

Family-Centered Care During Acute Neonatal Transport

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ABSTRACT

PURPOSE: To evaluate current transport team communication practices and identify areas for improvement from the parents' perspective. We also sought to determine whether parents perceived that they were active participants in the care of their infants during the transport process, consistent with the concepts of providing family-centered care (FCC).

SUBJECTS: Purposeful sampling of mothers and fathers (or maternally designated support person if the father was not involved) of 25 infants who were transported for acute care to a level III neonatal intensive care unit (NICU) between October 1, 2012, and September 18, 2013.

DESIGN: This quality improvement project used quantitative and qualitative analysis of a parent questionnaire.

METHODS: Mothers and fathers (or the support person) of transported infants were invited to complete a questionnaire consisting of yes/no and open-ended questions within the first 2 weeks of their infants' transport to a level III NICU. The questions were related to the communication and information parents received and their ability to participate in the transport process.

RESULTS: Twenty-seven parents completed the questionnaire. Responses to yes/no questions identified areas for improvement for the transport team. These included providing parents the opportunity to view an informational video; ensuring that mothers had the opportunity to provide colostrum or breast milk before transport; and providing an explanation to parents about their role as active participants in their infants' care. Responses to the open-ended questions indicated that approximately 40% of parents felt they had received adequate information about their infants' care during the transport and many parents (40%) cited separation from their infants as very concerning and causing distress. More than one-third (40%) of the parents specifically stated that at least 1 parent should accompany the infant during the transport. One father in this sample had been able to accompany his infant to the tertiary center.

CONCLUSIONS: The integration of FCC core concepts during an acute neonatal transport is important to parents. The orientation of parents to FCC during the transport process may facilitate communication and help them become active participants in their infants' care.

Key Words: communication, family-centered care, information, neonatal, parent, parent involvement, quality improvement, transport

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This work occurred at Children's Hospital at Dartmouth, Lebanon, New Hampshire.

The authors thank Michelle Beauchesne, DNSc, RN, CPNP, FNAP, FAANP, and Karla Damus, PhD, MSPH,

MN, BSN, FAAN, for their support and assistance with the development and analysis of this DNP Capstone project.

The authors declare no conflict of interest.

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DOI: 10.1097/ANC.000000000000119

The integration of family-centered care (FCC) core concepts including parents as partners in care is recommended as a model to achieve the best outcome for infants and their families.¹⁻¹⁷ Four concepts are necessary for FCC: dignity and respect; information sharing; participation; and collaboration.^{3,4,18} Neonatal units that practice FCC may be able to decrease parental distress through the enhanced participation of the parents in the care of their infants.^{3,4,7,17,19-21} The neonatal unit that embraces FCC places the needs of the infants within the context of the family. The parents and family are acknowledged as the constant in their infants' life, with parents responsible for the physical, emotional, social, and developmental needs of their infants.^{5,6,13,22,23} This recognition encourages parents to become fully engaged and active participants in the team caring for their infants, and as such, changes the dynamic between the parents and the healthcare team. Reis et al¹² identified strategies and goals to facilitate the development of the relationship between parents and healthcare providers that include creating a culture and philosophy of partnership, enhancing continuity of care, assessing the need for parental education, and providing appropriate and adequate educational resources. The healthcare team's acknowledgment of parental perspectives about their infant and his or her care may facilitate the development of the parental role.

Although the inclusion of FCC concepts is common in the intensive and intermediate neonatal care environments, there has been less emphasis on implementing these concepts as thoughtful components of the care provided during acute neonatal transports. However, more than 65,000 infants in the United States are acutely transported from their birth hospital to a tertiary (level III or level IV) neonatal intensive care unit each year.²⁴ In addition, acute neonatal transports may cause distress and be a negative experience for parents.²⁵⁻³⁰ They may not have anticipated the birth of an ill neonate and may be unable to immediately accompany their infants to the tertiary facility, thus limiting their ability to fully participate in the care of their infants.^{23,30-34}

Providing FCC during neonatal transports presents a unique challenge to the transport team. The team must efficiently evaluate and stabilize the infant for transport. Because of the time constraints inherent in the transport process, the team may have very little time to spend with the family. Their communication must be concise and informative and meet the immediate needs of the parents.³⁵⁻³⁹ The team's communication should integrate the core concepts of FCC and provide the foundation for information sharing and collaboration with families throughout the infants' hospital course. However, it is currently unclear how to best employ the concepts of FCC to provide sufficient information and initiate collabo-

ration with parents during the transport phase of care.

