Cultural Humility in the NICU

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The National Perinatal Association (NPA) is an interdisciplinary organization that strives to be a leading voice for perinatal care in the United States. Our diverse membership is comprised of healthcare providers, parents & caregivers, educators, and service providers, all driven by their desire to give voice to and support babies and families at risk across the country.

Members of the NPA write a regular peer-reviewed column in Neonatology Today.

The scope of NICU care was once focused solely on the medical needs of the neonate. Today, compelled by an international movement towards family-centered care, many NICU environments now prioritize attending to the psychosocial needs of the patient's family. As society has grown increasingly attuned to the unique experiences and needs of diverse populations, so too is healthcare adopting the idea of cultural humility. Cultural humility goes above and beyond cultural sensitivity or competency; rather, practicing cultural humility in healthcare "incorporates a lifelong commitment to self-evaluation and self-critique, to redressing the power imbalances in the patient-physician dynamic, and to developing mutually beneficial and non-paternalistic clinical and advocacy partnerships" (Tervalon & Murray-Garcia, 1998). Each person who comes through the NICU, be they patient, provider, or family member, brings with them a unique experience of healthcare and the medical environment. As such, practicing cultural humility when serving NICU family members is paramount. After all, the provision of good psychosocial care is not, and should not be; one size fits all.

"The First 1,000 Days was initiated in 2010 by Secretary of State Hillary Clinton in response to ground-breaking scientific evidence that identified a powerful window of opportunity from a woman's pregnancy to a child's 2nd birthday when nutrition has a long-term impact on the future health and development of both children and societies. "

What space, if any, should religion and spirituality occupy in a modern NICU? Research suggests that patients and providers may hold incongruent attitudes towards the role and relative importance of religion, spirituality, and folk medicine in the NICU; one study found that 45% of professionals reported that they prefer parents not express their religious or spiritual beliefs (i.e., engage in religious or spiritual practices) in the NICU setting (Lloreda-Garcia, 2017). Delivering care that acknowledges and accepts parental religious and spiritual practices can and should be a priority in the NICU, particularly surrounding difficult end-of-life decisions.

Religion and spirituality can be an important means to help parents cope with life in the NICU.

While some parents with a strong religious background may experience a deepening of their faith as a result of the NICU experience (Brelsford & Doheny, 2016), others may demonstrate a more questioning or negative religious coping style (i.e., questioning "why me?" or feeling abandoned by or angry at God). Negative religious coping has been associated with poor family cohesion and the use of denial (Brelsford et al., 2016). A growing body of literature has revealed that religion and spirituality, particularly spiritual coping skills, may protect against poor mental health and grief outcomes in NICU parents following the death of a child (Hawthorne, 2013). In response to such findings, a subset of NICUs around the world has begun to implement spiritual care interventions for families. Two recent randomized controlled trials reveal that spiritual care interventions may increase the quality of life (Sekhavatpour et al., 2018) and decrease stress (Küçük Alemdar et al., 2018) in NICU parents. While some culture- or belief system-specific guidelines do exist in the literature – for example, culturally competent guidelines for withdrawal of life-sustaining treatment from a Hindu perspective (Das, 2012) – there currently are no written guidelines for standard of care in the NICU. One strategy that providers might use is to ask parents for their input while remaining curious and open to their feedback. For example, providers might ask questions such as: How does your culture or religion view the end of life? How might we best support your religious practices surrounding these decisions?

Within the United States, the ethnic-racial background has been associated with differential experiences. People of color may experience unique stressors in the NICU setting, putting them at increased risk for negative psychosocial outcomes. A recent study found that Black parents were less satisfied than their White peers with the nursing care they received in the NICU, wanting compassionate and respectful

communication but feeling dissatisfied by the level of support from nurses (Martin et al., 2016). Chinese American parents similarly have reported limited support from healthcare providers in the NICU. Parents from an Asian cultural background may be particularly distressed by uncertainty surrounding the impact of their infant's current illness on the infant's future (Lee et al., 2005).

Mother's own milk (MOM) feeding is associated with significant health benefits in preterm infants (Schanler, 2007). One recent study revealed that, although initiation rates of mother's own milk (MOM) feedings were similar across racial/ethnic groups, Black infants were significantly less likely to receive MOM at NICU discharge (Patel et al., 2019). This relationship was, in part, mediated by daily pumping frequency in the first 14 days postpartum, a factor that is potentially modifiable with support from NICU staff and the provision of free breast pumps to socioeconomically disadvantaged mothers.

Perinatal/postpartum depression (PPD) is a debilitating condition that can have a lasting impact on the mother and baby. PPD has been associated with impaired maternal-infant interactions (Reck et al., 2004), decreased parenting quality and effectiveness (Paulson et al., 2006), and negative infant health and cognitive outcomes (O'Hara & McCabe, 2013). A study by Barroso and colleagues (2015) revealed that, amongst a sample of mostly Black and Latina mothers, preterm birth was associated with a significant increase in PPD symptoms. This is particularly notable due to the fact that, compared to their non-Hispanic White peers, 1) African American, Hispanic, and Asian/Pacific Islander women may be at an increased risk for postpartum depression (Liu & Tronick, 2013) and 2) non-White women, particularly non-Hispanic Black women, are at a dramatically increased risk for preterm birth (Martin, Osterman, & Sutton, 2010). For an overview of empirically supported interventions to reduce PPD in NICU mothers, practice guidelines, and information about the increased risk for PPD amongst "ethnic minority status and low socioeconomic status" women, please see Hall et al., 2019.

