Chapter 4 Equitable Care in the NICU

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As data continue to indicate, the burden of disease remains extremely high among the U.S. minority populations. The frequency of diseases such as diabetes, obesity, hypertension, asthma, and cancers are comparably much higher among African-Americans, Latinos, and Native Americans than in the Caucasian population. This is also the case for disorders plaguing mothers and their infants in the perinatal period. Although rapid advances in neonatology over the last three decades have dramatically improved the overall risk of mortality and morbidity for critically ill newborns, disparities in care and outcomes for infants born to ethnic minorities persist, and may even have worsened.

Infant Mortality in the Minority Population

In 2002, the infant mortality rate in the United States, defined as death within the first 365 days of life, was 7 deaths per 1000 live births.1 Although the U.S. is one of the wealthiest countries in the world and expends more per capita on medical care than any other country, our infant mortality rate is higher than that of many other industrialized countries. When comparing infant mortality in the U.S. by race, the infant mortality rate among African-American infants was almost 2.5 times higher than the rate among white infants (13.9 and 5.8 per 1000 live births, respectively). This gap has increased by more than 40 percent since 1960. Overall, the three leading causes of infant mortality are (1) congenital abnormalities; (2) prematurity (<37 weeks gestation)/very low birth weight (birth weight <1500g; [VLBW]); and (3) sudden infant death syndrome (SIDS).2 However, despite being the second leading cause of death overall, the number one leading cause of death for African-American infants is prematurity/VLBW. What’s more, although VLBW infants make up less than 2 percent of all births, they contribute to 64 percent of all neonatal deaths (death during the first 28 days of life).3 This finding is especially striking because neonatal mortality accounts for the majority of all infant deaths.

Data on Disparities and Discussion in the Literature

One has to wonder, what are we doing as neonatal intensive care providers, if anything, to contribute to the disparities in outcomes that we see in infants? Are we caring for our patients differently?

Very little data exist regarding how the equity of the care we provide our families affects infant outcomes. In fact, a look at the national neonatal and infant outcomes data based on birth weight suggests that these patients are cared for in similar manners regardless of race/ethnicity and that it is the gestational age/weight that has the greatest influence
on survival. While there are as yet no hard data documenting that unequal treatment of patients exists in the NICU, we do know that cultural barriers exist, that they play a role in parent satisfaction, and that they also come into play as we strive to provide the best possible care in the NICU. Several important reports suggest ways to think about and address these barriers.

The first is the Institute of Medicine 2002 report, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, which revealed the uncomfortable reality that people of color receive a lower quality of care compared to their white counterparts across the board. This was the case even after taking into account factors such as co-morbidities, health insurance, socioeconomic status, and staging at time of presentation. The report suggests providing tools to help healthcare professionals become more “culturally competent.” “Clinical cultural competence,” as defined by Dr. Joseph Betancourt, director of the Disparities Solution Center at Massachusetts General Hospital, is “using training and education to raise providers’ awareness of how socio-cultural factors affect health beliefs and behaviors; improving communication across cultures; empowering patients to take active roles in medical encounters; building trust between providers and patients and between patients and the health care system; being attentive to the effects of race, ethnicity, and culture on clinical decision-making.”

Culturally competent healthcare ties into efforts to address inequities in health outcomes, but simultaneously addresses efforts to develop a system that delivers high-quality care.

In addition to culturally competent care, the *Unequal Treatment* report highlighted the importance of improving “provider-patient” communication as a method of addressing racial and ethnic disparities in healthcare. When an infant is in the neonatal intensive care unit, the “patient” being cared for is not just the infant; it’s the infant along with the parents and/or family. As providers, we often find ourselves “treating” the whole family. One could argue that the overall well-being of our infants is affected by how we succeed in taking care of the family unit.

Most recently, with insight from the 2007 annual *National Healthcare Disparities Report* produced by the Agency for Healthcare Research and Quality, the U.S. Department of Health and Human Services’ Office of Minority Health (OMH) collaborated with the National Public Health and Hospital Institute, the Institute for Healthcare Improvement, and the Disparities Solution Center on a 2008 report entitled *Assuring Healthcare Equity: A Healthcare Equity Blueprint*. This report offers various strategies for providers and healthcare organizations to better address disparities. The proposed strategies focused on 5 areas: creating partnerships with the community, patients, and families; exercising governance and executive leadership for providing quality and equitable care; providing evidence-based care to all patients in a culturally and linguistically appropriate manner; establishing measures for equitable care; and understanding and being responsive to cultural needs and expectations while communicating in the
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patient’s (family’s) language.” Given that no two healthcare settings are identical, these interventions can (and should) be tailored to the specific, unique needs of each.