A review of the literature from 1992 to 2013 yielded a total of 11 articles examining parental needs around the transport process.^{28,39,40-48} These articles did not deal exclusively with acute transports and one⁴⁵ did not distinguish between neonatal and pediatric transports. All emphasized the need to recognize the impact acute neonatal transports have on parents. These articles consisted of qualitative studies, descriptive studies, literature reviews, and the development of a family support module for transports.

Transport impacts parents and their ability to bond with their infants.²⁹ Several studies reported that infant transport is associated with parent psychological distress,^{29,34-40} specifically anxiety, and worry.⁴⁰ While the healthcare team may consider the transport process routine, parents have a markedly different perspective,⁴⁰ generally perceiving neonatal transport negatively.⁴⁶ Parent participation in the review of transports with the goal of understanding the stressors parents face is recommended as one way to better understand parental needs.^{28,47}

Parents also report information needs regarding infant transport⁴⁰⁻⁴³ and needing time to process the information they are given.⁴³ Parents want to know the details of their infants' condition,⁴³ to understand what the transport process will entail,⁴⁰ directions to the referring hospital,⁴³ and to be able to maintain their parental control.^{42,43} Other parental needs include the need to see and touch their infants before transport and reunite with their infants as soon as possible.⁴³ Family-centered care during transport with a focus on assessment of parents' emotional needs^{33,39,41} and clear communication is essential to providing parental support and keeping parents informed and engaged in their caregiving role.^{28,46}

Collectively, this literature review yields valuable information about parental involvement during infant transport. It reveals the benefits of decreasing parental distress through education and participation. Although it is clear that the information should be honest and accurate, suggestions about what information should be given to parents were generally from the viewpoint of the health care provider, not from the parents themselves.

Therefore, this quality improvement activity was designed to evaluate the communication and information needs identified in the literature using a parent self-report questionnaire. Parents were asked to identify specific information that might help decrease some of their distress at having their infants acutely transported. The quality of communication the transport team provided was not addressed, rather specific information the transport team should communicate to the family at the time of transport was assessed.

PURPOSE

This project was developed to evaluate current transport team communication practices and identify areas for improvement from the parents' perspective. We also sought to determine whether parents perceived that they were active participants in the care of their infants during the transport process, consistent with the concepts of FCC.

Methodology

This quality improvement project was conducted between October 1, 2012, and September 18, 2013. It was approved by the Northeastern University Internal Review Board and Dartmouth College Committee for the Protection of Human Setting and Subjects.

Mothers and fathers (or maternally designated support person if the father was not involved) whose infants were transported to a level III regional referral hospital averaging 150 to 200 acute neonatal transports per year were recruited by purposeful sampling. Parents under the age of 18 years and non-English-speaking/-reading parents or support persons (the questionnaire was available only in English) were excluded from participation. Parents whose infants were in imminent danger of dying were not approached to participate.

Procedures

Parents were approached by the project lead and invited to participate within the first 2 weeks after the transport, while the infant was still a patient in the neonatal unit. This timing was chosen, as the transport experience would be recent in the minds of the parents. Parents were not approached the first time they were reunited with their infants.

Parents were informed that participation was voluntary and involved completion of a questionnaire. Completion of the questionnaire implied consent to participate and they were given an information sheet describing the project. Parents were told that they could decline to answer any question(s) they were not comfortable answering and were encouraged to meet with the family support specialist or the unit social worker for support if answering the questionnaire made them uncomfortable in any way. A maximum number of two questionnaires were left for each transported infant: one to be completed by the mother and a second to be completed by either the father or the maternally designated support person. The questionnaire took less than 30 minutes to complete and completed questionnaires were returned to a locked box near the entrance to the neonatal unit.

The questionnaire consisted of 9 yes/no and 8 open-ended questions developed by the project lead with input from the Intensive Care Nursery Parent Council, the section chief of neonatology, and a rep-

resentative from the Institute of Patient- and Family-Centered Care. Literature-based recommendations for improving acute neonatal transports were used to develop the questions, as they were already considered standards of care for this transport program.^{28,43,48} Demographic data collected included the gestational ages of the infants, the infant's ages at the time of transport (in hours), admitting diagnosis, maternal age, paternal age if available, and the relationship of person completing the questionnaire to the infant (mother, father, or support person).

Data Analysis

Twenty-five families of infants transported from their birth hospital were approached and 50 questionnaires were distributed. Twenty infants had at least 1 questionnaire completed and returned. There were a total of 27 questionnaires analyzed, 16 from mothers and 11 from fathers. The yes/no questions were analyzed using descriptive statistics and parents' written comments were analyzed to determine common themes.

