



Clinician–family relationships may impact neonatal intensive care: clinicians’ perspectives

Jennifer J. Miller¹ · Janet R. Serwint¹ · Renee D. Boss¹

Received: 3 February 2021 / Revised: 11 May 2021 / Accepted: 25 May 2021 / Published online: 5 June 2021
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Abstract

Objective Collaborative clinician–family relationships are necessary for the delivery of successful patient- and family-centered care (PFCC) in the NICU. Challenging clinician–family relationships may undermine such collaboration and the potential impacts on patient care are unknown.

Study design Consistent caregivers were surveyed to describe their relationships and collaboration with families of infants hospitalized ≥ 28 days. Medical record review collected infant and family characteristics hypothesized to impact relationships. Mixed methods analysis was performed.

Results Clinicians completed 243 surveys representing 77 families. Clinicians reported low collaboration with families who were not at the bedside and/or did not speak English. Clinicians perceived most clinician–family relationships impact the infant’s hospital course. Negative impacts included communication challenges, mistrust or frustration with the team and disruptions to patient care.

Conclusion This study identifies features of clinician–family relationships that may negatively impact an infant’s NICU stay. Targeting supports for these families is necessary to achieve effective PFCC.

Introduction

Patient- and Family-Centered Care (PFCC) is the “gold-standard” of health care delivery in pediatrics. This model of care treats the family unit as an essential component to the well-being of the child, with six key elements: collaboration, respect, providing support, information sharing, flexibility and empowering children [1]. The implementation of PFCC principles can have a beneficial effect on patient care in the neonatal intensive care unit (NICU) by reducing an infant’s length of stay [2, 3], readmission rate [2], improving weight gain [4, 5], increasing rates of breastfeeding [4–6], decreasing parental anxiety [2–4] and increasing parent satisfaction [7]. While a handful of studies have identified operational challenges to providing PFCC

in the NICU [8, 9], very little research has focused on exploring how the medical teams’ relationships with families could impact the delivery of PFCC. In limited pediatric data, the frequency of difficult relationships in the outpatient setting ranged from 15 to 40% [10], (similar to adult medicine estimates [11, 12]) yet occur at an unknown frequency in the NICU [13]. Difficult relationships do not have a precise definition in the literature, but are consistently portrayed as interactions which evoke negative emotions during clinician–patient encounters [10, 11]. These relationships necessitate further investigation given research showing that when physicians and nurses are confronted with challenging patient encounters in simulated exercises, clinical reasoning and diagnostic accuracy are impaired [14, 15]. Adult emergency medicine providers report that encounters with angry patients have a detrimental effect on their clinical performance, but interactions with patients showing appreciation had the opposite effect [16]. An improved understanding of how provider–patient (and provider–family) interactions impact clinical care deserves further attention.

In the NICU, many infants have prolonged hospitalizations that include high-stakes decisions regarding interventions, surgeries or implementation of chronic medical

Supplementary information The online version contains supplementary material available at <https://doi.org/10.1038/s41372-021-01120-8>.

✉ Jennifer J. Miller
jennifer.j.miller@medstar.net

¹ Johns Hopkins Hospital, Baltimore, MD, USA

technology. Building a therapeutic relationship between NICU providers and families is necessary to make value-based medical decisions for these infants [17], but several features of the NICU environment may undermine such collaboration. A family must form relationships with a rotating medical team (versus a consistent, individual clinician) [18, 19] and the extraordinary amount of stress NICU parents experience [20] can interfere with their communication with clinicians [21] and satisfaction with care [22].

The purpose of this study was to explore clinician perceptions of their relationships with families of infants currently hospitalized in the NICU and their experience of how these relationships may impact patient management. We hypothesized clinicians would report congruent experiences with families and challenging clinician–family relationships would be perceived as having a negative effect on patient care. The ability to prospectively identify the elements of clinician–parent relationships that may put them at risk of becoming challenging, or difficult, could help clinicians achieve more successful PFCC in the NICU.

