

## **Psychologists in the NICU: Current issues and challenges**

Approximately 10-15% of all infants born in the United States each year are treated in a neonatal intensive care unit (NICU; March of Dimes, 2007), with a certain proportion spending the entire duration of their short lives in the NICU. A growing literature is establishing that the parents of these extremely fragile and acutely ill infants exhibit elevated rates of post-traumatic, depressive, and anxiety symptoms (e.g., Carter, Mulder & Darlow, 2007). While coming to terms with their child's medical condition and navigating complex medical systems, parents must also develop their parental identities and cope with their own feelings of sadness, anger, fear, guilt, helplessness and grief (Davis & Stein, 2004). As such, there is an increasing role for psychologists in providing assessment, support, and direct intervention to parents and families in the NICU. With training in domains such as lifespan development, individual and family assessment, disease process and management, behavioral medicine, and interdisciplinary team care (Aylward, Bender, Graves, & Roberts, 2009), psychologists are well suited to provide a wide range of clinical and consultative services in the NICU.

This symposium will highlight the essential need for psychological services for parents and families with critically ill and dying infants in the NICU, as well as the challenges faced by psychologists who care for these families in pediatric settings. The symposium begins with a presentation discussing system-level challenges to offering psychological support to parents in a NICU based in a pediatric facility. The second presentation discusses the assessment of postpartum depression in the context of ongoing screening projects for mothers in the NICU, while the third addresses the role of psychologists on NICUs in providing evidence-based psychological care and facilitating critical bioethical decision-making for parents in the NICU by using two case studies. This final presentation offers a conceptual model of psychosocial care that bridges perinatology and neonatology, thereby providing a vision for psychologists who care for families within the NICU and beyond.

This symposium also will provide an opportunity to reflect more broadly on psychological issues relevant to the NICU, emerging roles for psychologists, and future challenges and directions for clinical and research opportunities in the NICU.

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## **System-level challenges surrounding psychological support for NICU parents**

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For parents with a child in the Neonatal Intensive Care Unit (NICU), struggling to maintain one's emotional composure while having to make major life or death decisions regarding the care of one's child takes a tremendous psychological toll. Stress, guilt, anxiety, depression, and sometimes even acute psychotic episodes are responses to this overwhelming pressure. In addition to information about the impact of pre-existing mental health conditions and the stress of being in the NICU, existing literature provides some direction for understanding the psychological trauma induced by this experience and how healthcare providers might support families through their journey in the NICU. System-level challenges arise when the team attempts to initiate such support by introducing psychological or psychiatric care to these parents. However, once these services are deemed necessary, questions arise –

- Who is trained to see adults at the pediatric hospital?
- Where are the parents seen for a medication evaluation or psychotherapy session?(on-site, off-site)
- If medication is warranted, who will write for the medication?
- Where will medication information be kept –baby's chart, parent chart?
- What will be included in parent notes – diagnostic information, suicide assessment?
- What is the liability to the hospital in offering this service?
- How will the hospital bill for services knowing that the parents are not patients in the pediatric institution?

During this presentation, system-level challenges to offering psychological or psychiatric support to parents in a NICU based in a pediatric facility will be discussed. This will be compared with the mechanisms in place in a maternity unit and a NICU based in an adult care facility. While the goal of care is clear--support families, optimize parent-baby attachment, address parental mental health needs, and make sure parents receive training for post discharge care--the pathway to achieving these aims is not.

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## **Assessment of Postpartum Depression in the NICU**

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Depression is the leading cause of disease related disability for women (Kessler, 2003) and the most common complication of childbirth. Postpartum depression (PPD) is associated with significant negative child health outcomes as well as continued negative maternal health outcomes. Due to the public health significance of PPD, the reduction of depression after delivery, as a postpartum complication, was one of the Healthy People 2010 (HP, 2010) targets for reduction of maternal illness and complications due to pregnancy.

