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## The impact of parental presence in the NICU on hospital alienation and other distress measures

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### Cover Page Footnote

We would like to express our appreciation to Dr. Dmitry Tumin for his valuable and constructive suggestions during editing of this manuscript as well as his expertise in statistical analysis. This article is associated with the Patient, Family & Community Engagement lens of The Beryl Institute Experience Framework. (<http://bit.ly/ExperienceFramework>). You can access other resources related to this lens including additional PXJ articles here: [http://bit.ly/PX\\_PtFamComm](http://bit.ly/PX_PtFamComm)

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### Abstract

Parental presence in the neonatal intensive care unit (NICU) positively impacts infant development. Few studies have examined the impact of presence on parental distress. Alienation, or lack of trust in the healthcare team, may occur independently from other forms of distress. Increased parental presence was hypothesized to reduce alienation by allowing for more positive in-person interaction with hospital staff. Parents of infants born < 28 weeks or < 1000 grams were prospectively enrolled and completed several surveys measuring distress prior to discharge, including a novel hospital alienation questionnaire. Spearman correlation was used to compare distress measures and visitation rates of 68 mothers and 6 fathers. Alienation was rarely reported and was uncorrelated with other distress measures. Maternal presence was most strongly correlated with anxiety, though this was not statistically significant. Fathers who were more alienated were present in the NICU less and correlation between maternal and paternal alienation was strong. These results were not statistically significant, however. Though statistically significant results were not produced in this research, hospital alienation does appear to be a distinct concept that has been unstudied previously.

### Keywords

Patient experience, communication, healthcare, patient- and family- centered care, NICU, neonatology, hospital alienation, alienation, parental distress, parental presence, family engagement

### Introduction

Family engagement is an important and integral part of caring for infants in the neonatal intensive care unit (NICU). Parental involvement and presence have been shown to positively impact infants' developmental outcomes and parents' ability to follow a post-discharge care plan.<sup>1-3</sup> However, while in the NICU, parents often experience distress, which can have negative impacts on child cognitive and behavioral outcomes.<sup>4-6</sup> While many studies have provided a descriptive analysis of parental presence in the NICU, there is a paucity of research addressing the influence of parental presence on parent distress.<sup>7</sup> In one study, lower maternal presence predicted increased risk of maternal depression at 4 months corrected age.<sup>8</sup> In a Swedish study, parents who reported poor communication with NICU staff also experienced feelings of loneliness and abandonment.<sup>9</sup> A recent study of parents of hospitalized children also found that self-reported marginalization was associated with worse hospital outcomes.<sup>10</sup>

In the NICU, patients' medical care can be complex and technical. Difficult care-related conversations and decisions take place, though parents may not fully understand the diagnoses, treatments, prognoses, or consequences of these decisions. Further, parents may experience feelings of helplessness as the parental role is altered. These experiences and uncertainties could prompt many different forms of distress. In previous work, interviews and validated scales used to screen for depression and anxiety have been used to measure parental distress.<sup>4,8,9</sup> Yet, no research to date has focused on the concept of hospital alienation, which can be described as feelings of isolation and distrust in the hospital system and staff. One study examined marginalization among parents of hospitalized children, finding this was associated with worse hospital outcomes and social disadvantage.<sup>10</sup> If parents feel alienated from the hospital and NICU providers, then they may be more likely to experience distress, and perhaps even be less likely to engage with post-discharge health care recommendations for their infants.

Our study aimed to determine the incidence of alienation amongst parents of extremely preterm or extremely low birth weight infants and to determine if parental presence is a mitigating factor in the incidence of alienation. Secondary aims include exploring correlations between parental presence and other measures of distress, and between maternal as compared to paternal presence. For our primary aim, we tested the hypothesis that increased parental presence would correlate with lower alienation.