Methods

This mixed methods study took place at a 45-bed level 4 NICU with single-family rooms and an average daily census of 43 in the northeastern United States. The daily census is primarily made up of acutely ill and complex patients; convalescing infants are typically transferred to other sites for continued care.

Between March 2018 and April 2019, we prospectively recruited a convenience sample of NICU clinicians (NICU hospitalists, neonatologists, neonatal-perinatal medicine fellows, registered nurses (RNs), and neonatal nurse practitioners (NNP)) caring for individual NICU patients who had reached at least 28 days of hospitalization. Once an infant was identified with a length of stay ≥ 28 days, four clinicians (two providers (MDs or NNPs) and two nurses) per infant/family were recruited to complete a survey, with the goal of prioritizing consistent caregivers. Physicians, NNPs and RNs were eligible for recruitment if they had taken care of the infant for ≥ 7 shifts; RNs were also eligible for recruitment if they were “prime” nurses who self-select to work consecutive shifts with the infant. Eligible clinicians were approached in person or by letter (via staff mailboxes) and reminders to complete surveys were sent by email. Participants could choose to complete the survey in written or verbal form and were provided candy in appreciation of their time.

Since no relevant validated instrument exists, survey questions were designed based on a review of PFCC literature [1] and written by JJM and RDB (see Supplementary Material). Clinicians were asked to quantify the collaboration

between (1) clinician and the family (self-collaboration score) and (2) the broader NICU medical team and the family (team collaboration score) using an unnumbered visual analog scale. Responses were coded as dichotomous variables: low (measured equivalent to < 5) or high (measured equivalent to ≥ 5) collaboration scores.

Open ended questions asked clinicians to describe relationships with families, identify family characteristics impactful to forming relationships, and report whether clinician–family relationships may have affected the infant’s care. One author (JJM) initially coded clinician perceptions of relationship with family as positive (based on descriptions such as “great,” “good,” “close,”), neutral (based on descriptions such as “okay”), negative (descriptions included “difficult” or “challenging”) or nonexistent (description such as “don’t really see them much”). The same author used conventional content analysis to code the remaining open-ended questions. All authors then met to review and agree upon initial codes and any disagreement was resolved through iterative discussion.

Following NICU discharge, retrospective infant chart review collected demographic information and factors hypothesized to impact clinician–family relationships. These included the family’s primary language, frequency of family visitation, number of multidisciplinary family meetings, calculation of the infant’s SNAPPE-II (Score for Neonatal Acute Physiology with Perinatal extension II) score, palliative care and/or ethics consultation, resuscitation limitations, history of maternal substance abuse, and Child Protective Services (CPS) referrals. This study was IRB approved and completion of the survey served as informed consent to be included in the study.

Results

A mean of 3.15 surveys were completed on each family, representing 77 families (243 surveys total) and 83 infants (6 sets of twins). There were 114 surveys from MDs (13 attending neonatologists, 10 neonatal-perinatal fellows, and 1 pediatric hospitalist), 27 surveys from 10 NNPs, and 102 surveys from an estimated 70 RNs. Five infants/families had only one clinician complete a survey. The most common reason for poor recruitment was the lack of a prime nurse assignment. The number of surveys completed by any one individual was not tracked.

Infant characteristics are displayed in Table 1. Most patients were inborn, < 34 weeks gestation, hospitalized > 60 days and eventually transferred to a lower-level care. Half had ≥ 1 surgery, 10% had a palliative care consult and 5% had limits of resuscitation in place. Table 2 displays family characteristics; 12% did not speak English, 14% visited the NICU < 3 times a week, and 69% did not have a

Table 1 Infant characteristics during NICU admission ($n = 83$).

