

Parent Perceptions of NICU Safety Culture: Parent-Centered Safety Culture Tool

Project Team: Jason M. Etchegaray, PhD (PI; RAND Corporation); Madelene J. Ottosen, PhD (The University of Texas Medical School at Houston); Eric J. Thomas, MD, MPH (The University of Texas Medical School at Houston)

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## **Structured Abstract**

**Purpose:** We had two main purposes: 1) interview NICU parents to understand how they conceptualize patient safety and 2) develop and test a survey to measure parent perceptions of safety culture in NICU settings.

**Scope:** We conducted the study over 3 years and collected data from NICU parents at two children's hospitals in Houston, TX.

**Methods:** We used qualitative methods to conduct interviews with NICU parents, including asking open-ended questions and coding responses based on themes. We then developed a survey based on themes and feedback from a parent advisory board to assess NICU parent perceptions of safety culture. The survey was tested in two hospitals with two versions – an English-speaking version and a Spanish-speaking version.

**Results:** We learned from the interviews that NICU parents viewed infant safety based on 1) security of the NICU environment, 2) clinician-parent communication, 3) infection control, and 4) provider interactions with infants. We also learned that NICU parents adopt a variety of roles in the NICU – caregiver, advocate, decision maker, guardian, and learner. We are in the process of analyzing all survey data.

**Key Words:** NICU parents, safety culture, infant safety, parental roles

1. **Purpose** (Objectives of Study).

We had two aims in our study that we successfully accomplished:

Aim 1: To determine how parents conceptualize (1) various aspects of culture, such as patient safety, communication and teamwork, in the NICU, (1a) their role as patient safety advocates, and (1b) their relationship with caregivers in contributing to patient safety efforts within the NICU.

Aim 2: To develop and psychometrically test a survey to measure parent perceptions of safety culture in the NICU.

2. **Scope** (Background, Context, Settings, Participants, Incidence, Prevalence).

We engaged a parent advisory board (PAB) throughout our project. The PAB provided input about an interview protocol that we developed to interview NICU parents about patient safety. We shared our results from the interviews with the PAB and obtained additional input from them about survey items that can be used to measure parent perceptions of safety culture. The PAB was fundamental in helping us develop interview and survey questions that were meaningful to NICU parents.

3. **Methods** (Study Design, Data Sources/Collection, Interventions, Measures, Limitations).

We conducted interviews with neonatal parents whose babies were currently in the NICU at the Children's Memorial Hermann Hospital in the Texas Medical Center to understand their perceptions of patient safety. We then used content analysis to understand the interviews, and we developed survey items to measure parent perceptions of safety culture. We translated our survey into Spanish and have two versions – English and Spanish – that we tested in NICUs. The final survey tested contained 10 items about the security of the environment, 12 items about clinician-parent communication, six items about infection control, seven items about provider interactions with the baby, and some additional open-ended questions about experiences as well as demographics. The English-language version of the final survey tested is located in Section 5 below.

4. **Results** (Principal Findings, Outcomes, Discussion, Conclusions, Significance, Implications).

We learned from the interviews that NICU parents viewed infant safety based on 1) security of the NICU environment, 2) clinician-parent communication, 3) infection control, and 4) provider interactions with infants. We also learned that NICU parents adopt a variety of roles in the NICU – caregiver, advocate, decision maker, guardian, and learner. We are in the process of analyzing all survey data. As seen in Section 5, though, we developed a large number of presentations from this project that we are currently

working on transforming into manuscripts. As an example of conclusions from one of the presentations, we noted that parent perceptions of staff competency to provide safe care are not solely based on skills and expertise but rather on staff behaviors that support a partnership with parents. When present, these staff behaviors are key facilitators in building this partnership, but, when absent, these can be significant barriers in the relationship and how parents engage in their parental roles. Parents want to function as a balanced unit in this partnership. Maintaining an ongoing assessment of parent perceptions of care and training nurses in the behaviors that impact the parent-clinician partnership can facilitate the roles of parents in the NICU.

