



# The Lived Experience of Parents who have Infants in Long Term Care in the Neonatal Intensive Care Unit

Ashley Blair, OTS; Dr. Sarah Tucker, PhD, OTR/L  
Department of Occupational Therapy | University of Alabama at Birmingham

## Introduction

### Background

Occupational therapy details a core standard for the neonatal intensive care unit (NICU) of partnering with families to provide them with resources, support, and guidelines during their administration period with their infant (O'Brien & Kuhaneck, 2020). Despite that this standard exists, there is limited information on what is needed from the parents to adequately support them as individuals and to navigate the barriers that are occurring. In the NICU, parents are at risk for a decline in their mental health status which could include depression, anxiety, and post-traumatic stress disorder (Grunberg et al., 2022). In previous literature, there are minimal suggested themes from parental experiences including feelings of isolation from infant care, worry, confusion, and a lack of support (Bry & Wigert, 2019; Williams et al. 2018). Overall, there is a gap in the literature where common themes need to be identified and reviewed by occupational therapy practitioners (OTPs) to enhance the holistic experience of the parent and infant in the NICU (Grunberg et al., 2022).

### Theory: PEO Model

The PEO model was established to focus on the relationship between how the person, environment, and occupation can promote or inhibit performance (Strong et al., 1999). As practitioners are developing a deeper understanding of NICU parents, this model helps to frame a perspective around understanding support systems through values, decision-making, extended family, friends, and the occupation of caring for others such as other children, the NICU infant, and spouses (Strong et al., 1999). This model is helpful to understand the strengths and weaknesses of the NICU.

### Occupational Therapy and the NICU

OTPs can address how the parent and infant are affecting each other and promote the most effective way to help the parent. NICU parents continue to show increasing mental health deficits along with distress in the environment that is continuing to not be addressed (Grunberg et al., 2022). Despite the suggestion that occupational therapy could be beneficial to the parental NICU population, there is very limited information found in research to accurately provide quality care and understand specific occupations that are being affected.

## Methods

### Design

This study utilized a phenomenological qualitative approach by participants answering semi-structured, open-ended interview questions asked by the primary investigator over a HIPAA-compliant Zoom platform. Interview questions were designed based on information collected from the Occupational Therapy Practice Framework-4 (OTPF4), the needs assessment, a review of the current literature available, and peer-reviewed articles.

### Inclusion Criteria

- Parents or caregivers whose child completed at least a month's stay in the NICU.
- English should be reported as their primary language.
- Participants must have access to the internet or a hot spot to complete a Zoom interview.

### Recruitment

- 12 participants were recruited to participate in this study through word of mouth and the use of a digital flyer published on UAB social media platforms (10 women; 2 men)
- Services received in: Alabama (58.33%), Mississippi (25%), Tennessee (8.33%), Ohio (8.33%)
- 10 participants reported receiving OT services

### Data Collection and Analysis

The interview questions reviewed around concepts of the overall parental experience in the NICU, including emotional well-being, autonomy, communication, occupational impact, and supports or barriers that exist in the environment. Each interview took about 1 hr., was transcribed verbatim, and reviewed three times to ensure accuracy during theme collection. An independent reviewer confirmed accuracy of decided themes.

## Results

### Theme 1: Personal Affect

- Role Shift
- 66% described adopting an advocacy role
- 58% reported experiencing interference with parental involvement

"I wanted to bathe my child... it was going to be a special moment for me, but I felt like I didn't have the authority to do so. Felt like the hospital had more authority over my own child and her care... so I didn't feel like her parent"

### Mental Health

- 100% identified a time of emotional hardship
- 75% felt mental health was not addressed and seven identified a lack of resources

"The problem is that you stuff those emotions so much that then they build up and build up, and then you have a break... And I think that women don't like to admit that we have issues sometimes because we think we need to be a strong mom, and moms aren't allowed to have issues"

### Theme 2: Environmental Affect

- Inadequate communication (75%)
- Misunderstanding medical terms (66%)
- Dismissed concerns (83%)

"What he said was, I just think you need to go out and get a drink. And I was like I need to go get a drink? Like it, it kinda, it really upset me"

### Environmental Support

- 91% received support from therapy services
- 75% received support from nursing staff

### Support Systems

- 50% reported times of isolation
- 58% felt disconnected due to others not understanding
- 66% reported a lack of parental support groups

"I definitely felt alone and felt like I was living a separate life on another planet... we don't ever get invited to do anything. I almost feel like they look at me as like the wounded bird"

### Theme 3: Occupational Impact

- Parent-infant occupations
- "I definitely felt there were times that I was just like, this is my kid, and I wanted to do more"

### Affect on Parent-Infant Occupations

Occupation	No/Minimal Affect	Negative Affect
Bathing	5	6
Talking	12	0
Dressing	11	1
Functional Mobility	9	3
Feeding	10	2

\*out of 12 participants

### Parent occupational performance

"We were always either at the hospital or transition to where we needed to go"