Characteristics	No. (% of n)
Hospital of birth	
Inborn	60 (72%)
Sex	
Male	45 (54%)
Gestational age (in weeks)	
<28	42 (51%)
28 ^{0/7} –33 ^{6/7}	26 (31%)
34 ^{0/7} –36 ^{6/7}	8 (10%)
≥37 ^{0/7}	7 (8%)
Birth weight (in g)	
<500	2 (2%)
500–999	37 (45%)
1000–1499	21 (25%)
1500–2499	17 (20%)
≥2500	6 (7%)
Race/ethnicity	
Asian	5 (6%)
Black	29 (38%)
Hispanic	6 (8%)
Middle Eastern	1 (1%)
White	27 (35%)
Unknown	9 (12%)
SNAPPE-II score ^a	
<38	45 (54%)
≥38	17 (21%)
Unknown	21 (25%)
Length of stay (in days)	
28–59	19 (23%)
60–89	34 (41%)
≥90	30 (36%)
Surgery	
Yes	42 (51%)
Presence of:	
Ethics consult	0
Palliative Care consult	8 (10%)
Limitations of resuscitation	4 (5%)
Disposition	
Home	8 (10%)
Rehab Hospital	42 (51%)
Inpatient pediatrics	21 (25%)
Pediatric intensive care unit	6 (7%)
Outside Hospital ICU	4 (5%)
Death	2 (2%)

^aSNAPPE-II (Score for neonatal acute physiology with perinatal extension); infant mortality risk score for neonates immediately following birth [42]. A score >38 has been shown to be associated with higher mortality [43, 44].

Table 2 Family characteristics of enrolled infants ($n = 77$).

Characteristics	No. (%)
Parents' primary language	
English	68 (88%)
Spanish	5 (7%)
Other	4 (5%)
Documented family visitation ^a	
<3 days a week	11 (14%)
Number of family meetings	
0	53 (69%)
1–2	19 (25%)
≥3	5 (6%)
Maternal substance abuse during pregnancy	11 (14%)
Child Protective Services referral	13 (17%)
Discharge to foster care	1 (1%)

^aDuring the infant's first 28 days of hospitalization.

documented, multidisciplinary, family meeting in the NICU.

Perceptions of relationships with families

General descriptions of relationships with families were categorized as positive, neutral, negative or nonexistent. In 168/243 of surveys, clinicians described relationships with families using positive language (“good”, “great”, “friendly” or “comfortable”). In 45/243 of surveys, the clinician reported minimal to no interaction with the family and half of these responses were from attending physicians. Another 25/243 of surveys describe relationships with families using neutral nomenclature (“fair”, “inconsistent” or “ok”) and 5/243 surveys use negative descriptors (“challenged” or “difficult”).

For the 72 families in which ≥2 surveys were completed, whether clinicians reported similar descriptions was evaluated, as shown in Fig. 1. For 59/72 families there was agreement regarding general descriptions of relationships, with a majority of positive relationships described. No family had a majority consensus by clinicians of a negative relationship.

Clinicians reported family characteristics perceived to impact the ability to form relationships and these responses were coded as positive or negative factors; characteristics which facilitated or created barriers to the formation of clinician–family relationships (see Fig. 2). For 66/72 families there was clinician agreement regarding these factors, with clinicians most often reporting barriers (see Fig. 1).

Clinicians overwhelmingly described positive relationships with families but perceived most families have barriers to building relationships. When families exhibited characteristics