In light of these pervasive disparities, the promotion of cultural literacy, and the practice of cultural humility in the provision of NICU care is crucial. One of the first intervention studies to mention cultural sensitivity in the NICU aimed to match NICU mothers with language, culture, and ethnically congruent peer-support partners (Preyde, 2007). This type of matched, peer-to-peer support model has been shown to increase parent satisfaction and access to support services (Ardal et al., 2011). One study reported that increased levels of nursing support were linked to increased parenting efficacy amongst parents of color in the NICU (Denney, 2004).

Communication barriers, such as parental lack of fluency in the primary language of NICU staff (i.e., parents in the United States whose preferred language is not English) and low literacy, have been identified as major stressors and sources of anxiety for NICU parents (Denney et al., 2001; Fabiyi et al., 2012). Facilitating clear communication between staff and parents is a cornerstone of family-centered care. Parents are able to play an active role in their infant's care when their needs, questions, and opinions can be conveyed clearly to the medical team. Many modern NICUs utilize language interpretive services in an attempt to bridge the communication gap. This may come in the form of in-person interpretation or telephonic. While this approach is preferred by professionals, it is important to note that some parents may wish to be independent and speak for themselves, or to translate through a trusted friend or healthcare professional (Patriksson et al., 2019). Low-literate parents and family members may benefit from additional interventions to increase communication of important information, such as web-based education utilizing visual aids, audio recordings, and simplified text (Choi & Bakken, 2010).

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Mindfully delivering culturally humility-consistent, individually tailored care to each family that enters the NICU may seem like a formidable task. In an attempt to make the provision of this type of care actionable in the NICU setting, Wiebe and Young (2011) proposed the following four tenets, which "are infused with the sociopolitical history and dynamics of culture, ethnicity, immigration, and colonization that patients bring to their experience of health and health care." Beneath each tenet, we offer recommendations for implementation in the NICU.

1. Building a provider-patient relationship of caring and trust

    a. Take time to get to know your patients' families. Ask them questions about their past experiences of healthcare, hospitals, or the NICU.

    b. Ask parents for their opinions or preferences whenever possible, and take steps to make sure that the family's wishes are honored.

    c. When in doubt, "strive to understand rather than inform" (Perryman et al., 2019).

2. Engaging in respectful and appropriate communication

    a. Ask parents, especially parents whose primary language does not match yours, how they would prefer to communicate (e.g., directly with the provider themselves, through an interpreter, through a language-matched trusted healthcare provider). If interpreter services are utilized to facilitate communication, efforts should be made to foster a relationship of trust between the interpreter and the family.

    b. Mirror word and language choices that parents make when communicating with you. For example, family members may express their distress as "anxiety," "stress," "fear," "feeling overwhelmed." Utilize the individual's own words in your communications.

3. Making available culturally responsive and accessible social and spiritual supports

    a. Do your research. If a family comes in with a cultural or religious background with which you are unfamiliar, educate yourself. In addition, ask the individuals themselves to describe their beliefs and preferences. Serve as a liaison to work with the family and hospital system to carry out parental preferences when possible (particularly with cultural practices surrounding death/dying and treatment of remains).

    b. Support efforts to expand social and spiritual supports within your hospital, department, unit, clinic, and team. Make it a priority.

c. Be an ally to families. Help to connect families with social and spiritual supports within the NICU and hospital, as well as in the larger community.

d. Involve NICU graduate families as cultural humility consultants, as well as providers of additional support for current families who share faiths/backgrounds.

4. Fostering a welcoming and flexible organizational environment

a. Be an advocate for diversity and inclusivity. This includes staffing and hiring decisions to create a diverse NICU staff that reflects the patient population served by the NICU.

b. Do not fear what you do not know. Be open to welcoming new practices, programming, and supports into your NICU environment.

c. Seek out and promote educational opportunities (e.g., workshops, trainings, webinars) to expand your knowledge and that of your fellow NICU providers.

d. Be introspective. Be aware of your own personal and cultural biases (both implicit and explicit), reflect on how your cultural context has shaped your perception of your role as a provider, and consider how your unique perspective differs from that of your patients and other NICU staff members.

i. To aid in your understanding of your biases, consider taking an Implicit Association Test from Project Implicit®: https://implicit.harvard.edu/implicit/takeatest.html.

Just as life-saving medical interventions are tailored to fit each neonate's unique medical needs, psychosocial care and support for families must also be tailored to address the social, emotional, cultural, and spiritual needs of the family. Prioritizing culturally informed, humility-based family-centered care has the potential to positively impact a NICU family long after they leave the hospital.

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Disclosure: The National Perinatal Association www.nationalperinatal.org is a 501c3 organization that provides education and advocacy around issues affecting the health of mothers, babies, and families.

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