Interdisciplinary Family Conferences to Improve Patient Experience in the Neonatal Intensive Care Unit

Jennifer A. Trujillo, Yesenia Fernandez, Lyla Ghafoori, Kristina Lok, and Arwin Valencia

Parents play a significant role in the development of their neonate. They can affect the length of stay in a neonatal intensive care unit (NICU) and are seen as an integral part of the team. Parents are often put in positions where difficult decision making is required of them in the care of their critically ill child. Studies suggest that one way to improve the family's experience and to encourage their involvement is by establishing a formal and focused family conference. Therefore, the NICU social workers and the interdisciplinary team collaborated to formulate strategies to improve communication that would enhance current practice. As a new initiative, the team decided that holding an interdisciplinary family conference (IFC) within the first two weeks of a baby's NICU admission is critical for parental involvement of infants less than 32 weeks gestation and those with congenital birth anomalies. The team determined that the primary outcome measure would be family satisfaction scores from hospital surveys. Since the implementation of IFCs, satisfaction scores showed steady improvement. This quality improvement project demonstrated that IFCs are an integral part of the family-centered care approach in the NICU. IFCs foster partnerships with families to ensure their involvement in all aspects of patient care and improve their experience in the NICU.

KEY WORDS: *interdisciplinary family conference; neonatal intensive care unit; parental involvement; parents; patient satisfaction*

Communication with families is one of the most essential responsibilities of clinicians in the neonatal intensive care unit (NICU) (Gay, Pronovost, Bassett, & Nelson, 2009). Parents and family members are not only the primary caregivers but, more important, act as surrogates for neonates in medical decision making. Facilitating complex discussions with families about their infant's diagnosis, prognosis, and treatment plans may foster active participation and also provide opportunities for concerns and expectations to be expressed.

Family-centered care models not only recognize the family as an integral member of the NICU health care team, but also include them as collaborators and decision-making partners (Craig et al., 2015; Hladík, Jakšová, & Sikorová, 2016). Family-centered care reminds us that families are a constant presence in the child's life, whereas the hospital personnel and service systems continually change during the course of the hospital stay. This exceptional role that families play in enhancing the quality of care and safety is being recognized and acknowledged (Dokken, Parent, & Ahmann, 2015). The NICU is an ideal area in which further understanding of family-centered culturally competent care is required because of its unique patient population, acuity, and circumstances (Schim, Doorenbos, Benkert, & Miller, 2007).

Although the main focus is on the sick neonate, the profound effect of NICU communications on the family's long-term mental health also requires careful consideration. The experience of anxiety, depression, trauma, and grief by families (particularly parents) of NICU patients is well documented (Pochard et al., 2001). Therefore, partnering with families is fundamental in developing confidence and trust in the care provided and may also help alleviate their emotional distress.

Communication has been ranked as the families' preeminent concern while dealing with a loved one in the intensive care unit (ICU) (Gay et al., 2009; Khalaila, 2014). A recent examination of the compassionate care model for NICU families and caregivers underscored an approach that included both interpersonal and informational communication to be most

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effective (Altimier, 2015). Parents' understanding of their baby's care plan depends on the clarity of the information provided and the empathy expressed by the physician. Furthermore, when their family values and concerns are respected, parents are more likely to make better judgments on behalf of their child (McGrath, Samra, & Kenner, 2011).

The participation of interdisciplinary team members in the ICU further expands the discussion to include the family's overall social background, which can significantly influence their decision making process (Wigert, Dellenmark Blom, & Bry, 2014). Research has shown that when families and team members engage in a meaningful way, both family satisfaction and the quality of patient care increase (Voos & Park, 2014). Conversely, parents described feelings of frustration when they had to actively seek out information rather than receiving it unprompted (Boss, Donohue, Larson, Arnold, & Roter, 2016).

The lack of effective communication between families and clinicians has been documented to be associated with adverse outcomes (O'Daniel & Rosenstein, 2008). However, surveys continue to reveal inadequacies in the ICU communication. One of the major issues is that timely family meetings fail to occur or there is a total absence of a comprehensive meeting even during a prolonged ICU stay (Nelson, Walker, Luhrs, Cortez, & Pronovost, 2009). Parents find interdisciplinary family conferences (IFCs) particularly beneficial for ongoing communications, appreciating the physicians' readiness to share unbiased disclosure of their child's information in a supportive manner (Bruns & Klein, 2005).

Recognizing this complex but vital aspect of patient care in the NICU setting, the care team at Miller Children's & Women's Hospital Long Beach, in Long Beach, California, set out to improve the family's experience over a 12-month period. Involvement was encouraged by arranging a formal and focused IFC with a goal of at least 95 percent compliance within seven to 14 days of admission for eligible babies.

METHOD

The NICU social workers introduced IFCs to all eligible families and discussed their benefits. Once the family agreed to participate, a time and venue was coordinated for the family, physician, and the rest of the interdisciplinary team. Eligibility included patients less than 32 weeks of gestation and those with congenital birth anomalies. Social workers were also responsible for tracking and recording attendance compliance, beginning in September 2014. A total of four months' data was used as baseline. Subsequent analysis revealed a poor compliance rate of only 71 percent. Challenges were identified, and a better approach was developed and adapted.