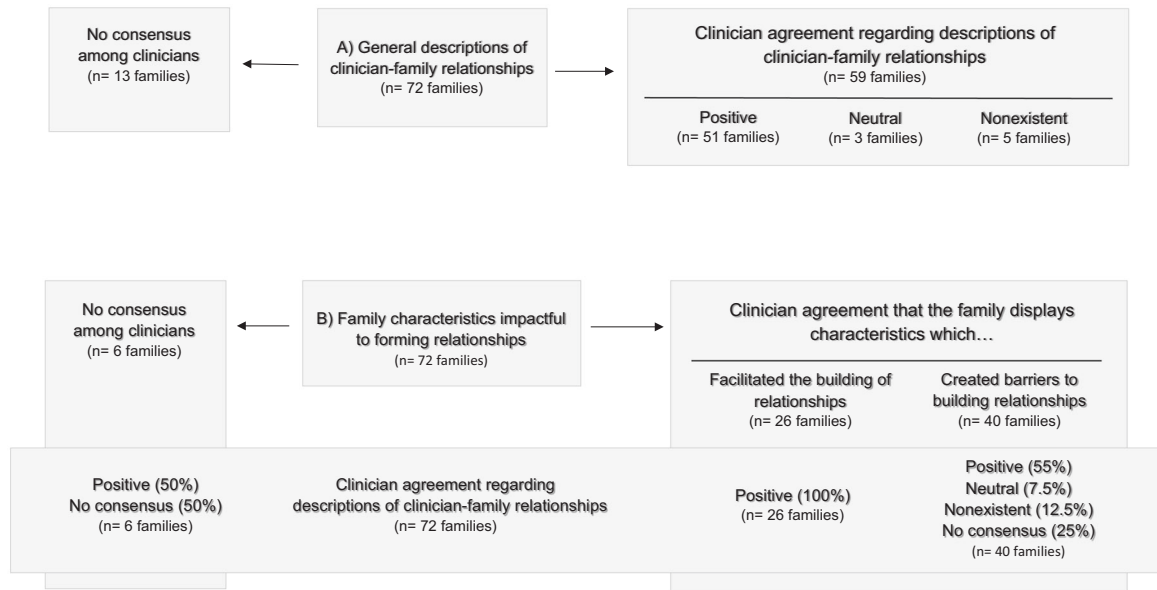


Fig. 1 Clinician agreement regarding: A) general descriptions of relationships with families B) family characteristics impactful to forming relationships overlaid with clinician agreement of general descriptions of relationships with families.

