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# Parent and Infant Occupational Performance in the Neonatal Intensive Care Unit

Ashlea D. Cardin

A doctoral project submitted in partial fulfillment of the requirements for the degree of
Doctor of Occupational Therapy,
St. Catherine University, St. Paul, Minnesota

May 3, 2015

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**St. Catherine University**
**Doctor of Occupational Therapy**

**Certification of Successful Doctoral Project**

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Parent and Infant Occupational Performance in the Neonatal Intensive Care Unit

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## Dedication and Acknowledgments

I take solace in the fact the Lord God has a plan for my life. Not just any plan, though: A perfect plan. A perfect plan that began when I was born with a host of surprising orthopedic anomalies. I had a body that moved less-than symmetrically. A left side that looked quite different than my right. Feet that needed to be redirected. But it was my hands, specifically the differences in my left hand, that influenced and shaped my life story. I became an occupational therapist because I was an occupational therapy patient, and I have no doubt this was part of God's perfect plan for my life.

As part of this plan, He has provided me with endlessly selfless, supportive, encouraging parents. Family and friends have surrounded me throughout my personal, professional, and academic journeys. He has given me a loving and tireless husband, Kelly, to whom I dedicate this work. It is because of Kelly that I confidently embarked on this doctoral adventure; he has been my navigator, my compass, my constant companion, and the captain of our family ship. Along with him, my three children have cheered me on, patiently waited for (very late) goodnight kisses, and understood when mommy just needed "to get a little more reading done." This doctoral degree belongs equally to him.

I would also like to acknowledge the incredible faculty and mentors who have championed my efforts and challenged me to become more than I was the day before: Dr. Kate Barrett, Dr. Julie Bass, Dr. Kathleen Matuska, Dr. Kristi Haertl, Dr. John Fleming, Dr. Karen Sames, Dr. Penelope Moyers, Dr. Barbara Gilbertson, Paula Rabaey, Nancy Hendrickson, Sue Ludwig, Dr. Jennifer Pitonyak, Dr. William Wedenoja, Dr. Jay Lemery, Dr. Ginny Stoeffel, Dr. Wanda Mahoney, Dr. Tona Hetzler, Dr. Sapna Chakraborty, Traci Garrison, Tara Boehne, Peter Fayard, Leslie Bruce, Janet O'Flynn, Sharon Gartland, Jill Fyksen, and Dr. Melinda Slack and her entire NICU team at Mercy Kids Hospital, Springfield.

And to think it all began with a slightly asymmetric baby girl; I am thankful for that plan.

"May the favor of the Lord our God rest upon us; establish the work of our hands for us - Yes, establish the work of our hands." -Psalm 90:17 (NIV)

## Abstract

The earliest of occupational therapy interventions often commence in the Neonatal Intensive Care Unit (NICU), where mothers and fathers begin learning how to parent in unexpected surroundings and with unexpected complications. This project seeks to present an innovative approach to neonatal occupational therapy practice, framed using the Person-Environment-Occupation-Performance (PEOP) Model (Baum et al., 2015). A phenomenological approach was employed to build a picture of understanding by gathering and recording information about context, insights, events, and influences on parent and infant occupational performance in the NICU. Qualitative methods were used to explore the concept of occupational and co-occupational performance in the NICU and to provide rich descriptions of parent and infant occupations in the NICU setting. Five themes of active engagement emerged, serving as global descriptors of parent and infant experience and representing key aspects of the phenomena of parent and infant occupational performance in the NICU: Perceiving "They" vs. "I"; Maintaining Proximity; Expressing Emotions, Values, and Beliefs; Addressing Health Issues; and Analyzing. With increased knowledge and awareness of NICU-based occupations, neonatal occupational therapists can utilize The Person-Environment-Occupation-Performance (PEOP) Occupational Therapy Process (Bass et al., 2015) to guide occupation-based practice in the NICU setting. Thus, the purpose of this project was twofold: (a) to explore occupation and co-occupation as described by parents, and (b) to explicate the PEOP Occupational Therapy Process for use in the NICU.

*Keywords:* neonatal, infant, occupation

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# Parent and Infant Occupational Performance in the Neonatal Intensive Care Unit

The earliest of occupational therapy interventions often commence in the Neonatal Intensive Care Unit (NICU), where mothers and fathers begin learning how to parent in unexpected surroundings and with unexpected complications. Worry about the infant's health, the unfamiliar setting, technology, medicine, and constant monitoring can interrupt normal family functioning and bonding. It is within this hyper-technical and complex environment that occupational therapists have the unique opportunity to harness the power of occupation and support parents' engagement in their infant's care in order to achieve positive family outcomes (Altimier & Phillips, 2013). Family life in the NICU exists; however, it may look and feel very different from parents' expectations and dreams.

Recognition of the existence of NICU-based family life is fueling recommendations for a shift in neonatal occupational therapy practice. Although there will always be a need for specialized medical care and technology, occupational therapy has the opportunity to introduce and support family occupations in the NICU. There is increased recognition of the infant as an active participant in care and of the philosophy that neonatal caregiving should be family- (and not just infant-) centered. In an effort to bridge the gap between the infant's medical fragility and emerging family life, neonatal occupational therapists look beyond the infant's person factors to address interrupted

family engagement and participation, which in turn may affect family health and well-being.

This shift in thinking about infants as occupational beings and active participants in their environment coincides with the profession's transformation back to a "discipline focused on occupation" (Polatajko, 1994, p. 591). This contemporary paradigm, as described by Kielhofner (2009d), reminds neonatal occupational therapists that "occupational performance is a consequence of the interaction of person, environment, and occupation factors" (p. 44). Although this shift in process is recognized as important, a complete transformation of neonatal occupational therapy practice has not yet occurred. Three possible barriers or limitations to occupation-based practice in the NICU were examined as part of this doctoral project.

One limitation of occupation-based practice may be the lack of clarity surrounding what infant and family occupations exist in NICU. Without clear definitions of these constructs, occupational therapists may not recognize or value them as part of practice. While recommendations for neonatal occupational therapists' skill level, knowledge base, and general practice have been established (AOTA, 2006), there is paucity of literature describing parent and infant occupations in the NICU, as well as the role of occupational therapy in supporting family participation in these occupations. The *Specialized Knowledge and Skills* paper (AOTA, 2006) discusses related knowledge necessary for practice and introduces a paradigm of common vision defining the nature and purpose of occupational therapy (Kielhofner, 2009b). Considerations for the future evolution of this document might include the addition of construct definitions for NICU-based occupation and co-occupation, and examples of how occupation-based conceptual

practice models can serve to guide appropriate therapeutic application in this highly specialized setting.

Second, there is increasing interest in and consideration of interactions and activities *shared* by the infant and family. These interactions may be more appropriately categorized as *co-occupation* (Pickens & Pizur-Barnekow, 2009; Pierce, 2009, 2014; Price & Miner, 2009) due to the infant's innate dependency on others and the reciprocal nature of many activities. The term co-occupation is described briefly in the American Occupational Therapy Association (AOTA)'s *Occupational Therapy Practice Framework (3rd edition)* (AOTA, 2014) and recommendations are made for therapists to consider "an integrated view of the client's engagement in context in relationship to significant others" (p. S6). Yet, while the concept of co-occupation has been applied to generalized parent-infant populations (AOTA, 2014; Olson, 2004; Pickens & Pizur-Barnekow, 2009), there is paucity of research directly examining the nature of co-occupation in the NICU. This limited area of study raises multiple questions: Should neonatal occupational therapists address the *co*-occupational performance of both parent *and* infant? What are examples of co-occupation in the NICU? Should therapists facilitate the occupational performance of just the infant? Or widen the focus to include assessment of the parent? Who, truly, are the occupational therapy clients in the NICU?

Finally, A NICU-specific, occupation-based practice model or standardized assessment tool has yet to be developed, and there is scant literature outlining the occupational therapy *process* in the NICU. A host of relational and interventional studies have been conducted (Ludwig & Waitzman, 2007; Moore, Anderson, Bergman, & Dowswell, 2009; Pinelli & Symington, 2010; Price & Miner, 2009; Sheppard & Fletcher,

2007; Vanderveen, Bassler, Robertson, & Kirpalani, 2009; White-Traut et al., 2002), but little research exists describing the foundational key concepts and dynamics of occupation (Pierce, 2014) in the NICU setting. According to Pierce (2014), "Research on how occupation is implemented has always been the research type of greatest interest…[however], knowledge needs…have been met only by borrowed knowledge and therapist intuition, which has provided a rather rickety foundation for practice" (p. 249).

Thus, the innovative purpose of this doctoral project is twofold: to both *inform* and *transform* neonatal occupational therapy practice. First, in an effort to *inform*, this project provides occupational therapists, multidisciplinary NICU professionals, family members, and other stakeholders with rich definitions of parent occupations, infant occupations, and parent-infant co-occupations experienced in the NICU. Using a phenomenological approach, examples of occupations and themes emerged from an inductive qualitative analysis of parent interviews conducted in the NICU. Second, in order to *transform* practice and encourage a shift from a biomedical, sensory, or purely environmental view of the NICU infant toward one that assesses the infant and family in concert, this doctoral project employs a strong occupational focus and outlines the process guiding occupational therapist and client interaction in the NICU. This interactional process is framed using the Person-Environment-Occupation-Performance (PEOP) Model (Baum, Christiansen, & Bass, 2015) as a theoretical foundation for neonatal practice.

# Literature Review

Within the Neonatal Intensive Care Unit (NICU), care is focused on the infant's medical survival. While necessary, this medical-model approach puts infant and family development at risk. NICUs have historically been professional-centered, functioning predominantly under a hierarchical medical model of care (Lane & Bundy, 2012). Technical and clinical, the NICU is considered less-than-nurturing (Als, 1982), while the intrauterine environment is one most conducive to appropriate brain development and sensory experience (Altimier & Phillips, 2013). In the NICU, invasive procedures, frequent handling, and the risk of death disrupt family cohesion and alter parental roles (Woodward et al., 2014). The depth and breadth of this literature review explores the complex components influencing and shaping parent and infant experience in the NICU: The NICU environment, parent factors, the NICU admission process and journey, interrupted parenting, family-centered caregiving, and occupational therapy's role in the NICU.

## The NICU Environment

One mother of an infant in the Neonatal Intensive Care Unit (NICU) described the environment as "An 'alien world' filled with wilderness and without landmarks" (Hall, Brinchmann, & Aagaard, 2012, p. 86), and another mother described feeling overwhelmed when approaching professionals and technology in such a foreign

environment (Hall et al., 2012). Parents have described feeling "in the way" (Owens, 2001, p. 67) and perceiving themselves as burdens on the staff (Cescuti-Butler & Galvin, 2003). In one parent narrative, a mother contrasted the feeling of eerie, silent emptiness with the bright lights, constantly ringing monitors, and the incessant hum of her infant's ventilator (Owens, 2001).

When born prematurely or with medical complications, the NICU environment does not support typical emotional, cognitive, and physical development of the infant nor family unit. Infants are challenged by the sounds, touch, temperatures, movement, and positioning experienced (Altimier & Phillips, 2013), and parents' days can "melt" together (Owens, 2001, p. 67) and be filled with fear and frustration. For parents to manage these challenges, it is essential for parents and infants to be together. Infants need to be with a parent, to be gently handled, flexed or swaddled, to eat when they are hungry, and to be calmed when they are uncomfortable (Case-Smith, 2010). Infants inherently seek reciprocity and physical closeness with a parent, a feature of early coping and attachment behavior (Whitcomb, 2012). As the primary comforters and constants in their infant's life, parents of infants admitted to the NICU immediately begin trying to adapt to an unexpected situation, manage interrupted proximity to their infant, and cope with "premature parenthood" (Lubbe, 2005, p. 55).

**Parents of NICU Infants**

In the United States, more than 450,000 infants are born prematurely or with medical complications each year (www.marchofdimes.org). A vast majority of these infants are admitted to the NICU, where at least one devoted parent or caregiver struggles to define their role as parent (as opposed to visitor). Mowder (2005) defined parents as

individuals who view themselves as fulfilling a social role and perceive parenting as including six primary characteristics: responsivity, bonding, discipline, protection, education, and general welfare. Other authors have stated that parents are to be recognized as the main constant in an infant's life (Lawlor & Mattingly, 1998) and should be honored as the most accurate interpreters and explicators of parenting in the NICU (Pierce, 2014). Parenting behavior is considered an "important mediator between biological risk and developmental outcome" (Reynolds et al., 2013, p. 636) and typically includes externally observable activities such as looking, light touching, gazing, smelling, and holding against the chest (Redshaw, Hennegan, & Kruske, 2014). There are cultural influences to parenting as well, as evidenced by soothing techniques that vary across individualist and collectivist cultures (Vinall, Riddell, & Greenberg, 2011), hospital practices that differ across socioeconomic status and geographic location (Redshaw et al., 2014), and mothers' perinatal health status (Muzik & Borovska, 2010).

