit nurses are in a position where they exercise power, but they can change the culture if they are aware of what seems to facilitate or create a barrier to a partnership with parents.

Relevance to clinical practice: This new evidence may inform a change in policies and guidelines which could be integrated into nurses' clinical practice in NICUs.

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1. INTRODUCTION

Worldwide, more than one in 10 infants are born prematurely (before 37 completed weeks of gestation) each year – a total of approximately 15 million (WHO., 2018). Internationally, the number of premature infants has increased during the last decade (Blencowe et al., 2012) and, owing to advances in medical technology, the survival rates of these infants have increased (Group, 2009), especially in high-income countries (WHO., 2018). Preterm infants require highly specialized treatment and care in a neonatal intensive care unit (NICU) (Blencowe et al., 2012; WHO., 2018). Besides the infants' medical treatment needs, the parents also need support during the stay in the NICU: their feelings may range from the joy of having a living infant to constant fear that the infant may not survive, as well as a fear of later complications or disabilities (Agerholm, Rosthøj, & Ebbesen, 2011). Furthermore, mothers' and fathers' experiences may differ and may change over time. Accordingly, there is a focus today on the Family-Centered Care (FCC) approach (Hutchfield, 1999; L. Shields, Pratt, Davis, & Hunter, 2007; L. Shields, Pratt, & Hunter, 2006), where the family includes parents, siblings and significant others.

Family Centered Care is recommended (Committee on hospital care & Institute for patient and family-centred care, 2012) and is recognized as a frame of reference for treatment and care in NICUs (Gooding et al., 2011; McGrath, Samra, & Kenner, 2011; L. Shields et al., 2012). Key elements of the FCC approach are dignity and respect, communication and sharing of unbiased information, shared responsibility, as well as partnership between healthcare professionals and families of infants (Griffin, 2006; Mikkelsen & Frederiksen, 2011). A partnership exists "when there is a relationship between two or more people that have a shared goal" (Reis, Rempel, Scott, Brady-Fryer, & Van Aerde, 2010) [page 677]. Such a partnership is characterized by complex interpersonal relationships and interactions between nurses and parents/families, (Henderson, Reis, & Nicholas, 2015) and therefore appears to present a significant challenge.

A successful partnership will not be reached if the goal of care and collaboration is not shared, negotiated and agreed between the nurses and parents (Reis et al., 2010). According to Hutchfield (1999) there is a hierarchical relationship between involvement, participation and partnership, where the degree of partnership lies with the nurses (Coyne & Cowley, 2007; Matro, Flynn, & Preuster, 2014). To achieve a partnership, nurses must be able to facilitate the partnership by respecting parents' perspectives (Coyne & Cowley, 2007; Espezel & Canam, 2003; Reis et al., 2010; Trajkovski, Schmied, Vickers, & Jackson, 2012). Nurses need to acknowledge each infant and family as unique, and need to develop an equal and respectful partnership in delivering the highest quality of care (Henderson et al., 2015). However, in an effective relationship, collaboration and partnership, parents must have a choice and determine their level of involvement in negotiation with nurses. Parents should not act as substitute nurses by providing the nursing care (Coyne & Cowley, 2007), but should be acknowledged as having equal status as caregivers and should be perceived as knowledgeable and skilful (Hutchfield, 1999). Fegran et al. (2008) found that partnerships

between parents and nurses developed in a process from closeness to detachment. It is suggested that it is difficult to achieve partnerships based on parent-led care with nurses serving as consultants during hospitalization in an NICU (Fegran, Fagermoen, & Helseth, 2008; Fegran & Helseth, 2009), possibly because parents do not always know what they can expect in the cooperation or how to partner with the nurses (Espezel & Canam, 2003).

Often, and unconsciously, nurses will act as gatekeepers between parents and their infant (Cleveland, 2008; Trajkovski et al., 2012). Nurses' varying communication styles are also a critical factor in the establishment of the nurse/parent relationship (Cleveland, 2008). The parents' need for open communication is not always met by the NICU staff (Wigert & Dellenmark, 2013), and cooperation, collaboration, and negotiated care with shared decision-making are not always evident in the care provided to premature infants and their families (Hutchfield, 1999; Mikkelsen & Frederiksen, 2011). Accordingly, a change in the roles and attitudes of the NICU staff is required to facilitate a successful partnership (Greisen et al., 2009).

The realization of partnership seems difficult in clinical practice, possibly because there is a lack of comprehensive knowledge about what nurses and parents perceive as important in the mutual relationship and how they identify the partnership. This meta-synthesis explores what characterizes a successful partnership and identifies potential barriers or facilitators among parents and nurses in NICU. The resulting knowledge could pave the way for developing strategies to support the establishment of partnerships, thereby achieving successful FCC in NICUs and improving neonatal care and outcomes (Trajkovski et al., 2012). According to Medline, PROSPERO, the Joanna Briggs Database of Systematic Reviews & Implementation Reports and the Cochrane Database of Systematic Reviews, no systematic review is available about this phenomenon.

1.1. Aim

To explore how parents and nurses experience partnership in a neonatal intensive care unit, and to identify existing barriers and facilitators to a successful partnership.

2. METHODS

2.1. Research design

The qualitative review was based on a published protocol (Brødsgaard, Larsen, Weis, & Pedersen, 2016) and followed the Joanna Briggs Institute's (JBI) approach to systematic reviews (JBI, 2018), which supports the entire review process and provides a sound and rigorous methodology. The Qualitative Review and Assessment Instrument QUARI/ SUMARI data management software for facilitating appraisal of studies, data extractions, and generation of meta-syntheses was used. The systematic review and meta-synthesis was conducted in close collaboration between all authors, each contributing with their unique competencies within clinical practice, methodology and research. No ethical permits are required for meta-synthsis and no external funding was sought. The equator checklist document used in this systematic review was PRISMA, see supplementary file 1.

Search strategy

A three-step search strategy began with a preliminary search of PubMed (MEDLINE) and CINAHL. Keywords were identified from relevant article titles, abstracts and index words. Secondly, a comprehensive search strategy was developed and conducted by a research librarian in close cooperation with the other authors. Finally, the reference list of all included articles and reports was manually searched for additional studies.

The PICo (Participants, phenomena of Interest, Context) mnemonic was applied to identify the body of evidence. Types of participants (P) consider studies that include parents of infants

during hospitalization in NICU and nurses. Phenomena of interest (I) consider studies that investigate partnership from the perspective of nurses and parents. Context (Co) considers studies within the context of all levels of NICUs.

The keywords used:

(P) *Parent, Mother, Father, Health care providers, Health care professional, Staff, Nurses, Caregivers, Health Personnel.* (I) *Partnership, Partnering, Partner, Parental participation, Nurse-family partnership, Partnership with parents, Parent-nurse relationship, Nurse-parent relationship, Collaborative nurse/parent relationship, Complex interactions, Form relationship, Effective relations*hip*, Nursing attitudes to parents participation, Care by parents, Familycent*red care.* (Co) *Neonatal, Neonatal Care, Neonatal intensive care unit, NICU, Neonatal nursing, Neonatology, Neonatal intensive care nursing*

Database searching for published studies and reports were conducted in September 2017 and updated in November 2018 in PubMed (MEDLINE), Embase, CINAHL, Scopus, PsycInfo, SweMed+. Searches for unpublished studies were conducted in MedNar, Proquest Dissertations & Theses Global, Open Grey, Google Scholar, relevant homepages e.g. www.ipfcc.org and manually searched reference lists.

2.2. Eligibility criteria and study selection

Studies identified and assessed for inclusion were limited by year from 2000 onwards This period was chosen as it reflects current clinical practice including various levels of FCC implementation worldwide as ell as the years when parent were allowed more than just short-term visit in NICUs. Marerial included qualitative data from interviews and obersvational studied published in English, Danish, Norwegian and Swedish.

All the studies were exported into the Referencing System EndNote X8.2 (Clarivate Analytics) and sorting was performed in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guideline (Moher, Liberati, Tetzlaff, Altman, & Group., 2009). The exclusion criteria for primary studies were quantitative or mixed methods studies. Studies on special topics, such as pain, end-of-life, neonatal abstinence syndrome and breastfeeding, were also excluded because these involved additional elements to a partnership. A total of 42 studies were full-text assessed, and 21 of these were excluded (Table 1). In accordance with Figure 1 the PRISMA Flowchart Diagram, 21 studies were included in the qualitative meta-synthesis. The search profiles are available in the supplementary file 2.

2.3. Quality assessment, data extraction and synthesis

The identified studies were critically appraised by three independent reviewers (AB, PL, JW) for methodological quality. Disagreements among the reviewers were resolved through discussion. Following critical appraisal, studies that did not meet the quality threshold were excluded. Extracted characteristics of the included studies comprised specific details about the populations, the context, study methods, phenomena of interest and main results. Performing the qualitative syntheses, the findings and their illustrations were extracted and assigned a level of credibility: Unequivocal – evidence beyond reasonable doubt – illustrated with participant quotations from the original study; Credible - interpretations that are plausible in the light of data and theoretical framework; Unsupported – when findings are not supported. Through a qualitative analysis findings were then aggregated into categories based on similarity in meaning, and syntheses were generated based on these categories. These tasks were performed by two independent reviewers (AB, JW). During all steps of the process, agreement was achieved by discussion and moving back and forth between the primary studies, findings, categories, and generated meta-syntheses.