AVATAR surveys are highly valued as patients and families are able to provide true and personal experience information that otherwise might not be received. According to the Avatar Solutions Web site, it is the leading company in patient satisfaction surveys and its software is used nationwide by a variety of hospitals. The surveys are often patients' only opportunity to provide anonymous feedback in which they can honestly express their satisfaction or dissatisfaction with their experience. The surveys are given such credibility due to their ability to obtain information from patients and families after a family has returned home and had the opportunity to process their entire admission or experience at the hospital.

Family satisfaction scores, specifically related to physicians' care, were followed as an outcome measure in this study. At many different hospitals, AVATAR surveys are sent to families who were discharged from a variety of different units within the hospital as a tool to improve patient care and customer satisfaction. At our hospital, surveys are sent to families who were discharged from the NICU within the past month. The surveys are sent through a third-party company anonymously and confidentially. For the NICU, 100 percent of all families receive a survey after discharge, which is on average about 80 surveys a month due to the slow turnaround of a NICU and may vary depending on census. Although the response rate has not been ideal, it has been consistent over the 2014 and 2015 year ends. In 2014, the response rate was 12.88 percent and it was 13 percent the following year, which indicates congruency during the study years of the IFCs. All returned surveys are received by a third-party company; the data are then collected and returned to the hospital.

For statistical analyses, a total of four quarters' (between January and December 2015) worth of data were prospectively collected and examined. Two data intervals (years 2014 and 2015) were combined to show trends in patient satisfaction scores with physician communication before and after the implementation of IFCs in the NICU. The trending was done using a weighted linear regression. The combined dependent and independent variable scores is an integer sequence for months (January = 1, February = 2, and so on)

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and the weights are the square root of the respondent counts for each month. The p value is from the test statistic on the correlation coefficient obtained in that regression using an alpha criterion of .10 to determine statistical significance. Relaxing the significance criteria seemed better to increase statistical power and the ability to detect either increasing or decreasing trends. A test of equality of trend correlations ($z = 4.011$, $p < .001$) was also performed.

RESULTS

This study revealed some unique challenges that individual families have. Some families declined a formal IFC as they felt that they were not yet mentally prepared to hear a delineated update of their infant's condition within 14 days of admission, but instead preferred a later date. This response came from a diverse group of parents with infants of varying diagnoses. These were parents who reported feeling "too overwhelmed" with receiving too much information at once. In addition, a majority of parents of premature infants between 30 and 32 weeks' gestation appeared to already be well informed on the status and prognosis of their child, even before the scheduled IFC. They found the daily bedside rounding by the physician team combined with updates from the interdisciplinary team sufficient enough and declined a formal IFC. In addition, ineligible babies included babies who required a facility transfer (see Figure 1 for overview of families who attended, declined, or failed to schedule their IFC).

As demonstrated in Figure 2, the goal of 95 percent compliance was not only attained, but exceeded, nearing 100 percent in numerous months. Compliance rates, affected by the volume of patients and the occasional limited staff availability, ranged between 80 percent and 100 percent over the course of a 12-month data collection period.

Although this may not be the only driver, it was also noticed that the physician's AVATAR scores for family satisfaction during the study phase trended upward (see Figure 3). Process measures included percentage of IFCs that occurred within 14 days of admission. Overall, IFCs appeared to have contributed to families' increased satisfaction and opened communication between the interdisciplinary team members and families.

DISCUSSION

This study reaffirms the importance of communication between families and the NICU team. Scheduling IFCs within the first 14 days of admission has demonstrated an increase in family's understanding of their infant's plan of care; their satisfaction with the NICU team; and, consequently, a significant improvement in physician AVATAR scores.

Figures 1 and 2 illustrate a compliance rate of 100 percent for all but two months during the study period. December 2014 was a busy holiday season, and there was a more limited staff availability. May

Figure 1: Interdisciplinary Family Conferences (IFC) Held, Declined, or Not Scheduled

