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Health Communication in Neonatal Intensive Care: Results of Focus Groups or Interviews with Parents, Nurses and Physicians

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Abstract

Background and Purpose: Health communication interventions to successfully promote satisfaction with care among parents in the Neonatal Intensive Care Unit (NICU) are limited. This study investigated strategies for effective health communication in the NICU through focus groups with parents and nurses, and individual interviews with neonatologists. **Methods:** Eight parents, seventeen nurses, and three neonatologists from one NICU in Genesee County, Michigan participated. **Results:** Parents expressed a preference for daily, face-to-face communication with the physician. They recommended the use of visual aids to help with understanding infants' conditions. One such aid would be a baby diary to serve as the infant's daily progress report for the parent to review during the visit. A communication strategy used by nurses was providing parents with the most up-to-date information in an approachable, reassuring manner. Physicians suggested interactive communication practice sessions as strategies to increase effective communication between physicians and parents. Physician-to-nurse strategies consisted of building trustworthy relationships by holding scientific forums, discussing health care disagreements, and accepting differing opinions. **Conclusion:** Future research may assess the influence of strategies recommended in this study on parental satisfaction with care and adherence to treatment recommendations as well as on health care provider self-efficacy.

Keywords: Communication, neonatal intensive care, parents, nurses, neonatologists

Introduction

The neonatal intensive care unit (NICU) treats infants who have high-risk medical complications. According to the Centers for Disease Control and Prevention, of the 3 million live births in 2015, 8.1% of infants were born with low birthweight (less than 5 pounds 8 ounces) and 9.6% of infants were born preterm (less than 37 weeks gestation) (Hamilton, Martin, & Osterman, 2016). A research study indicated an increase in admissions into the NICU in the U.S. based on data from 38 states and the District of Columbia (Harrison & Goodman, 2015). From 2007 to 2012, the rate of infants admitted into the NICU rose by 23%, adjusting for maternal and newborn determinants (Harrison & Goodman, 2015). Increases in admissions were seen for infants with all birth weights including normal birth weights (Harrison & Goodman, 2015). The study could not determine the reasons for the increases in NICU admissions. It speculated that one explanation was an increased patient access to NICU care. Another explanation was that NICUs were becoming overused by infants who did not need intensive care (Harrison & Goodman, 2015).

Building understanding and trust between providers and parents/patients may lead to successful treatment plans (Hall, Roter, & Katz, 1988; American Academy of Pediatrics, 2003), decreased parental anxiety (American Academy of Pediatrics, 2003; Wertlieb & American Academy of Pediatrics Task Force on the

Family, 2003), improved parental/patient satisfaction with care (Wissow, Roter, & Wilson, 1994; American Academy of Pediatrics, 2003; Wertlieb & American Academy of Pediatrics Task Force on the Family, 2003; Kodjebacheva, Sabo & Xiong, 2017), and increased adherence to treatment recommendations (Zolnierek, & DiMatteo, 2009).

The literature was searched to identify strategies to improve communication either between parents and providers or among providers in the NICU. In 4 of 5 communication interventions in the NICU, there was no increase in parental satisfaction with care (Penticuff, & Arheart 2005; Byers, Lowman, Francis, Kaigle, Lutz, Waddell, & Diaz, 2006; Koh, Butow, Budge, Collie, Whitehall, Tattersall, 2007; Clarke-Pounder, Boss, Roter, Hutton, Larson, & Donohue, 2015). Only 1 of the 5 interventions in NICU demonstrated an increased satisfaction with care among parents (Van de Vijver, Bertaud, Nailor, & Marais, 2014). This two-group pre-post repeated measure quasi-experimental program was implemented in one NICU in London (Van de Vijver, Bertaud, Nailor, & Marais, 2014). The intervention used baby diaries where doctors and nurses wrote about the baby's progress while the 44 participating parents added notes and questions (Van de Vijver, Bertaud, Nailor, & Marais, 2014).

The Current Study

Our study seeks to identify recommended communication strategies used by parents, nurses, and physicians (referred to as neonatologists) in the NICU. Parents, nurses, and neonatologists best understand their needs and are all included in the study to investigate communication from their different perspectives. The findings may be used to develop future interventions to improve parental satisfaction with care and increase provider self-efficacy in NICUs.