When an infant is admitted to the NICU, however, the parent-infant dyad is disrupted, and physical separation underscores an extremely stressful experience (Melnyk et al., 2006; Sannino, Plevani, Bezze, & Cornalba, 2011). Typical parenting behaviors and active participation may be stunted, leading to difficulties with early relationship-building and emotional functioning, and suboptimal outcomes such as abandonment and child abuse (Reynolds et al., 2013). Additionally, parenting in the NICU is both public and shared; families must interact with a multitude of professionals while reexamining previously-held beliefs about parenting, redefining values, and reconstructing ideas about parent roles and responsibilities.

Parenting actions are known to be influenced by the parents' perceptions of infant behavior. Winstanley and Gattis (2013) discussed infancy as a period of high caregiver dependency and proposed that the principles of *structure* (routines and regularity) and *attunement* (close physical contact and reliance upon infant behavioral cues) guide parents' care. These cues, or infant behaviors, allude to the conceptualization of infants as active participants in their environment (Als, Lester, & Brazelton, 1979; Als, 1982, 1986). Infant behaviors include directly observable activities such as rooting, sucking, gazing and grasping (Redshaw et al., 2014) as well as other behaviors that fall within the autonomic, motor, state organizational, attention and interacting, and self-regulatory subsystems identified by Als (1986). Interpretation of these cues serves as early parent-infant communication and facilitates contact, providing foundation for relationship-building and emotional attachment. According to Melnyk et al. (2006), early parent-infant interaction includes confident assessment of infant behaviors and characteristics, considered critical to coping and mental health outcomes.

**The NICU Admission**

The nature of NICU admission disrupts typical infant development, and instead necessitates assignment to an environment where infants are stressed, parenting becomes fragmented, familial participation in childcare changes abruptly, and mothering strategies are suspended (Esdaile & Olson, 2004). The physical environment poses multiple challenges, and infants of all ages innately search for proximity with their mothers and "protest upon separation via communication with the mother vocally and through body movement" (Esposito et al., 2013, p. 739). To the detriment of the infant and parent, however, Lemmon, Friestedt and Lundqvist (2011) reported that parents may fear

approaching or touching their frail infant because of medical wires, tubes, and inserted lines. Holding may be delayed because the infant must spend time in a warming bed or specialized incubator. Parents describe emotional distress and demonstrate lack of confidence in parenting (Hall et al., 2012) and use terms like devastation and "crisis" to describe the parent experience in the NICU (Miles & Holditch-Davis, 1997, p. 254). Zimmerman and Bauersachs (2012) reported that parents also experience stress from the unexpected delivery and loss of an anticipated "normal" infant (p. 50). Parental health, lack of social and emotional support, financial concerns, miscommunication, and family constraints have also been shown to disrupt parent participation in NICU-based caregiving. Following admission of their infant to NICU, parents are at increased risk for depression, posttraumatic stress disorder, acute stress disorders, and anxiety, all of which interfere with their ability to care for their infant in the NICU environment and once discharged to home (Hall et al., 2015).

**Parenting, Interrupted**

Acute, hospital-based health care systems are certainly not immune to hierarchical and ethnocentric practice, and the NICU is no exception. The perception of distinct, dominant and submissive groups within the NICU is well documented, as are examples of powerlessness and feelings of victimization by families of infants in the highly technical world of the NICU (Owens, 2001). Families have described their status in the NICU as one of inferiority, filled with desperation, uncertainty, stress, fatigue, and fear. They connote the hospital has perceived ownership of their baby and that they are ineffective caregivers (Hall et al., 2012). Despite medical professionals espousing high-regard for parent interaction and decision-making, family perception is that parents are

practically powerless (Albersheim, Lavoie, & Keidar, 2009) and are expected to conform to the reigning medical authority. Chavez, Duran, Baker, Avila and Wallerstein (2008) discussed this power relationship and defined a concept called internalized oppression, where parent and staff perceptions of powerful and powerless groups within the NICU result in feelings of oppression by families (Albersheim et al., 2009). Contributing to skewed power differentials, professional caregivers may also undervalue the parent role, which is not only harmful to the parent-child dyad but represents lost opportunities to support infant and family well-being.

As uniquely poised liaisons between professional and familial caregivers, neonatal occupational therapists have the opportunity to reduce power differentials, representing the interests of both caregiver groups and contributing to family well-being through assessment and intervention aimed at optimizing occupational performance. Occupational therapists may offer voice to the families, helping parents advocate for their infant and build confidence as experts in caregiving.

**Family-centered Caregiving in the NICU**

Recognizing these common parental stressors, both neonatal occupational therapists and other allied NICU caregivers try to normalize the infant's environment and medical status in order to facilitate critical parent involvement. For example, interventions in which the professional caregiver can respond with empathy are considered effective in helping NICU mothers cope (Holditch-Davis & Miles, 2000). Altimier and Phillips (2013) stated that all families bring strengths to their infant's experience, and reiterated that "Parents must be viewed as vital members of the caregiving team and as partners in the care of their infant, rather than visitors to the

NICU" (p. 14). Mutual respect for expertise has been shown to facilitate effective partnerships (Dallas, 2009), with collaborative, informative, and multidisciplinary caregiving recognized as best practice in the NICU (AOTA, 2006; Sturdivant, 2013).

In response to these known concerns, there has been a call to shift from a NICU culture driven by professionals to one that is family-centered in order to improve holistic, individualized, and relationship-based care (Ballweg, 2001) and to facilitate parent-infant attachment (Gibbs, Boshoff, & Lane, 2010). In family-centered care, family members are considered essential team members and are involved in the process of service delivery (Mulligan, 2012). Gooding et al. (2011) stated that family-centered care is considered a necessary element of developmentally supportive caregiving, but cite the need for higher-level studies and research evaluating long-term outcomes. In family-centered care, there is equal partnership of parent and child decision-making, care provision, and goal-setting (Mulligan, 2012). Accordingly, AOTA (2013) has stated that parents serve as the ultimate decision makers for their children, and that occupational therapists must recognize and tend to the special needs of families in the NICU in order to support optimal developmental outcomes (AOTA, 2006).

**Occupational Therapy in the NICU**

Family-centered occupational therapy services support the family unit and are built on the family's strengths (AOTA, 2013). Occupational therapists have had a presence in the NICU since the late 1970s/early 1980s (Anderson & Auster-Liebhaber, 1984), representing a neophyte specialty area within a century-long history of hospital-based pediatric therapy service (Hall & Buck, 1915; Quiroga, 1995). During that time period, pediatric occupational therapists practiced under the paradigm of Inner

Mechanisms, which focused on "looking within the person at those mechanisms that were disrupted and in need of repair" (Kielhofner, 2009c, p. 32). Over the ensuing 20 years,

> The mechanistic paradigm achieved much of its promise to ground occupational therapy in sound medical and scientific concepts. Nonetheless, it also had some unforeseen and undesirable consequences….The early appreciation of the occupation along with the themes of mind-body unity, self-maintenance through occupation, and the dynamic rhythm and balance of occupation were lost. (Kielhofner, 2009d, p. 42)

Despite Mary Reilly's earlier call to return to holistic intervention rooted in occupation (Reilly, 1962), neonatal occupational therapy remained historically delineated and focused on a medical-model paradigm of identification and remediation of dysfunctional inner mechanisms. In Anderson and Auster-Liebhaber's (1984) example of NICU therapy program design, principles for care centered around neurodevelopmental treatment, where occupational therapists "maximize the infant's developmental potential by…facilitating normal development patterns through normal sensory-motor experiences appropriate to the infant's developmental level… enhancing the NICU experience through coordinated handling, sensory experiences, and social interactions, thereby normalizing secondary deprivations" (p. 96). Twelve years later, Dewire, White, Kanny, and Glass (1996) conducted a survey of 174 neonatal occupational therapists, inquiring about current practice, specific activities performed, training experience, and competency measures for those practicing in the NICU. Of evaluation processes used frequently, respondents indicated that 80% of therapists utilized neurobehavioral assessments, 77%

relied upon motor assessments, 72% used feeding assessments frequently, and 70% spent time sequentially reevaluating the infant. When selecting frequently-used direct-service activities, 89% of therapists employed neurobehavioral organization techniques, 84% cited infant positioning, and 75% of therapists identified developing feeding skills as a frequently utilized therapeutic activity. Knowledge of infant person factors was identified as essential by 80-97% of respondents, addressing family dynamics was considered essential by 63%, and the use of standardized occupational therapy measures was considered essential by 55% of respondents (Dewire et al., 1996). During the 1990s, neonatal occupational therapists were being reminded of:

> [Our] unique perspective on the treatment of neonates and their families in the NICU. We look at the neonate in a holistic way, considering not only the underlying performance components, such as motor or sensory performance, but also how those components are organized in relation to each other and into functional activities. We also consider how the family can assume a modified parental role within the NICU environment. (Anzalone, 1994, p. 563)

As neonatal occupational therapy evolved, the profession deemed that skilled therapy intervention should extend far beyond that of a generalized model of biomedical or family-centered care, to a practice that places parents (and an emphasis on occupational performance) firmly in the center of all intervention. According to Wilcock (1999), occupational therapists should stretch beyond interactions based in medical science and focus on the strong relationship between occupation and health. In their study of professional and familial partnerships in the NICU, Bruns and McCollum (2002) noted that therapist-parent partnerships were increasingly necessary to fulfill the philosophy of

family-centered care. The American Occupational Therapy Association expanded on previous statements guiding neonatal practice, stating occupational therapists are required to demonstrate advanced knowledge of family-centered care practice, infant medical conditions, and environmental influences (AOTA, 2006). One article (Nightlinger, 2011) described the role of NICU occupational therapists as evaluating the infant's capabilities and balancing the physical and social environments to foster development; however, a call has been made for occupational therapists to expand their practice lens beyond the infant and "provide interventions that not only promote the 'technical aspects' of feeding, positioning, and neurodevelopment…(but to) also consider parents…as service recipients" (Price & Miner, 2009, p. 72).

Hunter (2010) reinforced this concept and stated neonatal care has evolved beyond assessment of infant medical conditions to encompass consideration of family occupations. Speaking to the idea of family occupations and specifically to the co-occupation of feeding, Pitonyak (2014) stated,

> Occupational therapists are called to expand their intervention approaches for the occupations of feeding and eating to encompass the co-occupational needs of infants, mothers, and families during child rearing and health management and maintenance. This top-down, contextual approach aligns occupational therapy services with broader societal health objectives and offers opportunities for emerging practice in health promotion. (p. e95)

Similarly, Arbesman, Lieberman, and Berlanstein (2013), stated that occupational therapists working in the NICU are expected to practice in a way that is family-centered, collaborative, and responsive to the individualized and diverse needs of each family.

Therapists are also expected to appreciate the social-emotional implications of NICU admission for future child and family development (Case-Smith, 2013), and to have an understanding of "family health and well-being" (DeGrace, 2003, p. 347). Lemmon et al. (2013) applied these concepts to professional caregiving practice in the NICU and stated,

> For parents to manage their fears of approaching the small infant, they need to be encouraged to touch their infant. They want to be involved in health care but to venture to come close to their infant the parents need a lot of support. (p. 41)

Within occupational therapy practice, a holistic family-centered approach includes normalization of disrupted routines and occupations of parents. Acknowledging that routines and rituals are considered essential for family stability and identity (DeGrace, 2003), neonatal occupational therapists can facilitate typical parenting occupations (Redshaw et al., 2014). Therefore, beyond consideration of the infant's motor, sensory, and neurodevelopment, there is opportunity to consider multiple aspects of *both* infant and parent occupational performance.

**NICU-based Occupations and Co-occupations**

A family-centered occupational therapy approach would include consideration of parent occupations, infant occupations, and parent-infant co-occupations. According to Pierce (2014) occupations in the NICU are individually created and reflect what parents say they are doing or what they desire to do—whether that occupation is snuggling, playing, gazing, cleaning, listening, talking, reading, bathing, watching, protecting, touching, recording the moments, or holding of the infant by the mother or father. Occupation, as defined by Pierce (2014), "is a specific individual's personally constructed, nonrepeatable experience….occupation has a shape, a pace, a beginning and

an ending, a shared or solitary aspect, a cultural meaning to the person, and an infinite number of other contextual qualities" (pp. 3-4). Using this definition, occupations in the NICU *are what parents say they are* and may include activities that are not directly observable by outside caregivers.

Many of these meaningful, parent-identified activities could also be defined using the occupational science term, co-occupation. Zemke and Clark (1996) stated that most caregiving occupations are actually made up of two actors, the parent and the infant, engaging in meaningful, reciprocal occupation. According to Olson (2004), feeding, cuddling, rocking, socializing, and Kangaroo Care (holding the infant skin-to-skin) are examples of highly interconnected engagement occurring between the infant and parent. Pickens and Pizur-Barnekow (2009) described co-occupation as "embedded in shared meaning" (p. 152) which "requires aspects of shared physicality, shared emotionality, and shared intentionality" (p. 151). Expanding on concepts of family-centered care and co-occupation, Price and Miner (2009) stated, "Occupational therapists provide opportunities for co-occupation that promote the development of the family and support parents by providing the knowledge that family life is still possible even if the infant has severe disabilities" (p. 72). As part of an ethnographic study of how occupational therapists practice from an occupation-based perspective, Price and Miner (2009) observed the interactions between a neonatal therapist, a mother, and her premature infant as they participated in ordinary (yet extremely significant) parenting activities. The authors referred to the historically psychosocial nature of the profession and discussed how successful outcomes often reach far beyond biomedical stability. The therapist's narrative revealed her belief that the infant's neurodevelopment "was best facilitated

through understanding how [the mother] wanted to parent her infant and promoting attachment and becoming a family through co-occupations of feeding, playing, bathing, and rocking" (Price & Miner, 2009, p. 77).

