Improving Parental Satisfaction in Transition to Home from the NICU:

A Quality Improvement Project

by

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Abstract

Bringing an infant home from the NICU can mean caring for a baby with multiple health care needs, or minimally, feeding and growth issues. The infant may require a regimented feeding schedule, medication administration, an apnea monitor, a feeding tube, home oxygen, and multiple follow-up appointments; not to mention potential lifelong complications. This situation may also be coupled with parental fears, lack of preparedness for discharge, increased readmission to the hospital, and decreased satisfaction with the discharge process from the NICU. The purpose of this quality improvement project was to conduct a needs assessment of newly discharged parents from the NICU to ascertain their perceived needs leading up to and upon discharge from the NICU.

A non-experimental, descriptive, exploratory study was completed using a researcher-developed questionnaire. Convenience sampling at a Level III NICU was used to gather data. Each parental response indicated that education regarding their infant was initiated within the first week after admission although the majority of discharge education was received just prior to discharge. Discharge information was consistent and most patients were discharged with prescription medications. Lack of communication, disorganization, and delay in discharge procedures was evident.

The study reiterated the importance of initiating discharge education upon admission and continuing throughout the hospital stay. This will allow for a decrease in the amount of education received on the day of discharge and increase the parental preparedness in caring for the infant once at home. Improved communication and a discharge-planning tool may be utilized to create a smoother discharge process.
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According to the March of Dimes (2011), each year an estimated 500,000 infants are born prematurely in the United States. Most of these babies are admitted to a Neonatal Intensive Care Unit (NICU), requiring care for days, weeks, or months. The complications a premature infant can face are plentiful, often life threatening and can potentially create a lifetime of challenges. The March of Dimes (2011) stated the cost of prematurity on society is approximately $26 billion per year, not only creating a strain on the economy but also a strain on the family unit.

Admission of a newborn to the NICU can create a stressful situation for parents due to the uncertain future of the child. The stress created during the hospitalization is caused by many variables; the lack of knowledge regarding the child’s outcome, increased costs associated with hospitalization, separation of the family, and decreased bonding opportunities between the parent and child. Another stressful situation can be the transition to home after discharge.

Bringing an infant home from the NICU can mean caring for a baby with multiple health care needs, or minimally, feeding and growth issues. The infant may require a regimented feeding schedule, medication administration, an apnea monitor, a feeding tube, home oxygen, and multiple follow-up appointments; not to mention potential lifelong complications. Many of the previously listed scenarios related to the transition to home are unfamiliar or uncomfortable for parents and present a situation that frightens many parents. During this transition to home, many parents face unanswered questions or problems and become dissatisfied with the management of the discharge provided by their child’s health care team. This was shown in the patient satisfaction scores at the Level III NICU where this quality improvement project is took
place. The parents who fill out these surveys after discharge were dissatisfied with the discharge process.

On evaluation by the NICU staff, the cause of parental dissatisfaction may be the result of the parents being unprepared at discharge or their lack of involvement in the discharge process. The questions or problems previously raised by parents of NICU graduates while still hospitalized have included feeding, sleeping, interactive play, signs and symptoms of illness, community programs, and immunizations. These questions or problems are reasons a parent may seek advice from healthcare providers in the form of office visits, telephone calls or emergency room visits. Office visits and readmissions to the hospital are costly and also cause unnecessary strain on the caregiver, the economy, healthcare providers, and insurance companies. The rate of readmission for infants born near term is significantly lower than infants born extremely premature or infants with chronic health care needs. Seki et al. (2011) found readmission within one year after NICU discharge to vary based on the gestational age at birth. Infants born between 22-25 weeks gestation had a readmission rate of almost 27% and for infants born 26-34 weeks gestation 7.4% were readmitted (Seki, et. al 2011). The negative effects of readmission may be prevented by proper discharge planning and follow-up care.