Methods

Study Design

A purpose of our qualitative research is to understand strategies for effective communication between parents and medical providers. Another purpose is to explore communication among providers, specifically among nurses, among neonatologists, and between nurses and neonatologists. Focus groups were conducted with two groups of parents, two groups of nurses, and individual interviews with 3 full-time/permanent physicians from an NICU in a midwest medical center.

Setting

The study took place in Genesee County, Michigan. In 2016, Michigan's estimated population was 9,928,300 (United States Census Bureau Population Estimates, 2016). In 2016, Genesee County's population estimate was 408,615 (United States Census Bureau Population Estimates, 2016). In 2015, it was ranked the 5th largest county in population among the 83 counties in Michigan (U.S. Bureau of the Census and Michigan Department of Management and Budget, Office of the State Demographer, 2017). According to the 2016 Kids Count in Michigan Data Book, Genesee County ranked 75th worst out of 82 counties within Michigan in terms of overall child well-being (Warren, 2017); there was no data on one of the 83 counties.

According to the 2016 Kids Count in Michigan Data Book, Michigan's infant mortality rate was "unacceptably high and above the national average" (Warren, 2017). In 2016, the infant mortality rate in Michigan was 6.3 per 1,000 live births (Michigan Department of Health & Human Services, 2017) compared to 5.9 per 1,000 live births (CDC, 2017) in the United States. Approximately 25% to 35% of mothers within Genesee County received poor prenatal care during the period 2011-2013 (Warren, 2017). Genesee county, had a higher infant mortality rate than the state's average in 2011-2013 (Warren, 2017). In 2011-2013, Genesee County was ranked one of Michigan's 5th worst counties in terms of having low-birthweight infants, with a rate of 10.2% (Warren, 2017).

A midwest medical center, Hurley Medical Center, located in Genesee County, was the site for the study. This medical center has a membership in the American Hospital

Association, the Michigan Health and Hospital Association, and America's Essential Hospitals (Accreditation and Affiliation Hurley Medical Center, 2017). As defined by the American Academy of Pediatrics, a Level III NICU specializes in care to infants who are born under 32 weeks gestation, weigh less than 1500 grams, or possess medical conditions (American Academy of Pediatrics Committee on Fetus and Newborn, 2012).

Procedures

Institutional Review Board (IRB) approvals for the study were obtained from both the university institution and the midwest medical center. Nurses and physicians received invitation letters to participate in the study. Parents received invitation letters from NICU nurses. The nurses explained to the parents that they would be divided into focus groups to discuss effective communication strategies between parents and NICU nurses and physicians. Parents who agreed to participate were provided a consent form to take home and review. Parents were given the telephone number of the university investigator and were asked to telephone with any questions about the study.

At the start of each focus group, the study was explained to each participant and each participant was allowed to voice questions or concerns about the research. Researchers emphasized that participation was voluntary. Participants then submitted a signed consent form, if indicating their willingness to participate. Any personal/sensitive experiences with communication in the NICU that may have been shared by parents during the focus groups were not relayed to NICU providers. In addition, participants were asked to respect each other's privacy and to not discuss information shared during the focus group with others.

The focus group guides and consent materials were developed with the input from the co-authors, who had diverse expertise in the areas of public health, neonatal nursing, and medicine. At the end of the focus group, each parent was provided with a gift card of $25. Physicians and nurses did not receive gift cards. Light refreshments were served at all of focus group meetings.

Analyses

All focus group discussions were recorded and transcribed. To protect privacy, participants did not state their name on the digital recordings. Focus group transcripts were read and analyzed independently by two authors using the constant comparative framework, to identify common themes such as the most preferred intervention strategies at the provider and parental levels. Any disagreements when analyzing the information were resolved through discussion.

Results

Focus Groups with Parents

Eight parents participated in 2 focus groups (4 parents per group) to discuss their suggestions for communicating with the physicians and nurses in the NICU. The majority (75%) of parents were female (Table 1). Most were non-Latino White and aged 18 to 39. All of the parents were employed and 50% had at least some college education. The majority of parents earned an average income of $20,000 to $40,000. Seventy-five of parents (6 out of 8) had infants in good condition and 25% (2 out of 8) had infants in satisfactory condition in the NICU.