## Methods

### Study Setting

This prospective study was conducted from 2016-2019 at an academic, 50 bed Level 4 / 21 bed Level 2 NICU in North Carolina, USA, which serves a catchment area of 29 primarily rural counties. A large proportion of the patients' families are of low socioeconomic status. The study was approved by the local Institutional Review Board. English-speaking parents of infants < 28 weeks gestational age or < 1000 grams birth weight born at the study site were eligible for the study. Parents of eligible infants were approached in person by a study team member to obtain written consent to participate. Parents of infants deemed by the study team (neonatology attending physicians or fellows) to be unlikely to survive to discharge were not approached.

The study team aimed to obtain consent within one week of life and no later than one month of life. The consenting process was delayed in some cases by the availability of study team members, availability of parents, or if the infant's medical status was deemed too tenuous initially. At the beginning of the study, only mothers provided consent and were enrolled. After 69 subjects were enrolled, the study protocol was amended to enroll both mothers and fathers and collect data from both, if possible. Enrolled subjects were excluded from the analysis if they failed to complete surveys prior to discharge, if their child died after enrollment, or if the infant was transferred to another hospital prior to discharge home.

### Study measures

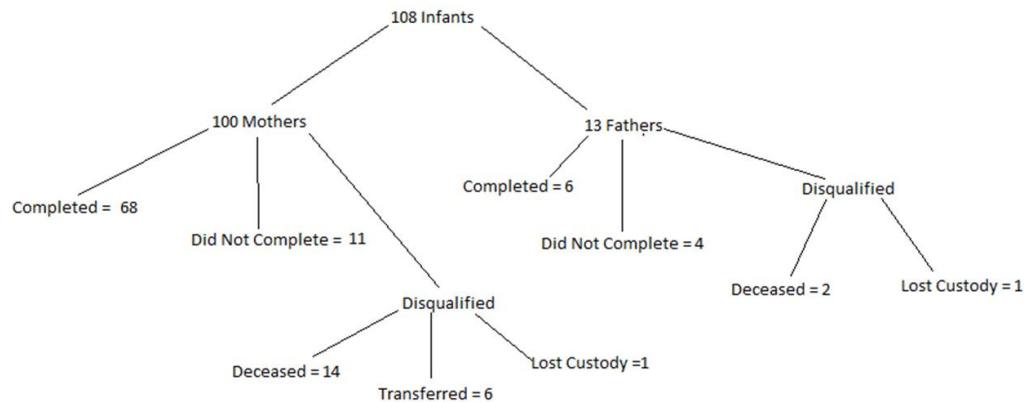
Infants of enrolled parents were followed prospectively throughout their hospitalization. Once discharge was anticipated within the next week, a survey containing measures of parental distress (described below) was placed at the bedside in an envelope. After the study protocol was amended starting with the 70<sup>th</sup> subject, parents were asked to complete a basic demographic survey that included questions about educational attainment and availability of leave from work. Because the study team included physicians who may have been involved in the infant's care, parents were provided with privacy while they completed the surveys to minimize any potential bias. Parents placed surveys in a sealed envelope to protect the confidentiality of responses. Bedside nurses were instructed to collect the envelopes upon discharge and give it to a study team member. Surveys were stored in a secure locked cabinet. Alternatively, if parents provided an email address to the study team, they were invited to receive the survey via a secure link upon discharge. Rates of parental presence of both mothers and fathers were retrospectively collected using nursing documentation in the electronic medical record (EMR), where contact with families was recorded as part of standard unit practice. The parental presence rate was calculated as the number of days present divided by the total days of admission. Remote contact, such as phone calls, was not included in the rate. In the case of twins, the parental presence rate for the twin with the longer length of stay was used for data analysis.