RESULTS

Twenty-five mothers received the questionnaire and 16 (64%) were returned completed. Twenty-three fathers received the questionnaire and 11 (48%) were returned completed. Two grandmothers were designated by the infant's mother as her support person and received a questionnaire; neither of those was returned. The average maternal age was 26 years (± 4 years; range, 18-34 years). Paternal age was unable to be collected.

A list of admission diagnoses for the infants is found in Table 1. The average gestational age of these infants was 38 weeks and 1 day (± 2 weeks and 4 days; range, 33 weeks-41 weeks and 4 days) and average birth weight 3078 g (± 666 g; range, 1845-4280 g). The average age of the infant at the time of transport was 19.7 hours (± 26 hours; range, 2-96 hours). The transport team was present at the delivery of 1 infant.

The 9 yes/no questions parents were asked to respond to are shown in Table 2. Findings revealed that neither mothers nor fathers reported having an opportunity to view the video *Welcome to the ICN [Intensive Care Nursery]* ($n = 0$); only 7 mothers (44%) had an opportunity to provide colostrum or breast milk before the transport; and 10 parents (37%) received an explanation about the role of parents in the care of their infants. Thirteen parents (48%) reported they had photographs of their infants to look at after the team departed. In contrast, most parents reported that they received the informational parent packet ($n = 17$; 63%); received a telephone call to reassure them their infants had arrived safely at the tertiary center ($n = 18$; 67%);

TABLE 1. Diagnoses at the Time of Transport

1. Abdominal mass
2. Anemia
3. Apnea
4. Hypoxic ischemic encephalopathy
5. Imperforate anus
6. Meconium aspiration syndrome
7. Neonatal abstinence syndrome
8. Prematurity
9. Perinatal depression
10. Persistent pulmonary hypertension
11. Respiratory distress
12. Rule out sepsis
13. Rule out congenital cyanotic cardiac defect
14. Seizures
15. Tracheoesophageal atresia
16. VACTERL syndrome

Abbreviation: VACTERL, vertebral defects, anal atresia, cardiac defects, tracheo-esophageal fistula, renal anomalies, and limb abnormalities.

TABLE 2. Yes/No Questions

1. Were you given the opportunity to view the video *Welcome to the ICN* before being reunited with your baby in the ICN?
2. Were you given the opportunity to provide colostrum/breast milk for your baby before the transport team departed?
3. Did the members of the transport team introduce themselves and explain their roles in caring for your baby?
4. Did the transport team describe the role of parents and families in the care of babies in the ICN?
5. Did the transport team give you information about the care they were going to provide to your baby during the transport?
6. Were you given the opportunity to ask questions prior to the departure of the transport team?
7. Did you have a photograph of your baby to look at after the transport team departed?
8. Did you receive a copy of the parent packet from the transport team?
9. Did you receive a phone call from the transport team once your baby arrived in the ICN?

Abbreviation: ICN, intensive care nursery.

TABLE 3. Open-Ended Questions

1. What was your biggest concern when you learned your baby was going to need to be transported?
2. What do you remember about your baby's transport to the ICN?
3. How long was it before you were reunited with your baby?
4. Were there specific barriers that prevented you from coming to the ICN to be reunited with your baby?
5. What information provided by the transport team was most helpful?
6. What additional information did you need?
7. Were you able to get as much information as you needed about your baby after the transport team left?
8. We realize having your baby transported is a very stressful experience for parents and families. What do you think could have made the experience less stressful for you?

Abbreviation: ICN, intensive care nursery.

remembered the transport team introducing themselves ($n = 23$; 85%); and recalled the team provided information about the care provided to their infants ($n = 24$; 89%) and were given the opportunity to ask questions of the transport team ($n = 24$; 89%).

The open-ended questions (Table 3) were designed to elicit the parents' perspectives about the transport process. These revealed a wide array of parental worries and needs. Responding to the question of their biggest concern relating to their infants' acute transport, parents expressed fear that their infants would die ($n = 3$; 11%), concerns of being physically separated from their infants ($n = 11$; 41%), uncertainty about what was happening to their infants ($n = 7$; 26%), and wanting reassurance their infants "would be OK" ($n = 8$; 30%). One father reported the emotional dilemma of whether to travel to the tertiary facility to be with the infant or stay with the mother and support her.

Parental remembrances of the transport ($n = 15$; 56%) included how the team cared for their infants, being able to see and touch their infants prior to the team departing, the team telling the parents that they would take good care of their infants, and the reality that they were going to be separated from their infants. One set of parents wrote that they could not remember anything in particular about the transport, which may be an indication of the immense distress they were experiencing. Direct quotes from families reflecting their distress at being separated from their infant may be found in Table 4.