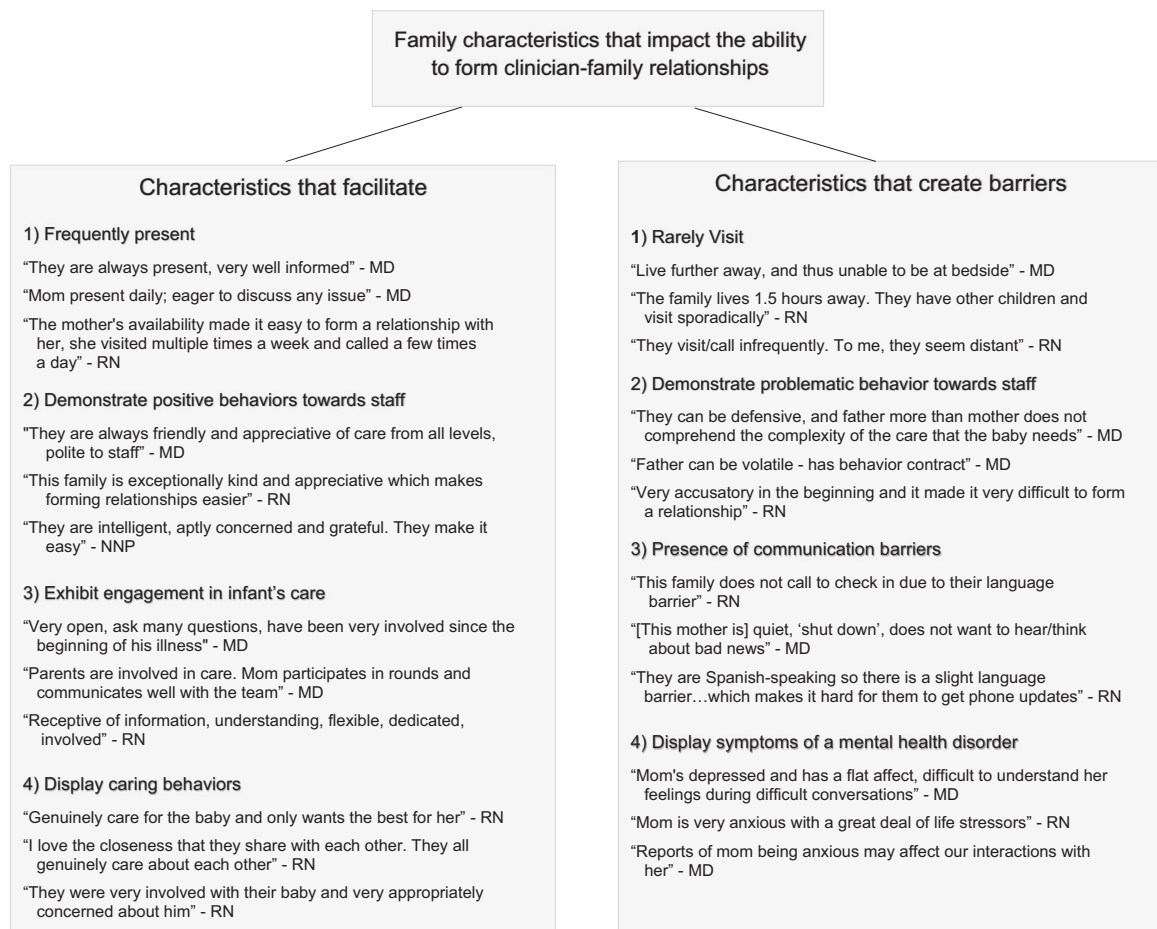


Fig. 2 Descriptions and supportive clinician quotes of perceived family characteristics that facilitate and create barriers to the formation of clinician–family relationships.

which facilitated the building of clinician–family relationships, all of these relationships were described as positive. When clinicians identified families with barriers to building relationships, the descriptions of relationships were more variable and more likely to differ.

Perceptions of collaboration with families

For the 72 families with surveys from at least two clinicians, collaboration scores were examined across the medical team. For 37 of these families, self-collaboration scores were consistently high or low across the team.

For 24/72 families, clinicians unanimously assigned high self-collaboration scores; these families were described as kind, engaged, inquisitive, frequently visiting, and/or involved in their infant's care. None were in the low visitation group, only one was non-English speaking, and 12/24 had a documented family meeting. The families were of White (14/24), Black (7/24) and unknown (3/24) ethnicities. 18/24 of these families also received unanimous high team-collaboration scores; 6/24 families received at least one low team collaboration score. Low team collaboration was ascribed to team–family conflict about medical decisions, dwindling family visitation, or inconsistent communication from the NICU and/or subspecialty teams with the family.

For 13/72 families, clinicians unanimously assigned low self-collaboration scores; this was generally ascribed to language barriers and/or infrequent visitation. Chart abstraction revealed that 5/13 were amongst the families with the lowest NICU visitation rates (Table 2), 6/13 did not speak English, and no family meetings were documented. These 13 families were either of non-White (12) or unknown (1) ethnicity. 6/13 also received unanimously low team-collaboration scores.

In contrast to the above descriptions of consistently high or low self-collaboration scores, perceptions were more variable for the remaining 35 families. This often correlated with differential contact with families related to staff schedules. For two families, RNs described close and positive relationships while prescribing providers reported communication challenges, maternal anxiety and family lack of trust in the medical team.

When evaluating team collaboration score trends, for 50/72 families a majority of clinicians reported high collaboration. A majority of low team collaboration scores was assigned to 15/72 families and for 7/72 families the scores were split between clinicians.

Perceptions of relationships impacting NICU course

For 58/77 of families evaluated, at least one clinician perceived that the medical team's relationship with the family had an effect on the infant's hospital course. For 19/77

families, the clinician–family relationship was not perceived to impact hospital course, but 9/19 had ≤ 2 surveys/family, potentially representing an error in under-sampling. Clinician perspectives of how relationships with families affected the infant's clinical course, is shown in Fig. 3. For 10/77 families, clinicians reported both positive and negative effects, the “mixed-effect” group.