In the NICU, advanced practice nurses impact the outcome of the patient by the direct care they provide and also by educating the parents. The education provided to parents allows for safe care of the infant once they are discharged from the NICU. Advanced practice nurses are an integral part of the healthcare system. The neonatal nurse practitioner (NNP) is specifically trained to care for infants with complex medical conditions. The delivery of a high-risk neonate is often attended by a NNP, which allows the advanced practice nurse to see the patient from delivery to discharge. Because the NNP follows the patient from delivery to discharge, the NNP
has many interactions with the child’s parents. These interactions can leave many impressions on the families regarding their NICU stay. The NNP can encourage family-centered care and parental involvement in caring for their child, increasing the parent’s feeling of competence.

Decreased parental satisfaction with home transition management may affect the parent’s ability to care for their infant safely as well as to feel competent in the care they provide. The purpose of this quality improvement project was to conduct a needs assessment of newly discharged parents from the NICU to ascertain their perceived needs leading up to and upon discharge from the NICU. This needs assessment will then serve as a baseline to make recommendations for further follow-up and improvement in the transition to home process to improve parent satisfaction.

**Literature Review**

After evaluation of the literature regarding parent satisfaction in the NICU, several key factors have been reported. Anderson, Barbara, and Feldman (2007) suggested parents valued follow-up after discharge, because this practice demonstrated that providers cared about the health status of their infant. Parents valued receiving post-discharge interaction with staff members, and staff stressed the importance of compliance with discharge instructions and follow-up appointments. Nehra, Pici, Visintainer, and Kase (2009) determined that contact with family following discharge increased attendance at follow-up visits. Other factors that increase parent satisfaction in the NICU are practicing family-centered care, providing education, and including parents in the discharge process.

A limited number of studies have been done to assess parental satisfaction with preparation for discharge from the NICU. The common themes noted in the literature on preparing for discharge were 1) discharge teaching, 2) transition to home, and 3) follow-up after
discharge. As stated previously, the purpose of this quality improvement project was to improve parental satisfaction with transition to home management by conducting a needs assessment of newly discharged parents from the NICU.

**Discharge Planning**

Discharge from the NICU can be an exciting yet stressful time for the parents. The stress surrounding discharge can be magnified if parents perceive they are not prepared for discharge. In reviewing articles related to discharge from the NICU, the process of discharge planning should begin at admission or once the patient is known to survive (Sneath, 2009; Mills, Sims & Jacob, 2006). Discharge planning includes assessing parental and infant needs at home and providing education to the parents on how to care for their infant. The education provided can be basic such as taking a temperature, changing a diaper or more extensive care needs such as feeding regimens, medication administration, oxygen use, or apnea monitor use. Early implementation of discharge education allows parents to gain confidence in caring for their child and may reduce anxiety at the time of discharge. Discharge planning allows health care staff to complete a learning needs assessment of the parents. A common theme within the research was the utilization of a discharge-planning tool that emphasized education and approved materials (Mills, et. al 2006). In order for the planning tool to be effective, health care staff should ensure parents understand the material before documentation of discharge education. The checklist enables staff to ensure appropriate information has been discussed with the parents. Notable differences between research articles were the discussion of staff and parent satisfaction tools utilized in the NICU, integration of parents as part of discharge planning, and documentation of discharge education (Sneath, 2009; Mills et al., 2006).
**Transition to Home**

Transition to home after days, weeks, or months in the NICU can be challenging for parents. The transition to home is often coupled with a medically-complex child to care for and adjustment for the family as a whole. A smooth transition to home can be accomplished by properly preparing the parents for discharge. Proper preparation for discharge can include integrating the family to provide care during hospitalization and, when discharge is imminent, allowing for a “rooming in” experience (Griffin & Abraham, 2006). “Rooming in” is when the family stays overnight in the NICU to provide all care to their child with professional help readily available if necessary; this also allows the nurse to assess the parent’s readiness for discharge.

Integrating family-centered care into nursing practice in the NICU can influence the discharge process. Parental involvement during the hospital stay is not only beneficial at discharge, but it is also beneficial in bond formation between the family and their child and in the transition process to a new healthcare provider after discharge (Moyer, Singh, Finkel, Giardino, 2010). Moyer, et al (2011) discussed the importance of communication between NICU care providers and primary care pediatricians to decrease the risk of complications for the NICU graduate after discharge and ease the transition to home.

