


Parent Stress in Relation to Use of Bedside Telehealth, an Initiative to Improve Family-Centeredness of Care in the Neonatal Intensive Care Unit

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Abstract

Since the onset of the COVID-19 pandemic, telehealth technologies have become critical to providing family and patient-centered care. Little is known about the impact of these technologies on parent stress levels in the Neonatal Intensive Care Unit (NICU). We sought to determine the impact of bedside web cameras on stress levels of parents in the NICU in order to work toward interventions that might improve family-centered care. A validated survey, the Parental Stress Scale NICU, was administered to parents of babies admitted to the Children's Hospital of Philadelphia Neonatal/Infant Intensive Care Unit on days 7 to 10 of hospitalization. Parents were also asked if they used the available AngelEye Camera while their baby was hospitalized. Stress levels were analyzed for associations with the use of the bedside cameras. Parents who reported using the bedside camera also reported lower levels of stress relating to being separated from their babies. Bedside web camera interventions may hold potential for reducing parent stress related to separation from their babies, especially in the setting of a global pandemic.

Keywords

stress, telemedicine, telehealth, camera, neonatal, communication

Introduction

Prior to the COVID-19 crisis, telehealth and related technologies were becoming increasingly prevalent in all health care settings. Since the onset of the pandemic, such technologies have become critical to providing family and patient-centered care. Though such innovations hold enormous potential, little is known about their impact on families, both positive and negative. It is suspected that telemedicine and other telehealth modalities may provide the opportunity to increase connectedness and therefore decrease parent stress during prolonged hospitalizations, but this has not yet been borne out in the literature. The COVID-19 pandemic has forced some health systems to rely more heavily on these technologies, despite the lack of data (1). Studies that have been conducted to date have focused primarily on feasibility and implementation (2). This study was part of a quality improvement (QI) initiative which was started in the hopes

of improving the effectiveness of bedside telehealth, determining best practices for its implementation, and establishing its impact on the parent experience of hospitalization in the Neonatal Intensive Care Unit (NICU). Specifically, we sought to determine the impact of bedside web cameras on stress levels of parents in the NICU in order to work toward

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interventions that might improve family-centered care in our NICU. We hope that our findings may be helpful to institutions as they increase their reliance on these technologies.

Neonatal Intensive Care Unit hospitalization as a source of parental stress has been well established in the literature (3–6). Both mothers and fathers undergo parental role alteration which results in significant stress (4,5). For mothers, distance from the hospital predicts stress related to this alteration, and prolonged separation has been observed to be a contributing factor (4). Such stress is associated with maternal depression, which in turn impacts infants' long-term cognitive outcomes (7).

A variety of interventions aimed at reducing parental stress in the NICU have been studied (6). These include educational programs, empowerment, behavioral strategies, psychological interventions, and peer support among others (6). Additionally, increasing parents' involvement in care and interaction with their infants has been shown to both decrease stress and improve outcomes (8). Interventions that address mothers' emotional needs and knowledge deficits in a culturally sensitive manner have been the most effective (6). The literature suggests that keeping mothers and infants together reduces parental stress and increases bonding (9). Thus, this is the preferred approach when possible. However, circumstances often arise which interfere with keeping parents and infants together, especially when infants are critically ill or require extended hospitalizations. It is under such circumstances that telehealth interventions may be particularly useful.

Previous literature assessing the impact of telehealth interventions in the NICU is limited and there has been no research to date on the impact of bedside video on parent stress levels. A recent systematic review identified 8 studies that looked at eHealth interventions in the NICU (2). The authors described the majority of these studies as low to very low in quality and identified 3 "very low quality" studies assessing the impact of eHealth interventions on parent stress and anxiety (2,10–12). Epstein and colleagues studied a small group of 26 parents who received Facetime or Skype updates while their infants were in the NICU. Though they did not test for stress using a validated instrument, they did ask parents about worry and found a slight decrease in reports of worry after the intervention (10). Globus and colleagues evaluated the use of text message updates in the NICU and similarly asked parents about levels of anxiety after the intervention but did not use a validated measure and did not detect a statistically significant difference but rather a trend toward decreased anxiety in the group exposed to the study intervention (11). Hoffenkamp and colleagues performed a randomized controlled trial of "video interaction guidance" in the NICU, aimed at improving interaction between infants and their parents. They used the Parental Stress Scale (PSS) (13) to evaluate levels of stress among parents who underwent the intervention and those who did not. They did not find a significant difference in stress among groups (12). Findings from these 3 studies trend