When clinicians perceived their relationship with families had a positive effect on the infant's hospitalization, the infants were more commonly in-born and had fewer surgeries. Five of these families (5/40) were reported to have low team collaboration. When clinicians perceived a negative effect, the families more commonly had a low visitation rate, were non-English speaking, referred to CPS and discharged to foster care. Ten of these families (10/36) were reported to have low team collaboration.

The ten families of the “mixed-effect” group had infants with a distinct phenotype. These infants were more likely to have high SNAPPE-II scores, hospitalizations >90 days, palliative care consults, and multidisciplinary family meetings. The two infants who died were in this cohort, as were 3/5 who received a tracheostomy. The theme of the medical team disagreeing with parent's decisions (see Fig. 3) was unique to these families. Clinicians assigned low team collaboration scores to only two of these families.

Mitigating barriers to relationships

When a family had low team collaboration scores, yet a clinician reported a positive effect on care, this was often because an alternative strategy was in place to address relationship challenges. For families that lived far away and had limited visitation, some clinicians or parents proactively made phone contact (“The residents call mom with updates every other day”—*Nurse*; “Mother asked to be called during rounds or immediately after.”—*NNP*). Dedicated and scheduled meetings could sometimes overcome limited contact (“[There was] one productive family meeting about the progress of the twins and diagnoses.”—*Nurse*). Language barriers could be breached with technology (“I utilize the video machine or language line...I was able to help them with education regarding kangaroo care.”—*NNP*) and for families exhibiting distress from the hospital stay, extra clinician attention could be an effective intervention “[The mother] asks lots of questions, exhibits anxiety, but with good communication she is able to be calmer.”—*Physician*; “I encouraged mom to process her emotions and I used clinical knowledge and emotional intelligence to reassure her and build trust.”—*Nurse*). These reflections suggest that some relationship barriers can be overcome when individuals enact targeted communication strategies and/or skills.