**Occupation-based Practice in the NICU**

In an effort to bridge the gap between biomedical and occupational or co-occupational dysfunction, neonatal therapists look beyond the physiologic and neurobehavioral to address interrupted parenting and occupational performance barriers. Unfortunately for the profession, DeGrace (2003) stated that "we have yet to clearly articulate how we are (a) addressing the family unit, (b) measuring change within the family unit, and (c) helping the family unit to meaningfully participate in everyday life" (p. 347). DeGrace also argued that while concepts of family-centered care have been central to pediatric occupational therapy service for many years, the profession has not clearly articulated how family occupations are evaluated and measured. DeGrace (2003) also spoke of the importance of routines and rituals as the means and foundation for family stability and identity, and discussed why family-centered occupational therapists should acknowledge this concept as one that promotes health and growth of the family unit. She suggested that as occupation-based practitioners, occupational therapists "need to learn how each family unit has collectively constructed its meaning of family" (p. 348) so that interventions and interactions help infants and parents engage in meaningful experiences together.

Occupation-based therapy service models are grounded in scientific theory—and neonatal practice is no exception. According to Case-Smith (2005), theory is defined as "a set of facts, concepts, and assumptions that together are used to describe, explain, or

predict phenomena….Using theory, occupational therapists organize knowledge, understand observations, and explain or predict occupational function or dysfunction" (p. 54). In an effort to explain the occupational performance of both parents and infants, neonatal occupational therapists draw from a wide range of theories based in occupational science, medicine, biology, psychology, architecture, neonatology, nutrition, neurology, social science, and the humanities. From these theoretical foundations, conceptual practice models emerge and "provide the unique concepts, evidence, and resources" used in practice (Kielhofner, 2009b, p. 10). In support of occupation-based practice, the Person-Environment-Occupation-Performance (PEOP) Occupational Therapy Process (Bass, Baum, & Christiansen, 2015) has been proposed as an intervention- and evaluation-guiding approach that is appropriate for use across health care settings, client lifespan, and human conditions. Accordingly, neonatal occupational therapists can utilize this process in everyday practice.

**Outlining the Neonatal Occupational Therapy Process**

In neonatal occupational therapy practice, there has been limited exploration of conceptual practice models guiding therapist-client interaction in the NICU. The Person-Environment-Occupation Model (Law et al., 1996) was proposed for use in the NICU setting in one previous literature review (Gibbs et al., 2010). In this publication, the authors discussed application of the PEO Model as a framework for parental role-acquisition in NICU. The PEO model emphasized occupational therapy's unique goal of providing client-centered care and maximizing fit between the person, their capabilities, and their wants and needs as a function of health and well-being (Baum & Law, 1997). As a concluding thought, the authors (Gibbs et al., 2010) suggested that application of the

PEO Model can provide a systematic means of assessing and promoting occupational adaptation of parents in the NICU.

The Person-Environment-Occupation-Performance (PEOP) Model (Baum, Christiansen, & Bass, 2015) is an alternative person-environment-occupation model that emphasizes performance. The PEOP Model is a framework guiding occupational therapy practice, which focuses on client characteristics and the influence of the client's environment on participation in meaningful everyday activities, tasks, and role fulfillment. As part of this doctoral project, the PEOP Model was proposed as a bridge for neonatal practice, focused on addressing both the NICU infant and parent client factors (AOTA, 2014) and the sociocultural aspects influencing occupational performance of infants and parents in the NICU. Application of this model to NICU practice offers a framework whereby therapists can analyze and identify solutions for participation barriers and occupational performance issues (Broome, McKenna, Fleming, & Worrall, 2009).

The PEOP Model supports the profession's current values, reinforcing a collaborative top-down approach that addresses the whole system (client participation, performance, well-being) in interaction with person and environmental factors, as opposed to adhering to a bottom-up approach that positions the therapist as expert and focuses on diagnosis management and biomedical intervention (Baum et al., 2015). As a systems model, the PEOP Model reflects concepts inherent in neonatal Synactive Theory (Als, 1986), asserting that individual components within the system have the potential to impact other components in the system; in other words, all system elements act synactively, affecting performance and behavior.

The focus of the PEOP Model is on occupational performance, which is defined by Baum et al. (2015):

> Occupational performance…. [is] the doing of meaningful activities, tasks, and roles through complex interactions between the person and environment. We believe occupational performance supports participation (active engagement and involvement that contributes to the well-being of individuals and communities) and well-being (satisfaction and quality of life). (p. 52)

Application and utilization of the PEOP Model in practice have recently been referred to as the PEOP Occupational Therapy Process (Bass et al., 2015). This process was "designed to guide the practitioner through all the steps necessary for implementing the PEOP Model in traditional and emerging areas of practice" (Baum et al., 2015, p. 55). Different from other therapy processes that move through typical phases of assessment-intervention-outcome, the PEOP Occupational Therapy Process (hereafter referred to as The PEOP Process) is unique in that it is occupation-based and focused on the occupational performance issues identified by the client, group, or organization (Bass et al., 2015). For example, within the NICU setting, occupational therapists would not view an infant with a cleft palate as a solitary client with a craniofacial anomaly, but rather an infant who, together with the parent, may be struggling with the co-occupation of breastfeeding.

The PEOP Process begins with a narrative, or past, present, and future personal story. There is strength in the personal narrative, in that the narrative is the client's unique perception of life, is central to each person's experience, offers a view of the individual's understanding and knowledge, and aids in contextual understanding of the

client's story (Bold, 2012). Within the NICU setting, infants tell their story through their medical history, behavior, and parent interpretation. Parents tell their story through spoken and written word, non-verbal communication, creative works (Mouradian, DeGrace, & Thompson, 2013), and pictures and social media (Vijayalakshmi, Kumar, Gokulraj, & Malathy, 2015). Gathering the narrative as a first step in The PEOP Process serves to clearly establish the goals and needs of the parent and infant and to "provide a means to fully understand the client's problems and their meaning within the broader context of a person's life" (Bass et al., 2015, p. 60).

After gathering the narrative, the next step in The PEOP Process is assessment and evaluation (Bass et al., 2015). It is beyond the scope of this project to discuss standardized evaluations available for preterm infant neuromotor, behavioral, or feeding evaluation in the NICU. It is of note, however, that no *holistic, occupation-based* tools exist for occupational therapy evaluation of infants admitted to NICU. Current evaluative process is guided by recommendations in the *Specialized Knowledge and Skills for Occupational Therapy Practice in the Neonatal Intensive Care Unit* paper (AOTA, 2006), application of knowledge from related fields, and by therapist education, experience, and knowledge of published interventional and theoretical research. The purpose of the assessment and evaluation phase of The PEOP Process is to gather baseline information on the person, environment, and occupation factors affecting occupational performance, in order to prepare an intervention plan (Bass et al., 2015). Personal occupational performance factors include the psychological, physiological, cognitive, sensory, motor, and spiritual aspects influencing participation in meaningful activities (Baum et al., 2015). Environmental occupational performance factors include

the cultural, social, educational, physical, natural and technologic influences on participation. Occupation factors are concerned with each person's meaningful or required roles, activities, and tasks (Baum et al., 2015).

Following identification of person, environment, and occupation factors influencing occupational participation, a "graphic organizer" continuum scale (Bass et al., 2015, p. 61) is then used to visually represent the therapist's interpreted level of constraints and capabilities within separate person, occupation, and environment factors. The purpose of the graphic organizer is to "represent the complex connections across different factors and summarize the client's overall current status" (Bass et al., 2015, p. 61).

Following assessment and evaluation, occupational therapists select intervention approaches in collaboration with the client, considering whether the intervention is evidence-based, client-centered, and occupation-based (Bass et al., 2015). According to Baum et al. (2015), conventional occupational therapy interventions include approaches such as create-promote, establish-restore, maintain-habilitate, modify-compensate, prevent, educate, consult, and advocate.

Finally, outcomes related to occupational performance, participation, well-being, or specific results of therapy intervention are measured and documented (Bass et al., 2015) in order to demonstrate occupational therapists' unique contribution, skilled service, and value to internal and external stakeholders. Beyond fulfillment of hospital-based documentation and billing requirements, measuring occupational performance outcomes is one way in which occupational therapists contribute to fulfillment of

AOTA's Centennial Vision, where the profession envisions itself as both science-driven and evidence-based (Moyers, 2007).

**An Investigation of Occupational Performance in the NICU**

In an effort to promote evidence-based practice, neonatal occupational therapists have the opportunity to address the whole family's needs in pursuit of optimal outcomes (An, 2014), as well as the responsibility to disseminate findings beyond bedside practice. Heeding this obligation to advance the science of the profession, qualitative research can be utilized to honor AOTA's Centennial Vision and address parent and infant occupational performance in the NICU. Qualitative research allows generalizations to be drawn from data, facilitates critical thinking, encourages reflexive practice, and integrates new knowledge into practice (Robertson, Graham, & Anderson, 2012). As a method of scientific inquiry, qualitative researchers study people and context, with special concern for "how people develop meaning out of their lived experiences" (Hissong, Lape, & Bailey, 2015, p. 95). This particular approach is appropriate for this doctoral project, in that an investigation of parent and infant occupational performance in the NICU would be concerned with the parents' perspective of their current life experience, their participation within the NICU environment, and their modified or adapted views of parenting. According to Clark, Carlson, and Polkinghorne (1997),

> Designs for the study of human subjects are expected to attend to the various components that influence person's activity, such as their interpretation of past life experiences, their intentions to achieve a purpose or accomplish a goal, their awareness of what actions are possible within particular situation, and the strength of the determination and volition to perform an action. (p. 314)

There is increased opportunity to understand unique individual and group processes and experiences using qualitative methodology, which can lead to individual and systems-level change (Wener & Woodgate, 2013). In a paper outlining the trustworthiness of qualitative studies in occupational therapy, Curtin and Fossey (2007) noted that qualitative research is well suited for the profession, in that therapists often find relevance to their day-to-day practice. Whiteford's work (2005a, as cited in Curtin & Fossey, 2007) expanded on this relevance, stating that qualitative research focuses on the person's perspective, occurs in naturalistic environments, allows for exploration of new findings, and provides a basis for collaboration between researchers and study participants. Ballinger (2004) similarly stated that qualitative studies seem tailored for occupational therapy, in that complexity and richness are sought as outcomes.

Within qualitative research, occupational therapists may use a phenomenological approach in order to explore the experiences and perceptions of families in order to interpret how they make sense of their world (Kielhofner & Fossey, 2006). Phenomenology's central tenet is to carefully describe how individuals experience everyday life and then distill from the individual's narrative the essence of the meaning behind the experience (Luborsky & Lysack, 2006; Mouradian et al., 2013). "The intent of a phenomenological researcher in such a study would be to gain understanding of what it's like to live [in the body of another]…and know how these experiences shape the person's sense of themselves" (Luborsky & Lysack, 2006, p. 336). In order for occupational therapists to make valuable contributions to neonatal practice (AOTA, 2006), understanding parents' viewpoints and appreciating the meaning behind their actions is crucial.

Therefore, the purpose of this doctoral project is twofold: (a) to explore occupation and co-occupation as described by parents, and (b) to explicate the PEOP Occupational Therapy Process (Bass et al., 2015) for the NICU. This project seeks to present an innovative approach to neonatal occupational therapy practice, framed using the Person-Environment-Occupation-Performance (PEOP) Model (Baum et al., 2015). A phenomenological approach will be employed to build a picture of understanding by gathering and recording information about context, insights, events, and influences on parent and infant occupational performance in the NICU. Qualitative methods will be used to explore the concept of occupational and co-occupational performance in the NICU and to provide rich descriptions of parent and infant occupations in the NICU setting.

# Methods

## Research design

Human subjects approval was obtained for this exploratory project through both St. Catherine University, St. Paul, MN (IRB Approval ID#337) and Mercy Hospital-Springfield, MO (IRB Approval Protocol #MMRI-1409). Using a phenomenological approach, qualitative methods were used to explore the concept of occupational and co-occupational performance in the NICU and to provide insight into parent and infant occupations in the NICU setting. A semi-structured interview with guiding questions and prompts was used to explore the nuances and complexity of NICU-based occupation (see Appendix A). Coded interpretation and thematic extrapolation from transcribed parent narratives organized recurring patterns appearing in the parents' statements. A matrix framework was then used to display emergent themes (rows) with generalized definitions of parent occupations, infant occupations, and parent-infant co-occupations (columns), providing examples of meaningful parent-identified occupational performance activities in the NICU (row-column intersections). This interpretative approach examined the meaning of participant experiences and provided in-depth understanding of those experiences.