overall toward decreased stress among those who utilized telehealth, though significant methodological limitations exist, making interpretation difficult (2). Dol and colleagues identify a need for studies using standardized measures of stress and anxiety to learn more about how parents experience these new technologies (2).

We are not aware of any other research to date evaluating the use of bedside web cameras to allow parents to see their infants in the NICU remotely and the impact of this intervention on stress levels. Studies have explored challenges in implementation of this new technology as well as its effect on nursing workflow but have not formally assessed how the use of bedside cameras alter parent stress (14,15). Given the exciting potential of telehealth interventions for family connectedness, it is essential to subject this technology to further study in order to ensure that it is being used optimally.

Methods

In order to determine the impact of bedside web cameras on parent stress in the NICU, we administered the Parent Stress Scale NICU version (PSS-NICU) to parents of babies admitted to the Children's Hospital of Philadelphia (CHOP) Neonatal/Infant Intensive Care Unit (NI/ICU). We selected the PSS-NICU as it is a validated tool for determining levels and sources of parental stress with good reliability in the NICU setting (13). The PSS-NICU is a 52-item scale encompassing 4 separate domains. Parents were asked to rate their stress relating to each individual item on the PSS-NICU on a 5-point Likert scale ranging from "Not at all stressful" to "extremely stressful." Example items include "having a machine breathe for my baby" and "the small size of my baby." The CHOP NI/ICU is a 98-bed regional referral unit. Patients in the CHOP NI/ICU have complex medical and/or surgical needs such as genetic and metabolic disorders and congenital diaphragmatic hernia. In November of 2018, AngelEye cameras were installed at all bedsides in the CHOP NI/ICU over 8 months (16). The AngelEye platform provides remote video monitoring which parents can access at any time of the day or night while their baby is in the NICU. Our team consisted of an interdisciplinary group of nurses, nurse practitioners, psychologists, physicians, hospital leadership, and digital health stakeholders. All stakeholders were actively involved in project planning. The CHOP institutional review board determined the study to be exempt from review as study procedures involved only survey completion without collection of any identifying information. Parents provided verbal consent for study participation. The study was conducted in accordance with ethical standards and privacy regulations.

From April 2018 until July 2018, the PSS-NICU was circulated to a convenience sample of parents of patients in the CHOP NI/ICU. Any parent whose baby was admitted to the NI/ICU was eligible to participate in this study. Parents answered the survey in writing to enable them to respond when convenient for them and to maximize privacy

and thereby facilitate honest responses. Upon survey administration, parents were asked whether or not they had used the bedside camera during hospital admission. This yes/no question was asked after parents completed the full questionnaire. Surveys were circulated on hospital day 10. We sought to collect data from all parents of hospitalized neonates and infants in our unit. Though we were not able to collect completed surveys from all parents in our unit, we did obtain survey data from a majority of parents. Study team members collected surveys in-person on a daily basis during the study period. Minor modifications were made to survey formatting after initial circulation including increasing font size of the question relating to camera usage in order to increase completeness of data as this question was not answered by a significant portion of parents early on.

The Wilcoxon rank sum test was used to assess univariable association between camera use and scores reflecting each of the following 4 domains: sights and sounds, appearance of baby, relationships, and staff communications and behaviors where the scores are the percentage of questions in each scale that were answered as very or extremely stressful. The Wilcoxon rank sum test was chosen given the non-normal distribution of our results, which are presented in tabular form in the results section. All statistical analyses were conducted using STATA SE/13.1. P values < .05 were considered significant, and all tests were 2-sided.