Measures of parental distress were incorporated into the discharge survey. *Alienation* was measured via a purposefully designed scale adapted from a societal alienation scale previously used in the General Social Survey (Figure 1).<sup>11</sup> Each question was answered on a Likert-type scale, with a point value of 1 to 5 assigned based on strength of response. Points were totaled and analyzed on a continuous scale from 10 (most alienated) to 50 (least alienated). Both enrolled mothers and fathers completed the alienation questions. The *Edinburgh Postnatal Depression Scale* (EPDS), a validated tool used to screen for post-partum depression, was administered to enrolled

**Figure 1. Hospital Survey of Alienation**

The people running this hospital really don't care what happens to you (or your baby)
The hospital and staff are getting rich while you get poorer
The hospital staff do not value your opinions or care about what you think
You're left out of things going on around you at the hospital
This hospital and staff take advantage of people like yourself
The hospital staff is out of touch with people like you
You are just different from most of the people at this hospital
You do not really trust the people at this hospital
People where you live are different from the people who work at this hospital
You do not feel like you can be yourself around the people who work at this hospital

Responses scored on the rubric, (1) strongly agree, (2) mildly agree, (3) agree and disagree equally, (4) mildly disagree, (5) strongly disagree. Scores were summed to create a 10-50 scale.

**Figure 2. Enrollment Flow Diagram**

mothers.<sup>12</sup> Total scores ranged from 0 to 30, with 10 or more points indicating a positive screen for depression. The *Generalized Anxiety Disorder 7-Item Scale* (GAD-7), a validated tool used to screen for generalized anxiety was administered to all enrolled parents.<sup>13</sup> Scores ranged from 0 to 21 with scores of 5, 10, and 15 representing mild, moderate, and severe anxiety respectively.

### Statistical Analysis

Data were summarized using medians with interquartile range or counts with percentages. Spearman correlation coefficients were used to compare the distress measures to presence rate and to one another.

### Results

One hundred mothers were enrolled in the study, of whom 32 were excluded from the analysis (14 because of infant death, 6 because of transfer to another facility, 1 because the infant was discharged to state custody, and 11 because the mother failed to complete the survey; Figure 2). Further analysis included 68 mothers and their infants. Maternal characteristics included median age 29 (IQR

24,33) years, being present on median 77% (IQR 51%,92%) of the days their child spent in the hospital, out of a median 96-day hospital stay. Presence was somewhat lower among mothers who were enrolled in the study but did not complete the discharge survey, although this difference did not reach statistical significance (61% vs. 77%; 95% CI of difference: 0, 25%;  $p=0.087$ ). Mothers reported low rates of alienation (median score of 49/50 points, with higher scores indicating lower alienation). Only 8 mothers reported a score <40. Alienation was not correlated with EPDS or GAD-7 scores (Table 1). In this sample, measures of maternal distress or alienation were also not correlated with fathers' rates of NICU presence (median 24% of the infant's hospital stay; IQR: 11%, 55%; Table 1).

Next, we analyzed data from fathers who were approached and consented for the study. Of 13 fathers, we excluded 2 due to death of the infant, 1 due to the infant being placed in state custody, and 4 due to missing data on paternal distress measures. Among the remaining 6 fathers, alienation rates were low (median score of 49 points, IQR 46-50). Fathers who were more alienated at the time of

**Table 1. Spearman rank-order correlations among measures of maternal distress and parental presence in the neonatal intensive care unit (N = 68).**

Variable	EPDS	GAD-7	Alienation	Mother's rate of presence
GAD-7	Rho = 0.75 P < 0.001			
Alienation	Rho = -0.16 P = 0.182	Rho = -0.06 P = 0.641		
Mother's Rate of Presence	Rho = 0.08 P = 0.521	Rho = 0.16 P = 0.195	Rho = -0.04 P = 0.756	
Father's Rate of Presence	Rho = -0.08 P = 0.525	Rho = 0.06 P = 0.608	Rho = 0.17 P = 0.168	Rho = 0.52 P < 0.001

EPDS, Edinburgh Postnatal Depression Scale; GAD-7, Generalized Anxiety Disorder 7-Item

**Table 2. Paternal Characteristics**

Subject	Race	Education Level	Amount of Paternity Leave	Alienation Score	Rate of Presence
1	African American	Some college, no degree	Part of NICU admission (1 week)	39	23%
2	Caucasian	Some college, no degree	All of the NICU admission	50	54%
3	Caucasian	Bachelors	None	50	70%
4	Caucasian	Bachelors	Part of NICU admission	48	58%
5	Other	Some college, no degree	None	46	29%
6	Not available	Bachelors	Part of admission (7 weeks)	49	100%

discharge were also less present, but this correlation did not reach statistical significance ( $\rho = 0.67$ ;  $p = 0.148$ ). Likewise, the correlation between maternal and paternal alienation scores was strong but not statistically significant ( $\rho = 0.51$ ;  $p = 0.296$ ). Due to the small sample size, paternal demographic characteristics and leave from work were summarized at the respondent's level in Table 2.