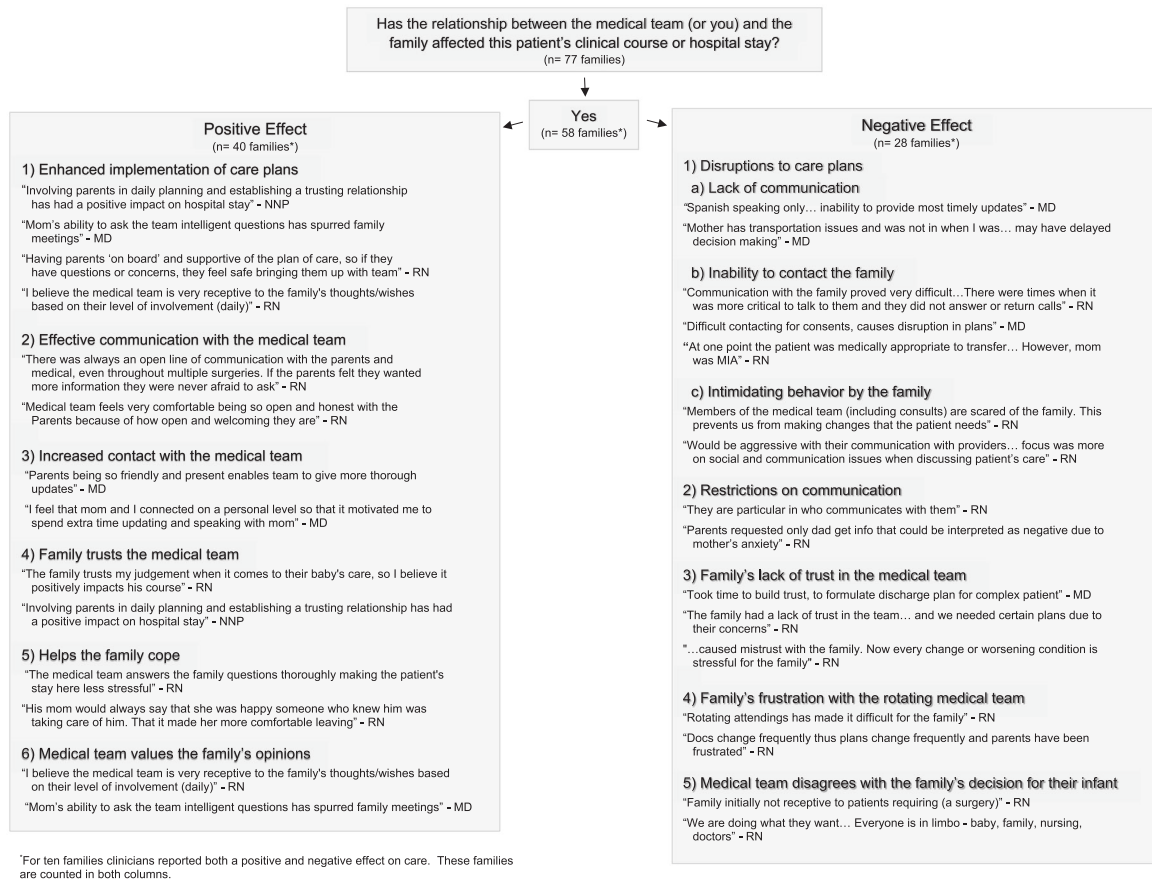


Fig. 3 Descriptions of clinician–family relationships that were perceived to impact an infant’s stay in the NICU.

Discussion

In this era of promoting PFCC, understanding how clinician–family relationships evolve and how they might alter clinical management is important. This is particularly true in the NICU where high stakes medical care and decision-making are common. In our study, neonatology clinicians reported similar descriptions of relationships with families and perceived that most families exhibited barriers to building relationships. The presence of barriers did not universally predict a poor relationship but signaled more variability and discordance in the clinician–family relationship. Perhaps this represents variability in clinician or family factors, and/or intrinsic qualities of the barrier itself. Many clinicians agreed that clinician–family relationships impact patient care, highlighting the need to identify high risk situations and effective partnering strategies. Our results identified family and infant characteristics that clustered with challenging clinician–family relationships, but some clinicians described ways to successfully partner with these families. Because negative clinician–family relationships were described to adversely influence patient care, teams should prioritize identification of at-risk clinician–family relationships.

When clinicians agreed that collaboration with a family was poor, they often described negative effects to the care of the infant. Asking the entire team to assess collaboration could be an easily implemented screening tool. If a majority of team members report low collaboration, or there are discordant opinions among the team, this could signal the need to identify relationship-building barriers and/or successful partnering strategies by individuals.

In our study, when a family did not speak English, clinicians frequently reported low collaboration with the family and perceived the clinician–family relationship (or lack thereof) to have a negative impact on the infant’s hospitalization, although our results are confounded by the observation that 44% of the families who did not speak English also had a low visitation rate. Other authors have shown that the delivery of PFCC is poor in low English proficiency (LEP) families [23, 24] and that LEP can affect health care delivery and outcomes in pediatric settings [25, 26]. In our unit, language access services are readily available, yet appear underutilized or ineffective. The reason for these families’ low visitation rates and provider barriers to routinely utilize language services deserves further investigation.

As alluded to previously, when families are infrequent visitors, clinicians report low collaboration scores. Understanding parental visitation to the NICU is complex and visitation barriers are multifactorial [27–29], but a strong parental presence is beneficial to delivering optimal PFCC and has a range of health benefits to the newborn [30, 31]. Videoconferencing could be an effective intermediary when physical visitation is not possible. The current COVID-19 pandemic has brought about the rapid expansion and normalization [32] of telemedicine [33, 34] and ideally, this service should be routinely used for patient care and communication with families.