This study was part of a QI project to implement and monitor interventions to reduce parental stress and was therefore exempt from review by an institutional review board. All parents were given access to the NI/ICU psychological support team per unit standard of care. Additionally, the NI/ICU psychologist was actively involved throughout the study period and able to respond should any parents report concerning levels of stress. There were no relevant conflicts of interest impacting this project.

Results

Parents of 114 children were eligible to participate in this project and completed surveys over a period of 3 months in 2018. We did not collect patient-specific demographic data as part of this QI project. Parents reported high levels of stress associated with being separated from their babies, with their babies appearing to be in pain, and with feeling helpless to protect their babies or help their babies (Table 1). Parents reported low levels of stress relating to the wrinkled appearance and small size of their babies. The large number of people working in the unit and the other sick babies in the room also were not associated with high levels of stress among parents.

Of the 48 parents who answered whether or not they used the bedside camera, 44% (21/48) utilized the bedside camera. Parents who reported using the camera also reported lower levels of stress relating to 3 of 4 domains assessed by the PSS NICU (Table 2). Parents who used the camera reported lower levels of stress related to the sights and

sounds of the unit, the appearance of the baby, and their relationship with the infant and parental role. There was no association between use of the bedside camera and levels of reported stress related to staff behaviors and communication. Parents who used the camera reported significantly less stress related to being separated from their babies than those who did not use the camera, with 22% of parents who used the bedside camera reporting that separation from their baby was very or extremely stressful in comparison to 63% of parents who did not use the camera ($P = .005$).

Discussion

In this study of 114 parents of babies hospitalized in a level IV NI/ICU, 48 of whom responded to a prompt relating to use of a bedside camera, parents who used the AngelEye system reported a statistically significant decrease in stress related to 3/4 domains measured using the PSS-NICU as compared to those who did not use the bedside cameras. Though we cannot determine causality from this observational study conducted as part of a quality improvement initiative, this finding suggests a potential correlation and highlights the importance of further study of this promising technology. Strengths of this study include the large sample size. Because of the size of our unit, we were able to capture data from a large number of parents in a short period of time, limiting the extent to which passage of time might confound our results.

The literature related to this topic is in general quite limited. Previous studies of telehealth interventions in the NICU suggest a trend toward decreased stress as a result of using technologies similar to that which was studied here (10,11). This study adds to these results by identifying the specific nature of the source of stress for parents that a bedside camera system may help decrease: stress related to separation. Additionally, the use of a validated measure of parent stress provides a more reliable result than was previously available.

Limitations of this study include its observational nature. Because of how our data were collected, we are unable to report a response rate and rather are limited to this convenience sample which may introduce bias into our results. Though we captured data on a large number of parents, not all parents completed surveys. Parents who opted not to respond to our survey may be different from those who did respond. Access to technology at home might limit which parents are able to utilize the AngelEye system, introducing confounders related to socioeconomic status. We do not have data on why parents chose not to use the system, limiting our ability to look for such confounders. We do not have demographic data about individual patients and so are not able to control for patient-specific confounders. The uniqueness of our unit among Neonatal ICUs and the fact that all data came from a single site limits the generalizability of this study.

Table 1. Parental Reports of Stress Levels Related to Survey Items.