**Follow-up After Discharge**

As described previously, discharge from the NICU is often a scary experience for parents. A unique follow-up program after NICU discharge called Parenting Preemies was started at the San Antonio Community Hospital. Willis (2008) described the function of the Parenting Preemies program to assist with transition to home by providing support through home visits, telephone calls and group meetings. The follow-up is tailored to meet the needs of each
parent individually. The Parenting Preemies support group is open to all NICU admits; this support group includes meeting ten times weekly where parental support is provided by discussing various topics of interest with multidisciplinary group members (Willis, 2008). As part of the meetings, lunch is provided and the topics discussed include: program description, introductions, infant behaviors, developmental follow-up, feeding and nutrition, advocating for their child, family night, infant massage, exercise after birth, interaction with their child, and a summary (Willis, 2008). The Parenting Preemies follow-up program is funded by the hospital at no charge to the parents, and eligibility for individualized home visits is based on specific criteria (Willis, 2008).

Telephone calls after discharge have been utilized to decrease parental anxiety with caring for their child and to improve parental satisfaction. A common theme of the literature was that follow-up after discharge was influential in the developmental outcome of the patient, parental support, parent education, and the assessment of community resources (Willis, 2008; Pattison, Dolan, Townsend & Townsend, 2007; Moscato et al, 2007).

Conclusion

In conclusion, a thorough amount of research is found on discharge teaching and its influence on parent satisfaction surveys. If a parent is properly educated prior to discharge a smooth transition to home is more likely to occur. The smooth transition can also influence the satisfaction of the parent; an additional factor of parent satisfaction is proper follow-up care and support. A gap in the knowledge of research was indicated by the lack of studies regarding telephone follow-up after discharge from the NICU. This quality improvement project described the perceived parental needs before and after discharge to evaluate the need for implementation of a new process for discharge planning in this NICU.
Theoretical Framework

In reviewing the literature and analyzing the proposed scholarly project concept, the middle range theory of resilience was decided upon. The middle range theory of resilience is described as optimistic modification and adaptation of one’s experiences or perception in the presence of difficulties (Haase, 2009). In 2009, Haase described fundamental qualities of positive outcomes despite adverse conditions that persist when defining resilience.

The proposed scholarly project of improving patient satisfaction in the NICU relates to the middle range theory of resilience. The relationship between the two is declared when a parent accepts their child with complex medical needs or demands at discharge (adverse condition) with a positive outlook. The parents adjust their life to caring for this infant after discharge and adapt to life with a “new normal” filled with medical visits or equipment and most likely challenges in the future. The perception of preparedness, ease of adjustment and confidence in providing care for a medically complex child is influenced by discharge education and support from health care workers, family and friends. Haase (2009) reviewed nursing literature on resilience by McCubbin & McCubbin as illness affecting a family member and the family’s response to this illness; the influence of an optimistic attitude and the family’s capacity to adapt under stress while preserving the wellness of each member and group as a entirety. The variables influencing resilience were the family’s ability to restructure and to obtain support from numerous individuals (Haase, 2009). The variables influencing patient satisfaction in the NICU are support from health care workers as well as the family’s preparedness to care for their child.

An example of resilience is the adolescent resilience model (ARM) with the following influencing factors: individual protective, family protective, social protective, individual risk, illness-related risk, and resilience (Haase, 2009). Each of these variables is interrelated.
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proposed project, the individual protective factor is specific to each parent and influenced by their past experiences and coping mechanisms. The family protective factor is influenced by the family’s ability to adjust, work together and effectively communicate. The social protective factor is influenced by support received from the health care team and friends and community when caring for a medically complex child. The individual risk factor is described by protective coping. The illness-related risk factor in caring for a medically complex child is the unknown future and special needs associated with the medical condition. The resilience factor is family’s confidence in caring for their child, adjusting to the “new” normal and finding positives in their journey.