TABLE 4. Parental Quotes About Separation From Their Infants

"Being separated from him"
 "That he was gonna be away from me"
 "Not being with her"
 "When can I see him?"
 "That she was going without me"
 "That I wouldn't be able to see him for days; I just wanted to hold him"
 "Not being with my baby and unsure of how long I would be separated"
 "Not being with baby"
 "How long it would be till he was going to be held by mommy"
 "The travel, we live an hour away"
 "... provided the info I needed to be as comfortable as possible while being away from my baby"
 "It's a hard thing to see your baby sick and need to be taken away from you"
 "We didn't even get to hold him or really give him love"

TABLE 5. Parents' Suggestions to Decrease Their Emotional Distress

"Nothing really, just being here is stressful"
 "Being able to be with or see our child during transport"
 "Me being able to stay with my baby at all times, even through transport"
 "Being able to go with her"
 "If I was allowed to ride in the transport with my baby and my husband—I understand from a logistical standpoint, but being separated from my baby for such a length of time was and is the most stressful part of the ordeal for me"
 "Let us ride along with him"
 "Let a parent come, whether mother or father"
 "I felt that my son's mom should have been able to be with him so she felt safer and so she knew what was going on"
 "To be transported with my baby and be with him every step of the way"
 "If I could have gone with him, so that I'd feel more comfortable—I felt like he needed his mother and father to be with him at all times"

For mothers, the biggest barrier to being reunited with their infants was their own health ($n = 9$; 56%), particularly if they were recovering from a cesarean birth. The average length of time before the parent was reunited with his or her infant was 16.75 hours (± 17 hours; range, 2-72 hours). When mothers could be discharged from the birth hospital, most parents were reunited with their infants within a few hours. One set of parents cited health insurance as a barrier to their being reunited with their infants. In this instance, the mother could not be transferred to the tertiary facility until approved by the family's insurance company. The family was reunited with their infant approximately 16 hours after the neonatal transport.

Parents were appreciative of all the information the transport team provided. The information they found most helpful was about specific care the team would provide to the infant ($n = 13$; 48%) and the reassurance the team would provide the best possible care ($n = 4$; 15%). Seventy percent of parents ($n = 19$) reported also receiving information about their infants from the team at the referring facility, family members who had gone to the tertiary facility, the team at the tertiary facility, or by going to the neonatal unit themselves.

Parents were asked whether there was something they could identify that might help decrease the stress of having their infants transported. Several

expressed being separated from their infants as highly stressful and the most common parental recommendation ($n = 11$; 41%) was the suggestion that a parent be able to accompany the infant on the transport to the tertiary facility (Table 5). One parent indicated that the calm and caring attitude of the team was helpful in decreasing stress. Once they were reunited with their infants, it was beneficial for parents to see members of the transport team still caring for their infants ($n = 3$; 11%). One set of parents expressed dismay that they learned their infants were going to be transported at almost the same time the transport team arrived; they felt that their stress would have been decreased if they had more time to process the information.

DISCUSSION

This project sought to evaluate the current transport process and identify parental needs during an acute neonatal transport. It revealed several areas in the current transport process that could be improved on. The video, *Welcome to the ICN*, displaying a virtual tour of the neonatal unit is available at each referring hospital, yet none of the parents indicated that they had the opportunity to view it. If this tool is to benefit parents, a better understanding of how and when to make it available to parents is needed. It is possible that when an infant needs to be acutely

transported, the referring team is so involved in caring for the infant that they do not remember to offer the video to the family.

The parental responses also highlight the need to gain an improved understanding of the healthcare providers' beliefs around the early initiation of breast milk feedings. Only 7 mothers in our sample reported that they were given an opportunity to provide colostrum or breast milk for their baby before the transport team departed. The American Academy of Pediatrics is supportive of breastfeeding as a method for improving the long- and short-term outcomes of infants,⁴⁸ and a major goal of this neonatal unit is to support breastfeeding for all mothers who are willing and physically able to breastfeed. In an effort to support this goal, a function of the transport team is to encourage the team at referring hospitals to have mothers express some colostrum or breast milk prior to the transport team leaving with their infants.

Only 37% of parents indicated a positive response toward the question about the role of parents and families in this neonatal unit. The unit philosophy is "We believe the parent and child relationship is essential. We believe in providing a nurturing environment where the child is part of the family and the family is part of the care team." As such, we strive to orient parents to their role as an integral part of the team and active participant in their infant's care. If the transport team is practicing according to the concepts of FCC and the unit philosophy, parents should receive this orientation during the transport process.