## Interview Methods

### Participants.

Participants were recruited from the state of Missouri. The setting was a 48-bed Level III NICU with single-family rooms, where the medical care team providing developmentally supportive service included five neonatologists, two nurse practitioners, 100+ nurses, two occupational therapists, two physical therapists, and one speech-language pathologist. Eligibility criteria included parents (age 18-40 years) of infants hospitalized and admitted to the NICU at the time of the study. Parents younger than 18 years old were excluded from the study. In order to avoid parents feeling obligated to participate in the study, the author did not attempt to recruit project participants. Instead, NICU secretaries gave an informational recruitment flyer to parents entering the NICU. Flyers were also posted at the phone entrance to the NICU, in the waiting room, and at the entryway scrub sink. The flyer presented parents with an opportunity to share their experience and stated "Would you consider sharing your NICU experience in order to help future families and improve care?" If parents were willing to participate, they signed the informational flyer, provided a contact number, and returned the flyer to their nurse. Nurses then notified the researcher that a family had volunteered to be interviewed. Once parents self-selected participation in the project, written information, and a consent form was provided. Parents were offered the choice to conduct the interview in the naturalistic environment of the infant's room or a private waiting room near the NICU. Additionally, parents were offered the opportunity to interview together or singularly. Fourteen parents (ten mothers and four fathers) self-volunteered for the project; all chose to be interviewed at their infant's bedside.

**Data collection.**

A conversational, semi-structured interview was created (Silverman, 2013). Semi-structured interviews provide light structure with organized questions, but allow researcher latitude to sequence the questions for different respondents (Miles, Huberman, & Saldaña, 2014). Interview questions were informed by a previous doctoral course assignment using parent interviews and a focus group exploring barriers to co-occupation in the NICU, the author's 15 years of experience in NICU practice, and a literature search examining parent participation in the NICU environment. The author's previous contact with NICU parents was necessary to promote understanding of the culture, relationships, history, problems, and resources available in the NICU; accordingly, an exploration of the author's personally-held beliefs was necessary to avoid bias in questioning. To address credibility and trustworthiness of interview questions, three multidisciplinary colleagues (A NICU nurse, occupational therapist, and speech-language pathologist) reviewed the questions and offered feedback. One question was amended to reflect less bias for barriers to occupation and reworded to include both barriers and supports of parent occupation in the NICU.

Interview questions were organized into two general categories: activity-focused questions and parent-perspective questions (see Appendix A). Participants also answered brief demographic questions identifying their age, gender, ethnicity/race, distance lived from hospital, living accommodations while infant was admitted to NICU, and number of children in the family (see Appendix B). Pseudonyms were assigned to ensure confidentiality and protect parents' identity.

Activity and perspective questions were supplemented by prompts such as 'can you explain that further' and 'can you give me an example?' Questions were general and

open-ended, and included questions such as ‘What does parenting look like in the NICU,’ ‘What activities do you value doing with your child in the NICU,’ and ‘Tell me about your infant’s stay’ (this question took the place of medical record information).

Parent interviews were conducted over a two-month period and were carried out at a time determined by the parent, to include evenings, nights and weekends. Interviews were digitally recorded on a password-protected smartphone application, and the author took field notes. Each interview lasted approximately 30 minutes. At the conclusion of the interview, the author’s contact information was provided to parents.

**Data analysis.**

During repeated playback of the interviews and review of field notes, the author transcribed the parent narratives line-by-line, allowing the author to become more familiar with the data (Riessman, 1993; Ritchie & Spencer, 1994). This iterative process (Butler-Kisber, 2010) supported ongoing reflection and early analysis of language used to describe the NICU parent experience. To address trustworthiness, the researcher kept detailed notes, listed action steps, and recorded reflexive thoughts throughout the research process (Aiken, Fourt, Cheng, & Polatajko, 2011). Data were then analyzed in two phases.

***Phase 1.*** Once the first interview was transcribed, the author used inductive content analysis to identify meaningful units and establish codes (Graneheim & Lundman, 2004; Rezaee, Rassafiani, Khankeh, & Hosseini, 2014). Meaningful units have been described as content (such as words, phrases, or sentences) that are contextually related, with succinct codes acting as labels for the meaningful units (Graneheim & Lundman, 2004). Codes, by definition, are prompts used to cluster and categorize similar

responses in order to aid further data analysis and conclusion-drawing (Miles et al., 2014). Two approaches to elemental coding were used to analyze meaningful units: in-vivo and process coding methods. In-vivo coding "uses words or short phrases from the participant's own language in the data record as codes" (Miles et al., 2014, p. 74), and process coding uses gerunds to describe either conceptual or observable action (Miles et al., 2014). An example of this process is provided in Appendix C.

Phase 1 analysis of the first parent interview resulted in approximately 60 codes. Codes were then grouped by similarities and assigned to "data chunks" (Miles et al., 2014, p. 73) in order to detect reoccurring patterns or themes. A theme can be defined as a reoccurring idea, concept, or issue, often derived from respondents' lived experiences or from theory (Gibbs, 2007). Themes have also been described as codes grouped together based on differences and similarities and sorted into categories that share commonality (Rezaee, Rassafiani, Khankeh, & Hosseini, 2014), or similar ideas grouped together and renamed (Burnard, Gill, Stewart, Treasure, & Chadwick, 2008). As defined by Graneheim and Lundman (2004), a theme "…cannot be an object or thing; A theme answers the question 'how?'…A theme can be seen as an expression of the latent content of the text" (p. 107).

Cross-case analysis was then employed, using the first interview's initial codes and themes. In cross-case analysis, themes are compared and contrasted across various cases, or for this project, parent interviews (Jansen, Capesius, Lachter, Greenseid, & Keller, 2014). The primary goal of cross-case analysis is:

> To increase generalizability, reassuring yourself that the events in one well-described setting are not wholly idiosyncratic. At a deeper level, the purpose is to

> see processes and outcomes across many cases….and thus to develop more sophisticated descriptions and more powerful explanations. (Miles et al., 2014, p.101)

Caution was taken in the process of early cross-case analysis, as initial themes are to be considered suggestions for important variables, not silos within which the rest of the data can be forced. Bearing this in mind, coding and chunking of the remaining nine interviews was completed. In addition to the four originally-identified themes, a fifth theme (Analyzing) emerged and was compared against the first parent interview for consistency and accuracy of application (Gibbs, 2007). For verification purposes, a second party assisted in the categorization of data extracts and renaming of groups and thematic analysis.

***Phase 2.*** In Phase 2 analysis, an organizational matrix (Matuska & Erickson, 2008; Miles et al., 2014) was used to organize and compare thematic results with definitions of parent occupations, infant occupations, and parent-infant co-occupation. For this project, parent occupations were defined as much more than a set of concrete actions or externally observable behaviors. Continuing, parenting occupations were defined as "extraordinarily ordinary moments" (Price & Miner, 2009, p. 72), with parents being identified as "the authors and most accurate interpreters of their own occupations" (Pierce, 2014, p. 5). Despite their perception as mundane, parenting occupations were the personally constructed, richly symbolic, deeply meaningful, socially influenced, and goal-directed activities of caring for a child.

Infant occupations were defined as "…any tasks and activities that are valued within the family (or Neonatal Intensive Care Unit – NICU) culture in which the infant is

expected to engage" (Vergara, 2002, p. 9). Previously explored examples of infant occupations include elicitation of nurturing and caregiving (Holloway, 1998), communicating, searching, regulating, protecting, and developing (Olson, 2004).

Finally, parent-infant co-occupations were defined as different from parallel or shared occupations (Pierce, 2003; Zemke & Clark, 1996). Within this project, co-occupation was described as highly interdependent, reciprocal relationships, where the "…occupations of two or more individuals are interactively shaping each other" (Pierce, 2009, p. 204) and "one person's response directly influences the response of the other" (Pickens & Pizur-Barnekow, 2009, p. 151).

Columns represented each definition mentioned previously. Rows represented each of the five themes emerging from parent interviews. The intersection of each column and row catalogued the interpreted examples of parent occupations, infant occupations, and parent-infant co-occupations engaged in while in the NICU setting (see Appendix D). Appendix D represents a descriptive summation of parent-responses to the main interview topic: "What do you *do*" and "What does your infant *do*" while in the NICU?

Following matrix organization and identification of NICU-based parent occupations, infant occupations, and parent-infant co-occupations, the author used the PEOP Model as foundation and applied examples of occupation to the PEOP Process outlined by Bass et al. (2015). A case example was developed using activities identified by parents in this doctoral project, which outlined occupation-based intervention and evaluation within the NICU setting.

**Application of the PEOP Process to NICU Practice**

A critical step in this doctoral project was to empower neonatal occupational therapists with knowledge of NICU-based occupations and provide a practical guide to occupation-based practice in this specialized setting. In an effort to bridge the research-to-practice gap, an exploration of tools used to assist occupational therapists in the NICU took place. The author examined the OTPF (AOTA, 2014); practice guidelines (Als, 1986; AOTA, 2006, 2013); caregiver approaches (An, 2014; Bader, 2009; Humphrey & Thigpen-Beck, 1998; Hunter, 2010; Lane, 2012; Nightlinger, 2011; Pierce, 2003, 2014; Price & Miner, 2009; Vandervenn et al., 2009; Winstantly & Gattis, 2013); algorithms (Philbin & Ross, 2011; Ross & Philbin, 2011); protocols (Dewire et al., 1996; Lubbe, 2005; Ludwig & Waitzman, 2007; Moore et al., 2009; Pinelli & Symington, 2010; Quaraishy, Bowles, & Moore, 2013; Tanta et al., 2012; White-Traut et al., 2002); and practice models (Christiansen & Baum, 1997; Esdaile & Olson, 2004; Gibbs et al., 2010; Hall et al., 2015; Kielhofner, 2009d; Law et al., 1996). This exploration revealed that while several tools, models, and resources existed to help guide certain aspects of occupational therapy practice, none addressed systematic *occupational performance* assessment and intervention in the NICU. Thus, the decision was made to apply The PEOP Process to describe neonatal occupational therapy's approach to care and provide a practical example of how to deliver occupation-based services in the NICU setting. For this final step, parent occupations, infant occupations, and parent-infant co-occupations elicited from the study were imported into the "Person-Centered PEOP Occupational Therapy Process" figure (Bass et al., 2015, p. 66) and a case example was created that depicted application and utilization of The PEOP Process in the NICU.

# Results

Addressed in this section are parent participant characteristics, activity-based themes emerging from parent interviews, occupational outcomes of matrix data analysis, and an illustrative case example of use of The PEOP Process in the NICU.

## Participant Characteristics

Interview participants were recruited from a large urban hospital in the Midwest United States. The setting was a 48-bed Level III NICU designed with private, single-family rooms. Fourteen parents (aged 19-36 years) self-volunteered for the study. The majority of parents were Caucasian (93%, n=13), with 7% Native American representation (n=1). Ten mothers and four fathers (four couples, six individuals) participated in the parent interview; of this group, 65% were married (n=9), 14% were engaged (n=2), and 21% (n= 3) were single. On average, participants lived 53.5 miles (range 1-150 miles) from the hospital. Eleven percent of parents commuted daily (n=2), and 89% stayed at the hospital during their infant's admission to the NICU (n=12). Parents were allowed to either room-in with their infant or seek housing at the 10-room Ronald McDonald House (www.rmhc.org) located within the hospital. Sixty-four percent of participants were first-time parents. The average gestational age of the participants' infants was 33.8 weeks (64% premature, 36% term), with infants being approximately 11 days of age at the time of the interview (range 2-42 days of age). The acuity of infants ranged from critically ill to stable and preparing for discharge home.

## Themes Emerging from the Interviews

Following completion of parent interviews and Phase 1 data interpretation (see Methods section), five themes describing active engagement emerged: Perceiving "They" vs. "I"; Maintaining Proximity; Expressing Emotions, Values, and Beliefs; Addressing Health Issues; and Analyzing. Described below, each theme served as a global descriptor of parent and infant experience and represented key aspects of the phenomena of parent and infant occupational performance in the NICU.

**Perceiving "They" vs. "I".** The predominant theme emerging from interview narratives was the parents' perception of distinct caregiver groups and roles in the NICU: Perceiving "They" vs. "I". Within the theme itself, three subthemes emerged, as parents provided *positive* examples (those representing accepted or appreciated differences between groups), "*It depends*" examples (those that, according to one father, could be perceived as positive or negative depending on the context and timing of the interaction between groups), and *negative* examples (those representing opposition or resistance felt between groups).

***Positive examples.*** One mother, Donna, spoke positively of the relationship with professional caregivers and stated:

> They've helped me feel more comfortable. They've asked me if I want to do this or that…then I feel comfortable doing it because [they] casually offered…if I am never offered or allowed to do a certain thing, then I'm not gonna feel that I can do that…Even though I know they're the ones taking care of him now—I'm just helping a little bit—I really enjoy being able to do everything that I'm told I can. (p. 3)

Another mother, Julie, mentioned her confidence in professional caregivers. “It makes me feel more comfortable when, you know, they know what they’re talking about, what they’re doing. So it makes me feel a lot better that way” (p. 1). Alisha applauded the NICU team members and stated, “They keep us updated; the nurses make me feel like I’m actually the mother. I’m not, like, this passerby that has to keep my hands off them” (p. 1). Kelly stated, “They are here for you no matter what. And they’re very safe. There’s no one gonna come in and snatch your baby. That means a lot. There’s peace of mind” (p. 2). Similarly, Olivia stated, “It’s nice that we get to be in here when they’re doing their stuff. They give you the option…they give you the choice” (p. 3).

***“It depends” examples.*** While oversight from neonatal caregivers was often described as comforting, Bobby, a father of twins, discussed how difficult public parenting can be: “I like the fact they pay so much attention…but at the same time I hate that it exists” (p. 4). Cathy reiterated this sentiment and stated, “They teach you a whole lot…I know they’re going to stare and observe me, but it makes me nervous, makes me feel like, ‘I’m going to mess up a couple time, if you could please not watch me?’” (p.3). One mother described her baby’s NICU admission as “bittersweet” (Laney, p. 1), while Julie stated, “I feel like a parent, but then sometimes….it can be tough. It’s shared parenting” (p. 2-3). “Some people feel like [professionals] are trying to step in and take the parents’ spot. And at first, I kinda…but you learn to appreciate the help. You learn quick to appreciate it” (Olivia, p. 6).

***Negative examples.*** Parents commented on the perceived gap between “They” and “I”, and gave examples of barriers to parenting in the NICU. “It seems like we can’t do everything we want to do…you know, we play by the rules. And we do exactly as

we're told because it's 'better for the babies'" (Bobby, p. 2) "We need to find a way to break down [medical terminology] into layman's terms, so that parents and patients can communicate and break down that silence barrier. Like a translator" (Major, p. 6). "I haven't been told 'no', but I haven't asked to do a whole lot, you know? It's…what they allow me to do" (Nancy, p. 3). "I really want to see him eat out of the bottle. They're doing it through the syringe…but maybe today. Yeah, I hope" (Kelly, p. 1). "They brought her in here and started doing everything. So we just kinda had to stand back and watch. She probably thinks, 'What a cruel world! I come out and you start a-pokin' and a-proddin me'" (Greg, p. 4). "My biggest fear is being hotlined…I don't like walking around on eggshells" (Alisha, p. 1).

Another mother expressed feelings of frustration and stated,

> I haven't [held her] yet. She's still on a ventilator. The doctors can't tell me an exact day or nothing, but they're hopeful it's gonna be in the next few days. I can't wait. That's kind of why I've been hanging around all day, hoping today is the day. I keep thinking, 'She's doing good, come on, Doc! I'm right here! This is home for her!' (Nancy, p.2)

"We are very conscious people, about what somebody else may think of us….sometimes I feel, a little bit, like they're casting judgment, you know? It's probably all our mental demons…but we worry a lot about how we're doing" (Alisha, p. 1).

> I just have to keep my mouth shut. And you don't know – like should I say something about that…or do I not? [It's] just so up and down…I don't want to be one of 'those' parents, where they dread [you] coming in here. I feel like I've been branded with a scarlet letter 'P'. (Heather, p.3)

**Maintaining Proximity.** The second theme, Maintaining Proximity, summarized and reflected emergent parental statements about the importance of achieving and maintaining physical closeness with the infant. One mother, Kelly, repeatedly expressed her need to "Get him close. I just want to hold him…Get him close" (p. 2). "You want to be involved in every second. You wanna see every breath. And be with him" (Major, p. 3). Elsa stated that her "best day" was "the first day I got to come down here. Because I finally got to meet him" (p. 4).

Within the theme itself, four subthemes emerged, functioning to categorize parent participatory activities: Responding to the Infant, Caregiving, Temporal Considerations, and Addressing Interruptions.

***Responding to the infant.*** Parents repeatedly used the phrase "it's the little things" (Heather, p. 5) when referring to seemingly insignificant interactions with their infant at the bedside. "Sometimes I just kinda hang out in here, check on 'em" (Julie, p. 2). "The fact that he got to go over and pick him up and change his diaper…it felt like he was actually playing a part. Little things like that mean a lot" (Alisha, p. 2). "Taking their temperature, changing their diapers, little things. Even….lifting him up so I can put a new blanket under him, just little things like that" (Bobby, p. 2). "We sit and stare at him, like an owl on a limb. We talk to them…we spend a lot of time praying around them" (Alisha, p. 2). "When she's awake…I am as hands-on as possible. I spend a lot of time just looking at her, though" (Nancy, p. 2).

> If I see that he's upset or crying, I want to be able to pick him up…hold him and comfort him. I can't do that right now…you see him crying, but of course you

> can't hear him....I gather his feet and hands, and he'll calm right down when I do that….I talk to him…he likes me to do the talking. (Donna, p. 6)

***Caregiving.*** Frequently, parents identified the difference between providing or assisting with medical caregiving and "normal" (Greg, p. 4) caregiving. "The focus was on getting her to eat. When I was there…she would thrive….she would eat double what she would went I wasn't there" (Elsa, p. 3). "I've cleaned his mouth a couple times. They seem to do such a thorough job, I don't want to do that all the time…[but] I still try to put my hands on him" (Donna, p. 2). "I like to touch her. And put a little bow on her – make her feel fancy" (Nancy, p. 2). "Not being able to hold him. That's what's really hard. When they're awake and you can't pick them up…that's sad" (Cathy, p. 2). "I haven't been able to hold them yet…because of all the hookups and stuff. There's maneuverability problems. I think [maybe] here in a couple weeks" (Julie, p. 1). "I'm always in danger of pulling something off" (Donna, p. 3).

> I'll do whatever [they offer], besides the obvious like diaper and temperature [and] baths. Before they got him on the pump feedings, I would 'feed' him. I'm not sure what you'd call it—inject the feeding? Was I injecting his food in the little syringe? It sounds weird to say that. (Donna, p. 2)

***Temporal considerations.*** Parents also made comments about attempting to balance time spent in proximity to their hospitalized infant and with other routine aspects of their personal and family lives. "We knew we weren't gonna get to hold her right away….It's January –she wasn't supposed to be here until March. She's got plans, I guess" (Heather, p. 2). "You know, she's not at home, sleepin', so we're not up in the middle of the night, we don't get to hold her laying on the couch watching TV, you

know, any stuff like that" (Greg, p. 4). "I can't wait to get him home….our anniversary is the 17th. I'm prayin' he gets to go home on our anniversary. I'm prayin'" (Kelly, p. 2). "I could happily sit here from one touch time to the next…I like the days when…I can just sit here in my chair and read and go over every once in a while and peek at him" (Donna, p. 5).

> [I'm] commuting. We have dogs and cats at home, and my husband's in school right now, and he's going back to work tomorrow…so it's my only option at the moment…We're still trying to adjust to the schedule and figure out what works for us, as far as being here. I'm probably going to go back to work…so I can take my maternity leave when she comes home. When I can actually be a mom to her then. (Nancy, p. 1-2)

***Addressing interruptions.*** Often, parents verbalized strategies to address interrupted proximity with their infant. "I went home one night and took a shower, and that was nice, but it stressed me out…I had an alarm set every hour on my phone, and it went off and I'd call up here" (Cathy, p. 1). "The first night…it was really hard to leave her by herself…God knows anything might happen…we got home and called up here twice to make sure she was okay. It's been a roller coaster" (Heather, p. 1). To cope with separation, one mother, Alisha, stated, "I study their reactions, their facial expressions. I take pictures while they're sleeping. A lot of pictures" (p. 3).

> When they brought her over here the first night, I just sat over there and cried. 'Cause she wasn't there. It was weird for me….to be away from my baby. I thought neither one of us would get to stay with her…so being able to be here and

> *see* that she's okay…and to have at least one of us here makes it a lot easier to handle. (Olivia, p. 1)

To cope with interrupted proximity, many mothers anticipated discharge day: "To see all the mommies leaving with their babies was devastating. Devastating that I couldn't take her home with me…but someday I'll get to leave with my baby" (Nancy, p. 4).

**Expressing Emotions, Values, and Beliefs.** The third theme, Expressing Emotions, Values, and Beliefs, emerged from the multitude of parent actions taken to address their perceptions, motivations, personally-held truths, purpose, and emotions during the NICU admission. Similar to the first theme, parents provided examples of engagement in occupation that were perceived as positive, negative, or dependent upon variables within the context and environment.

***Positive examples.*** Despite having times when she felt overwhelmed, Julie stated, "It's a little bit nerve-wracking, but you know…I think I can really do this [parenting]. I really do" (p. 2). Kelly spent time dreaming of life at home, Floyd enjoyed "rooting" his son on in "whatever he's doing" (p. 2), Alisha and Bobby talked about journaling and taking pictures for fear of "los[ing] those memories" (p. 3), and Olivia demonstrated resiliency, stating "This is not what I planned at all..but I'm ready to be home with her. I am ready" (p. 2).

***"It depends" examples.*** Many parents spoke to the importance of professional caregivers recognizing "firsts" (Floyd, p. 2) in the parents and infant's life, and several discussed their emotional responses to firsts. Some spoke with excitement about an infant first –others spoke regretfully or sadly.

> I remember when I was just starting to pump, and we got the first drop. (Greg: I ran it down here from her hospital room!). When you change that first diaper, and it's like 'oh I got this! I can take care of a baby'…it makes you feel…confident. We didn't get that first initial bond, right as she came out, you know? She was born and put in a bed." (Heather, p. 3-4)

In addition to discussing bittersweet firsts, parents often used the phrase "We know it's for the best, but…." (Greg, p. 3) signaling inner conflict or a parental head-heart disconnect. "It's been tiring and stressful, you know. It's like I have no knowledge of medical anything….so I've learned a lot about how all this works. Trying to figure it out" (Nancy, p. 1). Kelly described dealing with disappointment, stating "I got to try (bottlefeeding) last week, but then he had a backslide on the oxygen, so they had to stop his eating" (p. 1).

> They're like, 'We're gonna do this IV.' Well, I don't want my baby poked. You know? But it's like, at the same time, do you want them to not do it and go home, and end up back here for however many months? I don't want that either. So for the greater good, I'm going to let you poke my baby. (Olivia, p. 4)

***Negative examples.*** Parents discussed episodes of grief, frustration, anger, emptiness, and exhaustion – all variables affecting their engagement in caregiving and occupational performance. "As a first-time mom, you're like, am I just overreacting about everything? I think I'm overreacting…emotionally I'm drained" (Olivia, p. 5). "This is nerve-wracking beyond belief, as a new parent. I'm really concerned with that" (Laney, p. 5). "Feeding them, comforting them, nurturing them, I don't know…I feel insecure in a lot of areas when it comes to that" (Alisha, p. 3).

> They said once you get him home, and everything's regulated, he'll be good to go. But I'm still going to worry about it. It's hard to get used to not worrying. I worry about everything. I worry when I change the diaper, or I feed him. I wonder if I'm doing this right. They say I'm doing it right, so…. (Cathy, p. 2)

**Addressing Health Issues.** The fourth theme, Addressing Health Issues, reflected parents' statements about their attempts to manage their physical, emotional, and psychological well-being. Parents expanded on this concept, discussing the need to address their own health while at the same time addressing their infant's health (to the extent they were capable). "We spend about…about 16 hours a day [at the bedside]. I've backed off a little so I can rest…when I have an hour, it's usually spent sleeping or eating" (Elsa, p. 1). "I'm still in recovery mode, so I try not to overdo it and push my body too much…you have to get rest…I feel guilty, but if you do that, you'll be able to [be here] for your children more " (Julie, p. 1). "He's been so tired and worn out, maybe, being sick was draining his energy. So now he's coming to" (Major, p. 4). "It's hard to sit still…can I go outside? Literally, I felt myself slipping back into depression, and we went outside and it fixed everything" (Alisha, p. 2).

> I was in the hospital previously for a month – before I had [the baby]…I'm an outdoorsy person, so that drove me absolutely nuts. I was on modified bedrest, so I couldn't really do anything. It can really wear on your mind…it can make you depressed. It takes a lot. You really gotta put your coping skills into play and try to calm you mind. You get a couple days into it, and you're about to go crazy. (Julie, p. 5)

**Analyzing.** The final theme, Analyzing, emerged from the parent narratives as they discussed activities undertaken to methodically study and separate into parts their interactions with their infant. Three parenting actions subthemes were identified: Analysis of the Infant, Analysis of Previous Experience, and Analysis of Others.

