Peer support for mothers with infants with medical challenges

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Learning Objectives
1. Understand the impact of the NICU experience for families with medically fragile infants.
2. Identify protective factors for families and the role of breastfeeding.
3. Define the role of peer support in supporting a breastfeeding family with a medically fragile infant.

- No disclosures

About prematurity

15 million babies are born preterm.

The rate of preterm birth ranges from 5% to 18%.

**Leading cause** of death among children under 5 years of age.

Three-quarters of them could be saved with current, cost-effective interventions, such as warmth, breastfeeding support, and basic care for infections and breathing difficulties.

In low-income countries, 50% of very preterm babies die.

Long term consequences include learning disabilities, visual and hearing problems.

(World Health Organization, 2015)
Mothers Experiences
Parental Role Development
Going Home Transition
Maternal Wellbeing and Social Supports

The NICU bubble
“One word to describe the experience: challenging, the NICU bubble” (28 weeks)
“The hardest part was driving home without your baby, your life is not normal” (33 weeks)
“Parents are like the quarterback, but you don’t know what the play is” (35 weeks)
“There were too many cooks. Too many opinions.” (33 weeks)
“The most helpful were the nurses. The doctors were great, but I got to know the two nurses who were there with him. They didn’t try to sugar coat anything, they were honest and that helps when you are trying to know how your baby is doing” (34 weeks)

The rollercoaster experience
“The ups and downs are constant, one day they tell you they (the babies) are progressing and next day they have developed complications... you never know what to expect” (Mother of triplets born at 32 weeks)
Mothers sought detailed information about the health of their babies and demanded to be part of their care.

“My aunt is a NICU nurse in another state, so I took pictures of the monitors from my phone every day, morning and night, for her to help me read what they meant. I didn’t trust the nurses as much as [I trusted] my aunt.”

(mom of a baby born at 34 weeks gestation)

Understanding their babies’ condition brings comfort to parents; additionally, being considered in the decision-making affirms their role as caregivers.

“In the other NICU, we were present at hand-off. It was important to me to be part of that because they would ask me too what I saw; I was part of it. Then we transferred and I was asked to leave [during hand-off]. It was shocking to me.”

(mom of baby born at 28 weeks gestation, who was transferred to a different NICU for a month before going home).

On going home
Ready to go home, but not really...

The altered parental role was perceived to be the most stressful aspect of having an infant in the NICU (Obeidat, Bond & Callister, 2009).

“I worry, I am not an expert”

(32 weeks, Spanish-speaking)

Preterm birth negatively impacts the attachment relationship between mother and baby and on maternal responsiveness to the infant (Evans, Whittingham & Boyd, 2012).

The effect of the lack of understanding of infant cues (due to separation or baby’s development) disturbs the bond, leading parents to label their babies as difficult. Additionally, the vulnerability of parents to suffer mental health issues leads to increased negative outcomes for their babies (Craig et al. 2015).

“For the first three months they didn’t even look at me, like I wasn’t there day and night. They were 5 month when they smile. They were little people who knew I was their mom”

(triplets 32 weeks gestation)
Research supports the inclusion of families as true collaborators in the care of their children in the NICU (Hall et al. 2015b).

“We practically did everything for him. The nurses told us “we will split the check.” Knowing what to do made me feel better” (mom of a baby born at 32 weeks, Spanish speaking)

Research shows that it is not only positive to facilitate the transition home, but it has multiple positive benefits such as mothers showed lower levels of stress, babies gained more weight, babies were discharged earlier, and breastfed more often and for longer (Craig et al, 2015).

“The NICU time was beautiful for us. We held them all the time, but I couldn’t imagine coming home with them… it was easy there because someone else was doing all the work” (mom of triplets born at 30 weeks gestation)

Parents’ perception of readiness is highly impacted by the cues from the baby and the NICU staff (Burhman, Fealey and Sherrard, 2013).

Half of the mothers interviewed had difficulties getting coordinated and capable continuation of care.

These situations were particularly unsettling for mothers, while at the same time, caused a strong sense of maternal role attainment when successfully resolved.

Most mothers mentioned the lactation consultant at the hospital as their main source of support and information, even when not nursing.