## 5. List of Publications and Products

### Publication:

1. Ottosen, M.J., Engebretson, J.C., **Etchegaray, J.M.** Steps in Developing a Patient Centered Measure of Hospital Design Factors. *HERD*. 2017 Jul;10(4):10-16. doi: 10.1177/1937586716685290. Epub 2017 Jan.

### Presentations:

1. Ottosen MJ, **Etchegaray JM**, Aigbe A, Sedlock EW, Bell S, Gallagher T, & Thomas EJ. Creating IMPACT: A Patient-Centered Engagement Tool for Hospitals to Improve Post-Event Analysis Communication with Patients and Families. Poster presentation for 2015 Annual Research Meeting Academy Health, Minneapolis, MN, 2015.
2. Ottosen, MJ, Engebretson J, Thomas EJ & **Etchegaray, J.M.** A parent-centered model for engaging parents in patient safety within the neonatal intensive care unit. Podium presentation, 2015 International Conference on Communication in Healthcare, New Orleans, LA, October 28, 2015.
3. Ottosen, MJ, Engebretson, J, **Etchegaray, J.M.**, & Thomas, E.J. A conceptual model of parent perceptions of patient safety in the neonatal intensive care unit. Podium presentation to UT School of Nursing 2016 Research Day, Houston, Tx, April 2016.
4. Ottosen, M., Sedlock, E., Jaiswal, N., Ngwe, B., Story, B., Ren, Y., Thomas, E., **Etchegaray, J.M.** What parents can tell us about patient safety in the NICU. Houston Methodist Symposium, September 24, 2016.
5. Thomas, E.J., Driver, J., **Etchegaray, J.M.**, Ottosen, M.J., & Bell, S.K. Engaging harmed patients for healing and safety. Institute for Healthcare Improvement presentation at Annual Conference, Orlando, FL, December, 2016.
6. Jaiswal, N., Ottosen, M., Sedlock, E., Thomas, E., Ren, Y., Torre, L., Ngwe, B., Story, B., Hokanson, K., **Etchegaray, J.M.** Parent-reported Barriers to Being Present with their Infant in the NICU. Edward Randall, III Internal Medicine Quality Fair at UT Health-McGovern Medical School, April 14, 2017.
7. Jaiswal, N., Ottosen, M., Sedlock, E., Thomas, E., Ren, Y., Torre, L., Ngwe, B., Story, B., Hokanson, K., **Etchegaray, J.M.** Parent-Reported Concerns of Safe Care within the Neonatal Intensive Care Unit. Pediatric Academic Societies, San Francisco, CA, May 8, 2017.
8. Jaiswal, N., Ottosen, M., Sedlock, E., Thomas, E., Ren, Y., Torre, L., Ngwe, B., Story, B., Hokanson, K., **Etchegaray, J.M.** Impact of nurse behaviors on parental roles and involvement in the NICU. UT Health School of Nursing Day, Houston, TX, June 9, 2017.

9. Jaiswal, N., Ottosen, M., Sedlock, E., Thomas, E., Ren, Y., Torre, L., Ngwe, B., Story, B., Hokanson, K., **Etchegaray, J.M.** Comparisons in Perceptions of Patient Safety Between Spanish-speaking and English-speaking parents in the NICU. UT Health School of Nursing Day, Houston, TX, June 9, 2017.
10. Ottosen MJ, **Etchegaray JM**, & Engebretson J, & Thomas, EJ. How Parents In Neonatal Intensive Care View Patient Safety. Poster presentation for Council for the Advancement of Nursing Science, 2015 Special Topics Conference: Emerging Areas of Family Health Research Across the Lifespan, Washington, DC, October 2015.

Product: Final version of English-language survey that we tested

### Parent-Centered Safety Culture Tool

Instructions: Please reflect back on your and your baby’s experience in this NICU and indicate the extent to which you agree with each item below, for which 1 = Strongly Disagree through 5 = Strongly Agree. We use the term 'healthcare team' in the items below. For the purposes of this survey, the healthcare team refers to the doctors, nurses, and other clinical persons who help take care of your baby/babies in the NICU.