***Analysis of the infant.*** Parents reported spending the majority of their time interpreting their infant's behavior and the meanings behind those behaviors. "I think they're trying to figure out who's going to be the constant in their life, like who are my mommy and daddy?" (Bobby, p. 3). "I notice they're calmer when we, like, come on the scene…I notice when I go in there and put my hand on their head they just stop cryin' and just relax" (Alisha, p. 4). "She really likes to either lay right on your chest, where she can hear your heart or she likes to be in your arms and gently moved…whatever makes her happy and content you remember" (Olivia, p. 2). "I have a specific song…and I started singing to him yesterday when he got fussy, and he hushed up immediately. Which made me feel really great" (Major, p. 4). "I have to tickle him while I'm feeding him to keep him awake…he's pretty lazy" (Cathy, p. 1-2). "The most amazing thing with both my children is that they recognize my voice. And they look for you…they even recognize dad's voice. So that's pretty amazing" (Elsa, p. 3). "It helps her to know I'm here. Like somebody's here to support her—somebody she's used to" (Heather, p. 1). "They know when I'm here. I know they do" (Julie, p. 3).

> I hope he can tell me apart; like I said, that's one of the reasons I try to talk to him when I'm leaving out or going in…I'll tell him I'll be right back and he'll always turn toward me and his eyes open a little bit. (Donna, p. 3)

***Analysis of previous experience.*** Many parents reflected on previous experience with other children and previous hospital admissions. They also compared the beginning of their admission to their current status and compared their infant's progress to other infants. "This has been an easier stay, for me, compared to the first time because I knew what was going on...it made it less emotional" (Floyd, p. 1). "I'm glad he's not as sick as my niece or a lot of babies in here" (Cathy, p. 1 ).

> As an experienced mother, you know, you're more comfortable with what you can do with a baby than someone who doesn't have any children…I guess I had to kinda…go through that again, feeling comfortable doing things with him because he looked and is so much more easily broken than term ones. (Donna, p. 2)

***Analysis of others.*** NICU parents also engaged in interpretation and analysis of others' actions, verbal communication, and non-verbal communication. They perceived their infant analyzed these features as well. "He's focusing on us—looking at us" (Major, p. 2). "I'm the type of person, or mother, that is…[if] you come in and do something, you need to explain to me what you're doing. Or why you're doing it. It doesn't have to be detailed" (Heather, p. 5). "I try to listen and learn….there's just a lot to it…but give me all the information you can. I like knowing what's going on" (Julie, p. 1).

> My experience down here is that they've been very comforting, reassuring…It was worded to me yesterday by a nurse, 'This is your room. These are your children. You are free to come and go as you please because you just birthed these pretty little things'. (Alisha, p. 5)

**Matrix Organization**

Following Phase 1 coding and thematic analysis, a matrix framework was used to organize and compare project-identified themes with generalized definitions of parent occupations, infant occupations, and parent-infant co-occupation. At the intersections, interpreted actions of parents, infants, and parent-infant dyads represented examples of occupation and co-occupation in the NICU setting (see Appendix D).

**The PEOP Occupational Therapy Process**

In an effort to address meaningful occupational or co-occupational performance goals identified by parents (such as those in Appendix D), neonatal occupational therapists can apply and utilize the Person-Environment-Occupational Therapy Process (The PEOP Process) to guide practice (Bass et al., 2015). In The PEOP Process, a parent or infant's occupational (or co-occupational) performance is systematically promoted through gathering of the narrative, assessment and evaluation of person, environment, and occupation factors, intervention, and measuring of individualized family outcomes. Appendix E provides a blank template of an *adapted* PEOP Process model, specifically modified for neonatal occupational therapy practice and using findings from this doctoral project. Appendix F utilizes the template to provide an illustrative case example of neonatal occupational therapy assessment and intervention using The PEOP Process. For purposes of this doctoral project, the case example used the following fictional scenario to illustrate practical application of the adapted PEOP model for NICU practice: An occupational therapist has received a physician's order for evaluation and treatment of a NICU infant with cleft lip and palate and is asked to assess oral feeding skill.

Using the above scenario, the therapist's step-by-step progression through The PEOP Process begins with a chart review and parent meeting to gather the narrative (see

Appendix F, first column). During the narrative interview, the therapist takes note of occupations and co-occupations verbalized by the parent and makes observations of parent-infant interaction.

Utilizing information learned from Appendix D, the therapist then identifies the dominant themes influencing the parent and infant's participation in meaningful activities. In the fictional scenario, the mother of the infant mentions a host of parenting activities related to Perceiving "They" vs. "I" and Maintaining Proximity. She speaks less frequently of Expressing Emotions, Values and Beliefs, and Addressing (her own personal) Health. When speaking of her infant, the mother describes her infant's efforts at Addressing (his own) Health and Maintaining Proximity. She talks infrequently of the infant's perception of "They" vs. "I" or his efforts spent Analyzing. The occupational therapist then ranks the dominant themes influencing participation, listing them from most influential to least influential (see Appendix F, second column). The purpose of this ranking step is to increase therapist awareness of not just the potential barriers and supports of occupation in the NICU, but the degree to which the barriers or supports influence participation.

Next, referencing the PEOP Model (Baum, et al., 2015), the occupational therapist identifies two (or more) occupation factors, person factors, and environmental factors affecting occupational performance for both the parent *and* the infant (see Appendix F, third column). The therapist also lists in this column two (or more) co-occupations to consider as part of the intervention plan. Beneath each occupation, person, or environmental factor is a continuum scale. The continuum scale illustrates the distance between the constraints/barriers and capabilities/enablers affecting occupational

performance; a marker on the continuum scale represents the therapist's interpretation of the client's status on the continuum (see Appendix F, third column).

Following the assessment phase of the occupational therapy process, the therapist chooses an intervention to address the factors influencing parent and infant occupational performance. In the illustrative case example, the therapist uses approaches such as creation, promotion, maintenance, modification, prevention, and education to maximize developmental and health outcomes not just for the infant, but for the parent and parent-infant dyad as well (see Appendix F, fourth column). The examples provided are not an exhaustive list, but rather a sample of approaches to be considered in this particular case.

Finally, the occupational therapist identifies general and specific outcome measures to help the infant and parent achieve successful occupational performance resulting in optimized health and well-being (see Appendix F, lower row). In the case example, the therapist identified general outcomes such as increased participation and performance, as well as specific outcomes such as mastery of the co-occupation of feeding, mother's verbalization of coping strategies and depression management, safe infant feeding, and initiation of an infant-driven feeding and caregiving schedule. Leading from the outcomes section is an arrow representing cyclical reassessment and reaffirmation of appropriate occupational therapy intervention.

**Summary of Results**

From coded interpretation and thematic extrapolation from transcribed parent narratives, five themes of active engagement emerged; each theme served as a global descriptor of parent and infant experience and represented key aspects of the phenomena of parent and infant occupational performance in the NICU. The five themes identified

were: Perceiving “They” vs. “I”; Maintaining Proximity; Expressing Emotions, Values, and Beliefs; Addressing Health Issues; and Analyzing. Within the identified themes and subthemes, participants provided examples of parent occupations, infant occupations, and parent-infant co-occupations. With increased knowledge and awareness of NICU-based occupations, neonatal occupational therapists can then utilize The PEOP Process to guide occupation-based practice in the NICU setting.

## Discussion

Occupation is multifaceted and complex, and defining occupation or occupational performance in the NICU setting is challenging. Even more challenging is attempting to define how neonatal occupational therapists provide occupation-based care in this highly technical and specialized environment. This doctoral project used a phenomenological approach and qualitative methods to investigate occupation in the NICU and proposed utilization of The PEOP Occupational Therapy Process (Bass et al., 2015) to guide neonatal practice.

For participants in this project, NICU-based occupational performance represented the pursuit of meaningful engagement and included not only the execution of directly observable caregiving activities and tasks, but involvement in "extraordinarily ordinary" (Price & Miner, 2009, p. 72) and oft-unseen purposeful events extending over time. Surprisingly, the vast majority of parenting activities discussed were unseen, yet extremely powerful, influences over parenting action in the NICU. Erlandsson and Eklund (2001) described these types of occupations as "hidden" or "unexpected" occupations (p. 31), stating that occupational therapists should look beyond traditional occupations to recognize "small islands within the [occupational] pattern" (p. 35). While some authors have stated that occupations, by definition, contain observable action components (AOTA, 2014; Polatajko et al., 2004), others have defined occupation as

something beyond the observable "doing" process—one that includes the subtleties of "being" and "becoming" (Wilcock, 1999, p. 4):

> Being encapsulates such notions as nature and essence, about being true to ourselves, to our individual capacities and in all that we do. Becoming adds to the idea of being a sense of future and holds the notions of transformation and self-actualization….Occupational therapists are in the business of helping people to transform their lives through enabling them to do and to be and through the process of becoming. (Wilcock, 1999, p. 1)

The findings from this doctoral project were consistent with the latter thought, suggesting that parent occupations, infant occupations, and parent-infant co-occupations are delicately layered (Hasselkus, 2006) and comprised of much more than a list of outwardly observable activities like oral feeding, socializing, basic caregiving, and holding. Accordingly, parenting occupations such as decision-making, dreaming, grieving, habit changing, interpreting behavior (and other *being* or *becoming* occupations) may be unintentionally overlooked by occupational therapists in the effort to support hands-on or directly observable *doing* activities and caregiving.

Subtle, yet extremely meaningful infant occupations were described as well; parent participants in this study identified learning, tolerating, parent-seeking, responding, recovering, relaxing, and sleeping as just some of the activities in which they believed their infant actively participated. Examples supported the definition of infant occupations offered by Vergara (2002), wherein infant occupations are defined as any valued task or activity that the family or NICU culture expects the infant to engage in.

Parents also provided examples of co-occupation, or meaningful, synactive, parent-infant interaction in the NICU. Among other examples, determining their own schedule, providing consistency and continuity, communicating, nurturing, learning to feed, studying each other, and comforting were just a few valued co-occupations in the NICU. These examples provide strength to the definition of co-occupation and add a new component to the construct, suggesting that beyond co-occupation's reflective and reciprocal *doing* nature lays a host of interdependent *being* and *becoming* occupations that are unseen yet essential to meaningful existence and role performance.

Each NICU-based occupation and co-occupation was organized within one of five emergent themes of active engagement identified during qualitative analysis of parent interviews: Perceiving "They" vs. "I"; Maintaining Proximity; Expressing Emotions, Values, and Beliefs; Addressing Health Issues; and Analyzing. Themes were reflective of previously published literature on barriers to and supports of parenting in the NICU, parent and infant coping strategies, family development, effects of parent and infant health on participation in caregiving, psychological and emotional stressors in the NICU setting, neurobehavioral observation, and acclimatization to the NICU culture.

Surprising was the number of occupations and co-occupations that fell under the theme Perceiving "They" vs. "I". This resonated with previously published literature summoning postcolonialist critical theory when evaluating patterns of group dominance and the effects of inclusion and exclusion on recipients of healthcare services. Likewise, apparent in parent interviews was the concept of "othering" in healthcare, defined as the perception of distance from the dominant medical group and identification as a caregiving "other" (Johnson et al., 2004, p. 263). Beyond provision of biomechanical or

sensory intervention, neonatal therapists must consider their roles as collaborators in the infant's care and frequent liaisons between the groups and act as instruments of social change within the NICU environment.

Captured within each theme were previously documented examples of parenting occupations and parent-infant co-occupations, as well as unique, unpublished examples of parent and infant occupations and co-occupations. Finally, using novel examples of occupation and occupational performance in the NICU, The PEOP Process (Bass et al., 2015) was employed as a practical framework guiding occupation-based practice in the NICU setting. The case example illustrated the integration of emergent themes as global framers of parent and infant experience, and highlighted the importance of therapists addressing occupations seen and unseen, positive and negative, predominant and seemingly inconsequential.

**Project Limitations and Challenges**

The physical environment in which this project took place could be a limitation of this project. The NICU design included private rooms and an in-hospital Ronald McDonald House, affording parents the ability to stay overnight either at their infant's bedside or within the hospital proper at no additional cost. Single-family room designs and in-hospital housing accommodations are not a universal feature of NICUs, so transferability of findings may affected. Additionally, specific NICU policies and procedures could have affected parental perception of participation and resulting themes; the location in which the project took placed had open visitation hours, family-centered participation guidelines, parent participation in physicians' rounds and nursing shift change, and sibling visitation allowances. With increased access to their infant, parent

responses may not have captured the perceived barriers to participation experienced in units that are more restrictive. Regarding interview participants, the group was homogenous (which limits generalizability), consisting of mostly Caucasian mothers ages 19-37 living in Missouri. Limitations inherent in qualitative methodology and applicable to this project included issues of trustworthiness (the author was unable to member-check emergent themes with parent participants as all had discharged prior to data analysis) and objectivity (the omnipresent risk of interviewer bias and personal assumption). A final limitation included the potential danger of categorization methods often used in qualitative investigations:

> We have a penchant for pulling things together into entities that give us a sense of unity, into categories. What is seen is the common denominator, the anonymity of the everyday; *what are often unnoticed are the complexities and singularities of the everyday* [*emphasis added*]. (Hasselkus, 2006, p. 629)

**Implications for Occupational Therapy Practice**

This doctoral project suggests that neonatal occupational therapists have the opportunity to practice in a way that supports AOTA's Centennial Vision (2007), addresses social policy barriers, and honors Reilly's (1962) call to return to holistic intervention rooted in occupation. With increased awareness of parent occupations, infant occupations, and parent-infant co-occupations, therapists can embrace the unique role of neonatal occupational therapy in the lives of both parents *and* infants within the NICU setting. The researcher proposes reconsideration of who the NICU client truly is—might the profession pursue an expansion of referral guidelines that includes not only infants at risk for occupational performance challenges but parents as well? Additionally, neonatal

occupational therapists practice under physician referrals historically grounded in and triggered by biomedical dysfunction; should the profession advocate for a policy-level paradigm shift and seek proactive referrals to address the occupational needs of the family at all ages and stages of NICU admission? Is there an opportunity for occupational therapists to proactively play a role in supporting family occupations through services provided to women on bedrest? The author is in agreement with Pitonyak (2014) who stated, "occupational therapists have opportunities to expand their consultation and advocacy to healthy-population families to lessen environmental and contextual barriers to [co-occupation]" (p. e95).

To address current practice issues, application and use of the PEOP Model and The PEOP Process can guide neonatal assessment and intervention, allowing occupational therapists to address influences on occupational performance in a logical and evidence-based manner. Use of a systematic therapy process would not only maximize benefits for infants and families, but would aid in the training and education of neonatal occupational therapy practitioners and support future research efforts and outcomes measures.

**Considerations for Knowledge Advancement**

Further development and exploration of NICU-based parent and infant occupation and co-occupation is warranted. Conducting parent interviews in multiple settings with increasingly diverse populations would add to the richness of occupational and co-occupational definitions in the NICU. Development of a standardized tool or co-occupational model of practice and continued study of application of The PEOP Process (Bass et al., 2015) in the NICU environment would serve to expand the art and science of

neonatal occupational therapy. A final consideration for future knowledge advancement would be expansion of the *Specialized Knowledge and Skills for Occupational Therapy Practice in the Neonatal Intensive Care Unit* paper (AOTA, 2006) to include a discussion of how occupation-based conceptual practice models serve to guide appropriate therapeutic application in this highly specialized setting.

The innovative purpose of this doctoral project was twofold: to both *inform* and *transform* neonatal occupational therapy practice. In an effort to *inform*, this project presented occupational therapists, multidisciplinary NICU professionals, family members, and other stakeholders with rich definitions and examples of parent occupations, infant occupations, and parent-infant co-occupations experienced in the NICU  In an effort to *transform* practice and encourage a shift away from a purely biomedical, sensory, or environmental view of the NICU infant, this doctoral project employed a strong, family-centered occupational focus and outlined the process guiding occupational therapist and client interaction in the NICU.

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## Appendix A

*Parent Interview Questions*

| Interview Question Category | Interview Question |
|---|---|
| Activity-focused | Before baby was born, what activities did you imagine yourself doing as a parent?<br>Now that baby is here, what does "parenting" look like in the NICU?<br>Tell me about what you do when you are here.<br>What are your favorite things to do with your baby?<br>How do you feel when are doing those things?<br>What does your baby spend time doing?<br>What activities are you most confident in?<br>Which activities are you unsure of? |
| Parent-perspectives | Describe how your baby responds to you.<br>Share your experiences in NICU when you are unable to interact with your baby.<br>What gets in the way of parenting in the NICU?<br>What supports parenting in the NICU?<br>How would you describe your best day here?<br>How would you describe your worst day here?<br>How would you describe the NICU or NICU experience to a new parent?<br>What dreams do you have for your baby? For yourself? For your family? |

# Appendix B

*Interview Participant Characteristics*

| Participant | Parent Role | Age (yrs) | Self-identity | Marital status | Distance lived from hospital (miles) | Living arrange-ments while baby in hospital | Other children | Infant gest-ational age (weeks) | Infant current age (days) |
|---|---|---|---|---|---|---|---|---|---|
| 1 (Family 1) | Mom "Alisha" | 28 | Native American | Married | 20 | In-hospital | Yes | 34 | 4 |
| 2 (Family 1) | Dad "Bobby" | 27 | Caucasian | Married | 20 | In-hospital | Yes | 34 | 4 |
| 3 (Family 2) | Mom "Cathy" | 19 | Caucasian | Single | 10 | In-hospital | No | 37 | 7 |
| 4 (Family 3) | Mom "Donna" | 37 | Caucasian | Married | 90 | In-hospital | Yes | 26 | 42 |
| 5 (Family 4) | Mom "Elsa" | 34 | Caucasian | Married | 105 | In-hospital | Yes | 34 | 8 |
| 6 (Family 4) | Dad "Floyd" | 36 | Caucasian | Married | 105 | In-hospital | Yes | 34 | 8 |
| 7 (Family 5) | Dad "Greg" | 32 | Caucasian | Married | 45 | Commuting | No | 31 | 18 |
| 8 (Family 5) | Mom "Heather" | 33 | Caucasian | Married | 45 | In-hospital | No | 31 | 18 |
| 9 (Family 6) | Mom "Julie" | 25 | Caucasian | Single | 150 | In-hospital | No | 31 5/7 | 14 |
| 10 (Family 7) | Mom "Kelly" | 33 | Caucasian | Married | 90 | In-hospital | No | 40 | 13 |
| 11 (Family 8) | Mom "Laney" | 29 | Caucasian | Engaged | 4 | In-hospital | No | 38 | 2 |
| 12 (Family 8) | Dad "Major" | 28 | Caucasian | Engaged | 4 | In-hospital | No | 38 | 2 |
| 13 (Family 9) | Mom "Nancy" | 33 | Caucasian | Married | 60 | Commuting and in-hospital | No | 25 1/7 | 5 |
| 14 (Family 10) | Mom "Olivia" | 22 | Caucasian | Single | 1 | In-hospital | No | 40 | 3 |
| Averages and totals: | 10 moms, 4 dads | 29.7 | 93% Caucasian 7 % Native American | 65% married, 14% engaged, 21% single | 53.5 | Staying in hospital 89% Commuting 11% | New parents: 64% | 33.8 weeks. (64% pre-mature, 36% term) | 10.6 |

## Appendix C

*Example of Inductive Content Analysis*

| **Meaningful unit** | **Condensed meaningful unit** | **Code** |
|---|---|---|
| Going on trips, taking him fishing | Going on fishing trips | Going fishing together<br>Outings<br>Being outside |
| We're a fishing family, we love to fish | Enjoying fishing together as a family | Doing together<br>Expressing enjoyment<br>Identification as family |
| I get to hold him a lot now – get him close | Holding him close; holding him often | Holding<br>Frequency of interaction<br>Proximity<br>Rule following |
| I really want to see him eat out of a bottle | Desire to see infant bottlefeed | Oral feeding<br>Anticipating |
| They're doing it (feeding) through the syringe | Being fed with a syringe | Syringe feeding<br>Medical caregiving<br>Shared parenting |
| I just hold his little hand | Holding his hand | Touch<br>Comforting |

# Appendix D

*Thematic Matrix with Resultant Occupations*

| | Parent Occupations | Infant Occupations | Parent-infant Co-occupation | |
|---|---|---|---|---|
| **Perceiving "They" vs. "I"** | <u>"Positive" Examples</u><br>Trusting others<br>"Owning" sharing of photographs on social media<br>Partnering with others<br>"Owning" breastfeeding/pumping<br>Decorating infant hospital room<br>Acknowledging skill level of professionals<br>Maintaining baby's bedding or bedspace<br>Appreciating consistency<br><br><u>"It Depends" Examples</u><br>Assisting with medical caregiving<br>Developing relationships with NICU staff<br>Staying informed<br>Finding their voice<br>Being "invited" to participate in cares<br>Sharing of parenting activities<br>Defining "family" and parental role<br>Refining/defining support systems<br>Accepting help<br>Decision making<br>Persevering<br>Rule setting<br>Balancing the statement "They say it's for the best" | <u>"Negative" Examples</u><br>Adhering to imposed, strict schedules<br>Public parenting<br>"Getting protective"<br>Comparing caregivers<br>Experiencing barriers to parenting<br>Answering to authority<br>Rule following<br>Experiencing occupational injustice and/or deprivation<br>Watching<br>Distrusting others<br>Standing back<br>Stepping away<br>Being monitored<br>Lamenting lack of continuity and/or consistency<br>Protecting | Learning to recognize parents vs. NICU caregivers<br>Interacting with multiple caregivers<br>"Driving" caregiver interaction through behavior (as opposed to task-based interaction)<br>Seeking parents<br>Tolerating medical interventions | Facilitating togetherness<br>Enjoying privacy<br>Establishing routines<br>Determining own schedule<br>"Owning" skin-to-skin holding<br>Establishing own rules<br>Establishing own schedule<br>Demonstrating predictability and continuity |

**Maintaining Proximity**

Responding to the Infant
"It's the little things"
Kissing
Touching
Studying baby
Holding
Communicating
Staying near
Responding to baby's needs
Singing to baby
Watching over
Reading to baby
"Saying hello and goodbye"
Rocking/swaying
Listening to baby
"Teaching him stuff"
"Loving on her"

Caregiving
Participating in general caregiving (bathing, diaper changes, dressing, temperature taking, lotion, brushing hair, etc.) Confidently providing care around medical equipment
Managing medical equipment
Positioning/re-positioning
Being available to talk to professional caregivers

Temporal Considerations
Balancing time with spouse/family members
Extended visiting
Balancing work/maternity leave
"Hanging out"

Addressing Interruptions
Calling to check on baby
Recording the moments
Personalizing baby's NICU bedspace
Driving/going home
Dealing with lack of proximity
Grieving the loss of "what should have been"

Tolerating hands-on care
Attempting socialization/looking
Orienting to sound
Responding to caregivers
Communicating through body language
Grasping/holding-on
Sucking on pacifier
Seeking parents
Listening
Recovering from interrupted sleep
"Getting spoiled"
"trying to figure out who their parents are"

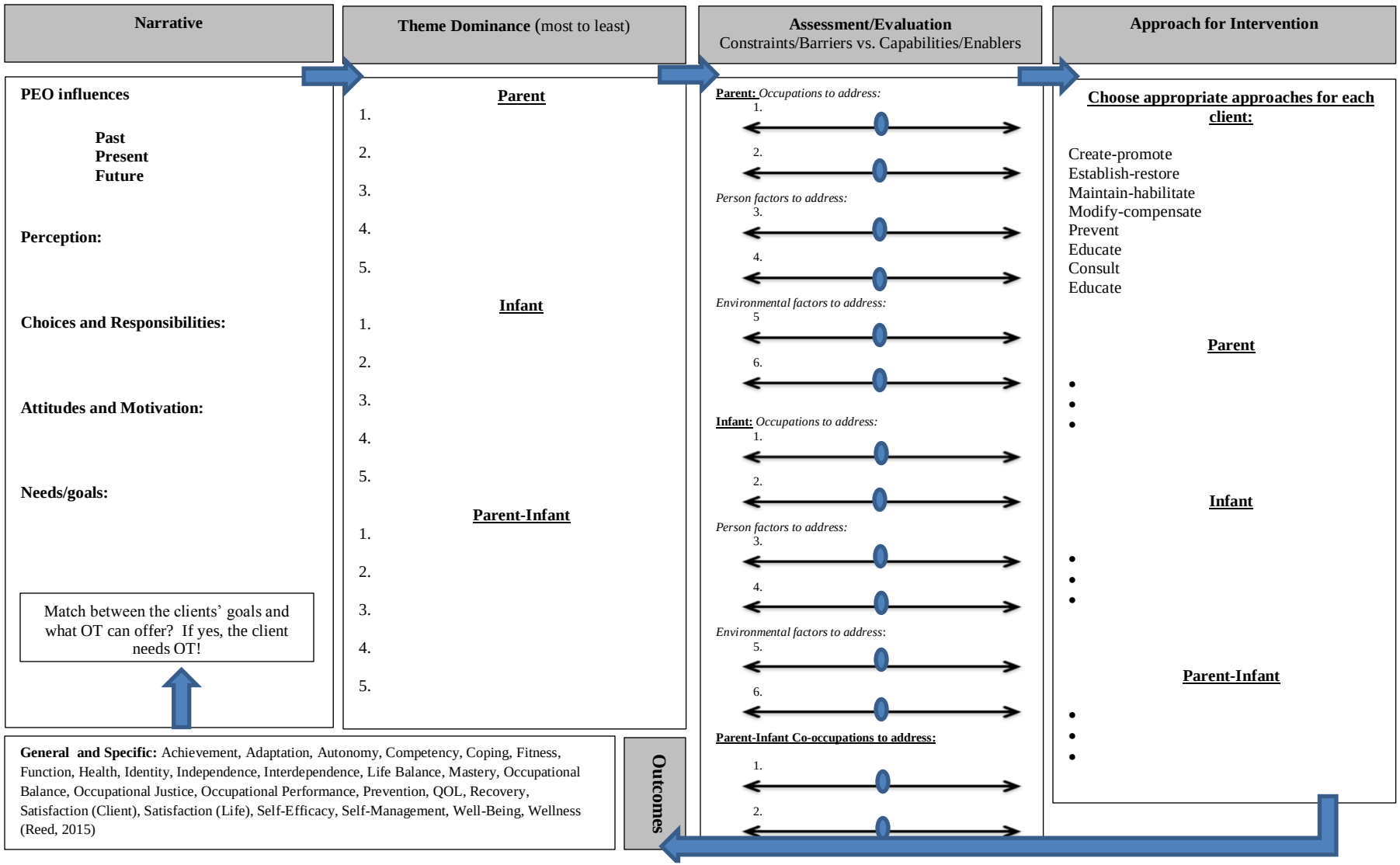
Reciprocal caregiving
Communicating
Comforting
Cuddling/snuggling
Sleeping while being held
Nurturing
Feeding
Sucking on pacifier
Interacting
Reading together
Responding to each other