**Barriers to Care**

What are the factors that may influence our ability to provide high-quality, equitable care to the racially and ethnically diverse families of the infants who come to the NICU? At least four broad issues may influence medical encounters:

- Language or cultural differences, both of which may lead to misunderstandings between the family and the provider.
- Mistrust and discomfort voicing concerns or asking questions of the provider as a result of previous encounters within the healthcare system or because of various cultural beliefs.
- A family’s relative or perceived health literacy.
- The economic challenges of families dealing with unexpected indirect costs of having a child in the NICU, such as transportation, child care for other children, and missed wages possibly creating enormous stresses for the family.

Any of the above may result in poor communication or interaction between the family and care team and, in theory, has the potential to impact the quality of care we provide.

In addition to the factors coming primarily from the family’s side of the interaction, as providers we bring our own issues to work, which in turn may negatively influence the quality of an encounter with a family. For instance, some care providers may simply have limited skills in interacting with families of diverse cultural backgrounds. Providers have various ways of expressing their own relative level of stress towards caring for critically ill infants or comfort related to dying infants, which in turn may negatively impact the interaction with the family if language or cultural differences have not been addressed. Last but not least, as caregivers we bring our own stereotypes and biases to work, whether consciously or unconsciously.

In our NICUs today, we are faced with families from diverse backgrounds, those who have unique family structures, and those with challenging histories. For example, in any given day, we may interact with parents who are non-English speaking, or from a different culture or background, with same-sex couples, interracial couples, couples from particular sects or faiths, single parents helped by surrogates, or even those dealing with a history of drug use. As caregivers, we are a diverse group as well. Some of our patients’ families resemble our own families or backgrounds, whereas others do not. Consequently, as providers we inherently interact better with certain families than others. Learning to be honest with ourselves and developing a greater awareness of our own feelings or belief systems—and how these influence our interaction with families—would certainly be a step in the right direction.
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Addressing Disparities through NICU Staff Education

We can make a number of interventions to address the needs of families while simultaneously continuing to provide high-quality care for their children. First, it is important that the NICU staff is equipped with the skills to interact appropriately with families from various cultural backgrounds. Cultural competency training has been shown to improve attitudes, knowledge, and skills of healthcare professionals by teaching ways to communicate with families who have limited English proficiency, limited health literacy, alternative health beliefs, and various religious beliefs. At the same time, such training has been shown to improve parent satisfaction. The most effective training enables staff to learn about themselves and their own reactions, raising awareness of subtle stereotyping and enhancing the ability to self-correct and compensate. Such training also demonstrates how to integrate cultural competency into all discussions of patient care and operations—for example, staff meetings, presentations, and other core activities.\(^5,9\) The U.S. Department of Health and Human Services Office of Minority Health, among other organizations, has created a set of standards known as the National Standards on Culturally and Linguistically Appropriate Services (CLAS standards), which are intended to aid providers and organizations in providing culturally competent care.\(^10\)

Addressing Disparities by Providing Resources for Parents

Resources include educational materials, social needs assessments, and interpreter services.

**Educational Materials**

The staff should be equipped to provide NICU families from diverse cultural and ethnic backgrounds with proper educational resources. An important purpose of this material is to help families better understand why their infant is in the NICU, what the staff will attempt to do to make their infant better, and what some of the care options and choices are or will be. Both web-based and printed resources should be available. This material should also be available in different languages. In terms of health literacy and general literacy, the material should be of ninth grade reading level to help ensure that it is easily accessible. Furthermore, it cannot be assumed that speaking a language also implies an ability to read in that language. For this reason, asking the family their language preference for written material is often helpful. When you create family educational material for your unit, consider using parent input about what families actually want to know.\(^11\)

**Social and Economic Needs**

In addition to information that helps families understand and make choices about the care of their infant, some families may demonstrate a variety of economic needs as a result of having a sick infant in the hospital for a relatively long period of time. As providers, we should be sensitive to these needs to the best of our ability. In a number of
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institutions, the social workers are able to provide subway or bus tokens or cab vouchers for transportation, parking vouchers, and hospital food vouchers. Establishing a standard way by which each family’s unique social needs can be assessed is essential, as is having team members designated as responsible for addressing these needs.

**Interpreter Services**

Interpreter services are another critical resource for working with families from diverse backgrounds. Because research has demonstrated significant healthcare inequalities for patients with limited English proficiency, interpreter services should be available as needed and at all times. There is clear evidence that interpreter use can improve communication between the team and parents/families, resulting in improved parent understanding and satisfaction. Language services can allow families to participate in clinical decision making by facilitating their understanding of uncertainty, risks, and treatment choices while at the same time enabling providers to obtain truly informed consent. Such services can also improve healthcare providers’ ability to ascertain families’ preferences, values, as well as alternative health beliefs. For example, one can understand how imperative interpreter services would be if an already critically ill preemie of a non-English speaking family had a sudden, life-threatening event such as a severe intracranial hemorrhage and the NICU team needed to alert the family and talk to them regarding subsequent steps in care. The proper use of interpreter services would be essential in helping the family and medical team make the appropriate joint decision for the patient and family about whether to continue or redirect care in some way.