Rates of PPD have been found to range from 28% to 70% in mothers of infants in the NICU (Mounts, 2009), which is significantly higher than the general population estimate of 15% (CDC, 2007). Studies have also shown that mothers with preterm infants experience higher rates of PPD than mothers of full-term infants (Veddocci et al., 2001). Mothers of preterm infants experience high stress levels and feelings of helplessness in the NICU and often lack adequate knowledge of how to parent and interact with their infants during the hospital stay (Cusson, 2003; Melnyk et al., 2001; Pinelli, 2000). Increasing literature suggests that symptoms of PPD associated with the NICU are significantly related to both parental and infant outcomes (Melnyk et al., 2006).

We will describe our work in the area of PPD in mothers of NICU infants at the Children's Hospital at the University of Oklahoma Health Sciences Center. Specifically, we will present on PPD screening projects completed in the NICU and discuss several critical areas: appropriateness of PPD screening measures for NICU; barriers to integrating PPD screening into routine clinical care; challenges in making community referrals for mothers; billing and reimbursement issues; and the role of pediatric psychology. Lastly, we will review our work with the national Pregnancy Risk Assessment Monitoring System (PRAMS) to examine PPD in mothers of NICU infants.

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## **The role(s) of psychologist in NICU bioethical decisions: Two case examples**

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As technologic and medical advancements continue, NICU's are faced with increasingly difficult decisions regarding provision of life-sustaining treatments within the context of uncertain survival or quality of life (Kuschel & Kent, 2011). Both from a family-centered care model and the obligation of parents to act as decision-makers for their infant, these bioethical dilemmas involve active participation from parents at a time of intense stress (Shaw et al., 2009). The emotional challenge that surrogate decision-makers experience (Wendler & Rid, 2011) coupled with clinical levels of psychological distress evidenced by parents at the time when decision-making is required highlight the importance of offering evidence-based psychological care to mitigate any negative impact of emotional distress on the ability of parents to act on behalf of their vulnerable child. The role of psychologists in facilitating bioethical decision-making by both promoting parents ability to effectively carry out their role as surrogate decision-makers within the NICU as well as consulting at the systems level with health care providers to facilitate effective communication around emotion- and value-laden topics will be discussed. Two case presentations will illustrate key themes of autonomy/informed consent; protection of the vulnerable; beneficence and nonmaleficence, role of EBT intervention with family members regarding mood concerns and coping with trauma/stress; systems work and communication interventions with medical providers; family grief intervention; and staff support.

Kuschel, C. A. & Kent, A. (2011). Improved neonatal survival and outcomes at borderline viability brings increasing ethical dilemmas. *Journal of Paediatrics and Child Health*, 47, 585-589.

Shaw, R. J., Bernard, R. S., Deblois, T., Ikuta, L. M., Ginzburg, K. & Koopman, C. (2009). The relationship between acute stress disorder and posttraumatic stress disorder in the neonatal intensive care unit. *Psychosomatics*, 50, 131-7.

Wendler, D. & Rid, A. (2011). Systematic review: The effect on surrogates of making treatment decisions for others. *Annals of Internal Medicine*, 154, 336-346.

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## **Pregnancy, the NICU, and Beyond: A Model of Psychosocial Care for Families and Children**

Lassen, S., Ph.D., University of Kansas Medical Center

Most NICUs throughout the country have psychosocial services available to families. Some NICU programs also have developmental follow-up clinics to track the development of infants discharged from NICUs. Additionally, most institutions have some modicum of supportive services to offer at-risk antepartum mothers. However effective and thorough these services are, they tend to be disjointed and operate in isolation from each other. What is needed is a broad and comprehensive model of psychosocial care for these children and families that can identify, support, and manage difficulties as they arise across each of these settings. Such a model would also serve as a blueprint for a systematic research approach to furthering our understanding of the psychosocial needs of children and families at each of these juncture points. Pediatric psychologists, with training in such areas as family systems theories, child development, research design, and the impact of chronic illness on family systems, are well-positioned to take a key role in coordinating this array of broad, yet related needs for children and families. Relevant concepts for such a model include a) the family-centered medical home where comprehensive health care is provided to families across the life span and b) the wraparound service provision model to at-risk youth and families that cuts across agencies and programs to provide comprehensive and coordinated services. This presentation will present a conceptual model of psychosocial care that bridges the areas of perinatology and neonatology, providing a vision for the role of pediatric psychology in its implementation.

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