Item	Percent of respondents who found this item to be very or extremely stressful
Sights and sounds in the unit	
The presence of monitors and equipment	7% (8/114)
The constant noise of monitors and alarms	11% (12/114)
The sudden noise of monitors and alarms	15% (17/114)
The other sick babies in the room	5% (6/113)
The large number of people working in the unit	4% (4/113)
Having a machine breathe for my baby	27% (31/114)
The appearance of my baby	
Tubes and equipment on or near my baby	25% (28/114)
Bruises, cuts, or incisions on my baby	27% (31/114)
The unusual color of my baby	19% (21/112)
My baby's unusual or abnormal breathing pattern	31% (35/114)
The small size of my baby	4% (4/114)
The wrinkled appearance of my baby	2% (2/114)
Seeing needles and tubes put in my baby	21% (24/114)
My baby being fed by an intravenous drip	16% (18/113)
When my baby looked to be in pain	47% (54/114)
When my baby looked sad	33% (38/114)
The limp and weak appearance of my baby	23% (26/114)
Jerky or restless movements of my baby	18% (20/114)
My baby not being able to cry like other babies	21% (24/114)
Relationship with infant and parental role	
Being separated from my baby	50% (56/112)
Not feeding my baby myself	26% (29/112)
Not being able to care for my baby myself (eg, nappy changing)	24% (27/112)
Not being able to hold my baby when I want	39% (43/110)
Feeling helpless and unable to protect my baby from pain	46% (51/110)
Feeling helpless about how to help my baby during this time	45% (50/111)
Not being able to be alone with my baby	22% (24/111)
Staff behaviors and communication	
Staff explaining things too fast	1% (1/111)
Staff using words I don't understand	4% (4/111)
Telling me different (conflicting) things about my baby's condition	12% (13/111)
Not telling me enough about tests and treatments being done to my baby	6% (7/111)
Not talking to me enough	9% (10/111)
Too many different people talking to me	5% (6/111)
Difficulty in getting information or help when I visit or telephone	5% (5/111)
Not feeling sure that I will be called about changes in my baby's condition	10% (11/111)
Staff looking worried about my baby	15% (17/111)
Staff acting as if they didn't want parents around	7% (8/111)
Staff acting as if they did not understand my baby's behavior or special needs	9% (10/111)

Table 2. Parental Reports of Stress Level in Relation to Camera Use.^a

Category	Percent of parents reporting items in this category to be very or extremely stressful who used camera	Percent of parents reporting items in this category to be very or extremely stressful who did not use camera	P value
Sights and sounds in unit; mean, median [IQR]	2.4%, 0 [0-0]	17%, 0 [0-0.25]	.0265
Appearance of baby; mean, median [IQR]	15%, 0 [0-0.31]	33%, 0.25 [0-0.54]	.0246
Relationship with infant and parental role; mean, median [IQR]	22%, 0 [0-0.29]	45%, 0.5 [0.07-0.79]	.0184
Staff behaviors and communication; mean, median [IQR]	9.3%, 0 [0-0]	29%, 0 [0-0.44]	.0534

^an = 48 total respondents.

Implementation of a bedside camera system has the potential to be costly and may negatively impact the workflow of nurses and others (15). As such, it is critical to determine the value of such technology in order to support widespread implementation. Our results suggest that this technology may decrease parent stress by reducing the impact of separation. This finding may imply an indication for use of telehealth in order to support parents through NICU hospitalization. Further research in this area is much needed in order to determine whether the costs of bedside telehealth can be justified by this and other benefits, and to establish best practices for its implementation. Our findings suggest a need for further study of this promising technology and its impact on parental depression, anxiety, sleep disturbances, and fatigue.

Conclusion

The COVID-19 crisis has highlighted the need for expedited implementation of telehealth technologies in the NICU (1). Though further study is needed, our results suggest that these technologies have the potential to decrease stress for parents who cannot be at the bedside. Given the need to limit visitation in the context of coronavirus, such technology is becoming more important than ever. Bedside telehealth may have the potential to make NICU care more family-centered, reducing parent stress and improving outcomes.

More broadly, as a result of the COVID-19 crisis, novel methods to connect families with their hospitalized loved ones are desperately needed across health care contexts. The application of our findings to other settings is not yet known, though similar approaches could be considered in adult intensive care units, for example, during the global pandemic. This certainly warrants further study in order to enable connection between patients and families when physical separation is necessary.

Authors' Note

All involved persons gave their informed consent prior to study inclusion. Guttman wrote the first draft of this manuscript.

Declaration of Conflicting Interests

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