

Essential Care in Neonatal Intensive Care (NICU): Using Parent Perspectives to Develop a Consensus Statement

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HENRY FORD HEALTH



NICU & COVID-19
Experiences Study

INTRODUCTION

- Parenting and family life were exceptionally susceptible to unanticipated changes during the COVID-19 pandemic.
- Pandemic-related practice changes may lead to elevated levels of stress and uncertainty especially for families experiencing an infant's admission to a Neonatal Intensive Care Unit (NICU).
- Prior to the COVID-19 pandemic, parental presence was encouraged through unrestricted visitation and family-centered care practices in the NICU.
- Parental caregiving is essential to an infant's healthy development, especially during hospitalization.

PURPOSE

To describe parent perceptions about a neonatal hospitalization during the COVID-19 pandemic and use findings to develop a consensus statement on essential care.



METHODS & ANALYSIS

- US-Based, online, anonymous survey
- Social media recruitment through Twitter, Facebook, and Instagram
- Data collected from May - July 2020
- Inclusion criteria
 - ✓ Infant admitted to a NICU on or after February 1, 2020.
 - ✓ Consent to participate in survey
- Free text responses to 4 open-ended questions qualitatively analyzed using NVIVO 11 software.



ESSENTIAL CARE (Quotes from Parents)

This whole experience has been the worst of my life and if my husband lives with me, and I'm allowed in the NICU, then he should be too.

He should be considered an essential caregiver and not a visitor. It's been incredibly hard to handle everything on my own and cruel.

The hospital as an institution put in place policies meant for the greater good, and yet seemingly not considering something that nurses, and doctors have long practiced and preached:
that family support of a baby in the neonatal intensive care unit is, in fact, essential.

Parents are not and should NOT be considered visitors.

We are essential for the baby's health and all of us need to be together as a family.

We also need to be present to advocate for our baby. We live together, eat together, my husband was dropping me and picking me up from the hospital. **So, we are exposed to each other, how does this reduce the risk?**

PARENTS ARE ESSENTIAL CAREGIVERS DURING COVID-19 ... AND BEYOND



FAMILY-CENTERED CARE

Advocates that families be respected as essential members of the care team.

- We believe parents and providers are allies in care
- We recognize and respect families' priorities, values, cultures, and beliefs.
- We encourage shared-decision making and partnership in care planning.

THE PARENT-INFANT DYAD

Parental involvement in the early days and months of life supports:

- healthy cognitive development.
- secure attachment.
- self-regulation, stability, and resiliency.



FAMILY PRESENCE

Family presence during infant hospitalization promotes:

- parental attachment.
- parental well-being.
- continuity of care.



We affirm the rights of parents to provide essential care for their infant during hospitalization, given the life-long importance of parent-infant attachment.

SUPPORTING PARENTS AS ESSENTIAL CAREGIVERS

Parental caregiving during hospitalization is essential care.

We encourage providers to value parental presence in the following ways:

- Promote policies and practices that prioritize parental presence and caregiving.
- Invite parent participation and input when revising policies that may limit parental presence.
- Set clear expectations. Openly and honestly communicate with families about shared responsibilities that are part of being an "essential caregiver."



• awhonn.org
• nann.org
• nationalperinatal.org

THEMES

- Emotional isolation and exhaustion.
- Parents desire to be valued as "essential" because parent presence is vital for infant health.
- NICU providers exacerbated or alleviated distress.

"Hospital policies [were] not in touch with the reality of families, making the impossible pain of [having] a baby in the NICU even more impossible."
(Parent Quote)

CONCLUSIONS

- Hospital policies viewed as 'non-sensical' and not in touch with the needs of families.
- Parents described the emotional struggle of being separated from support systems, feelings of isolation, lack of family-centered care, and exacerbation of emotional distress already known to be common to the NICU journey.
- To support families and advocate for unlimited parent presence, 3 professional organizations responded to the findings by creating a consensus statement on ESSENTIAL CARE IN THE NICU

SCAN for STATEMENT INFOGRAPHIC