Systems that use interpreter services successfully have identified bilingual and multilingual staff and trained them to be interpreters. In addition, it is important to train providers how to properly use both trained and untrained interpreters or telephone interpreters. Finally, it is important to post visible and accessible lists of local options for interpretation—including telephone interpreters or in-person interpreters—so that staff can arrange services in a timely manner.

Keep in mind that using family members as interpreters is not ideal, since family members can misinterpret medical information or even withhold information from both the staff and family. In addition, using family or friends as interpreters may improperly label the individual as being proficient in English, when in fact they are not.

**Addressing Disparities through Standardized Data Collection**

Standardized data collection is an essential first step in identifying and addressing potential disparities in healthcare and adequately measuring whether the intended change occurred, and if so, in assessing the changes in outcomes. It is essential that each NICU collect, analyze, and report patient population data, as well as quality and patient
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safety indicators, by race, ethnicity, and language. The integration of cultural competency measures into parent satisfaction assessments, internal audits, performance improvement efforts, and error reduction programs (for example, through the use of interpreters) would also provide key information. Ultimately, physicians and team members need to receive feedback on their performance. Remaining transparent when dealing with any errors and barriers to quality care in areas where disparities have been identified will be essential in moving closer to creating a more equitable, high-quality NICU.

Table 4.1 lists some aims and measures for improving equitable treatment, as developed by the 2007 NICQ collaborative.

**Table 4.1 Aims and Measures for Equitable Care in the NICU**

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<thead>
<tr>
<th>Aims</th>
<th>Measures</th>
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<tr>
<td>To collect data on race, ethnicity, and primary language</td>
<td>Is patient/parental data properly documented in the chart?</td>
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| To ensure that all patients receive standard of care that matches their need | • Did the patient (grouped by gestational age, disease process, and so on) receive those treatments documented as the standard of care in your unit?  
  • Of those that did not receive the standard of care, stratify by race/ethnicity/language |
| To improve the cultural competency of staff | • Percent of staff who completed cultural competency training  
  • Results of parent satisfaction surveys |
| To make appropriate use of interpreter services | • Percent of parents/families who are documented as not having English as their primary language and who actually received interpreter services  
  • Results of parent satisfaction surveys |
| To create and ensure the optimal use of education material | • Was parent input a part of the creation/approval process for educational materials used in the hospital?  
  • Results of parent satisfaction surveys |

**Case Study**

During the 2007 NICQ collaborative, the Children’s Hospital Central California in Madera decided they would establish a goal to provide equitable care for all of their patients and families in the NICU, with a primary focus on improving communication. In doing so, their aim was to “provide high-quality, comprehensive healthcare to our patients and families regardless of their ability to pay…recognizing the importance of delivering care that complements and incorporates our families’ religious and cultural beliefs...[and] respecting the language and race of each of the families we serve.”
This NICU sought to measure their aim using a parent satisfaction survey through which data were collected. The survey focused on such things as whether the explanations given to parents regarding their infants were given in a language they could understand; perceived existence of social services, chaplain/pastoral services, and interpreter services and parental level of satisfaction with these services. Special attention was given to parents’ perception of the availability and use of interpreters.

A number of changes were made within the NICU in order to adequately address the aim. Conferences were provided to the NICU staff on health literacy and quality of care in the NICU, with case scenarios provided by staff RNs and social workers. In addition, a system was created to forward parental concerns to staff in real time (as close as possible to when concerns were expressed) rather than retrospective. The NICU in Madera also stipulated that before patient/family education materials were approved for use in the hospital, the materials needed to be reviewed by English-speaking and Spanish-speaking families.

Ultimately, as a result of addressing the aim established by the NICU, all of the staff at Children’s Hospital Central California completed the annual cultural competency training by the end of the measurement period. During the same period, they also noted a corresponding improvement in parent satisfaction based on survey results regarding interaction with NICU staff and use of NICU services and resources. It can be argued that by integrating cultural competency teaching and concepts into daily NICU discussion, Children’s Hospital Central California not only made significant improvements in the tangible family resources given to parents, but was also successful in creating a more equitable environment for families of diverse backgrounds.

**Conclusion**

When the NICU staff is trained to engage in culturally competent exchanges, provide appropriate educational resources to families, consistently utilize appropriate interpretation services, and use agreed upon care and treatment plans inclusive of input from the family, our families are more engaged, empowered, and educated, enabling them to be active participants in their child’s care as part of the team. The impact of these interventions on neonatal outcomes cannot be easily measured. But knowing that significant barriers to equitable care in our NICUs exist, it makes sense that as providers, we would want to intervene to provide the best overall quality of care to our “patient-family.”

To enable your NICU to adequately identify those areas where concerns exist, it is imperative that your unit collect, analyze, and report data by race, ethnicity, and language. Doing so will enable the establishment of aims that are relevant and specific to your particular NICU in order to properly create a plan to address and later measure for improvement.
References


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