
NICU-2-HOME: Supporting the Transition to Home from the Neonatal Intensive Care Unit

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Abstract

Transitioning a Very Low Birth Weight (VLBW) premature infant from the Neonatal Intensive Care Unit (NICU) to home is stressful for parents. Few studies, however, examined the needs of parents of VLBW infants during the transition from the clinical setting of the NICU to the non-clinical home setting. Moreover, even less is known about information and communication technology strategies to support parents during the transition period. To address this knowledge gap, we are conducting a study that aims to develop a mobile application to support the parents of VLBW infants during this vulnerable period. We present preliminary findings from our on-going research involving 25 mothers and fathers of VLBW NICU infants transitioning home.

Keywords

Neonatal Intensive Care Unit, VLBW Infants, Pediatrics, Mobile Application, Healthcare, Transition

Introduction

Very Low Birth Weight (VLBW) infants are born prematurely and weigh <1500 grams and are among the most medically vulnerable NICU patients [1]. VLBW infants are medically fragile, requiring more medical attention and care than other newborns. With their

baby's admission to the NICU, parents of VLBW infants undergo stressful and terrifying experiences. Parents must quickly adjust from the dream that they had for their baby's birth to the new reality of a NICU admission and stay. Parents are often intimidated by the unfamiliar intensive care setting that includes various medical instruments, intravenous equipment, procedures, and hospital personnel and jargon. However, transitioning to home with a high-risk infant can be even more stressful as many VLBW infants are discharged from the hospital with special health care needs, including home oxygen and monitoring, gastrostomy tube feeds, and several medications requiring multiple daily doses. At the end of an infant's NICU stay, parents are expected to assume full responsibility for the VLBW child, monitoring the infant for changes in health and upholding feeding, medication, follow-up appointments, and outpatient treatment regimes. For these reasons, parents of VLBW infants are often apprehensive when they face discharge from the NICU, feeling ill-prepared, uninformed, and unskilled to provide a myriad of health care tasks by themselves at home.

To address this problem, we are conducting an NIH-funded study to assess VLBW parents' information and communication needs during the transition to home and to develop technology interventions to improve parental self-efficacy in caring for their medically vulnerable infants. A few previous studies examined technology solutions to support NICU parents (e.g., Baby CareLink), but they focused on a discrete part of the transition process (e.g., the hospitalization period or the postdischarge period), lacking a focus on their varying needs during the transition period from the

intensive clinical setting to non-clinical home setting [2,3].

As part of this on-going project, we conducted semi-structured interviews with twenty-five parents of VLBW babies to identify specific concerns/challenges that they faced at key time points during the transition to home. The key time points include 1) two weeks prior to NICU discharge, 2) the first 1-3 days after discharge at home, and 3) 1-3 weeks after discharge. We present preliminary findings from this study to highlight their evolving information and communication needs while transitioning from the NICU to home and identify potential areas of support or for intervention.

User study

Semi-structured phone interviews were conducted with twenty-five parents (15 mothers, 10 fathers) of 16 VLBW babies who had an average gestational age of 29.5 weeks and a NICU stay of >2 months. Parents were selected in a convenience sampling from a Chicago-area hospital and their average age was 31 years; 68% were White, 20 % Hispanic and 12% Black. Parents were asked to discuss their concerns and technology use leading up to discharge, days 1-3 at home and the first few weeks at home. All interviews were transcribed verbatim and analyzed by a multi-disciplinary team using narrative analysis to identify emerging themes. Several major themes arose along with three key time points, and we summarized them below as preliminary findings.

Two weeks prior to NICU discharge

Nearly all surviving VLBW infants spend more than 2-3 months in the NICU before being discharged to home at the 37th gestation week. For a typical VLBW infant, a

sentinel event occurs two weeks before discharge when the infant is transferred from an incubator to an open crib, and discharge preparations begin in earnest with their parents. In addition to general care of infants, typical discharge preparations for families include identification of post discharge needs, teaching general home care of the infant, as well as specialized care for specific disorders of prematurity, documentation of teaching, coordination of outpatient supplies and medications, and referrals to appropriate follow up specialty services. As parents need to gain confidence as well as develop expert knowledge in home care, the NICU staff encourages greater parents' participation and practice during the discharge process.

Despite efforts by the NICU staff, parents' information and communication needs are not always met, and parents often feel unprepared for discharge and desire more information and communication than is provided to them. For example, the NICU in this study classified the discharge preparations into a 30 item to-do-list. This to-do-list was presented in a "discharge checklist" to document parents' mastery of necessary skills and information acquisition prior to discharge. The checklist, however, includes only the titles of the items in medical jargon (e.g. PKU, ABR/BSAER) and lacks descriptions. The checklist served as a useful visual map for both nurses and parents to check their progress on the discharge preparation. However, we found that parents were not routinely introduced to the checklist and lacked understanding of each item of the checklist or of the discharge process overall.

Parents do receive a great deal of information during the transition period. Physicians routinely explain baby's medical conditions and possible treatment to

parents while nurses provide various teaching of everyday care-giving tasks. Unfortunately, such in-person explanations are not available to meet all parents' information needs (e.g., working parents), nor are they as readily accessible or retrievable. Currently, educational materials are rarely tailored to a specific baby's condition or the parents' health literacy. In addition, the traditional paper-based information packet also makes dynamic delivery or quick information search difficult. Finally, parents, especially fathers, tend to try and continue working in order to save their family leave or vacation days for when the infant finally comes home. Therefore, parents are not typically standing vigil at the bedside as the VLBW infant's stay lengthens.

Parents of VLBW infants use various forms of information technology (IT) including computers and smart phones, and their IT usage pattern varies over the transition time. When their infants are in the NICU, all parents used computers or smartphones to 1) gather information related to their baby's health, 2) communicate with NICU staff, and 3) update family/friends about infant's development. To better understand their infants' illness, parents often started their information search using a commercial search engine like Google, and retrieved health information from non-professional pediatric websites, such as personal blogs, more frequently than professional websites such as WebMD, which raises concerns regarding trustworthiness and accuracy of the information obtained. Parents also placed value on keeping friends and family updated on their infant's progress and spent significant time in updating them about their infant's development. Many of them used free patient blog websites such as CarePages.com to

connect friends and family during the hospital stay. They felt updating family/friends is a very necessary but time-consuming task, and they appreciated the convenience of using such patient blog sites compared to using emails.

A few days after discharge

Once home, concerns shift to being task-based, such as “how-to” care for their premature infant. Since this is the first time parents do all the tasks without support from the NICU staff, they frequently feel unprepared and desire more information and communication than before. In addition, the change in environment and care routine caused various additional clinical issues such as abnormal sleep or eating to arise. Additionally, rashes and other acute illnesses occurred that parents were not prepared for in advance. Parents often called the primary nurse at NICU to ask for help instead of the community pediatricians because the higher trust level was present in the existing NICU clinical relationship compared with the nascent community pediatrician.

Parents’ IT usage for communication purpose decreases significantly at this time as they are heavily occupied with providing moment-to-moment care for their infant. The decreased IT use resulted in frequent disconnections with the key social support systems of family and friends. Instead, parents became more engaged with maintaining home documentation of care. Most parents were found to diligently collect infant care information at home often with the help of IT (e.g., excel sheet, smart phone applications). Some parents maintained an extensive care diary to document feeding, bowel movements, medication administration, weight, height, illness symptoms, etc. However, these detailed data records maintained by parents were

rarely shared with the community pediatricians, indicating a potential technology development opportunity linking home with the medical home.

A few weeks after discharge

Finally, as days turned to weeks, parents became more experienced with providing care and spent more time consuming health information specific to their infant’s health condition. By this time, parents were disconnected with the NICU staff and completed a new connection with the community pediatricians. Parents’ IT usage increased compared to the previous time frame, and they often resumed gathering health information using the Internet. However, we found that a number of parents gathered information from websites as opposed to asking clinicians, indicating some level of disconnection between parents and pediatricians compared to the level between parents and NICU staffs, and again brought up issues of validity and accuracy in the information obtained.

Discussion

Parents of VLBW NICU graduates describe evolving concerns and information and communication needs during the transition time period from the most intensive clinical NICU setting to the non-clinical setting of home. We believe many of these concerns can be addressed with improved technology support regarding healthcare information research, supporting care of their infant, and remaining connected with their support systems. Major challenges remain in development of such technology to address these needs as they evolve in real-time and in the context of serious time-sensitive constraints during the transition to home.

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