## Discussion

In this study, we used a novel tool to explore the concept of hospital alienation in the NICU, reflecting parents' trust and relatability to the hospital staff. Only parents of infants < 28 weeks or < 1000 grams were enrolled, thereby creating a sample of subjects who would be exposed to the NICU environment for a significant period. These infants would most likely be among the sickest as well, leading to greater risk of parental distress. Increased parental presence was hypothesized to reduce parental alienation by allowing for more opportunities for interaction and understanding between parents and staff. Alienation measured via the "Hospital Survey of Alienation" was very rarely reported in our sample, however, and was uncorrelated with other measures of distress.

This study has several positive attributes. To our knowledge, this is the first study to explore the concept of hospital alienation and relate it to other measures of parental distress, especially in the NICU environment. Further, though the subsample size was small, we included paternal data, which are otherwise very limited in the literature. Our restricted sample of fathers reflects both our inclusion of them later in the study as well as challenges in coordinating in-person consents at bedside. Further challenges to enrolling fathers may have included barriers to presence such as limited paternal leave, as demonstrated in Table 2. Though conclusions cannot be made due to the small sample, it is interesting to note that

the father who reported the most alienation also had a relatively low presence rate and only one week of paternity leave. Importantly, paternal presence was found to be significantly correlated with maternal presence. This may be due in part to paternal presence facilitating maternal presence, especially in our population which included many families experiencing transportation difficulties.

Through interactions with parents of infants in the NICU, we have anecdotally seen instances of hospital alienation in this population. Our finding of low alienation rates calls into question the validity of the Hospital Alienation Survey as a way to identify parents who feel isolated and distrustful. It may be beneficial to administer the Hospital Alienation Survey and other measures of distress to NICU parents at other centers to examine the reproducibility of our findings. In regard to our low alienation rate, it is also possible that parents who did not complete the surveys or parents who could not be enrolled would have reported greater alienation. Due to limitations in our study consents and surveys, we were also unable to include non-English speaking parents. Additionally, even though confidentiality was assured, and surveys were administered close to the time of discharge, it is possible that parents may have provided answers they felt would be desirable by study team members. As the alienation score is intended to be a measure of distrust in the health care system, it would be interesting in the future to look for correlation between alienation measures and attendance at NICU follow-up clinic.

In addition to small sample sizes, our study had several limitations. Alienation was only measured at the time of discharge. The study could have been improved by measuring alienation both at the beginning and end of admission to see how and if the score changed. Also, parental presence was quantified as a rate and was extrapolated to reflect opportunities parents had to interact with the hospital staff. Prospectively recording

communication between hospital staff and parents may have added valuable information. Future efforts should focus on improving inclusion of parents at highest risk of alienation including those who are less frequently present in the NICU and non-English speaking parents. The alienation survey may also need revision and validation to increase sensitivity.

## Conclusion

In conclusion, we hypothesized that increased parental presence would reduce alienation by allowing for more positive in-person interaction with staff. This hypothesis was not supported by our research, likely in part due to the low alienation rates in our sample. Whereas depression and anxiety have been previously described among mothers of infants in the NICU, alienation does appear to be a distinct concept.<sup>4,8</sup> In contrast to prior research, no measures of parental distress were found to be associated with rates of parental presence in our study. Based on our research, parental presence alone does not mitigate distress. Therefore, further work is needed to identify which parents are most at risk of alienation or distress and how their interaction with NICU physicians and staff can be optimized to reduce this risk.

## Acknowledgement

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## Conflicts of Interest Statement

The authors declare that there is no conflict of interest.

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