Methodology

Design

A non-experimental, descriptive exploratory study was utilized in the first step of this quality improvement project. The project assessed the needs of newly discharged parents from the NICU with transition to home care. After the needs assessment was completed, a plan will be implemented to improve parent satisfaction with the NICU’s discharge process.

Sample

Twenty-four infants were eligible for the study. Eighteen of the twenty-four eligible infants parents’ responded to the survey, creating a response rate of 75%. The average gestational age at birth of the study participants was 34 6/7 weeks gestation. The average gestational age at discharge of the study participants was 41 6/7 weeks gestation. The average length of hospital stay was 48 days. All of the eligible study participants were discharged from the same level III NICU. None of the study participants were discharged on home apnea
monitors. All of the study participants were discharged to their mothers with extended family involved. Sixty-seven percent of the study participants were discharged home on medications.

Parents of newly discharged infants from the NICU were the target population. The participants were chosen by convenience sampling after discharge from the NICU. The target sample was fifteen participants. The sample did not exclude participants due to gender, ethnic background, diagnosis, length of hospital stay, or hospital course (Burns & Grove, 2009). The inclusion criteria of the sample included: (1) previously hospitalized child in the NICU who was recently discharged from the NICU, (2) English speaking, (3) parent is over 18 years of age (Minnesota residents), and (4) parent was accessible by telephone, and (5) parent was willing to answer the needs assessment questions by phone. Demographic information recorded on discharge included gestational age at birth and at discharge, main diagnosis, and medications on discharge if known (Appendix A). No identifiable information was collected. On discharge, the demographic sheet will be filled out by the RN in the NICU and given to the student project coordinators. Only the student coordinators will be collecting the information and making the phone calls. All data sheets will be secured in the NNP office. The phone numbers and mothers’ first name will be taken off the final data collection sheet after the phone calls are made. No identifying information about the infants will be recorded and all parent answers will be reported as grouped data.

Setting

A 30-bed level III NICU at St. Mary’s Hospital in Rochester, MN was used to conduct this study and collect data.
**Ethical Considerations**

Initial approval from the neonatologist and NICU nurse managers was given. After approval from the Mayo Clinic and Creighton University’s Institutional Review Boards (IRB) the project was conducted.

**Measurement Methods**

The needs assessment tool was a researcher-developed tool with 12 open-ended questions asking the parent questions about their discharge from the NICU and initial home experience (Appendix B). The questions were based on problems identified with the current discharge process from the parental satisfaction surveys. The tool was developed by the researcher to be specific for the information needed to assess the discharge planning process. Further parental comments were recorded on the last two questions.

**Data Collection**

The eligible study participants were identified as being recently discharged from the NICU between November 2011 and February 2012. All data was collected between January to March of 2012. Telephone contact was made to each of the eligible participants; explanation of the purpose of the telephone call was then discussed with the parents. The study participants/parents were informed of their rights prior to participating in the phone survey and verbal approval to collect the information was obtained from each mother upon starting the phone interview. The data collected was recorded onto a data sheet for this study with all identifying information removed.

**Data Analysis**

A descriptive analysis of each question was completed. Common themes were described.
Results

Each parental response indicated that education regarding care of their infant was initiated within the first week after admission. Based on the responses to the questionnaire; 50% of discharge education was received within two days of discharge. The majority of information regarding discharge and caring for the child was consistent throughout the hospital stay. Sixty-seven percent of the patient’s discharged went home on medications in which all parents verbalized understanding of the drug indication, dosage and administration method.

Preparedness was indicated by parental responses, although nerves and apprehension were mentioned several times. All parents appropriately stated whom to call with questions or concerns regarding their child. Lack of communication, disorganization, and dismissal procedures (hearing screen, car seat trial, prescription medications, and immunizations) was evident in the parental responses as an area of improvement in the overall discharge process. Once discharged from the NICU, the biggest challenge parents identified was adjusting and attending to the infant’s needs.