Communication with Physicians as Discussed by the Parents. Parents expressed a preference for daily, face-to-face communication with the physician, even if their infant's condition did not change from the previous day (Table 2). Parents preferred that nurses continued to notify the doctor of the parent's next visit. An effective communication strategy discussed among the parents included having permission to telephone the physician. This strategy would assist in keeping the parents updated in real-time on the infant's condition, as well as eliminate confusion when changes occurred. Further, parents suggested the physician should ask open-ended questions such as: *"…What do you need? …something as simple as, "What do you want? What are your expectations for us?*" The parents felt that by asking more questions, the

physicians would clearly convey their genuine concern for the needs of the parent.

Table 1

Socio-demographic Characteristics of Parents, n = 8

Characteristic	n	%
Female Gender	6	75.0
Hispanic/Latino Ethnicity	2	25.0
Race		
White	6	75.0
Black	2	25.0
Asian	0	0.0
Age		
18-39	7	87.5
40-54	0	0.0
55-64	0	0.0
≥65	0	0.0
No response	1	12.5
Mean age	36	
Employed 50 or last 52 weeks	8	100.0
Highest education completed		
8th grade or less	0	0.0
9th-12th grade - No Diploma	0	0.0
High School or GED test	1	12.5
Vocational, Trade, or Business School	1	12.5
Some College	4	50.0
Associate's Degree	1	12.5
Bachelor's Degree	1	12.5
Master's Degree	0	0.0
Doctoral Degree	0	0.0
Income		
Less than $20,000	1	12.5
$20,000 to $40,000	5	62.5
$40,000 to $60,000	1	12.5
$60,000 to $80,000	0	0.0
$80,000 and above	0	0.0
No answer	1	12.5
Baby's Current Condition		
Critical	0	0.0
Serious	0	0.0
Satisfactory	2	25.0
Good	6	75.0

Table 2

Preferred Provider-parent Communication Strategies in the NICU: Results of 2 Focus Groups with 8 Parents (4 parents per focus group)

Effective strategies that parents have used to communicate with physicians/ preferred methods for communication with physicians as discussed by parents

Create personal time with the physician

- Speak face-to-face with the physician
- Plan to meet with the physician in the morning
- Communicate with the physician about the baby's condition at least once per day (even if the condition has not changed from the previous day)
- Be able to telephone the physician
- Have physicians convey a pleasant mood when speaking to parents

Effective strategies that parents have used to communicate with nurses/preferred methods for communication with nurses as discussed by parents

Stay up to date via consistent communication with nurses

- Inform nurses by telephone of a list of items the parents would like to receive notifications about
- Receive information on available resources in the hospital (such as information on breastfeeding, water, etc.)
- Receive any information the parent may need to enhance parent-baby bonding

Effective strategy for communication between physicians and nurses that parents appreciate

Anticipate the parent's next visit

- Ask the nurse to notify the doctor of the parent's next expected visit or the parent's current visit so the physician is aware and can communicate with the parent

Aids in understanding conditions and medical terminology that parents have appreciated/recommend

Create parent-friendly teaching methods and encourage parent suggestions

- Define a list of medical terminology typically used when discussing the infant's condition
- Allow parents to create a list of questions to ask and hand to the nurse/physician
- Give parents booklets (baby diaries) with a space for questions that nurses/physicians can answer; booklets can serve as daily progress reports
- Create educational audios concerning the condition of the baby
- Provide pamphlets on the infant's condition and resources available to parents in the hospital
- Create a suggestion box so parents can write ideas for improvement

Questions that parents appreciate the nurses/physicians asking

Anticipate the parent's needs

- What do you need?
- What do you want?
- What are your expectations of us?

Cultural issues to consider during communication

- None.

Communication with Nurses as Discussed by the Parents. Effective communication strategies suggested by the parents involved nurses supplying the parents with aids in understanding the infant's condition and enhancing parent-baby bonding. Suggested aids included pamphlets, educational audios concerning the conditions of the baby, a defined list of medical terminology typically used when discussing the infant's condition, and especially baby diaries. The baby diary would serve as the infant's daily progress report for the parent to review during their visit. It would also serve as a method for parents to write questions and/or concerns for the nurse or physician to answer.