### Affect on Parent's Occupational Performance

Occupation	No/Minimal Affect	Negative Affect
Bathing	8	4
Talking	11	1
Dressing	12	0
Functional Mobility	9	3
Personal Hygiene	5	7
Child Rearing	5	7
Care of Pets	11	1
Home management	4	8
Religious/Spiritual Expression	10	2
Meal Preparation/Food management	5	7
Health management	3	9
Rest and Sleep	3	9
Social Participation	4	8

\*out of 12 participants

## Discussion continued

### Implications for OT Profession

OTPs should consider how to adapt current NICU interventions to provide improved family-centered care. Current findings support implications for:

- The continued validity of the PEO model
- The need for mental health interventions for the NICU parental population
- The call for advocacy for increased OT involvement to improve occupational performance of NICU parents

### Future Research

There is a need for research to explore avenues of effective interventions and resources due to the present study suggesting overwhelming declining mental health. When thinking about declining mental health, researchers should review potential contributing factors that this study identified, such as isolation, lack of support groups, major role shifts, and feelings of dismissal from staff. In addition to those already mentioned, a few other avenues of research may help close the literature gap, including the NICU's effect on the sibling and possible interventions for improving individual occupational performance during the NICU stay.

## Conclusion

The population's declining mental health, unaddressed isolation, diminished occupational performance and disconnected parental interaction continues to be neglected. This demonstrates the ongoing gap in care where NICU parents not only struggle emotionally but also leads to an effect on their occupational performance. OTPs have the skill set to evaluate, interpret, and provide services by providing effective interventions and resources to increase their well-being and occupational performance. OTPs must advocate for their position in the NICU to expand caring for the well-being of the parent and infant. The occupational therapy profession has the knowledge and the background to help break barriers and connect the medical world to a humanistic one.

## Discussion

### Key findings

#### Declining Mental Health

The results strongly imply that parental mental health continues to go unaddressed and ignored despite the high volume of parents experiencing emotional distress in the form of anxiety, stress, depression, or PTSD. Whereas past research has found around 50% of the NICU parental population experiences emotional hardship (Bry & Wigert, 2019), the present study has shown a significant increase with all twelve participants describing moments of emotional hardship.

#### Isolation

There is evidence of increased isolation caused by loss of friendship, inadequate support, and disconnection from others. There was a strong desire to be a part of a parental support group for these exact reasons; however, support groups and other similar resources were either non-existent or unavailable during other hours of the day for the working parent.

#### NICU Influence on Occupational Performance

The results indicated eight categories of occupations where at least half of the participants reported their occupational performance was negatively affected. Of the eight occupations, seven occupations came from questions about individual occupational performance, whereas only one occupation came from parent-infant occupations. An interpretation of these findings could indicate that parents dismiss opportunities to complete occupations to focus solely on the NICU infant. Another interpretation could look at the holistic picture of the individual. Many participants indicated declining mental health and feelings of isolation. This could result in decreased motivation towards completion of occupations or role overload when combined with expectations for the infant while in the NICU.

#### Limitations

Limitations included a smaller sample size, lack of variety in the demographics, reliance of self-reported data from the participants, and concerns for potential researcher bias.

## References

- Bry, A., & Wigert, H. (2019). Psychosocial support for parents of extremely preterm infants in neonatal intensive care: A qualitative interview study. *BMC Psychology*, 7(1), 76. <https://doi-org.uab.idm.oclc.org/10.1186/s40359-019-0354-4>
- Grunberg, V. A., Vranceanu, A. M., & Lerou, P. H. (2022). Caring for our caretakers: Building resiliency in NICU parents and staff. *European Journal of Pediatrics*, 181(9), 3545–3548. <https://doi-org.uab.idm.oclc.org/10.1007/s00431-022-04553-1>
- O'Brien, J. C. & Kuhaneck, H. (Eds.). (2020). *Case-Smith's Occupational Therapy for Children and Adolescents* (8th ed.). Elsevier: 565-600.
- Strong, S., Rigby, P., Stewart, D., Law, M., Letts, L., & Cooper, B. (1999). Application of the person-environment-occupation model: A practical tool. *Canadian Journal of Occupational Therapy*, 66(3), 122–133. <https://doi-org.uab.idm.oclc.org/10.1177/00084174990600304>
- Williams, K. G., Patel, K. T., Stausmire, J. M., Bridges, C., Mathis, M. W., & Barkin, J. L. (2018). The neonatal intensive care unit: Environmental stressors and supports. *International Journal of Environmental Research and Public Health*, 15(1), 60. <https://doi-org.uab.idm.oclc.org/10.3390/ijerph15010060>

## Acknowledgements

I would like to thank my faculty mentor, Dr. Sarah Tucker, the UAB Department of Occupational Therapy, my friends, and family for supporting me throughout this project.  
Ashley Blair, OTS | [ablair@uab.edu](mailto:ablair@uab.edu)