Discussion

As evidenced by the stress and anxiety several families feel prior to discharge, our study reiterated the importance of initiating discharge education upon admission and continuing the process throughout discharge. This approach to education will provide continuing education throughout one’s hospital stay rather than an increased amount prior to discharge when parents anxiety and stress levels are increased due to the transition they are about to endure. Family centered care, continuing education, and inclusion in the discharge process is essential for parents to gain confidence in caring for their child and to reduce anxiety experienced at the time of discharge. Utilization of a discharge planning tool emphasizing education and communication
can successfully prepare and educate parents for discharge care. Thorough education beginning at admission and continuing through discharge, proper follow-up care, and support by all health care providers involved enhances parental satisfaction easing the discharge process and transition to home.

In this study, we reviewed parental satisfaction with NICU patients in the transition to home and our outcomes revealed that collaboration, communication, and education beginning upon admission and continuing until discharge made the greatest contribution to parental satisfaction. An enhanced understanding of the knowledge and experiences that are associated with parental satisfaction and evaluations of child well being prior to discharge may aid parental discharge education in the NICU ensuring a well-organized transition to home for parents and health care professionals.

**Implication for Clinical Practice**

Given the responses received from the parental questionnaire, the overall discharge process needs improvement to meet the needs of the parent and infant. The discharge process appeared to be unorganized as demonstrated by this parent’s response, “My child didn’t get his Hepatitis B until 10 minutes prior to discharge, received his car seat trial on dismissal day and never had a hearing screen.” Due to this comment it would be optimal to have a discharge planning guideline in place to implement the discharge process/procedures in a timely manner. It is also evident that education regarding transition to home should be completed more than two days prior to discharge allowing the parent to feel more knowledgeable and prepared for caring for their child. In addition, a lack of communication amongst care providers was evidenced by the parental comment, “Would like more communication concerning discharge and education of process to better inform family members is necessary.” Parental responses indicate that
receiving the discharge summary and dismissal medication prescriptions earlier in the discharge process allows them to prepare and creates an efficient transition to home, all while facilitating effective communication among health care providers.

**Conclusion**

This needs assessment of parent experiences with the discharge process in the NICU was the first step in a quality improvement project. There is a need to improve the patient satisfaction scores at this institution. This needs assessment was the best method to explore the reasons for the dissatisfaction with the process, and assist in determining the best way to improve the discharge process of the infants in the NICU. In reviewing the parental responses; improvement is needed in the educational process, a discharge planning tool and coordination of care with all parties involved is necessary to improve parental satisfaction with transition to home from the NICU.
References


Appendix A

Needs Assessment: Demographic Questions

1. Mother’s First Name Only ________________ Over 18: YES / NO

2. Mother’s Phone Number ________________ (home) ________________ (cell)

3. Mom Speaks English: YES / NO

4. Mother Agreed to Phone Call: YES / NO / Not ASKED

5. Gestational Age of Infant at Birth___________________

6. Age of Infant at Discharge ________________________

7. Corrected GA at Discharge ________________________

8. Major Diagnoses at Discharge

   ____________________________________________

   ____________________________________________

   ____________________________________________

9. Discharge Medications:

   ____________________________________________

   ____________________________________________

   ____________________________________________

10. Home Apnea Monitor: YES / NO

Parents/Support:

11. Was infant discharge to mother? YES / NO

12. Is Dad involved? YES / NO

13. Is extended family (eg. grandparents) involved? YES / NO
Appendix B

Needs Assessment Tool: Survey Questions

14. When did you start receiving information about caring for your baby?

15. Was the majority of your discharge education provided within 2 days of going home? YES/NO

16. Did you receive **consistent** or **inconsistent** information regarding discharge and caring for your child? YES/NO

17. Did your child go home on any medications? YES/NO
   - Do you know what the medication is for?
   - Do you know how to administer it?

18. Did you feel prepared to take care of your child at home?

19. Did you know who to contact if you had a question about your child?

20. Was there anything regarding the actual discharge process (in the hospital) that would have made the transition to home easier? What are your recommendations?
    COMMENTS:

21. Once you were home, was there anything that would have made the transition to home care easier?
    COMMENTS:

22. What was the biggest challenge you identified regarding caring for your infant once you were home?
    COMMENTS: