

Support for parents of preterm infants post-NICU discharge

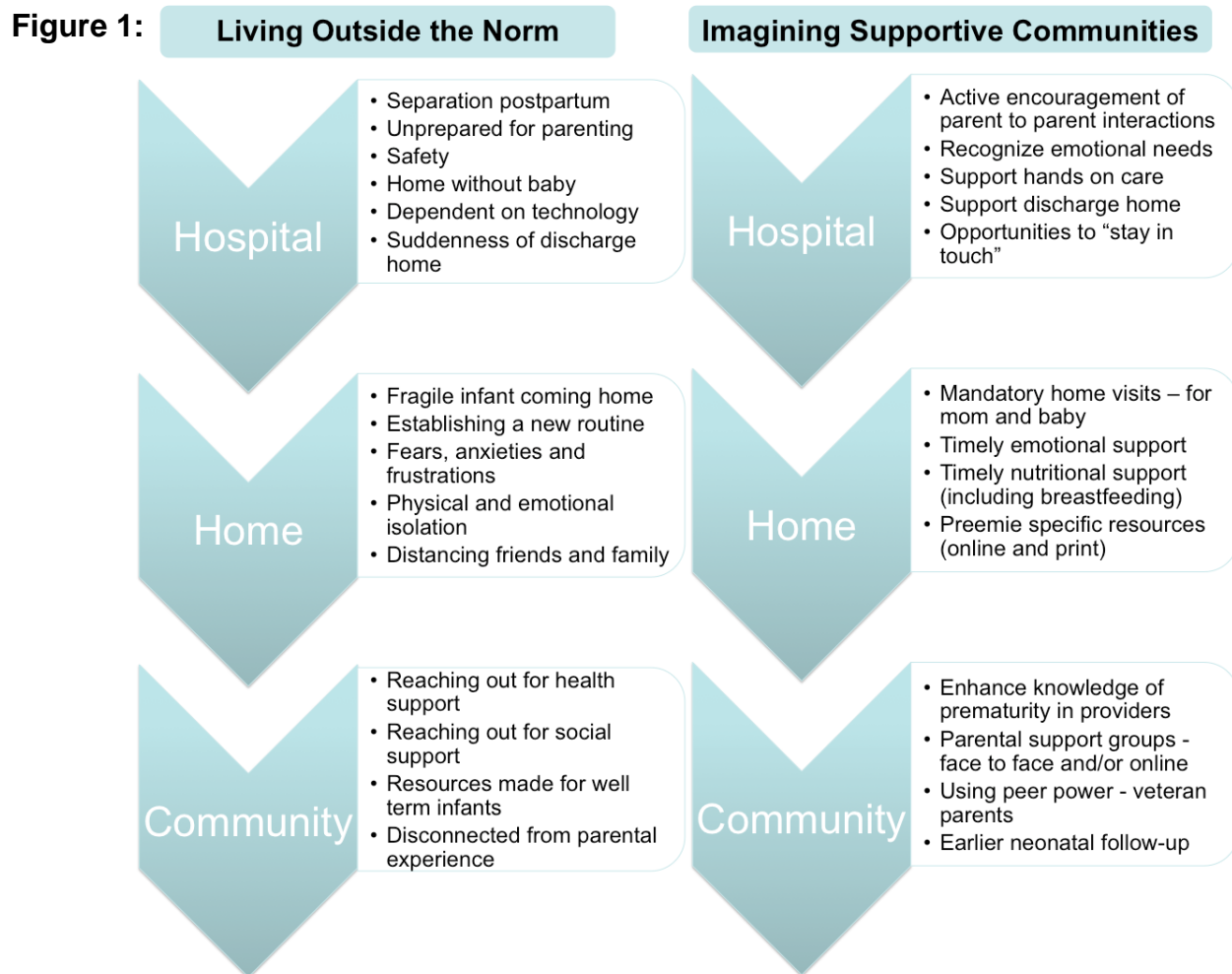
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Background: Preterm infants often require additional care and support after discharge and are at higher risk of neurodevelopmental disabilities¹²³. Parents of preterm infants have higher risk for short and long-term mental health issues (anxiety, depression, post-traumatic stress disorder) during neonatal intensive care unit (NICU) stays and following discharge¹²³. These issues can negatively impact the parent-infant dynamic¹²³⁴. The period immediately following NICU discharge is critical for parents as they navigate from the highly supportive NICU environment to an often-isolated home environment¹²³.

Objectives: To investigate parental perceptions of supports and services available following NICU discharge; including an exploration of how existing services could be improved and what community supports are perceived to be lacking.

Methods: A qualitative descriptive research design with secondary analysis was utilized. Two study groups included: 13 participants (11 mothers and 2 fathers; 2 couples) with preterm infants <32wks and 14 participants (8 mothers and 6 fathers; 6 couples) with preterm infants 32-37wks. Parents had infants that were 3-12 months post discharge. A combination of purposeful and convenience sampling was utilized. Individuals participated in focus groups with semi-structured question guide. Thematic analysis of the data was conducted.



Results: Two main themes were identified in the 2 groups: Parenting Outside the Norm & Imagining Supportive Communities (Figure 1). The themes spanned the continuum of parental experience from the NICU to home to community.

Parents perceived that their experiences of loss, fear, separation and trauma made them vulnerable to mental illness. However, they often did not see their health as a priority, particularly after discharge where their infant's interests were consistently placed above their own.

... You tend to ignore yourself... I'll deal with me later.

Parent 1, Mother, FG 2

Encouragement from NICU staff to seek out support was looked upon favourably.

It really feels like you can't talk to anybody else, when you are in the NICU... Parent 4, Mother, FG1, GP1

Participants identified peer support and emotional support as a need in the NICU and community. Parents reported self-imposed social isolation because of fears of illness and the lack of understanding of people who had not experienced preterm birth.

... when you come home you kind of start to process all those feelings and just and yes, the trauma, of feeling like uh not knowing if your baby's going to live, you know. And that's yes, something that other moms don't necessarily understand that sort of trauma.

Parent 2, Mother, FG 1, GP1

Belonging to support groups helped parents by providing them with hope, encouragement and reassurance; by building their confidence, validating their concerns and providing concrete advice for specific questions – some found that this “experiential knowledge” was *...more useful than [coming from] a health expert* (Parent 3, Mother, FG 1) to address *...specific mom-type questions* (Parent 2, Mother, FG 1).

Parents often perceived community services to lack expertise in preterm infants.

... he was 2.5 months old and I took him to public health for a weight and he was down a little bit. And they were like maybe it was because of his umbilical cord. I was like he is 2.5 months old – his umbilical cord fell off at like 2 weeks old. Like read the chart. You know it was frustrating. So I ended up stop taking him in altogether and got myself a scale at home ... it was really frustrating to deal with people who didn't get the premie thing.

Parent 3, Mother, FG3, GP1

Lastly, some fathers perceived the NICU environment to be predominately maternal orientated.

Conclusions: The study findings provide insight into the support parents need following discharge. Peer and emotional support were identified as particular areas of need. Further studies should focus on strengthening existing community resources and integrating peer support.

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