3. FINDINGS

3.1. Characteristics of the studies

Of the 21 qualitative papers included in the review (Figure 1), four studies came from Australia and the USA, respectively; three from Canada and Sweden, respectively; two from Denmark, Norway and the United Kingdom, respectively, and one from Mexico. Among the 21 studies, one was a thesis and 20 were journal publications. Participants in the studies comprised only mothers (2), only fathers (1), both parents (11), only nurses (4), nurses and parents (3). The settings for 19 studies were level III NICU's, including extremely premature infants; the settings for the remaining two studies were level II nurseries with moderately preterm infants. No studies reported conflicts of interest. Detailed information about the studies is presented in Table 2.

3.2. Meta-synthesis of qualitative data

A total of 102 findings were extracted from the 21 included studies, and they were all evidence classified as unequivocal (JBI, 2018). These findings were then aggregated into six categories describing characteristics, barriers and facilitators identified in the two sides of a reciprocal relationship between parents and nurses in NICUs. An example of category aggregation from study findings is presented in Table 3 and Figure 2. Two synthesised findings (Figure 3) were generated from the six categories:1) co-creation of mutual knowledge and 2) develop competencies and negotiate roles.

3.2.1. Synthesised finding one: co-creation of mutual knowledge

The three categories: Being respected and listened to; Trust; and Sharing knowledge were aggregated into the synthesised finding: Co-creation of mutual knowledge. This concept comprises context-specific knowledge. The nurses have medical expertise as well as

competence in healing and relieving suffering. Patients and families are experts regarding their own lives and living with illness; they have personal values, preferences, resources and experience. In the co-creation of mutual knowledge, nurses and families work together towards a new shared goal, integrating the knowledge and expertise of all parties. Meeting parents with respect and listening to them right from the start appeared to be fundamental for developing and/or maintaining trust and for sharing knowledge resulting in co-creation of mutual knowledge to benefit the infant and family during hospital admission and beyond (Figure 3).

Being respected and listened to

The category 'Being respected and listened to' appeared as a fundamental initial step to establish trust and mutuality. Findings describing the characteristics of this category included parents' positive experiences of being met with respect and understanding of their overall situation (Brødsgaard, Zimmermann, & Petersen, 2015). Parents referred to excellent competencies when they experienced staff gaining insight into their situation. This enabled the nurses to tailor support and information, respecting the parents' comfort zone, but also gently encouraging them to be the ones to provide care for the infant (Brødsgaard et al., 2015; Reis et al., 2010). Such competencies made them feel acknowledged as parents, as well as fellow human beings in a challenging situation. Parents also described 'caring' as a nurse competency that brought about a feeling of trust (Cescutti-Butler & Galvin, 2003).

Not feeling welcome (Cescutti-Butler & Galvin, 2003), not feeling important (Gallegos-Martínez, Reyes-Hernández, & Silvan Scochi, 2013), experiencing dictating and controlling nurses and feeling disrespected and frustrated due to inconsistencies in information and guidance (Cescutti-Butler & Galvin, 2003; Jones, Taylor, Watson, Fenwick, & Dordic, 2015), lacking acknowledgement of their emotional situation (Wigert, Dellenmark Blom, & Bry,

2014), and not feeling involved in critical decision-making, where parents found their observations of the infant were ignored (Sudia-Robinson & Freeman, 2000), were all barriers to parents feeling respected and listened to. Nurses were not always aware of how their interactions negatively affected the parents (Jones et al., 2015). When the infant was in a stable phase, nurses often withdrew from the family to enhance the parents' independence, not recognizing that they needed ongoing support from primary nurses to develop confidence (Fegran et al., 2008). Nurses, on their part, found that organisational and physical environment and lack of education were barriers to offering genuine support to the parents (Turner, Chur-Hansen, & Winefield, 2014).

Effective communication was perceived as a facilitator for being respected and listened to. Having regularly scheduled meetings with nurses and doctors (Arockiasamy, Holsti, & Albersheim, 2008; Weis, Zoffmann, & Egerod, 2015) was important, leading to parents feeling acknowledged through a deeper level of communication. Facilitating communication during daily care was also important to support parents in caring for their infant (Arockiasamy et al., 2008). This could be experienced as 'chatting' entwined with professional guidance (Fenwick, Barclay, & Schmied, 2001).

Trust

Nurse/parent trust arose when parents felt respected and listened to. The characteristics of 'Trust' included continuity in care with close nurse/parent relationships, which parents experienced as alleviating the stressful situation (Fegran et al., 2008). The nurses preserved trust by demonstrating medical expertise combined with empathy and affection for the infant (Smith, Steelfisher, Salhi, & Shen, 2012). Nurses emphasized openness, honesty and acknowledgement of parents' experiences as being essential elements to build and preserve trust (Fegran & Helseth, 2009; Trajkovski et al., 2012). Even though they valued trusting

nurse/parent relationships, they also perceived challenging and demanding aspects that might

form a barrier to building trust (Fegran et al., 2008). Their lack of trust in parents appeared,

for example, through perceiving parents as a threat to the safety of the infant. They were

concerned about their liability if the parents did something wrong (Heermann & Wilson,

2000). Mutual trust building was also obstructed when parents initially felt unable to

collaborate and actively entrusted decision-making to the professionals (Finlayson, Dixon,

Smith, Dykes, & Flacking, 2014). Another barrier arose when parents found open and honest

communicaton with the nurses difficult, because theyfelt frustrated over the healthcare

professionals' behaviour (Finlayson et al., 2014). This led to concerns about nurses' change

of shift (Sudia-Robinson & Freeman, 2000). Conversely, trust building was facilitated when

parents felt relieved by being ensured that healthcare professionals provided proper care for

their infant, especially in the beginning when parents felt they had no control (Arockiasamy

et al., 2008). During the critical phase, nurses considered the infant their responsibility, but

they also found it important that parents developed confidence in them as professionals

(Fegran et al., 2008). Trustful relationships with primary nurses seemed to strengthen

parents' confidence in assuming responsibility for the infant (Fegran et al., 2008). Meetings

scheduled between parents and nurses facilitated the development of such relationships

(Heermann & Wilson, 2000).

Sharing knowledge

Parents and nurses mutually found that sharing information on the infant's condition and

what to expect was essential to maintaining trust and security (Jones et al., 2015), and this

was identified as a characteristic of the category 'Sharing knowledge'. Mutual understanding

and shared decision-making helped parents to keep control of the situation and to find time

for their own recovery (Weis et al., 2015). Barriers to Sharing knowledge encompassed staff

communication skills, approach to nurse/parent collaboration, and type of information.

Feeling unequal to the staff impacted on parents' sense of control, so they did not ask

questions and then received limited information (Arockiasamy et al., 2008), and they missed

invitations to ask questions (Cescutti-Butler & Galvin, 2003). Often parents did not receive

adequate information about their infant's medical condition and what to expect. Even though

statistics were valuable they were left feeling that they needed more information. However,

they also realized that this information might not be available, owing to the uncertainty

associated with frequent changes in the complex condition of their infant (Arockiasamy et al.,

2008; Pepper, Rempel, Austin, Ceci, & Hendson, 2012). Obtaining information was an

important factor contributing to parents feeling in control (Arockiasamy et al., 2008). This

was facilitated by receiving consistent advice and guidance, where nurses and parents shared

different kinds of knowledge including experiences as well as evidence-based information

(Brødsgaard et al., 2015). Obtaining information about the infant's condition and progress

allowed parents to perform care and engage in shared decision-making (Smith et al., 2012).

When sharing knowledge, information could be tailored to the parents' emotional needs and

technical abilities. Furthermore, receiving consistent information supported parents' trust

(Smith et al., 2012). Hence, gaining insight into the parents' situation was central to nurses

for them to respectfully support parents, acknowledging their individual situation (Fegran &

Helseth, 2009). 'Chatting' was one way of communicating that facilitated an individualized

approach to collaboration, where both nurses and parents 'related', exchanged' and 'shared'

life-experiences (Fenwick et al., 2001). Using reflection-sheets filled in by the parents in

preparation for nurse-parent dialogues could also facilitate gaining insight into their lives, as

this helped them clarify their response to the situation and express their experiences, needs

and wishes (Weis et al., 2015).

3.2.2. Synthesised finding two: develop competencies and negotiate roles

This synthesis embraces a change from the traditional nurse/parent relationship, where the nurse is the expert and the parents are the outsiders/intruders, into a relationship as partners. The two categories 'space to learn with guidance' and 'encourage and enable' are fundamental for parents to reach the third category 'being in control' (Figure 3). When parents feel they are in control, they can further develop competencies in relation to their infant in the NICU. Feeling empowered to negotiate their roles within the nurse/parent relationship and integrating their family situation enabled parents to engage in an equal partnership. This helped nurses and parents to agree on common goals.

Space to learn with guidance

This category is characterised by being more than providing a physical space for parents to be involved in the care of their infant in the NICU (Heermann & Wilson, 2000). It includes a space or context with a supportive atmosphere, where nurses and parents can learn from each other by sharing knowledge. The nurse/parent interaction was a constantly changing process that evolved over time, acknowledging the parents' need for support (Trajkovski et al., 2012). Nurses could lead and guide parents, creating a space in which the nurses' professional skills and creativity came into play; they acted conscientiously and used foresight (Reis et al., 2010) when they involved the family in the day-to-day care of the infant. They shared information and guided families in developing their abilities in caring for the infant (Trajkovski et al., 2012) and parenting competencies. In this learning space, parents required nurses to fulfil roles as teachers, facilitators and guardians (Reis et al., 2010), as well as focusing on the family as a unit and integrating their needs. Furthermore, parents were appreciative when nurses gave the impression that they had all the time the family needed

and when they responded sympathetically to any issue the family might raise (Brødsgaard et al., 2015).

