

PRESS RELEASE
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Stories show disparities in the ways families are treated in the NICU environment

A recent National Institute of Health funded qualitative study by researchers at Stanford University School of Medicine and the [California Perinatal Quality Care Collaborative](#) (CPQCC) provides narrative accounts to illustrate how vulnerable families may receive unequal treatment in the NICU environment. These stories suggest that the degree to which a family is included in being a partner in their baby's care may depend on a variety of factors including a family's race/ethnicity, structure, and socio-economic status as well as language, cultural, and systemic barriers.

"That's troubling. It's also not surprising," says [Krista Sigurdson, PhD](#), first-author on the paper published in the Journal of Perinatology on April 5, 2018. "These stories really clash with how any family would expect care to be delivered in the NICU."

Types of suboptimal care

Researchers collected and analyzed 324 stories of disparities in care in the Neonatal Intensive Care Unit (NICU) setting. Importantly, these stories were provided to the researchers by health care providers and family advocates from across the nation. The vast majority of stories of perceived disparate care resulted in perceived worse care. Based on Dr. Sigurdson's analysis, stories were grouped into three broad themes: neglectful care, judgmental care, and systemic barriers to care.

- ***Neglectful care:*** The NICU staff provided less time or attention to families who were perceived as having unrealistically high needs, cultural differences, and/or who didn't speak English, (85 stories/26%).
- ***Judgmental care:*** Families were evaluated on their moral status by the NICU staff. Families' behaviors or circumstances were perceived to be judged differently based on race/ethnicity, socioeconomic status, or history of drug use, (85 stories/26%).
- ***Systemic barriers to care:*** Systemic, organizational, or cultural barriers to care prevented families from being able to be present in the NICU or behave in a way that was congruous with the institutional culture of the NICU. This category represents the largest number of stories, (142 stories/44%).

Stories were solicited from more than 1000 attendees of the [Vermont Oxford Network \(VON\) Quality Congress](#) in 2016. VON is designed to improve the quality and safety of medical care for newborn infants and their families, and Dr. Sigurdson thinks often of what happened at that annual meeting. [Jochen Profit, MD, MPH](#), who is Chief Scientific Officer of the CPQCC and Dr. Sigurdson's mentor, had presented findings from his quantitative research ([published in Pediatrics in 2017](#)) that showed racial/ethnic variation in quality of care metrics both within NICUs and between

and gave equal treatment to the babies under her care. Her comments resonated with part of the audience. “There was some agreement in the room that to be doing this kind of work on racial/ethnic disparities in care was objectionable,” Dr. Sigurdson says.

Paul H. Wise, MD, MPH, understands why people may feel uncomfortable discussing disparities in neonatal care. “The NICU is often thought of as a kind of social cocoon, insulated from the kinds of social forces that shape access to care and human interactions in a harsh, outside world,” explains Dr. Wise, Stanford Neonatology faculty member and core faculty member of the Center for Health Policy and the Center for Primary Care and Outcomes Research. “This paper documents that NICU’s are not social cocoons. Quite to the contrary, social differences do indeed find expression in the way care and compassion are provided, albeit in often subtle ways.” Dr. Wise is a member of the advisory board of the NIH grant that funded this work and engages in research focused on health-outcomes disparities by race, ethnicity, and socio-economic status.

Reasons why a family may receive worse care overlap with one another, and many are related to race or ethnicity. Race or ethnicity can be a marker for language, or language can be a marker for race or ethnicity. Accounts described perceived differences in care among racial/ethnic groups, with Hispanic/Latino making up the largest group (120 stories, 37%). Language barriers were cited in nearly half of the stories, cutting across all three types of suboptimal care (151, 47%).

It is important to note that this research describes lack of health care equity among families, not strictly babies, Dr. Sigurdson explains. She cautions against estimating how prevalent these problems are based on this qualitative data. Different from quantitative analysis, qualitative research aims to explore a given phenomenon and uncover common themes. Nevertheless, because over half of respondents indicated that the events occurred within the past six months, this study suggests disparities in today’s NICU environment are not rare.

How to refocus care to partner with families?

Based on the results of this study, CPQCC is exploring methods for measuring how well a NICU is able to partner with families. Family-centered care is the standard of care for NICUs and pediatrics in general. It aims to support families and respect each individual family’s needs and cultural preferences. A growing body of research is exploring the ways family centered care is better for families and babies in the NICU, and while guidelines for providing family-centered care aren’t new, implementation varies widely. In the coming weeks, CPQCC will be rolling out a series of action ideas for units looking to improve their adherence to family-centered care practices for diverse families.

3 sample action ideas to improve family-centered care (from CPQCC Tip Sheet):

- (1) Signal importance of family-centered-care. Provide multi-lingual signage welcoming all families as partners in care. For example: “NICU families, we welcome you as partners in your child’s care at ALL times
- (2) Offer opportunities for families to interact with their babies and care team in ways that works for family (e.g. by phone, in person or through remote participation tools such as web cams or iPads).

(3) Offer language assistance (translation and multi-lingual materials) to families with limited English proficiency, especially during critical phases of care (e.g. consider a translator on rounds, seek language concordance between providers and families).

Ultimately, researchers hope this study will start a dialogue on evaluating and optimizing family-centered care: What does it mean, and who are we helping? “Family-centered care is a great model because a lot of it is based on meeting a family where they’re at and having a strengths-based approach,” Dr. Sigurdson says. “It requires empathy and creativity, and letting go of the idea that there is one way to be a family in the NICU.”

Dr. Profit is optimistic about CPQCC’s role in promoting change. “We want to help providers create systems that ensure optimal care for all patients and families in the NICU environment,” he says.

Other Stanford co-authors include Christine Morton, PhD, Briana Mitchell, BS, and Dr. Profit, the study’s senior author.

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