It is somewhat concerning that only 63% of parents recall receiving a copy of the parent packet and 67% indicated that they had received a phone call from the transport team that their infants had safely arrived in the tertiary unit. The parent packet was developed to provide information to the family about the neonatal unit and includes important information such as the telephone number to the unit. A phone call back to the parents and to the referring team is also an expected function of the transport team. As indicated both in the literature^{27,39,48} and from responses to this survey, these communications are important to parents and efforts need to be made to ensure compliance.

The open-ended questions supported literature-based recommendations that having an infant acutely transported can cause distress in parents. Furthermore, parents identified concerns about the need for acute transport as well as the need to receive information about their infant and the care he or she was to receive. Written comments from the parents indicated the need for information and communication but were not specific about the type of information they need.

The literature also identifies separation as an important issue for parents when an infant is acutely

transported.^{28,29,40,42-46} The responses to the questionnaire suggest that allowing a parent or support person accompany the infant on transport may decrease the impact of the separation and possibly decrease parental distress. The feasibility of implementing this practice change warrants further exploration.

The parental responses were dependent upon their recollections at the time they were approached to participate. It is possible that they could not remember all of the communication and information the transport team provided and this could impact the results of the survey.

The gestational age of the infants belonging to this sample of parent participants was older than anticipated. However, during the period of this project, the average gestational age of a transported infant was 36 weeks and 4 days (± 4 weeks and 1 day; range 23 and 6 days–41 weeks and 6 days). This may be related to the practice of transporting mothers of extremely premature or low-birth-weight infants to the tertiary facility for delivery, preempting the need for neonatal transport. In addition, parents of gravely ill infants were not approached to participate out of respect for their privacy and to ensure minimal intrusions into the time they had with their infants.

IMPLICATIONS FOR PRACTICE

Findings from this project revealed specific opportunities for improvements in acute neonatal transport. The *Welcome to the ICN* video has now been uploaded to the tertiary center's Web site⁴⁹ and providing each parent with the link to the site will allow them the opportunity to gain knowledge of the neonatal unit before being reunited with their infant. Findings also demonstrated a need to reeducate the referring facilities and the transport team about the importance of early initiation of breast milk. A joint effort to encourage mothers to provide breast milk or colostrum for the infant could improve the overall outcomes of these infants, as well as encourage active participation of parents in their infants' care.

The process of affirming with parents their importance as a member of the healthcare team needs further exploration. Given the time constraints of the transport team, a brief explanation by the team and some written material in the Parent Packet may be within the realm of possibility to engage parents. This would provide the introduction to FCC that is so important to neonatal care.

Parents completing this questionnaire expressed distress to be separated from their infants. Several parents offered the suggestion that they be able to accompany their infants, thus minimizing separation. Currently a project is under way to develop a guideline that would facilitate a parent, or designated

support person, to accompany the infants to the tertiary facility.

The results of this quality improvement activity reinforce the importance of practicing the core concepts of FCC during the acute transport of an infant. Integrating FCC into the transport process requires a team that is educated about and dedicated toward practicing the concepts of FCC. An important component of FCC is acknowledging the importance of the parent role as partners in care, even within the constraints of the transport process.

Limitations

This project was conducted in a single unit and included only a small sample of parents, thus limiting the ability to draw conclusions or generalize the findings. Parents invited to participate in this project were recruited through purposeful sampling, and not all parents whose infants were transported were asked to participate.

Directions for Further Study

Although all of the parents approached about completing the questionnaire were eager to discuss their transport experience, only 54% of the questionnaires were returned. Other proven methods for obtaining parent perspectives such as individual or group interviews may reveal more specific details about parents' needs during the transport process.

Our small sample included parents of infants who were 33 weeks' gestation or older only. Parents of extremely premature infants whose hospital stay is generally anticipated to be much longer may also have different needs at the time of transport. Parents whose infants are gravely ill could offer valuable insights and should be included in future studies. In a larger sample, it would be interesting to analyze the responses of mothers and fathers separately to assess for differences in communication and information needs.

Interviewing the transport team about what information they routinely provide to parents could be very enlightening and lead to further dialogue about parent participation on transport. The evaluation of information the referring facility provides to parents and how they encourage family involvement could also reveal important information.

CONCLUSION

The integration of FCC core concepts during an acute neonatal transport is important to parents and can help facilitate communication and may possibly reduce parental distress. Investigations that measure and test interventions for reducing parental stress, at the time of transport, are needed to gain a fuller understanding of parental needs.

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