Parents appreciated the strategy to telephone nurses and provide them with a list of items they would like to receive notifications about. According to the parents, a suggestion box, in which parents could write and submit ideas for improvement, could be a helpful strategy as well.

Focus Groups with Nurses

Two focus groups with a total of 17 nurses were conducted to discuss communication strategies among physicians, parents, and fellow nurses within the NICU (Table 3). All of the nurses were female. The majority of nurses were non-Latino White and aged 18-39. Approximately 29% earned an Associate's Degree in Nursing (ADN), 58.8% earned a Bachelor's of Science in Nursing (BSN), 5.9% earned a Master's of Science in Nursing (MSN), and 5.9% received other education (Table 3).

Communication with Parents as Discussed by Nurses. The primary communication strategy used by nurses was providing parents with the most up-to-date information in an approachable, reassuring manner (Table 4). Nurses stated: *"…just sit down with them and be at the same level… call the parents if there's something significant that occurred…go over new orders, any changes, and how the baby is tolerating previous changes …and put it out there that you're willing to go into more detail."*

Table 3

Descriptive Characteristics of Medical Providers (n= 17 Nurses and n=3 Physicians)

Characteristic	n	%
Nurses		
Mean number of years at medical Center (range)	12.0 (1-35)	
Female Gender	17	100.0
Race		
White	15	88.2
Black	1	5.9
Asian	1	5.9
Highest Degree		
Associate's Degree in Nursing (ADN)	5	29.4
Bachelor's of Science in Nursing (BSN)	10	58.8
Master's of Science in Nursing (MSN)	1	5.9
Doctor of Nurse Practitioner/Doctor of Philosophy (DNP/PhD)	0	0.0
Other	1	5.9
Age		
18-39	10	58.8
40-54	4	23.5
55-64	1	5.9
≥65	0	0.0
No response	2	11.8
Mean age	38.8	
Physicians		
Mean number of years at medical center (range)	15.5 (1.5-39.5)	
Gender		
Male	3	100.0
Female	0	0.0
Race		
White	0	0.0
Black	0	0.0
Asian	2	66.7
Other	1	33.3
Age		
18-39	0	0.0
40-54	2	66.7
55-64	0	0.0
≥65	1	33.3
Mean age		49

An effective strategy nurses used to overcome communication challenges involved restructuring their approach depending on the situation. The nurses strived to assess the parent's level of understanding. Afterwards,

nurses selectively chose their verbiage based on that parent's level of understanding. In cases when parental anxiety was high, nurses recommended temporarily limiting the amount of detail given and revealing the information once parental anxiety decreased. Often times, nurses restructured their approach by using different healthcare personnel, such as a physician or another nurse, to help the parent reach a clear understanding.

Table 4

Preferred Provider-parent Communication Strategies in the NICU: Results of 2 Focus Groups with 17 Nurses (n= 9 and n=8)

Effective strategies that nurses have used to communicate with parents as discussed by nurses *Inform parents on the most up-to-date information in an approachable and reassuring manner* ● Sit down with the parents and approach them on their level ● Provide any new information to keep the parent updated on their infant's progress. ● Ask the parent open-ended questions and show willingness to explain information
Effective strategies that nurses have used to communicate with parents with different levels of understanding and anxiety as discussed by nurses *Utilize selectivity when communicating with parents based on a parents' understanding of medical terminology and level of anxiety* ● Perform an assessment upon initial introduction, to establish the parent's level of understanding ● Selectively choose verbiage based on the parent's medical background and/or level of understanding ● Temporarily withhold stressful information when speaking to a parent who has a high level of anxiety; afterward, reveal the information once the parent's anxiety level decreases
Effective strategies nurses have used to overcome challenges when communicating with parents *Create a different approach* ● Restructure the information to reach an explanation the parent can better understand ● Use different personnel – a physician or a different nurse – to explain the same information in a different way
Type of communication training nurses recommend *Emphasize communication training in nursing school* ● Incorporate a communication aspect in nursing school, distinct from the task of medical care ● Incorporate a clinical course in nursing school to heighten the importance of effective versus non-effective communication
Effective strategies nurses have used to communicate with physicians *Take proactive measures* ● Be present when important details are being discussed ● Maintain awareness of the physicians concerns ● Voice one's own concerns ● Direct questions/concerns to other personnel such as charge nurse or nurse manager, if relevant
Suggested strategies for effective communication between nurses and physicians *Create consistency* ● Eliminate numerous places to chart notes and information. ● Establish a universal tool/one area, which all personnel will utilize to communicate amongst each other. This includes having a universal screen where all personnel have the same view where notes and pertinent information will be communicated. ● Have nurses and social workers communicate any new, pertinent information to the incoming physicians during the physician shift change or rounds

Communication with Physicians. Nurses strategized their communication interventions around taking proactive measures. Such measures included being present when important details were discussed, maintaining awareness of the physicians' concerns, voicing concerns, and directing questions towards other personnel when relevant. In addition, nurses suggested incorporating group meetings, in which the nurses and social workers could communicate any new, pertinent information to the incoming physicians during the physician shift changes, or rounds.

Communication among Nurses as Discussed by the Nurses. Nurses agreed that consistency was important when communicating with fellow nurses. The strategies nurses suggested primarily involved reducing the amount of areas available for charting patient information. If too many areas are available when charting, the chances of important messages being overlooked increases. Also suggested was, every nurse should keep the most up-to-date information in the notes area of the patient's electronic medical record as well as review it regularly for new messages.

Table 5

Preferred Provider-parent Communication Strategies in the NICU: Results of 3 Individual interviews with 3 Physicians

Strategies that physicians have used to effectively communicate with parents
Prepare, introduce, inform, re-affirm
● Prepare beforehand by gathering information so when the physician meets the parent, s/he is able to gain their confidence
● Compose a standard introduction, stating the physician's name, background, and tasks as the infant's physician
● Explain the reason why the physician is meeting with the parent and discuss the condition of the infant
● If the parent has not obtained a full understanding, the physician will re-explain the area in which the parent lacks understanding
Provide parents with updates
Have more communication if the infant's condition is worse or worsens
Use honesty and empathy with parents
Strategies to overcome challenges when communicating with parents
Use a multidisciplinary team
● Involve social workers and other colleagues from different disciplines in care
● The charge/coordinating nurse helps bridge any gap in communication between the physician and the family
Types of training recommended for more effective communication
Training sessions and seminars (2 of 3 physicians would find these helpful)
Presentations and handouts (1 of 3 physicians would find these helpful)
Interactive/simulated sessions, case scenarios for physicians (2 of 3 physicians would find these helpful)
Online modules are questionable (1 of 3 physicians would find these helpful)
● The effectiveness of online modules depends on the user and if the user is understanding the information.
Booklets or other educational visual materials for parents (3 out of 3 physicians believe these are helpful)
A diary for parents to write notes and questions (3 out of 3 physicians believe these are helpful)
● Should be locked to ensure that the Health Insurance Portability and Accountability Act of 1996 (HIPAA) is not violated
Strategies that physicians use to have effective communication with nurses
Meet with them at a regular interval, have open communication, hold scientific forums
Listen to nurses
● Let the physician's body language show active listening
● Build relationships by getting to know the individual
● Discuss any differences of opinion

Interviews with Physicians

All physicians were male. Two self-identified as Asian and one as Other. Two were aged 40-54 and one was aged 65 or older.

Communication with Parents as Discussed by the Physicians. One of the primary communication strategies used by physicians was composing a proper introduction (Table 5). First, physicians gathered information prior to their meeting with the parent. Once the physician and parent met, the physicians introduced themselves and explained their tasks as the infant's physician. When performing the introduction, physicians stated it was important to "*be honest right from the beginning… give all the information I can when I get it…rather than give them patchy information at regular intervals."* After the introduction, physicians asked the parents to provide feedback and summarize the information in their own words. During the infants' stay, if an acute change occurred, physicians provided the parents with a compassionate update on the infants' condition.

Physicians agreed that training on effective communication strategies was important. All three physicians stated providing baby diaries would increase effective communication with parents. Two out of three physicians suggested interactive/simulated sessions and case scenarios with role-playing between physicians and fictitious parents as effective strategies to increase communication effectiveness among physicians.

Communication with Nurses as Discussed by the Physicians. Physicians emphasized the importance of regular meetings between nurses and physicians. To enhance communication, physicians agreed on the importance of having trust between physicians and nurses. According to the physicians, suggested strategies to enhance trust included physicians and nurses spending more time listening to each other, discussing evidenced-based research, building relationships, and holding informal forums to scientifically discuss common medical disagreements.

Communication among Physicians as Discussed by the Physicians. To enhance communication among physicians, frequent face-to-face group meetings were suggested. Physicians believed that group meetings helped promote effective solutions to medical problems and increased trust among fellow physicians.

Discussion

An important communication strategy for parents was to have daily, face-to-face interaction with their infants' neonatologist. Parents suggested permission to telephone the physician to be updated on their infant's condition. Parents' communication strategies also included receiving visual aids in understanding the infant's condition.

Nurses suggested strategies involved providing information in a reassuring manner. Nurses suggested allowing parents to provide their nurse with a list of items they would like to receive notifications about. Afterwards, the nurse would contact the parent with the update the parent requested. Nurses suggested group meetings among nurses, social workers, and physicians during physician shift changes to discuss emerging issues.

Physicians' strategies consisted of establishing relationships with parents by providing the most up-to-date and honest information. Physicians' strategies included building trustworthy relationships with nurses through holding informal forums, acknowledging differing opinions, and scientifically discussing disagreements. Physicians suggested incorporating open communication forums. The forums would be attended by both physicians and nurses. The two groups would meet to discuss the recent scientific literature, review current practices, and discuss the effectiveness of proposed changes before implementing them in the unit.

One suggestion to improve parent-provider communication was to use a baby diary to serve as the infant's daily progress report for the parent to review during the visit. The diary would also allow parents to write their questions and/or concerns for the nurse or physician to

answer. A prior study used baby diaries in Croyton University Hospital, London (Van de Vijver, Bertaud, Nailor, & Marais, 2014). It was a quasi-experimental study that used a historical control and an intervention group. Surveys were administered weekly during the stay as well as at discharge to each family (both parents if present). More parents in the intervention group noted that they were receiving regular communication from providers and felt that their questions and concerns were answered than those in the control group. All parents in the intervention group stated that they appreciated reading the diary and 94% stated that the diary added to their understanding of how the baby was doing (Van de Vijver, Bertaud, Nailor, & Marais, 2014). We recommend a randomized-controlled trial to assess the effectiveness of a baby diary in the NICU.

We suggest that future interventions focus on improving communication not only between parents and medical providers but also among providers. Research may investigate whether strategies to improve communication among providers improve parental satisfaction with care. Suggested strategies to improve communication between parents and providers may include the use of baby diaries, a shared message system for daily interaction, and fact sheets and audio recordings on understanding the infant's condition and enhancing parent-baby bonding.

Suggested strategies to improve communication among providers included joint scientific forums, meetings during shift changes, and communication practice sessions with fictitious patients. Physicians also suggested the development of a process to appropriately analyze patient satisfaction surveys. Some parents may use their assessment of the cleanliness of the waiting room in their satisfaction score, which is not related to the quality of the interaction with the medical personnel. The survey data on medical communication should be isolated to understand parental satisfaction with communication. Physicians, nurses, and leadership should then follow-up on making improvements based on the communication satisfaction scores and comments.

To enhance communication among physicians, future interventions may include regular face-to face meetings among physicians to discuss patients' medical conditions. Such interventions may assess the influence of the face-to-face meetings on trust and collegiality among fellow physicians.

Limitations

Limitations of the study included the small sample size of parents and physicians. The majority of parents who participated were White, employed, and had education beyond high school. No parents with infants in critical or serious conditions participated. Parents stated that there were no cultural issues in the communication process they believed to be important. A more diverse group of parents could have uncovered cultural issues. Further, nurses may have felt uncomfortable to recommend changes in communication with physicians in a group setting. Another limitation is that the survey did not ask parents about their health insurance status.

Conclusion

All groups acknowledged the importance of effective communication in the NICU. Parents have a need for daily communication with medical providers regardless of the condition of the infant. A universal message screen that would include parent requests for notifications from physicians and communication updates from neonatal nurses is one method of ensuring daily communication. A baby diary is yet another method for parents to write questions and/or concerns for the nurse or physician to answer. Future interventions may test the effectiveness of the communication strategies identified by all groups in improving communication and parental satisfaction with care in NICUs.

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