A worrisome observation in our study was that being a non-White family clustered with low collaboration scores. This finding was confounded by non-English speaking families, but still concerning given the well-described disparities in morbidity, mortality and developmental outcomes of non-White infants born premature [35–37]. Our findings are consistent with literature describing strained relationships with staff based on race [24] and the serious role implicit bias has in medicine [38, 39].

Quantifying collaboration with a family was not sufficient to identify all at risk relationships, and this was especially true for the “mixed effect” group. These infants had the highest mortality and markers of morbidity (longer LOS, tracheostomy, palliative care consults) suggesting these infants were evolving to a subset of children with medical complexity defined as chronically critically ill (CCI) [40]. These clinician–family relationships were strained by issues surrounding complex medical decision-making (i.e., medical team disagreeing with family’s decisions) and frustration with a rotating medical team.

As described in simulation exercises [14, 15] and by ED physicians [16], NICU clinicians reported changes in their behavior based on interactions with families. Clinicians reported spending more time and communicating more often with parents who were engaged and inquisitive about their infants’ care and appreciative of clinicians’ efforts. These reflections are akin to simulated exercises that show maternal gratitude improves team performance, due to enhanced information sharing among the team [41]. Conversely, when clinicians perceived a family to be non-trusting or hostile, providers describe building trust taking time or care plans requiring extensive discussion and/or hesitation to change care plans. Although we have no evidence that clinical care was adversely affected in these cases, these reflections suggest such interactions have the potential for adverse effects on patient care and the need for ongoing research to discover effective partnering strategies.

We acknowledge several limitations to our study. As no similar tool exists, our survey is not validated. Clinicians were not asked to reflect on or report their own behaviors and/or biases towards families, which could significantly impact

interactions with families. Clinicians were also not asked to identify hospital- or systems-based barriers (i.e., the language line is frequently unavailable) that could have negatively contributed to clinician–family relationships. The families were not asked to reflect on their perspectives of the clinician–family relationship or perceptions of the medical team, which limits a comprehensive understanding of these relationships. Due to variability in an infant’s clinical status and family visitation over time, the timing of survey collection may have missed prescribing providers with more experience with a family. Nurses self-select to become a primary nurse and this factor likely over-selected for appealing infants/families and data are missing on infants without a primary nurse. Survey responses may represent clustered data as individual responses were not tracked. Reported infant ethnicity may reflect maternal ethnicity, as this information relies on the accuracy of personnel input into the medical record. The number of multi-disciplinary family meetings and family visitation relied on accurate staff documentation and reported values may be under-estimates.

Conclusions

Our study showed that clinicians report similar (and generally positive) relationships with families in the NICU with the caveat that most families are perceived to have barriers to forming relationships. We identified multiple family characteristics that are risk factors for a suboptimal clinician–family relationship including an inability to speak English, communication challenges, infrequent visitation, non-White ethnicity, displaying hostile or mistrusting behaviors, and/or having an infant with a medical course evolving towards CCI. Screening for low collaboration or discordant collaboration among team members could quickly identify relationships at risk for negatively impacting patient care. The prompt identification of these families and infants is necessary to implement strategies to build collaboration and promote effective information-sharing that will empower the family to make informed medical decisions for their infant. Future research should explore how clinician behaviors and/or biases impact clinician–family relationships, explore the perspectives of family members on what factors influence these relationships, investigate whether infant outcomes are impacted by the clinician–family relationships, and rigorously evaluate strategies to improve partnerships with families.

Acknowledgements Thank you to the providers and nurses of the Johns Hopkins NICU for their participation in this study.

Author contributions JJM conceptualized and designed the study, performed data collection, data coding and data analysis, and drafted and revised the manuscript. JRS assisted with interpretation of data

and critically reviewed and revised the manuscript. RDB conceptualized and designed the study, oversaw and assisted with data analysis, and critically reviewed and revised the manuscript. All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

Compliance with ethical standards

Conflict of interest The authors declare no competing interests.

Publisher’s note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

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