It appeared that there were some barriers to creating such a space to learn with guidance. Parents did their utmost not to interfere with the nursing routines, when they felt insignificant regarding their infants' care (Cescutti-Butler & Galvin, 2003). Furthermore, parents felt isolated if nurse/parent communication was absent, which amplified their concern and led to a sense of abandonment (Wigert, Hellstrom, & Berg, 2008). Some nurses felt challenged or intimidated when families were present in the NICU (Trajkovski et al., 2012) and wanted parents to ask their permission to do things around their infant (Cescutti-Butler & Galvin, 2003). Nurses were also aware of the importance of having parents' participation and perceived it as central to their activities in the NICU. However, they were unsure how to facilitate such participation, owing to a lack of guidelines and supervision (Wigert et al., 2008).

In this category, facilitators were identified when nurses provided parents with individualized bedside support (Turner et al., 2014), and when they maintained their technical expert role but at the same time could work with families as coaches, teachers and facilitators (Heermann & Wilson, 2000). Accordingly, when nurses acknowledged their professional role in the NICU as diverse and demanding at the technological level, as well as the emotional and interpersonal levels, they put great demands on their personal aptitude and capacity in the effort to create and balance a good relationship with the parents (Fegran & Helseth, 2009; Hermansson & Johansson, 2015; Turner et al., 2014).

Encourage and enable

The characteristics of this category included nurses feeling responsible for developing a caring relationship with parents (Hermansson & Johansson, 2015) by specifically encouraging parents to overcome their anxieties about caring for and handling their infant (Smith et al., 2012). This could be achieved through informal and formalized training of the parents in providing care for their infant, as well as providing opportunities for them to practice (Smith et al., 2012). At this stage, nurses were in the position to enable interactions between parents and their infant (Jones et al., 2015), so they could become familiar with the infant's signals, behaviour and needs. When parents truly participated in the infant's care, a partnership could evolve between nurses and parents (Heermann & Wilson, 2000); and a nurse/parent relationship characterised by negotiaton of role boundaries enabled a partnership where parents were meaningfully involved in the care of their infant (Reis et al., 2010). Furthermore, nurses' ability and willingness to respect and encourage parents to take the lead in decisions regarding the infant (Jones et al., 2015) and the family were essential for their development of competencies and roles.

Even though nurses stated that they loved to have parents present and involved in the NICU, there were some barriers to this. When nurses did not respond to the parents' greeting (Wigert et al., 2008) the parents did not feel welcome in the NICU (Sudia-Robinson & Freeman, 2000). They felt they disturbed the nurses and that their participation was on the nurses' terms (Wigert et al., 2008), rather than based on the parents' needs and desires. Another barrier occurred if the mother was primarily seen as a provider of food (Gallegos-Martínez et al., 2013) and not invited by nurses to participate in caring for the infant (Heermann, Wilson, & Wilhelm, 2005). It was also problematic if nurses did not actively support the parents in moving from passive to active caregivers (Heermann et al., 2005) to develop competencies and negotiate roles. Finally, nurses using non-supportive and ineffective communication

involving judgement and/or aggression conveyed a sense of incompetence among the parents (Jones et al., 2015).

In contrast, parents in the critical phase of the infant's admission could perceive themselves as spectators without feeling excluded, as long as they were informed and encouraged to give their infant physical contact (Fegran et al., 2008). Another facilitator was nurses who enabled interaction with a focus on developing parental competencies through encouragement, explaining, demonstrating and assisting parents to actively participate in the care of their infant (Jones et al., 2015). When parents perceived that they received particularly good support, it involved collaboration, conversations and advice that they felt was helpful to them (Brødsgaard et al., 2015). Furthermore, in the discharge phase, parents called for close nursing support, because of excitement and insecurity (Fegran et al., 2008). The more skilful the nurse was, and the more NICU experience the he/she had, the more confidence in the job he/she developed; consequently, routine tasks became easier, leaving more time for the nurse to support the parents as a basis for partnership (Trajkovski et al., 2012).

Being in control

Attaining the feeling of being in control was characterised by the parents moving from silence to advocacy and claiming responsibility for their infant's care (Heermann et al., 2005). When the parents had space to learn with guidance and were encouraged and enabled by nurses during the infant's transition through the NICU, it was a natural progression for them to be able to make appropriate decisions regarding their infant's care (Brødsgaard et al., 2015). This increased their sense of control (Arockiasamy et al., 2008). Furthermore, a supportive interpersonal nurse/parent communication style conveyed a sense of partnership and equality between nurse/parent (Jones et al., 2015).

However, attaining the feeling of being in control was not easy for all parents, since they felt that so much in NICU and in their lives was out of their control (Arockiasamy et al., 2008; Cescutti-Butler & Galvin, 2003). In frustration not being in control, parents sometimes chose not to be present in the NICU (Arockiasamy et al., 2008). Leaving the control to nurses was counterproductive for parents (Cescutti-Butler & Galvin, 2003), because they felt they needed to know everything about their infant (Finlayson et al., 2014). Mothers also experienced that not all nurses were willing to accept a mother in a partnering role (Heermann et al., 2005). They also found the nurse/parent power balance difficult if they felt disenfranchised in their relationship with nurses (Finlayson et al., 2014).

Nurses, on the other hand, felt intimidated and threatened by parents who told them what they could do and how they wanted them to care for their infant, since nurses were accustomed to think and feel they were experts (Heermann & Wilson, 2000). These negative experiences reflected some loss of control by nurses. When acknowledging the central role of parents to the infant's care it involved giving up a nurse/infant relationship, which many nurses treasured (Heermann & Wilson, 2000). Therefore, some nurses challenged the ideology of partnership, suggesting that there was an imbalance of equity, since they ultimately felt it was their decision and what they thought was best for the infant which counted at the end of the day (Trajkovski et al., 2012).

When nurses recognized, and were able to take pride in, positive changes for the infant and parents resulting from their nursing care, it seemed to be a strong facilitator for both nurses and parents to feel in control (Heermann & Wilson, 2000). If a nurse/parent partnership was established at an early stage of the infant's admission, the parents gained control and power over their infant sooner (Pepper et al., 2012). As their infant grew and became more medically stable, mothers found it easier to be more actively involved in providing care (Heermann et al., 2005). Thus, it was possible for nurses to withdraw their close support of

parents to enhance the parents' independence (Fegran et al., 2008), empowerment and control regarding their infant.

4. DISCUSSION

In this meta-synthesis we explored parents' and nurses' perceptions of the nurse/parent partnership in the NICU. Two synthesized findings were aggregated, each composed of three categories (Fig. 3). The three categories that formed the first synthesized finding 'Co-creation of mutual knowledge' appear to represent the precursors to developing relationships that are a fundamental characteristic of the nurse-parent partnership. The two concepts 'Develop competencies' and 'negotiating roles', which name the second synthesized finding, may appear to be two separate ideas. However, the thorough qualitative analysis revealed these to be two intertwined concepts. Parents developed competence in infant care and decision-making and this enabled them to negotiate and adjust their role over time. Support from the nurses and constant negotiation of role boundaries seemed to be fundamental for a successful process leading to a mutually beneficial partnership.

Co-creation of mutual knowledge

Co-creation of mutual knowledge is a dynamic process that appears to be critical for the establishment of a nurse/parent partnership. This exceeds the traditional view of communication in the NICU, frequently practiced by informing parents through one-way communication (Cescutti-Butler & Galvin, 2003; Finlayson et al., 2014; Pepper et al., 2012). Parents are often alienated and feel like outsiders in the NICU surroundings (Heermann et al., 2005; Wigert et al., 2014); hence the staff must do their utmost to be accommodating, welcoming parents to collaborate and participate, since these are the precursors to the formation of a trustful relationship (Fegran, Helseth, & Slettebø, 2006). By integrating parents' personal knowledge, values and preferences, the nurses obtain an understanding of

the family's individual situation, enabling them to tailor evidence-based information and support to the unique infant and family conditions (Weis, Zoffmann, Greisen, & Egerod, 2013). This, in turn, facilitates parents' participation in caregiving at their own pace, and promotes their empowerment and autonomy, resulting in parents experiencing acknowledgement of their personal situation (Brødsgaard et al., 2015; Fegran et al., 2008). This is fundamental for realizing shared decision-making between parents and healthcare professionals (Axelin, Outinen, Lainema, Lehtonen, & Franck, 2018; Hoffmann, Montori, & Del Mar, 2014). It is important, however, that collaboration and care plans are documented to guide different nurses in their daily work with the family, creating consistency and supporting parent trust.

Communication that integrates parents' personal values and preferences is central to reach a shared understanding and decision-making (Axelin et al., 2018; Weis, Zoffmann, & Egerod, 2014). Nurses may think they know what the parents want to say (Weis et al., 2014), but studies have shown discrepancies between the support provided by the nurses and the parents' actual perceptions and needs (Fegran et al., 2008; Franck & Axelin, 2013). One-way communication, where nurses display dictating and controlling attitudes, fail to meet the individual needs of the parents, causing distress and frustrations. Nonetheless, parents are cautious about challenging the system, trying to 'learn the rules' and 'fit in' (Cleveland, 2009). Conversely, through effective person-centred communication, parents are listened to and their views are respected. This has been described as reciprocal communication, where the first word is given to the parents, asking for their experiences and observations (Axelin et al., 2018). The professionals listen actively and confirm their understanding of the parents' account (Axelin et al., 2018; Weis et al., 2014). Using such effective communication techniques promotes obtaining the necessary insight into how parents experience life with a preterm infant in the NICU, their resources for handling the situation, as well as the limit for

when it becomes too overwhelming, to tailor support and information (Weis et al., 2013). Using this approach is a way to render transparency to the admission course and prepare the parents for the next step. For instance, if nurses explicitly discuss their strategy of withdrawing from the family for empowerment purposes, this process may be negotiated between the nurse and the parents, integrating parents' readiness as well as nurses' evidence – and experience-based knowledge. Being prepared, knowing why, and making plans together facilitates the transfer of responsibility to the parents in a process where the parents do not feel frustrated at being left to themselves.

Nurses consider the core concepts of FCC important to reinforce the establishment of a nurse-parent partnership (Griffin, 2013), but they also find it challenging to work with the families (Fegran et al., 2008; Trajkovski et al., 2012). Furthermore, the professional role has become unclear in the process of sharing responsibility with the parents (Axelin, Ahlqvist-Bjorkroth, Kauppila, Boukydis, & Lehtonen, 2014), and this may result in power struggles (Cleveland, 2009). Partnerships frequently develop informally on an ad hoc basis, rather than as the result of a deliberate process (Corlett & Twycross 2006), and some nurses view a positive nurse/parent relationship as nothing more than meshing of personality types (Cleveland, 2009). In general, though, there is agreement that lack of competence may form a barrier to building trust and sharing knowledge, and nurses demand education and guidance as well as organisational structures to support collaboration based on FCC principles (Trajkovski et al., 2012; Turner et al., 2014). Training nurses is effective in changing attitudes and care practices (Axelin et al., 2014), but this may not be enough to sustain a change of culture, as regression to past practice is a major threat to the implementation of improved parent support (Axelin et al., 2014; Frost, Green, Gance-Cleveland, Kersten, & Irby, 2010). Explicit guidelines and interventions to guide the nurses in their daily practice are needed to sustain the implementation of collaboration based on FCC philosophy (Frost et al., 2010). A recent

intervention based on structured nurse-parent communication, where parents prepare for nurse/parent dialogues by filling in reflection sheets, may be successful in maintaining guidance of nurses and parents in building trust and sharing knowledge (Weis et al., 2013).

In our findings we identified two rather similar situations that described collaboration in the critical phase, where parents felt out of control and unable to collaborate. One situation, where parents felt unable to collaborate, entrusting decision-making to the professionals, we categorized as a barrier to trust (Finlayson et al., 2014), whereas the other situation, describing parental relief by being ensured that the healthcare professionals provided proper care when parents felt they had no control, was categorized as a facilitator (Arockiasamy et al., 2008). Collaborating with the parents in the critical phase is a tough balance. The parents, feeling inadequate and in no position to act, are dependent on the healthcare professionals. Observing proficient care of the infant creates trust in the healthcare professionals. Conversely, welcoming the parents to collaborate from the first minute is a basic tenet of FCC, where parents must be respected as primary caregivers. This is important for supporting the initial bonding process. When transferring decision-making to the caregivers it may be difficult to restore the power balance, resulting in parents feeling excluded as time progresses (Finlayson et al., 2014). Hence, parents should be invited to participate in caregiving and decision-making from the very start. Through co-creation of mutual knowledge, parents and nurses may jointly determine nurse/parent roles and activities that may change over time during the stay in the NICU, in response to the changes in the infant's condition and the parents' competence (Fegran et al., 2006).

Develop competencies and negotiate roles

Development of parenting and competencies in the care of the premature infant requires first and foremost that parents feel welcome and are present in the NICU. Over the last decade,

substantial progress has occurred towards the unrestricted presence of parents and other relatives in the European NICUs (Greisen et al., 2009), although this is not the policy worldwide. Even with unrestricted policies, the parents' presence in NICU varies from a median of 3.3. to 22.3 hours per day and skin-to-skin contact with infants varies from 0.3 to 6.6 hours per day within the first two weeks of the hospitalization in 11 NICUs in six European countries (Raiskila et al., 2017). If the parents are not present and actively engaged in the infants' care and well-being, a delay in the development of their caring competencies and parental role may occur. A consequence of this can be negative perceptions of the preterm infants, because parents have too little time to bond with their infant during the stay in the NICU (Amama, Bayes, & Sundin, 2015). This can lead to parents having an incomplete sense of parenting their premature "fragile" infant after discharge (Amama et al., 2015).

This meta-synthesis has shown that nurses are in the position to invite parents into a nurse/parent partnership in NICU. This requires that the nurses invite, encourage and support parents to be active in the caregiving of their infant by creating a space to learn with guidance. In this space the nurse must step forward, guiding parents at the bedside or withdrawing to the back according to the explicit and implicit needs expressed by the infant and the parents. Thereby nurses can support the parent in developing their competencies, thus not leaving the parents vulnerable to parenting their infant following hospital discharge. Nurses must be curious about how to nurture the parents' development of competencies and that they become active in caring for the infant, whereby parents may gain confidence, self-efficacy and empowerment (Umberger, Canvasser, & Hall, 2018). The constantly changing and evolving process of the premature infants' needs (Arabiat, Whitehead, Fpster, Shields, & Harris, 2018), and correspondingly the need for the development of the parents' competencies in the process of moving from passive to active caregivers, call upon highly

skilful nurses possessing technical, empathic and communicative competencies. These nurses are in control and hold the power; however, they also have the challenge, responsibility and obligation to manage this power to benefit the infant and parents. When nurses purposefully provide a space to learn with guidance and encourage and enable the parents in their development of competencies, they simultaneously empower the parents to achieve the feeling of being in control and able to exercise their power as parents in an equal partnership with nurses. This process is facilitated when nurses fulfil roles as teachers, coaches, facilitators and guardians (Heermann & Wilson, 2000; Reis et al., 2010).

Communication needs to be expressive, clear and transparent so that parents' and nurses' expectations to each other's competencies and roles are clear when building a partnership. This is echoed by Arabiat et al. (2018) especially because parents' expectations are not universal, but grounded in the families' cultural and ethical beliefs, family structure and traditions (Gooding et al., 2011). When knowledge is shared freely in a reciprocal communicative relation (Arabiat et al., 2018), parents are valued as partners in the infants care and acknowledged for their unique role in the care team as well as included in decision-making regarding their infant. Thereby a collaborative relationship is nurtured (Umberger et al., 2018) supporting a partnership-in-care between parents and nurses. However, parents need to be empowered and feel in control to serve as natural advocates for their premature infants, whose emotional, social and developmental needs are serious and urgent (Gooding et al., 2011).

This meta-synthesis also emphasized that a successful partnership between parents and nurses includes the negotiation of roles. The term 'negotiated roles' suggests a duality in the nature of the interactions. Regarding these unique and complex nurse/parent interactions, negotiation does not refer to a linear process but rather to a relationship where parents' and nurses' skills are handled in a flowing collaboration for the infants' and families' well-being

(Reis et al., 2010). This reciprocal negotiation of roles can be viewed, as illustrated by Fegran and colleagues (2008), by moving from closeness to detachment within a short or longer period corresponding to the competencies developed. However, the negotiation of roles will be a natural progression (Brødsgaard et al., 2015) for both parents and nurses when the interaction and partnership are built around a shared goal (Reis et al., 2010). Furthermore, negotiation allows parents to retain the feeling of being in control (Corlett & Twycross, 2006).

Fostering a culture of partnership in NICUs has advantages. O'Brien et al. (2013) in Canada and Örtenstrand et al. (2010) in Sweden showed many benefits to both infants and parents when families are fully integrated in the NICU team and actively provide care for their infants. Mothers reported lower stress scores and felt more knowledgeable and confident, while infants exhibited improved weight gain and a higher rate of exclusive breastfeeding at discharge (O'Brien et al., 2013), as well as a shorter stay in the NICU (Örtenstrand et al., 2010).

5. STRENGTHS AND LIMITATIONS

The close cooperation between the authors was a strength, which ensured that each of them contributed with their unique competencies to qualify the keywords, the outcome of the search, identification of findings and the aggregation of the meta-synthesis. Another strength was that the comprehensive literature search was conducted in ten high-quality databases to minimize selection bias. To ensure that all studies fulfilled the inclusion and exclusion criteria, and to avoid missing any relevant articles, all keywords were customized to each database. Furthermore, the structured and exhaustive search methodology was well documented according to the standards of reproducibility and was confirmed by all authors. However, the synthesis also has some limitations. First, only studies published in English,

Danish, Norwegian or Swedish were included in the synthesis. Even though 21 studies were included, only one study came from outside native English-speaking countries or Scandinavia. Collaboration between parents and nurses in a partnership may be reported in other languages too, and studying partnerships in other cultures would have strengthened the synthesis. Second, limitations of the primary studies included in the synthesis, e.g. language, access, time frame etc., are not emphasized in the methodological assessment template. However, using an electronic template was a strength to handle data rigorously and systematically in the entire review/synthesis process. Third, studies on partnership with a focus on pain, end-of-life, neonatal abstinence syndrome and breastfeeding were excluded and might have provided a more comprehensive synthesis of these phenomena. Finally, the differences in mothers' and fathers' experiences, which could have highlighted gender specific issues, have not been addressed. Despite the limitations, meta-synthesis is the preferred approach for developing recommendations for action (JBI, 2018).

5.1. Suggestions for future research

Future studies on the development and evaluation of guidelines and interventions to ensure operationalization of findings of this meta-synthesis into NICU practice are required. Such new guidelines and interventions are important to support changing the culture in NICU towards facilitating the establishment of partnerships between nurses and parents.

6. CONCLUSION

This meta-synthesis identified how a successful partnership between parents and nurses can be achieved through the co-creation of mutual knowledge as well as the development of competencies and the negotiation of roles. Several facilitators and barriers to such a partnership have become visible through the synthesis. Neonatal Intensive Care Unit nurses are in a position where they exercise power, but they can change the culture by being aware

of what seems to facilitate or act as a barrier to a partnership with parents. Even though it is challenging to develop and sustain a balanced partnership, it is a dynamic process that changes over time. Nurses have the power to reduce and eliminate many of the identified barriers to enable a successful partnership with parents of premature infants in NICUs.

7. RELEVANCE TO CLINICAL PRACTICE

All included studies met the highest level of credibility. Practice according to the principles of FCC in NICUs continues to be a challenge for the nurses. Development of evidence-based policies and guidelines is needed to promote FCC, hence the findings from this meta-syntheses are relevant and important. When reviewing the policies in NICUs, ways could simultaneously be found to promote the presence of parents and to integrate them into daily life in the units (Greisen et al., 2009), in order to create a partnership and to support them in parenting their premature infants. Nursing leaders are well positioned to realize FCC. They are key actors and must take active ownership and ensure momentum of the implementation process. They are responsible for strategic change mangement, motivating and guiding the nurses (Weis et al., 2014). The implementation process requires organizational support, education and training of the nurses. The education and training must comprise an assessment of family needs, effective communication and supporting parents in becoming doers rather than observers (Trajkovski et al., 2012). Furthermore, daily open discussion among the nurses are a requirement for achieving an awareness of potential barriers. Nurses could work actively by mentoring and/or challenging each other on a daily basis in an attempt to reduce and eliminate barriers and promote facilitators to partnership with parents in their NICU. However, for families truly to experience FCC the principles must be disseminated within the multi-disciplinary team.

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TABLE 1 Excluded studies

Study

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TABLE 2 Characteristics of studies included in the meta-syntesis

Study/ Country	Methods for data collection and analysis	Phenomena of interest	Setting/context/ culture	Participant characteristics and sample size	Description of main results
Arockiasamy V, Holsti L, Albersheim S. 2008. Canada	Interview study applying content analysis. Semi-structured interview guide, fathers interviewed by male physician.	To learn how fathers of neonates who need protracted intensive care in a NICU describe their experiences and their need for support during this difficult time.	Level III NICU, Vancouver, British Columbia.	Purposive sampling of 16 fathers of very ill and/or very preterm infants who had been in the NICU for more than 30 days, English speaking. Three of the fathers had infants who died as a result of their illnesses.	Overarching theme was a sense of lack of control. Their worldview, as a 'backdrop' theme, provided context for the other four interrelated subthemes: Information, communication, roles, and external activities. Fathers reported that relationships with friends/family/health care team, receiving information consistently, and receiving concise written materials on common conditions were ways of giving them support. The fathers said that speaking to a male physician was a positive and useful experience.
Brødsgaard A, Zimmermann R, Petersen M. 2015. Denmark	Longitudinal growth assessments of 218 premature infants and a qualitative synthesis of two focus group interviews - analysed with content analysis - were used to evaluate an early discharge programme.	Describe the impact on the infant and families enrolled in an Early Discharge Programme model for preterm infants based on family-centered care.	Early discharge programme as an integral part of an NICU.	15 parents in 2 focus groups.	Parents in control with lifeline to neonatal intensive care unit based on 4 syntheses.
Cescutti-Butler L, Galvin K. 2003. United Kingdom	Focused conversational tape-recorded interviews were transcribed and thematically analysed. A modified grounded theory approach was used.	To explore and describe parents' perceptions of staff competence in a neonatal intensive care unit (NICU).	NICU 14 cots including 2 'intensive care' and 2 'high dependency care'.	8 parents who fulfil all the criteria: resident in NICU for more than 1 week, gestation at birth 28 weeks or above, baby ventilated for at least 3 days, discharged home within the last 6 months.	Four key themes which conceptualize competency as caring emerged from the data: parents are facilitated to integrate into the unit and do not feel burdened; parents feel in control whilst in the unit; parents have a choice to opt out from observing tasks and procedures on their baby; parents and the interprofessional team communicate well and provide appropriate information.
Fegran L, Fagermoen MS, Helseth S. 2008. Norway	A hermeneutic approach (Gadarmer) using participant observations (160 hours) and in-depth semi-structured interviews. Attention paid to prior	To explore the development of relationships between parents and nurses in an NICU.	13-bed Norwegian NICU.	6 mothers, 6 fathers, and 6 nurses, where redundancy of information was reached. Parents obtained the criteria 1) baby max. 32 gestational	A partnership between parents and nurses developed in 3 phases. The acute critical phase, the stabilizing phase and the discharge phase.

Study/ Country	Methods for data collection and analysis	Phenomena of interest	Setting/context/ culture	Participant characteristics and sample size	Description of main results
	understandings and prejudices as essential for the interpretive process.			weeks, 2) baby stayed in same hospital from birth to discharge. 3) family consisted of both a mother and a father, 4) both parents agreed to participate. Registered nurses obtained the criteria of 1) one of family's primary nurses, 2) employed in NICU for at least 1 year, 3) held at least a half-time position in NICU.	
Fegran L, Helseth S. 2009. Norway	18 individual in-depth interviews and 160 hours of participant observations with a Hermeneutic approach characterized by a dialectic interaction between data collection and data analysis.	Explore parents' and nurses' experience of the close parent-nurse relationship when a premature child is hospitalized.	13-bed NICU.	6 mothers, 6 fathers and 6 primary care nurses. Mothers' and fathers' mean age 31.3 and 36.1 years, respectively. Mothers had higher level of education than fathers. One pair of twins among the seven children. Nurses' mean age 34.5 years and 4 had undertaken postgraduate education, 2 of them in paediatric nursing, and average of 5.75 years of experience in an NICU.	Closeness based on interaction and building trust provided the findings essential to: the NICU environment, emotional involvement and closeness demanding commitment.
Fenwick J, Barclay L, Schmied V. 2001. Australia	Grounded theory analysis of over 60 hours of interviews with mothers, a thematic analysis of 50 hours of interviews with nurses and a content analysis of 398 tape-recorded interactions between nurses and parents. 28 mothers participated in a first interview and 23 in a second interview conducted 8-12 weeks	Explores the use of 'chat' or 'social talk' as an important clinical tool that can assist nurses achieve family-centred care in neonatal nurseries.	2 level II nurseries.	28 mothers and 20 nurses. Mothers: mean age 28.2 years, 15 giving birth at 30 weeks or less, 21 were first-time mothers and 3 had twins. Nurses: 18 RN with 1-20 years of neonatal experience, 2 were student midwives who had completed clinical practice	Both the context and method by which nursing care is delivered is important for the nurse-mother relationship. The verbal Exchange that takes place between mother and nurse influenced the mother's confidence, her sense of control, and her feelings of connection to her infant. The nurse's ability to effectively 'engage' the mother is dependent on the use of language that express care, support and interest in

Study/ Country	Methods for data collection and analysis	Phenomena of interest	Setting/context/ culture	Participant characteristics and sample size	Description of main results
	after discharge. 18 were face-to-face interviews and 5 were telephone interviews as the mothers had returned to their rural Communities. Unstructured open-ended questions, tape recorded and transcribed verbatim.			in level II nursery. 17 had both general and midwifery qualifications and 8 had completed NICU studies at postgraduate level.	parents. Language - a nurse's greatest assert and clinical tool.
Finlayson K, Dixon A, Smith C, Dykes F, Flacking R. 2014. England - northwest	Individual face-to-face interviews conducted in a private room in the hospital. A thematic network analysis was conducted on the transcribed interviews.	Explore mothers' perceptions of FCC in NICUs in England.	3 NICUs - 2 district-based with 20-25 cots and 1 regional unit with 54 cots also providing specialist facilities and expertise for extremely preterm infants.	12 mothers - 4 from each NICU, English speaking, over 16 years, whose baby had been treated on the unit for 7 days or more. Mothers whose infants were receiving intensive care at the time of the interviews were excluded. mean age 40 years. 11 were white British and 1 Asian British. None had spent time in NICU prior to this birth, all had a partner/husband who spent time in the NICU, 12 had elder siblings who rarely spent time in NICU.	Global theme: Finding my place supported by 6 organizing themes: 1) Mothering in Limbo, 2) Deference to the Experts, 3) Anxious Surveillance, 4) Muted Relations, 5) Power Struggles and 6) Consistently Inconsistent. Mothers experienced a state of liminality and were acutely sensitive to power struggles, awkward relationships and inconsistencies in care. To try to maintain their equilibrium and protect their baby they formed deferential relationships with the healthcare professionals and remained in a state of anxious surveillance.
Gallegos-Martinez J, Reyes-Hernandez J, Scochi CG. 2013. Mexico	Semi-structured interview taped and integrally transcribed. A content analysis using a thematic approach with 3 steps was conducted.	The significance of participation for parents in a neonatal unit.	NICU Level II in a maternity hospital in San Luis Potosi.	20 Parents of both sexes 18-39 years, with a preterm hospitalized child.	1) the NICU as a place of suffering and waiting, 2) dealing with the child's admission, 3) being excluded from the hospitalized child's care, 4) being aware of inadequacies in the child's care.
Heermann JA, Wilson ME, Wilhelm PA. 2005. USA	Interviewed once face-to-face in a room adjacent to NICU. They were audiotaped and transcribed verbatim. Analysed using the procedures outlined by Spradley (1979).	To explore and describe mothers' experiences of becoming mothers while their infants were receiving care in	32-bed Level III NICU in an academic health centre in the Midwestern United States.	15 mothers were included if their infants were premature, without congenital anomalies, and had received care in the NICU for at least one weak. Mothers of 4 sets	Mothers developed from outsider to parent along four continua: 1) focus: from NICU to baby, 2) ownership: from their baby to my baby, 3) caregiving: from passive to active, 4) voice: from silence to advocacy.

Study/ Country	Methods for data collection and analysis	Phenomena of interest	Setting/context/ culture	Participant characteristics and sample size	Description of main results
		NICU.		of twins and 11 mothers of singleton infants were include. All mothers were Caucasian and were in Hollingshead social status groups that represent the middle to upper-middle classes.	
Heermann JA, Wilson ME. 2000. USA	Interview study using broad open-ended questions. Analysis based on the first 2 phases of Spradley for qualitative data analysis.	To explore and describe NICU nurses' experiences while working with parents and infants receiving family-focused developmental care during an implementation process.	32-bed Level III NICU in an academic health science centre.	10 nurses in NICU, all female. 1 had less than 3 years of experience, 9 had between 5-20 years of experience. 5 were trained as intervenors and 5 had no training in this.	4 major themes: 1) Nurses' negative experiences of family-focused developmental care (FFDC), 2) transitions central to parenting with parents, 3) positive experiences of parental participation, 4) organizational transitions necessary for implementing the FFDC care delivery model.
Hermansson L, Johansson A. 2015. Sweden	Semi-structured interview with qualitative content analysis.	To explore paediatric nurses' experiences of practicing relationship-based care for premature infants and their parents.	Two Swedish NICU's.	10 children's nurses working in neonatal units.	The findings are portrayed in the following categories: development of a caring relationship, relationship promotion practices in the neonatal unit, the difficulties with practicing relationship-based care. The theme is a gentle and challenging guidance.
Jones L, Taylor T, Watson B, Fenwick J, Dordic T. 2015. Australia	A qualitative descriptive design with thematic analysis.	Parents' and nurses' interactions with each other in the context of the special care nursery.	Two special care nurseries in Queensland Australia.	32 parents and 12 nurses.	Nurses and parents focused on similar topics, but their perceptions differed. Provision of information and enabling parenting were central to effective communication, supported by an appropriate interpersonal style by nurses. Parents described difficulties accessing or engaging nurses. Managing enforcement of policies was a specific area of difficulty for both parents and nurses.
Pepper D, Rempel G,	Interpretive description, semi-structured face-to-face interviews.	To describe parental perceptions of decision	Regionalized level III NICU,	Purposeful selection of 7 parents of infants born at 24	Three central themes: Decision Making before and in the NICU; Culture Shock in

Study/ Country	Methods for data collection and analysis	Phenomena of interest	Setting/context/ culture	Participant characteristics and sample size	Description of main results
Austin W, Ceci C, Hendson L. 2012. Canada	Interviews conducted in families' homes.	making concerning their extremely premature newborns who received care in a level III NICU.	western Canadian city.	to 26 weeks' gestation – 2parent couples and 3 mothers.	the NICU; Relationships in the NICU. Although information and decision making are interconnected and fundamental to parents' experiences of their preterm baby's NICU stay, they also identified the culture and language of the NICU and genuine relationships formed with healthcare professionals as significantly influencing their experiences.
Reis MD, Rempel GR, Scott SD, Brady-Fryer BA, Van Aerde J. 2010. Canada	Interpretive description. Recorded face-to-face or telephone in-depth interviews based on semi-structured interview guide.	Development of an effective and collaborative nurse/parent relationship. Exploring parental perceptions of the nurse's contribution to the parents' NICU experience and satisfaction with care of their infants.	69-bed level III NICU.	Purposeful sampling of 10 parents – 9 mothers and one father - inclusion criteria: infants admitted to NICU for a minimum of 7 days; fluent in English or willing to communicate through an interpreter.	The nurse/parent relationship was the most influential factor affecting the parents' satisfaction with their NICU experience. Conceptualization of an evolving nurse/parent relationship led to a visual depiction of a model termed Negotiated Partnership, comprising three themes: Perceptive Engagement; Cautious Guidance; Subtle Presence. The model conveys the actions and roles that parents desire nurses to fulfil within the nurse/parent relationship.
Smith VC, Steelfisher GK, Salhi C, Shen LY. 2012. USA	Limited application of grounded theory using constant comparative method. Semi-structured interview script containing 100 open-ended questions developed based on 8 focus group interviews with NICU parents – current or graduate – physicians, nurses, social workers, neonatal advance practice nurses and neonatologists. Face-to-face or telephone interviews.	Parental report of their NICU experiences, coping strategies and views of the ways NICU staff supported them.	40-bed level IIIB NICU.	24 families - 29 current and graduate parents, 18 years or older, with a surviving infant, able to speak/read English, retaining custody of infant.	Parents used the following coping strategies: 1) Participating in care of the child; 2) getting away from the NICU; 3) gathering information; 4) involvement of friends and family; and 5) engagement with other NICU parents. Staff can support the parents' coping strategies in the following ways: 1) Facilitating participation of the parents with the infant's care; 2) emphasizing documentation of the infant's progress; 3) demonstrating affection for the infant; 4) addressing concerns that make parents hesitant to leave the NICU; 5) providing accurate, consistent clinical information; and 7) arranging voluntarily activities or

Study/ Country	Methods for data collection and analysis	Phenomena of interest	Setting/context/ culture	Participant characteristics and sample size	Description of main results
					programmes in which parents whose infants have similar medical conditions may interact.
Sudia-Robinson TM, Freeman SB. 2000. USA	Case study descriptive design. Videotape recording of the parent-professional conference and audiotape recordings of interviews with the parents and NICU professionals directly involved in the care of the infant, made subsequent to a family conference. Videotape-recorded interactions between parents and the healthcare team during the family conference and the audiotape- recorded (Kagan's Interpersonal process recall (IPR) methods) interviews were transcribed verbatim and content analysis was used according to the steps outlined by Waltz et al.	Examine patterns of communication and decision making among NICU healthcare providers and the parents of a preterm infant who required neonatal intensive care.	NICU in a large metropolitan hospital in south-eastern USA.	One set of parents of an infant born at 25 weeks' gestation and first child. They were Asian and the father was the primary spokesperson because of the mother's limited ability to understand and converse in English. 2 nurses (the infants primary nurses), an attending neonatologist, a paediatric resident and a social worker.	The findings are categorized according to their representation of critical-stage or daily-stage decision making. Critical-stage decision making revealed that the parents were not involved. Daily-stage decision making showed that the parents had 4 areas of concern regarding their infants' routine. These were focused on parental visitation, staff change of shift, their infant's transfer to the IMCU and the administration of immunization.
Trajkovski S, Schmied V, Vickers M, Jackson D. 2012. Australia	Inductive thematic analysis of four focus group and five individual face-to-face interviews based on semi-structured interview guide.	To explore neonatal nurses' understanding of the philosophy of family centred care in the NICU and to describe how nurses view their role when delivering family-centred care.	32-bed referral level III NICU in Sydney.	33 NICU nurses currently practicing in a level III NICU. This included nurses providing direct clinical care, including a clinical nurse educator, aged between 25-64 years, tenure in NICU ranging from first-year postgraduate nurses to senior experienced nurses with more than 15 years of service in NICU.	Four dominant themes: 1) Getting to know the parents and their wishes; 2) involving the family in the day-to-day care; 3) finding a 'happy' medium; 4) transitioning support across the continuum. Nurses reported the potential benefits and challenges of adopting a family-centred care approach to deliver optimal care for neonates and their families.
Turner M, Chur-Hansen A, Winefield H. 2014.	Thematic analysis of semi-structured interviews – telephone interviews (face-to-face offered).	To explore the nurses' views of their role, both in the NICU and in the provision of	52-bed level III NICU of a large teaching hospital.	9 nurses, all women, between 32-58 years, with varying experience in NICU nursing.	Participants viewed their role as an enjoyable yet difficult one, requiring seniority, training and experience. They provided support to parents by

Study/Country	Methods for data collection and analysis	Phenomena of interest	Setting/context/culture	Participant characteristics and sample size	Description of main results
Australia		interacting with and supporting families emotionally.			communication, listening, providing individualized support and by encouraging parental involvement with their baby. Constructive elements that contributed to the provision of support included a positive NICU environment and providing a parent support group. More obstructive elements were a lack of physical NICU space, little time available for nurse-to-parent conversation and language and cultural barriers between nurses and parents.
Weis J, Zoffmann V, Egerod I. 2015. Denmark	Descriptive and comparative design using semi-structured interviews. Thematic analysis was applied. Part of a larger study into the effect of an intervention on parental stress.	To explore how parents of premature infants experience Guided Family-Centred Care (GFCC) intervention, and to compare how parents receiving GFCC versus standard care describe nurse-parent communication in the NICU. GFCC is a structured nurse-parent communication intervention drawing on parent preparation of reflection sheets designed to support nurse-parent communication.	36-bed level III NICU at a university referral hospital.	22 parents – ten dyad interviews with parent couples and two individual interviews with mothers. Parents in the intervention group versus standard care group were 13 versus 9.	GFCC was generally experienced as supportive. Three interrelated themes were identified that illustrated how the intervention helped parents cope as persons, parents and couples: 1) discovering and expressing emotions; 2) reaching a deeper level of communication; and 3) obtaining mutual understanding. In contrast, standard care communication was more superficial and less structured. Factors such as inaccessibility of nurses, inability to ask for assistance and parent popularity impaired successful communication. Compared to standard care, GFCC provided structured delivery of supportive communication. GFCC promoted the discovery of the parents' individual preferences and concerns, which enabled more focused communication, and set the stage for better nurse-parent and parent-parent understanding.
Wigert et al. 2014. Sweden	A hermeneutic lifeworld interview study as described by Dalhberg et al. with attention to 'bridling pre-understanding'.	How parents in the NICU experience their communication with the staff.	University Hospital with level III NICU including 22 beds divided among 2	18 families whose children were treated in NICU.	Main theme: being given attention or ignored in their emotional situation derived from 3 themes 1) meeting a Fellow human being, 2) being included or excluded as a parent, 3) bearing unwanted responsibility.

Study/ Country	Methods for data collection and analysis	Phenomena of interest	Setting/context/ culture	Participant characteristics and sample size	Description of main results
			intensive care and 2 intermediate care rooms with 1,000 newborns a year and a staff of 120 persons. High turnover of patients transferred to level II NICU or paediatric care unit or discharged to home.		
Wigert H, Hellstrom AL, Berg M. 2008. Sweden	Field study with hermeneutic lifeworld approach as described by Dahlberg et al.with participative observations and interviews with representatives of management, staff and parents. Observations were directed at the phenomenon – i.e. conditions for parents' participation in the care. 39 interviews with parents (10), paediatric nurse assistants (6), nurses (8) and management staff (15) supplemented observations to deepen understanding. Some interviews were recorded; some were carefully described in field notes.	To elucidate conditions for parents' participation in the care of their child in NICUs – participation includes physical presence as well as actively partaking in the child's care.	Two specially selected NICUs: a 22-bed NICU at a university referral hospital and a 15-bed NICU at a regional hospital.	Staff and parents in the units. Parents (10), paediatric nurse assistants (6), nurses (8) and management staff (15) participated in interviews.	The results point to a number of contradictions in the way parents were offered the opportunity to participate in NICU. Management and staff both had good ambitions to develop ideal care that promoted parent participation. However, the care including the conditions for parental participation was driven by the terms of the staff, routines focusing on the medical – technical care and environment, and budgetary constraints.

TABLE 3 Example of category aggregation from study findings – Category: Trust

Study: Heermann 2000

BA-F50: Nurses perceived a threat to the safety of the infants and had serious questions about their liability if the parents did something wrong. (U)	"They [the non-intervenors] were really nervous that she [the mother] wouldn't give the right formula, that she wouldn't give the right amount, that she would give too much, that she wouldn't know what she was doing, because they had never met her before. They didn't know what she was capable of, and reading it or being told it wasn't the same to them as knowing it themselves. They were still really concerned about their liability." (nurse) p. 26
FA-F55: The scheduled meeting times were viewed as facilitating the development of positive relationships with families. (U)	"The best aspect is the communication key. If you have someone who knows the family very well, they're going to be able to communicate family and baby needs and wishes and desires. The communication between the family and the staff and then amongst the staff should lead to meeting the needs and wishes of the parents as well as meeting the needs of the infant." (parent) p. 27

Study: Sudia-Robinson 2000

BA-F74: parents were concerned about nurses' change of shift. (U)	"[We] like to know, in advance – know who the nurse [will be]…You know,…so every time when we leave we try to figure out who [will] take her turn next…so that way we feel very confident." (parent) p. 146

Study: Fegran 2008

FA-F23: Even though nurses considered the infant to be their primary responsibility during the critical phase, they also found it crucial for the parents to develop confidence in them as professionals. (U)	"I strongly emphasize that I am in control of everything around, so they can focus on the child. …I talk very little in the beginning. I think parents experience me as being very calm. …I very seldom become stressed, and I think that makes parents feel safe." (nurse) p. 367
CA-F24: Continuity and close relationships with their primary nurses meant a lot to the parents during the stressful stabilizing phase. (U)	"It was almost as if we became friends." (mother). p. 368
BA-F25: In the stabilizing phase, nurses experienced closeness as being crucial for creating a trusting relationship, but challenging and demanding aspects were also present. (U)	"It can be very difficult to help parents cope with the situation, especially if we are busy. Having time…or maybe the issue of time pressure is just an excuse, because when things have calmed down I sometimes still choose to avoid close relationships. The more you talk to parents, the closer you get." (nurse) p. 368
BA-F26: In the stabilizing phase, unfamiliar nurses and divergent instructions confused parents and made them less confident, while a continuing relationship with their primary nurses seemed to strengthen parents' confidence in assuming responsibility for their infant. (U)	"I don't like it when we have to encounter unfamiliar nurses…even up to our last day in the unit we have encountered new nurses. We just feel safe with the ones we know. Different nurses do things differently." (father) p. 368

Study: Fegran 2009

FA-F33: Nurses find openness, honesty and acknowledgement of parents' experiences to be fundamental. (U)	"If I make a mistake, I have to admit this and explain to parents that if they want somebody else to take care of their infant that is OK with me. I have to respect this, if they have lost confidence in me … We (nurses) are human beings like everybody else, I can also make a mistake … parents should not be afraid of me making mistakes, and if it happens I must admit it and apologize for it. I would do that even though it could be difficult." (nurse) p. 670

Study: Finlayson 2014

BA-F37: Parents were not able to collaborate effectively during the first few days of admission,	"To be honest, we had a baby three months' early and she's tiny and in an incubator, so you do whatever the doctors say at first, because they're the experts." (mother) p. 121

and actively devolved their decision making to the professionals. (U)	
BA-F39: Mothers found it difficult to have open and honest communication with the nurses. (U)	"I wouldn't talk to them [nurses] about feeling upset or depressed or if I had worries about her or anything, in case they thought I was some kind of psychotic mother. I've never felt. . . . I just couldn't speak to them about anything personal or anything like that." (mother) p. 122
BA-F40: It was distressing for mothers when their frustrations related the behaviour of the health professionals and this obstructed establishing relationships. (U)	"And I dread those two nurses being with xxx [the baby]. I just think I'm gonna have a nightmare day today. If I want to ask anything then I feel like I can't and it has got to the point, with one of the nurses, where I feel like I just can't ask any questions. So I spend the whole day standing there worrying about it." (mother) p. 122
Study: Smith 2012	
CA-F69: Parents gained confidence in the staff when they showed both medical expertise and affection for their infant. (U)	"I think we felt like we were part of . . . the entire team. . . . They made us feel like they really care about [our baby], they try to . . . keep us really updated about how [our baby is] doing on a daily basis and tell us about the game plan [longer-term] . . . [so] we don't have to worry about her 24/7." (father) p. 348
Study: Trajkovski 2012	
CA-F75: The nurses valued a need to develop and build trusting relationships. (U)	"It's important to build a meaningful relationship with the parents in order to assist these parents in a difficult time in their lives. Parents have no choice but to leave their babies in our hands, so it's important they feel as though they can trust us. In order to build this trust and meet their needs we need to develop a meaningful relationship." (nurse) p. 248
Study: Weis 2015	
CA-F86: Obtaining mutual understanding and facilitating shared decision-making between parents and nurses. (U)	"She met us where we were and listened to us. But she also prepared us for the next step." (parent) p. 292 "[Having explicit plans] made it possible for me to keep control of the situation – also knowing when it would be okay for me to go for a walk, as this was important to my own recovery." (parent) p. 292
Study: Arockiasamy 2008	
FA-F2: Fathers felt relieved by being ensured of proper care by professionals. (U)	"I felt I had no control over him because of the care he was getting. I knew he was getting the proper care and stuff that I couldn´t do for him, so it´s like, okay, you guys are in control; you know what you´re doing. I felt I didn´t have to worry about anything."

CA: characteristics; BA: barriers; FA: facilitators; F: findings; (U): unequivocal.
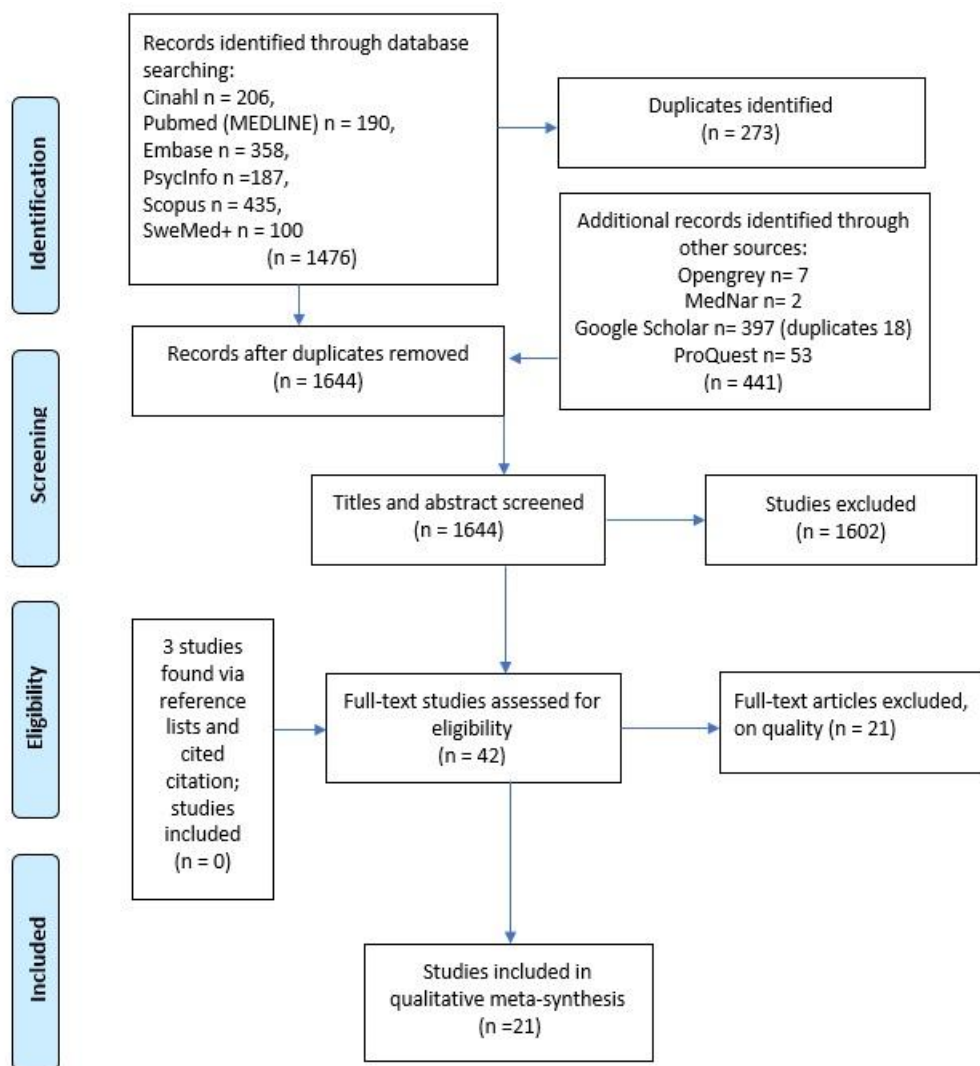
FIGURE 1 PRISMA Flow

FINDINGS

CATEGORY

Characteristics

CA-F24: Continuity and close relationships with their primary nurses meant a lot to the parents during the stressful stabilizing phase.

CA-F33: Nurses found openness, honesty and acknowledgement of parents' experiences to be fundamental.

CA-F69: Parents gained confidence in the staff when they showed both medical expertise and affection for their infant.

CA-F75: The nurses valued a need to develop and build trusting relationships.

CA-F86: Obtaining mutual understanding and facilitating shared decision-making between parents and nurses.

Barriers

BA-F25: In the stabilizing phase, nurses experienced closeness as being crucial for creating a trusting relationship, but challenging and demanding aspects were also present.

BA-F26: In the stabilizing phase, unfamiliar nurses and divergent instructions confused parents and made them less confident, while a continuing relationship with their primary nurses seemed to strengthen parents' confidence in assuming responsibility for their infant.

BA-F37: Parents were not able to collaborate effectively during the first few days of admission and actively devolved their decision making to the professionals.

BA-F39: Mothers found it difficult to have open and honest communication with the nurses.

BA-F40: It was distressing for mothers when their frustrations related to the behaviour of the health professionals and this obstructed establishing relationships.

BA-F50: Nurses perceived a threat to the safety of the infant and had serious questions about their liability if the parents did something wrong.

BA-F74: Parents were concerned about nurses' change of shift.

Facilitators

FA-F2: Fathers felt relieved by being ensured of proper care by professionals.

FA-F23: Even though nurses considered the infant to be their primary responsibility during the critical phase, they also found it crucial for the parents to develop confidence in them as professionals.

FA-F55: The scheduled meeting times were viewed as facilitating the development of positive relationships with families.
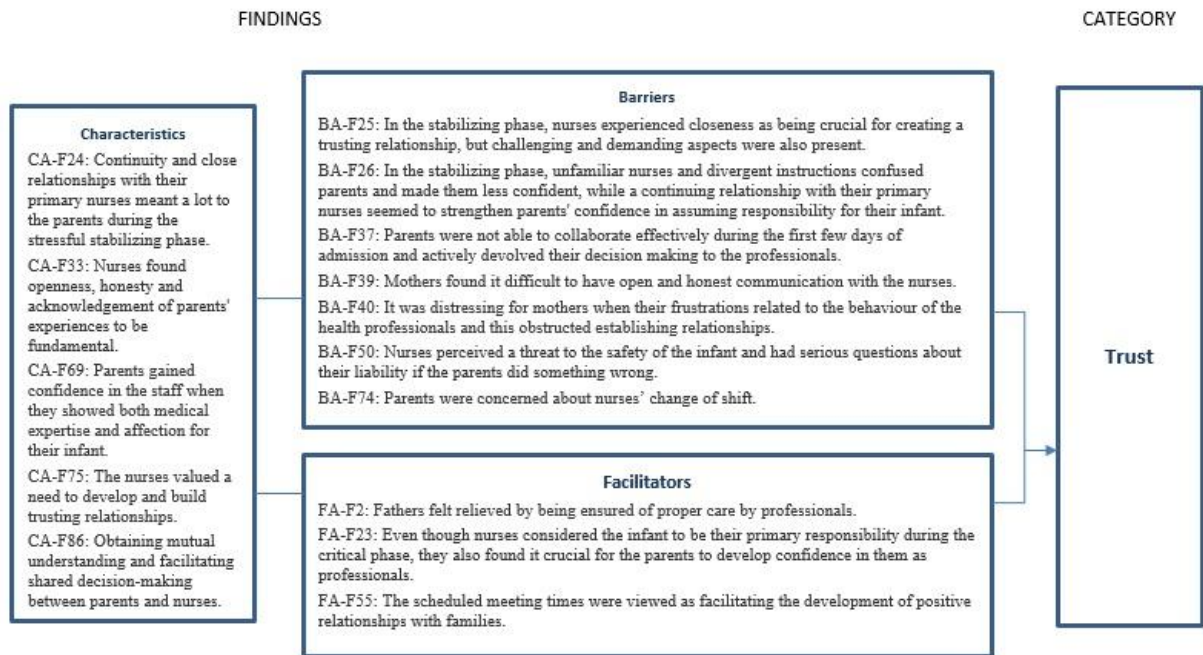
Trust

FIGURE 2 Category 3: Trust
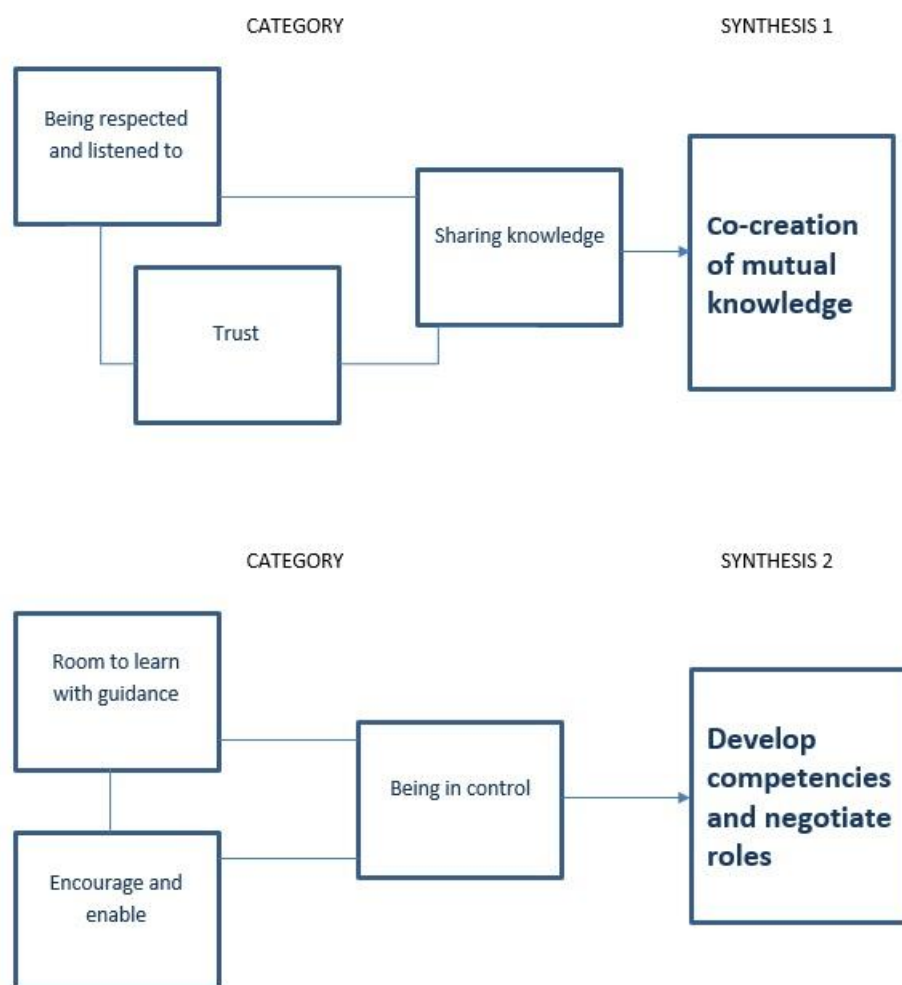CA: characteristic; BA: barriers; FA: facilitators; F: finding.

FIGURE 3 Synthesis of categories: Co-creation of mutual knowledge; Negotiate and develop roles and competencies