Theory-driven implications for improving Self-Efficacy and Mental Well-being of Parents of VLBW Infants

Abstract
Transitioning a Very Low Birth Weight (VLBW) premature infant from the Neonatal Intensive Care Unit (NICU) to home is stressful for parents. In this paper, we use Bandura’s Self-Efficacy Theory as a framework to investigate ways to increase parental self-efficacy in caring for their medically vulnerable infants, ultimately resulting in improved parent’s emotional well-being. This theory posits that parenting behavior and the quality of care can be improved by supporting the four major sources of self-efficacy: mastery experiences, vicarious experiences, social persuasion, and psychological responses. Based on findings from our past research activities such as rapid contextual inquiry at NICU, interviews with parents and NICU staff, we report the importance of providing emotional and social support for NICU parents to improve their parenting confidence and mental well-being. We also describe how technology can play a critical role in obtaining these goals.

Keywords
Neonatal Intensive Care Unit, VLBW Infants, Pediatrics, Self-efficacy Mobile Application, Healthcare, Transition
Introduction

Premature births now occur in more than 12 percent of pregnancies in the United States, a 36% increase since the early 1980s [1]. VLBW infants are born prematurely and weigh <1500 grams and are among the most medically vulnerable NICU patients. VLBW infants are medically fragile in the NICU, typically are discharged home after 2-3 months, and 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 NICU with special health care needs, including home oxygen and monitoring, gastrostomy tube feeds, and several medications requiring multiple daily doses. Parents take full responsibility for the VLBW child, monitoring the infant for changes in health and upholding feeding, medication, follow-up appointments, and outpatient treatment regimes. In addition, parents must balance other household responsibilities along with caring for the NICU graduate, which becomes a source of anxiety and fear for parents.

The stress of caring for premature babies can threaten parental relationships, stability, and marital satisfaction. Stressful life events are strongly related to a decline in marital satisfaction. Few studies have examined the effect of child-related factors on marital satisfaction, but parents with children born premature or with a physical handicap report increased rates of marital distress and divorce. The quality of the parental relationship significantly affects the mental and physical development of children with special medical needs; thus, there is great benefit for the family, parents and child in addressing the strain on the parental relationship in order to empower parents and promote positive family coping and healthy child development.

To address this problem, we are conducting an NIH-funded research study that aims to develop technology interventions to improve parental self-efficacy in caring for their medically vulnerable infants, ultimately resulting in improved child health outcomes and parents’ well-being. A few existing studies examined technology solutions to support NICU parents [2,3], but they focused on a discrete part of the transition process (e.g., the hospitalization period or the postdischarge period) while lacking a theoretical foundation. Therefore, adopting Bandura’s self-efficacy theory as a framework, we have conducted multiple studies to build an in-depth understanding of the current discharge/transition practices, including a rapid contextual inquiry at NICU, interviews with 25 parents, focus groups with six neonatologists and five community pediatricians. In the present paper, we provide a brief overview of the self-efficacy theory highlight parents’ inherent needs, especially relevant to their social and emotional support, and summarize implications for technology needed to improve their self-efficacy and well-being.
Self-Efficacy Theory
Bandura [4] defined self-efficacy as an individual’s belief in his or her ability to succeed in a particular situation, and this belief determines how people think, behave, and feel. Thus, parental self-efficacy refers specifically to the individual’s perception concerning their capability to parent a child successfully. The self-efficacy theory posits that a strong sense of parental self-efficacy can be developed by supporting four unique resources: mastery experiences, vicarious experiences, social persuasion, and physiological states.

Results and Discussion

Mastery Experience
The theory posits that helping parents master specific skills creates successful experiences and builds the confidence to succeed. 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 the identification of post discharge needs, teaching general infant home care, 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. However, such an expanse of information is not always available to meet all parents’ information needs (e.g., working parents), nor is easily retrievable or accessible. 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.

Computer-based discharge modules including online learning modules, can be an important asset to encourage and support parents’ self-learning. Such systems would provide an easy access to tailored educational material that can be engaged on the parent’s schedule. For example, an interactive discharge checklist can be developed for cribside tablets or in-room kiosks to give parents anticipatory guidance on their learning or baby’s conditions and medical treatment. Another approach to an effective parent education could take interactive multimedia strategies delivered through video or electronic channels. A media-based education material repository can be built in the form of a web service that is accessible to parents any time - even in the postdischarge period - using various computing devices (e.g., smart phones, tablets, and PCs).

Vicarious Experience and Social Persuasion
The self-efficacy values increase by observing other parents successfully completing a task or receiving verbal encouragement from others. NICU parents seem especially interested in both real and digital vicarious experiences. They were highly interested in the “NICU parent support group” that would connect them to other parents whose infants already graduated from the NICU. Using such support group, parents expected to receive informational and emotional support from the perspective of “been there, done that” parents. We found most NICU parents used blog websites, such as caringbridge.org and carepages.com to seek vicarious
experiences while seeking social persuasion from parents in a similar condition. However, parents reported that most website information was at a general level and sought for blog sites that are specifically designed for NICU infants and parents.

We believe that online communities and social networking sites would be a great benefit for NICU parents in finding other parents in similar conditions and sharing verbal encouragement. It should also provide an easy way for the parents to add infant’s health updates, diagnoses, and photos to facilitate interaction between the members of the NICU parent support group. It is always a challenging task for NICU parents to record their experiences and share them with others in a timely and efficient manner because they typically carry a great amount of stress and anxiety and have limited time. A mobile phone application, such as mobile multimedia care diary, that allows parents to keep a record of nursing/care (e.g., feeding length, supplementation, bowel movements, wet diaper frequency) as well as infants’ developmental data (e.g., weight and height) could help smooth data capturing. Tools that support lightweight communication among the social support network, such as text/multimedia message, could make a considerable contribution to increase the frequency and reach of the social persuasion as well.

Physiological Responses
The self-efficacy theory suggests that parents can improve their confidence by being aware of their stress level and remedies to minimize stress or elevate their mood. Mobile technologies can help measure parents’ stress and provide remedies to alleviate the stress. For example, a validated stress assessment tool, such as the Parental Stressor Scale-Neonatal Intensive Care, can be conducted using mobile technologies, allowing parents to assess their stress level and receive proper consultations. Alternatively, wireless sensors including Galvanic Skin Response provide an opportunity for measuring the stress level as a valid biological marker. Lastly, mobile applications that teach deep breathing, relaxation, and meditation technique can be of tremendous help to NICU parents.

Discussion
We summarized the needs of parents of VLBW infants during the transition to home based on our research experiences in this domain and shared implications for technologies that would increase parents’ self-efficacy and mental well-being. These findings lay a foundation for designing strategies and technologies that empower and provide emotional and social support to this vulnerable population.

References