| | | | | |
|---|---|---|---|---|
| **Expressing Emotions, Values, and Beliefs** | "Positive" Examples<br>Dreaming of home<br>Expressing positive emotions (joy, surprise, pride, accomplishment, happiness, gratefulness, feeling blessed, thankful, calm, confident)<br>Texting/calling support people<br>Anticipating<br>Imagining<br>Dreaming<br>Demonstrating resiliency<br>Journaling<br>"Rooting him on"<br><br>"It Depends" Examples<br>Discussing "Firsts"<br>"Taking things day-by-day"<br>Talking about expectations<br>Advocating<br>Balancing positive feelings with negative feelings<br>"We know it's for the best, but…"<br>Setting priorities | "Negative" Examples<br>Expressing negative emotions (helplessness, panic, anger, frustration, ambivalence, emptiness, stress, exhaustion, aggression, insecurity, paranoia)<br>Suffering from inability to "do anything"<br>Grieving "what should have been"<br>Experiencing an "emotional roller coaster"<br>"I worry all the time" | Self-regulating/calming<br>Self-organizing<br>Expressing positive emotions through behavior<br>Expressing negative emotions through behavior<br>"Being curious"<br>"Looking for attention"<br>"Relaxing" | Responding to each other<br>Socializing<br>Communicating<br>Learning to trust one another |
| **Addressing health issues** | Sleeping/resting<br>Managing "idle time"<br>Fighting fatigue<br>Praying<br>Healing/recovering<br>Seeking life balance<br>Modeling other parents<br>Using caution regarding own health<br>Changing habits<br>Listening | Seeking information about health<br>Going outside<br>Identifying/clarifying new roles<br>Encouraging infant's development and health<br>Eating/maintaining nutrition<br>Providing breastmilk<br>Delivering breastmilk<br>Using coping strategies<br>"Taking care of myself" | Protecting self<br>Sleeping/resting<br>Tolerating medical interventions<br>"Growing"<br>"Healing"<br>"Getting stronger"<br>"Staying stable"<br>"Getting better"<br>"Adjusting"<br>"Learning"<br>"Developing"<br>"Making progress"<br>Eating | Sleeping during skin-to-skin holding<br>Holding skin-to-skin<br>Holding while swaddled<br>Medical caregiving<br>General caregiving<br>Bonding and attachment<br>Feeding together<br>Transitioning infant between sleep/wake states |

| | | | | |
|---|---|---|---|---|
| **Analyzing** | Analysis of the Infant<br>Interpreting infant behaviors<br>Wondering about infant development<br>Problem solving<br>Relying on "instincts"<br>Calling for help<br><br>Analysis of Previous Experience<br>Comparing prior parenting experience<br>Comparing previous NICU experience<br>Comparing beginning of admission to current status<br>Comparing to other babies<br>Experiencing information overload<br>Repeating questions to caregivers | Analysis of Others<br>Interpreting medical professionals' actions, verbal and non-verbal communication<br>Interpreting NICU cultural norms<br>Learning from caregivers and applying knowledge at the bedside<br>Listening<br>Modeling caregiver behaviors and actions<br>Interpreting family member responses<br>Reassuring family members | Registering information from the world<br>"He's focusing on us—looking at us"<br>Learning<br>Recognizing<br>"Dreaming" | Responding to each other's needs<br>Learning from one another<br>Studying each other |

# Appendix E

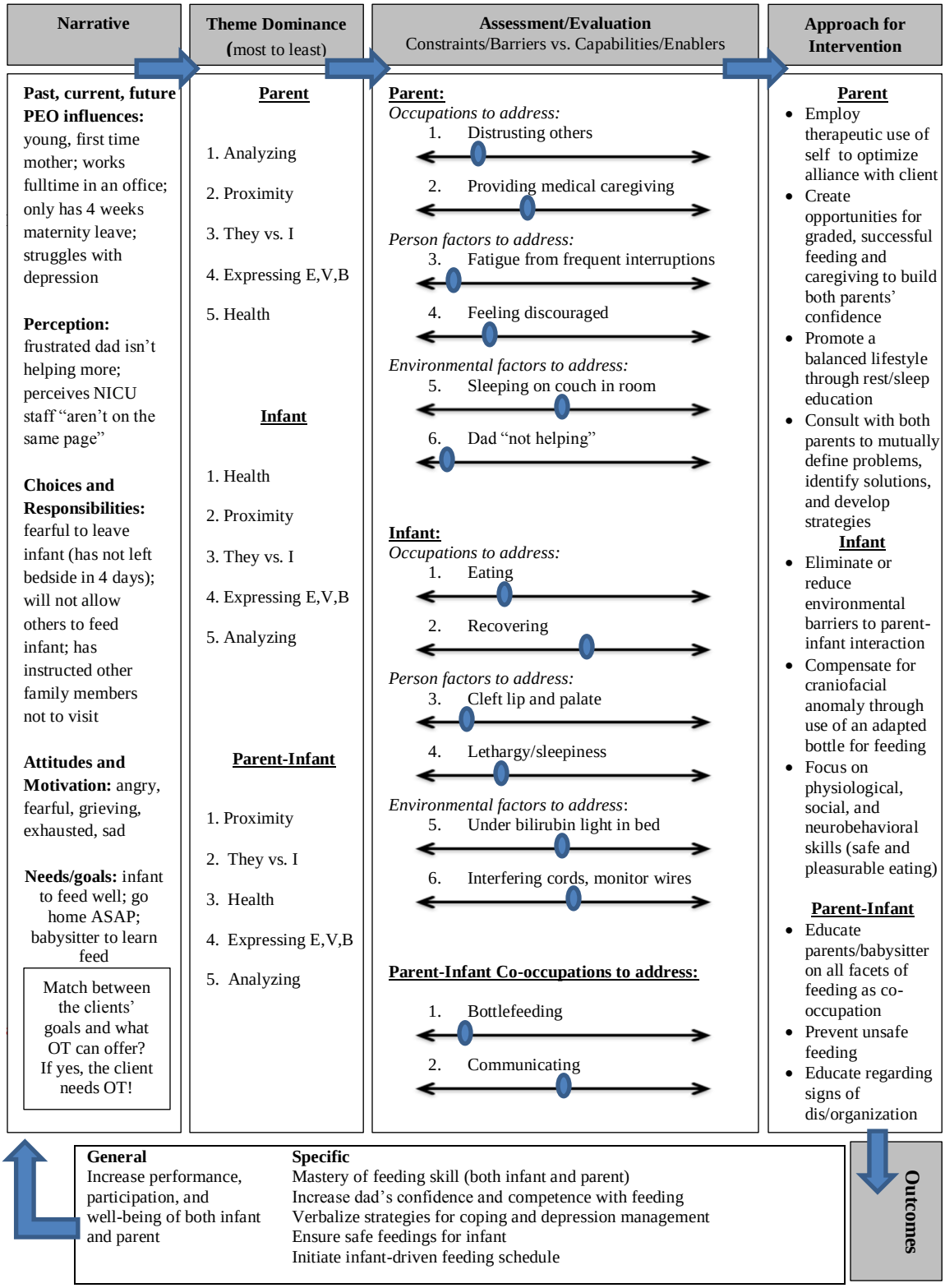
*The PEOP Process Model Adapted for NICU Utilization (Template)*




Model adapted from "Introduction to the PEOP Occupational Therapy Process," by J.D.Bass et al., 2015, *Occupational Therapy: Performance, Participation, and Well-Being (4th ed.)*, p. 59. Copyright 2015 Slack, Inc.

# Appendix F

*The PEOP Process Model Adapted for NICU Utilization (Case Example)*




Model adapted from "Introduction to the PEOP Occupational Therapy Process," by J.D.Bass et al., 2015, *Occupational Therapy: Performance, Participation, and Well-Being (4th ed.)*, p. 59. Copyright 2015 Slack, Inc.

# Appendix G

*St. Catherine University Institutional Review Board Approval Letter*

ST. CATHERINE UNIVERSITY

**Expedited Review Approved by Chair - IRB ID: 337**

**John Schmitt** <noreply@axiommentor.com> Mon, Dec 8, 2014 at 6:57 AM
Reply-To: John Schmitt <jsschmitt@stkate.edu>
To: adcardin@stkate.edu

St. Catherine University IRB Approval Notification

To: Ashlea Cardin
From: John Schmitt, IRB Chair
Subject: Protocol #337
Date: 12/08/2014

On behalf of the IRB, I have reviewed your response to stipulations for application **# 337: An investigation of parent and infant occupational performance in the Neonatal Intensive Care Unit** as an expedited level review. You have addressed all edits and clarifications as requested. As a result, the project has been approved as revised.

Once this project has been reviewed by the Mercy Hospital IRB, please submit a copy of their approval. If any changes are requested by the Mercy IRB, please submit an amendment outlining these changes through St. Catherine University's Mentor IRB program and I will approve. Once this process is complete, you may begin your research.

If you have any questions, feel free to contact me or email via the Mentor messaging system. Also, please note that all research projects are subject to continuing review and approval. You must notify our IRB of any research changes that will affect the risk to your subjects. You should not initiate these changes until you receive written IRB approval. Also, you should report any adverse events to the IRB. **Please use the reference number listed above in any contact with the IRB.**

This approval is effective for one year from this date, 12/08/2014. If the research will continue beyond one year, you must submit a request for IRB renewal before the expiration date. When the project is complete, please submit a project completion form. These documents are available in the St. Catherine University Mentor IRB site.

We appreciate your attention to the appropriate treatment of research subjects. Thank you for working cooperatively with the IRB; best wishes in your research!

Sincerely,

John Schmitt, PhD

# Appendix H

*Mercy Hospital Institutional Review Board Approval Letter*

**MERCY**
**INSTITUTIONAL REVIEW BOARD**
1235 E. Cherokee
Springfield, MO 65804
phone 417-820-5397
mercy.net

DATE: January 8, 2015
TO: Ashlea Cardin
FROM: Mercy Health Springfield IRB

Project Title: [702970-1] An investigation of parent and infant occupational performance in the Neonatal Intensive Care Unit
SUBMISSION TYPE: New Project
ACTION: APPROVED
APPROVAL DATE: January 8, 2015
Continuing Review Due: January 7, 2016
REVIEW TYPE: Expedited Review

Thank you for your submission of New Project materials for this project. The Mercy Health Springfield IRB has APPROVED your submission of the following items:
• Advertisement - Flyer to post in NICU
• Application Form - application (from St. Catherine's, and being used instead of standard form)
• Conflict of Interest - Declaration - Cardin Financial Disclosure 01-15.pdf
• CV/Resume - Cardin CV 01-15.docx
• Data Collection - Interview tool
• Letter - St. Catherine University IRB Letter of Approval
• Letter - Letter of Support from Dr. Slack At Pediatrix
• Training/Certification - Cardin CITI training 01-05-14.pdf
• Summary for Parents
• ICF dated 01/06/2015

This approval is based on an appropriate risk/benefit ratio and a project design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

Please remember that informed consent is a process beginning with a description of the project and insurance of participant understanding followed by a signed consent form. Informed consent must continue throughout the project via a dialogue between the researcher and research participant. Federal regulations require that each participant receives a copy of the consent document.

Please note that any revision to previously approved materials must be approved by this committee prior to initiation. Please use the appropriate revision forms for this procedure.

All local SERIOUS and UNEXPECTED adverse events must be reported promptly to this office. Please use the appropriate reporting forms for this procedure. All FDA and sponsor reporting requirements should also be followed.

All NON-COMPLIANCE issues or COMPLAINTS regarding this project must be reported promptly to this office.

Based on the risks, this project requires continuing review by this committee on an annual basis. Please use the appropriate forms for this procedure. Your documentation for continuing review must be

received with sufficient time for review and continued approval before January 7, 2016. **If a continuing review report is not received by this date the protocol will be suspended. In this case, no research activity can be conducted until the report is submitted and a reinstatement letter is issued from the IRB.** Consent forms are not re-stamped when the continuing review report is approved. Continue to use the most recent IRB approved consent form.

Please note that all research records must be retained for a minimum of three years after the completion of the project.

The Mercy Health Springfield IRB operates in accordance with Good Clinical Practices, as well as applicable national, local and institutional regulations and guidelines that govern IRB operations. If you have any questions, please contact Sandy Whittaker at 417-820-5397 or sandra.whittaker@mercy.net.

Please include your project title and reference number in all correspondence with this committee.
This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within Mercy Health Springfield IRB's record