The Spanish speaking mothers had many questions about their baby’s health and development, even at the time of the interview.
Check boxes

Facilitator 96%
Lactation Consultation 89%
Orientation 85%
Community Resources 92%
Colorado Early Intervention 87%
Information on Premature Infant Development 79%
Premature Infant Parent Support Group 81%
Coordination with PCP and Specialist 79%
NICU Parent Support Groups 84%
Assist Formula or Filling RX 84%
Mental Health Consultation 82%
Assist Medicaid 90%
Sibling Care Activities in NICU 81%
Transportation, WIC, Infant Supplies 81%

Support for siblings
Grandparents and friends
Home visitation
Someone to check in
Baby shower
Respite or postpartum doula

Family Dynamics and Social Support

"Everything was really stressful. I was so worried. My husband and I were arguing. I told the nurse that we might separate." (34 weeks)

"You are scared - out of control and don’t know what to do, what you can push for. We were too intimidated and needed someone else to assess what is normal - what you can do." (36 weeks)

I hemorrhaged and needed a transfusion. My husband didn’t want to leave me sad and lonely, but I told him: “go, he needs you more than I do.” (35 weeks)

"The hardest part is dealing with all the intervention people we have. My family and friends ask why are we doing all that." (36 weeks)

Difficulties providing care at home increased their feelings of isolation

"I took her home by myself so that was rough. I must have pulled over 5 times." (34 weeks)

"It felt like no one’s here for me." (34 weeks)

"My friends and family didn’t know what to do, how to help, so they stayed away. It would have been nice if someone had stopped for a cup of tea, just to check in. Everything changed since then, all of my closest friends now are moms who I have met after she was born." (34 weeks)
Mental Health

“I still have some postpartum depression; sometimes I have to remind myself that what happened wasn’t my fault. I get pretty hard on myself. Breastfeeding helps me a lot because that’s something I can do. He has never had formula, he used donor milk in the beginning. It’s hard to remember that I didn’t do anything to make this happen. Specially when he is on oxygen, it’s like my body didn’t keep him long enough.” (35 weeks)

“You are not in the right mind at the moment.” (35 weeks)

“I still have nightmares of those beeps. Sometimes I would fall asleep and I would wake up at the sounds of the alarms.” (34 weeks)

15-53% of mothers with infants in the NICU suffer PTSD. 8-33% of fathers

(Preemie Parent Alliance, 2016)

19% of all postpartum women suffer postpartum depression.

Increased risk for mothers of preterm infants, with prevalence estimates ranging from 28% to 67%.

“Whereas NICU mothers tend to be the most vulnerable to depression and anxiety symptoms in the postpartum period, they are unfortunately the ones that are most neglected.” (Chuff Siewert, Cline Segre, 2015)

Mothers with known high risk pregnancy were aware of vulnerability

None of the mothers recall to have been screened for PPD

They had suffered pregnancy lost, but not pregnancy loss counseling

None of them were receiving counseling services

Ask the hard question: How are you?
Protective factors in the transition NICU to Home

Being prepared
Family support
Personal background
Taking charge in the NICU
Positive interactions with NICU staff

Breastfeeding

Protective factors are individual or environmental characteristics, conditions, or behaviors that reduce the effects of stressful life events. These factors also increase an individual’s ability to avoid risks or hazards, and promote social and emotional competence to thrive in all aspects of life, now and in the future (Center for Disease Control and Prevention, 2016).

Breastfeeding

Every mother mentioned breastfeeding as a way to bond and “give life” to their babies, even if they nursed for a short time

Tangible way to know that they are essential for their babies

Bonded with their lactation consultants
  - breastfeeding
  - maternal role

Long-term goal, it kept them going

When it worked, they felt proud and accomplished

Common breastfeeding challenges

- Muscle tone
- Mouth-tongue coordination
- Higher caloric needs
- Low volume tolerance
- Primitive reflexes and integration
- Stamina
- Maternal trauma
- Misconceptions
What you need to know

- Adjusted/corrected age
- Asynchrony development/milestones
- High risk of maternal and paternal mental illness
- Information and support for siblings and grandparents
- Coordination of care is needed

Parent advocacy, resiliency and overall impact

- Identification as a NICU MOM
- Mothers rank peer-support as the most important factor in developing a maternal role.
- Breastfeeding peer counselors as a source of information, encouragement, and support because family and friends could not relate to their situation (Rosman, Green and Meyer, 2015).
- Psychosocial support is essential to mitigate the risks factors for mothers developing postpartum depression, anxiety disorder, and post-traumatic stress disorder. The shared experienced of peers allows for acceptance and provides foundations for the development of the caregiver role (Hall et al. 2015a).
Look at the latch, look at the mind, look at the heart
Teach baby's cues and communication
Model flexibility, set realistic goals, anticipate needs
Help normalize parent experience

Fathers want to be doers – give them a job
Siblings and grandparents need help too
Language barriers – Cultural competency
Conclusion
Parental role development
Family and social adjustments

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https://www.swhd.org/programs/disabilities-services/smooth-way-home/
http://www.who.int/mediacentre/factsheets/fs363/en/
http://babystepstohome.com/
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