#### Environment (Secure/Processes)

1. The NICU is a secure environment for my baby.
2. The NICU respects my wishes for who is allowed to visit my baby.
3. The healthcare team checks to make sure that they are giving the correct medicines to my baby.
4. The healthcare team checks to make sure that they are giving the correct formula or breast milk to my baby.
<b>5R.</b> Procedures are not done in the same way by all members of the healthcare team when caring for my baby.
6. I am able to see my baby in the NICU at a time when it is convenient for me.
7. I feel comfortable every time I have to leave the NICU because I know my baby is in good hands.
8. My family and I are always asked for identification when visiting the NICU.
9. I am asked for my password when calling to get an update about my baby.
10. I feel that babies are safe in this NICU.

#### Clinician-parent communication

11. I tell the healthcare team when I feel concerned about something with my baby.
12. I tell the healthcare team when I feel like something is wrong in the NICU.
13. The healthcare team includes me in their discussions about my baby.
14. I am asked to share my views about how my baby is doing.
15. I receive daily reports – either by phone or in person – about my baby’s condition.
16. I am comfortable with the frequency I am able to speak with the healthcare team – either by phone or in person – about my baby’s condition.
17. The healthcare team discussed my baby’s care in terms I can understand.
18. The healthcare team speaks openly when talking with me about my baby’s condition.
19. I was told about an error that occurred with my baby. (Please select “Not Applicable” if your baby did not experience an error).
20. I feel comfortable asking the healthcare team questions at any time.
21. I feel comfortable calling the NICU to check on my baby at any time.

22. I speak up if I think something is not being done correctly for my baby.

### Infection Control

23. The NICU has rules that must be followed to protect babies from infection.

24. The healthcare team takes action to keep my baby from getting infected by another baby.

25. The healthcare team protects my baby from getting infected by other families or visitors.

**26R.** The healthcare team does not always wash their hands or use hand sanitizer before touching my baby.

27. Members of the healthcare team come to work even if they are ill/sick (i.e., coughing, sniffing, etc.).

28. All visitors wash their hands before entering the NICU.

### Provider Interactions with Baby

29. The healthcare team responds quickly when something is wrong with my baby.

30. The healthcare team interacts with my baby as if my baby is their own.

30. The healthcare team is always present to care for my baby.

**31R.** The healthcare team seems distracted when caring for my baby.

32. My baby's needs are met by the healthcare team.

**33R.** The healthcare team is not as gentle with my baby (i.e., flipping my baby over quickly) as I prefer.

34. The healthcare team spends more time caring for my baby than completing paper work.

### Outcome – Overall patient safety grade for the NICU

35. Please rate the NICU with an overall grade on patient safety. (from A = Excellent to F =Failing)

### Empowering Parental Roles in the NICU

36. During your child's stay in the NICU, please indicate the degree (frequency) to which you were encouraged (or able) to fulfill the following parental roles in the NICU (from 1= not encouraged to do this to 5= regularly encouraged to do this).

**Caregiver:** ability to provide care for my baby while in the NICU, such as feed, bath, clothe, or hold

**Advocate:** ability to speak up for my baby's needs to the doctors, nurses, and other staff in the NICU

**Decision maker:** ability to help make decisions about my baby's care

**Guardian:** ability to protect my baby from harm and ensure that he/she is in a safe environment

**Learner:** ability to learn what I need to know to provide care, advocate, make decisions, and protect my baby from harm while in the NICU

### Open-ended Questions

37. What are the top three ways this NICU needs to improve to provide better care to babies?

38. How many hours per week on average are you able to spend with your baby in this NICU?

39. What prevents you from being able to visit your baby as often as you would like?

### Demographics

40. Gender

41. Education
42. Ethnicity
43. Marital status
44. Gestational age of baby when baby was admitted to the NICU
45. # of days baby has been in the NICU
46. First time having a baby in the NICU?
47. Once this baby comes home, how many children will you have living with you?