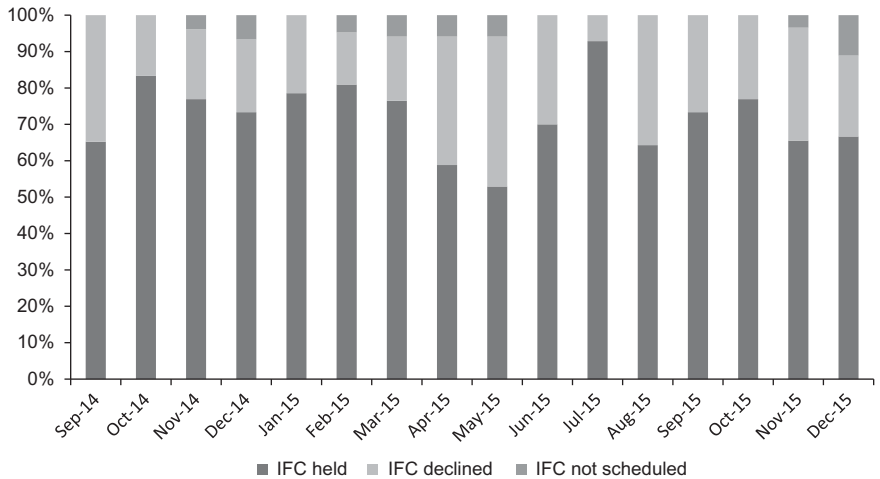

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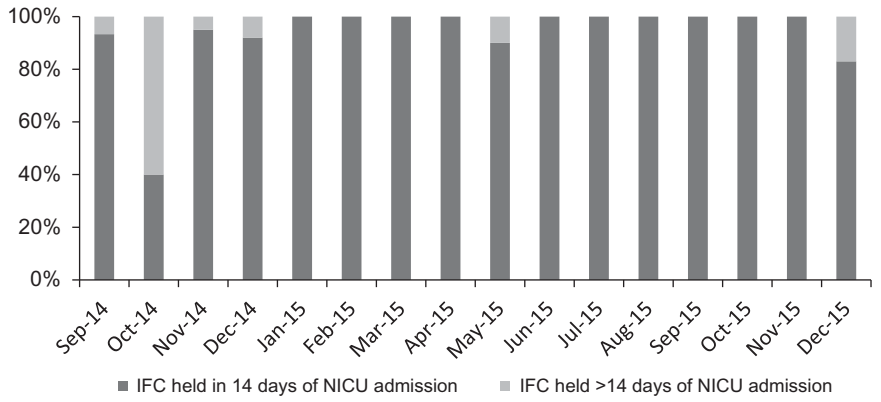
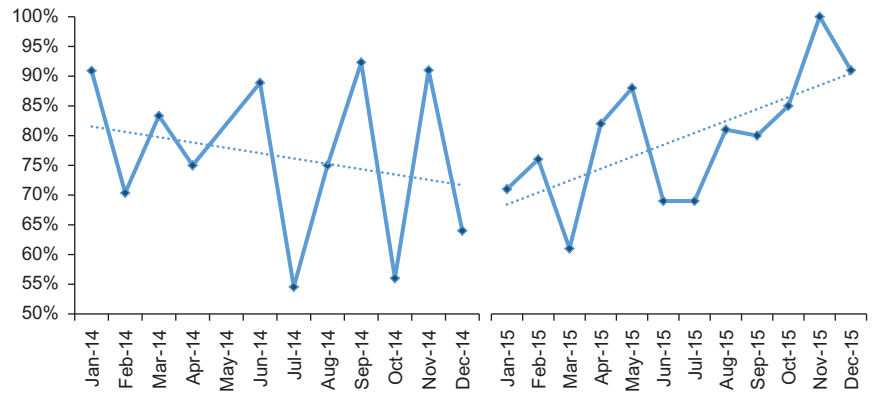
Figure 2: Proportion of IFCs Held within 14 Days of NICU Admission



Notes: IFC = interdisciplinary family conference; NICU = neonatal intensive care unit.

Figure 3: Neonatal Intensive Care Unit Family Satisfaction with Physician Communication



Notes: Before average = 76.5, $p = .326$ (nonsignificant); after average = 78.6, $p = .057$ (significant).

2015 also demonstrated shortcomings resulting from an increase in NICU census and a decrease in staff availability. Overall, although the interdisciplinary family meetings required extra coordination between social work and NICU staff, the families were more available than expected and were receptive to the IFC approach.

Even though the literature suggests that interdisciplinary family meetings decrease anxieties, some families reported feeling too overwhelmed to participate in an IFC, and this was one of the prominent inconsistencies found. The data also demonstrated that some parents who experience a traumatic birth, premature delivery, or for any other reasons requiring a NICU admission may experience mental health symptoms. Between 26 percent and 41 percent of mothers who experience a premature birth reported symptoms associated with posttraumatic stress disorder (Pierrehumbert, Nicole, Muller-Nix, Forcada-Guex, & Ansermet, 2003). Avoidance of discussions of topics of birth event, prematurity, and the current or potential health risks to the baby is a prevalent symptom observed in NICU mothers (Holditch-Davis, Bartlett, Blickman, & Miles, 2003).

The data indicate that the majority of the families that did decline initial interdisciplinary family meetings were of infants of 30 to 32 weeks' gestation. Perhaps this is because these babies tend to have less acute medical needs, less turbulent NICU courses, and an overall shorter length of stay. These families

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reported that the daily updates by the NICU team were already sufficient, eventually declining the need for an initial interdisciplinary family meeting.

As demonstrated in Figure 3, prior to the implementation of IFCs patients did not have a great experience with their physicians' communication practices. With the increase in scheduled and structured approaches to communication between the staff and family members, there was a significant improvement in family satisfaction with physicians.

As a result of this study and the improvements to the unit, the team's morale improved, and the coordination of IFCs became a much more collaborative effort for social workers. Overall, we have optimized family-centered care with this approach and will continue to spearhead and champion this noble movement. The team will continue to offer and plan IFCs for all eligible babies within 14 days of admission, and compliance will be periodically monitored to ensure adequate and timely communication with families. **HSW**

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