Using Experience-Based Co-Design Approach to Improve Communication between Mothers of Preterm Infants and NICU Staff

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Abstract

There is a growing interest in the Human-Computer Interaction (HCI) community to explore how technology can be used to support new mothers. However, little HCI research has been done to investigate the design of tools that can be used to support mothers of premature infants hospitalized in NICU, especially in the context of low-income mothers. Most mothers of premature infants are vulnerable to stress that is related to premature birth, which is often exacerbated by personal circumstances. To investigate how technological intervention can be used to support these mothers, we are using co-design approach, involving our participants (mothers and NICU staff) throughout the design process to ensure that the final prototype meets their needs. In this paper, we present our research work plan and initial findings from the interactions with NICU staff and mothers of premature infants.

Author Keywords

Premature infants; NICU; Stress; ICTs; Communication; Co-design; HCI.

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

Introduction

Preterm birth (less than 37 completed weeks of gestation) is a stressful event for most mothers since it is characterized by uncertainty and fear of child's possible outcome [1]. In addition, stress related to premature birth is aggravated by difficulty to initiate and sustain breastfeeding or breast milk supply, as they may not have fully developed hormonal and physiological mechanisms that promote lactation [10]. These mothers begin their experience of parenthood in unfamiliar and intimidating environment of the Neonatal Intensive Care Unit (NICU). Separation from the child is the most difficult aspect for most mothers and they may develop a sensation of being excluded, which is based upon feelings of despair, powerlessness and disappointment.

In developing world, most mothers would like to spend more time with their infants in the NICU and develop a mother/child attachment but they are often required to juggle between jobs, the care of older children, and other responsibilities for several weeks before their infants are strong enough to go home [7]. Furthermore, low-income mothers struggle with the cost of time and transport to visit and nurse their infants especially when care is provided in centralized tertiary care facilities and parents reside in outlying areas. While away from the NICU, these mothers rely on NICU staff to provide them with child's health status information [9]. However, NICU staffs are overwhelmed with NICU duties and they only communicate with the mothers when the child's condition is critical or when the mother has been away for a long time. It is evident that interventions to improve infant's overall wellbeing often take precedence over providing psychosocial support and care to mothers. There is communication barrier between NICU staff and mothers which is as a result of staffing resource constraints as well as changing staffing patterns in the NICU which creates an environment in which multiple care providers communicate with the mothers during the infant's hospitalization.

This is a Human-Computer Interaction (HCI) project being conducted in University of Cape Town Centre in Information and Communications Technology for Development (UCT4D)[1] at the Department of Computer Science. The overall objective of the proposed work is to understand how Information and Communication Technologies (ICTs) can be used to enhance communication between mothers and NICU staff to ensure mothers manage the stress related to premature birth. There is need for parental support interventions where educational and emotional aspects are simultaneously covered. New developments in ICTs are increasingly being proposed as technological enhancements to healthcare delivery. ICTs provide tools and knowledge that are needed to improve health care, enabling solutions that benefit patients as well as healthcare professionals [5]. We are using co-design approach to understand the challenges that mothers face while their infants are hospitalized in the NICU and thereafter collaborate with our participants (mothers of preterm infants and NICU staff) to design a technological intervention that can improve communication between mothers and NICU staff. We expect technological intervention will help the mothers to manage stress related to premature births.

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[1] http://ict4d.cs.uct.ac.za/

Background

This research is being conducted at Groote Schuur Hospital (GSH), a tertiary, government-funded, teaching hospital in the city of Cape Town, South Africa [2]. The hospital provides tertiary level neonatal intensive care, obstetric and antenatal services to women with pregnancy complications from the West Metropole of Cape Town. The 75-bed capacity neonatal unit admits approximately 2000 infants annually, majority of which are preterm infants and at least 500 with a birth weight less than 1500g. Most parents of these infants live in informal housing settlements on the periphery of the city where overcrowding, unemployment, and poverty are rife [15].

In this NICU, nurses work in 12 hours rotating shifts to ensure that the infants are fed, cleaned and provided with medication. Staff communication with mothers is mainly during ward rounds and when nurses are supporting mothers with Kangaroo Mother Care (KMC) and breast milk expression. The mothers rely on the instructions provided by the nurses to ensure that their infants' health status improve. The complexity of the NICU environment, medical care, individual circumstances, and the appearance of the infants are some of the factors that cause stress among mothers of premature infants. The nurses provide emotional support to mothers only when they have free time within their tight work schedule. To complement the information provided during the ward round, mothers are given pamphlet to help them learn about KMC and milk expression. Changing staffing patterns in the NICU creates an environment in which multiple care providers communicate with the mothers during the infant's hospitalization. The stress of communicating is intensified when the information mothers receive about their infant is incomplete, conflicting, or difficult to understand [8].

Despite the presence of mothers in the NICU, some have little information about their infants' medical conditions. This is common among mothers who cannot communicate in English or common South African languages such as isiXHosa and Zulu. The hospital sometimes uses interpreters who often provide incomplete information.

The NICU staff use phone calls and text messages to communicate with mothers who are unable to visit the unit. These modes of communication are expensive, and usually unreliable because some mothers provide incorrect phone numbers or they use shared phone in their households thus it is hard to reach them directly. In addition, mothers who call the hospital to check on their children often experience long delays before their calls are transferred from the main hospital switchboard to the NICU extension.

Literature review

Currently, there is a great improvement on the technology used in the NICU to care for preterm infants [14]. NICU environment is highly technological with equipment attached to wires, tubes and blinking lights. Despite the improvement of care provided to the hospitalized infants in the NICU, little work has been done to investigate how ICTs can be used to support mothers of hospitalized preterm infants manage the stress related to premature birth. In the developed world, several applications have been developed to support these mothers. These tools can be grouped into three categories: 1. ICTs used to provide infant neonatal status (i.e. baby Carelink [6] and Babytalk system [13]), (2) ICTs used to provide parental education (i.e.

myPreemies [4] and NICU-to-HOME [12]) and (3) ICTs used for logistic services and ad hoc communication in the NICU (i.e. phone calls, websites and Short Message Services).

In this study, we are working with mothers from low-income setting and the available tools used to support mothers of preterm infants are not appropriate in this context because most mothers cannot afford the high cost of internet connection and devices required to access infant related information. In addition, these tools do not represent mothers' needs because they were developed based on health practitioners' requirements and mothers were only involved in the evaluation process. According to Neuhauser [11], it is important to involve users/patients during the design process of a health system to ensure all their needs are met.

Our research primary contribution to knowledge will be in the Human-Computer Interaction (HCI) discipline. We seek to investigate the appropriate research methodologies that can be employed while working with mothers of preterm infants. We seek to understand how we can fully involve mothers from low-income settings in the design process considering the socio-structural factors that affect their use of technology, as well as the specifics of how the demands of motherhood affect the design process. To identify the methodologies and feasible tool that can enhance communication in the NICU, this study will be guided by these research questions:

1. How do NICUs and mothers currently use ICTs?
2. Do existing participatory methods support useful design dialogue with mothers? If not, what

modifications or alternate approaches will empower mothers to be active participants in participatory co-design?
3. What intervention and improvement to current communication modes can be employed to support mothers of preterm infants?

In the first two questions, we will try to understand the current modes of communication being used by the staff at the NICU and the mothers. We will identify the efficiency and affordability of these ICTs and try to identify their shortcomings and how they can be improved. The answers to these questions will help us understand what new technology might be introduced to make the available interaction channels more accessible, reliable, efficient and affordable. We will collaborate with our participants in the design of the suitable technological intervention and through this, we will identify the most appropriate participatory methodologies that will fully involve our participants in the design process. The identified participatory methods will be used in an iterative process to ensure that the final design meets users' needs.

After identifying and understanding the current ICTs being used communication purposes in the NICU, we will collaborate with our stakeholders and design a new intervention that will be used to support mothers manage the stress related to premature birth as well as improve communication between mothers and the staff in the NICU.

At the end of this study, we plan to have recommendations for future projects seeking to deploy tools that will support mothers of preterm infants. We

will draw these lessons and reflections from the design process, the uptake, use and impact of our intervention. We also hope to contribute to the literature on co-design across cultures and contexts and specifically with new mothers.

Co-Design Approach

For this research we take co-design approach [3], attempting at all stages to incorporate and empower the users with respect to any interventions developed for their needs. This will be an iterative process whose goals will be to understand the role of ICTs in this context and to design appropriate and sustainable mechanisms for supporting mothers of preterm infants. We do not immediately target specific mechanisms or even necessarily the development of a software artefact because we believe that it is premature to posit a solution before we have had the opportunity to understand the problem in more depth.

There are six phases in this study namely: 1. Needs assessment and problem identification 2. Idea generation 3. Idea exploration 4. Prototype 5. Deployment 6. Handover and testing. Interviews, focus group, observation, workshop, walkthrough, usability analysis will be the main research methods that will be used iteratively in this study. Some of these methods might be altered to ensure that we interact effectively with the participants during the design process.

Phase one: Needs Assessment and Problem Identification

We are currently in the initial phase of this study, where we are using ethnographic observation and one-on-one interviews methods to identify the challenges that mothers face in the NICU as well as the technologies that are currently being used for communication purposes.

We conducted participants observation in the NICU both during the day and night to identify the unit workflow and some of the barriers that hinder communication in the NICU.

After conducting participants observation for 16 days, we opted to use semi-structured interviews to further understand communication challenges in the NICU and assess the information that mothers needs while their infants are hospitalized in the NICU. In December 2017, we interviewed 14 staff from different sections of the NICU. We sought to talk to staff with different medical roles in the unit to understand the needs of these women from different perspective.

In January 2018, we interviewed 15 mothers who were attending infants' routine check-up at the hospital. We worked with mothers whose infants were out of NICU for at least six months to ensure that the health of both the mother and infant were stable during the interview sessions. We plan to work with mothers of hospitalized infants in the last two phases of our study.

We are currently analysing the data collected during participants observation and interview sessions and we have identified there is minimal communication between NICU staff and mothers. Most mothers experience stress and it is evident there is need for an intervention to enhance staff-mother communication in the NICU.

In the next session we discuss the preliminary findings from the first phase of our study.

Preliminary Findings

During the observation sessions, the first author identified that few mothers visit the clinic on a daily basis to nurse their infants. Most mothers in the NICU own smartphones which they mostly used to access social media and online chat channels. The mothers who are

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Co-design

Co-design is a design approach that allows all the stakeholders to be involved in the design process [3]. This approach enables a wide range of people to make a creative contribution to the formulation and solution of a problem with the ultimate goal being to create benefits for all the stakeholders.

admitted to the labour ward visit the unit in three hours interval to breastfeed their infants and their children are mostly under nurses care. Mothers who undergo caesarean section during birth are mainly in pain and they struggle to walk from the obstetric ward to the NICU when they visit the infants. Mothers who are new in the unit appeared lonely and could be seen crying as they express breast milk or watch their babies through the incubator. The NICU staff are extremely busy attending to the infants but they occasionally sit next to the mothers to provide psychological support. Most mothers appreciate this opportunity and tend to create good relationship with these staff so that they can receive more support.

During the night shift, there is shortage of nurses in the unit. Occasionally, the mothers will call the unit to check on their infants but the nurses are extremely busy to even answer the call.

To validate the data collected during participants observation we conducted interviews with the NICU staff and mothers. The NICU staff informed us that they mainly focus on ensuring the infants health stabilises. Three nurses confirmed this when they said:

"There is always shortage of staff in the unit and we mainly focus on ensuring that the health of the children improves."

We also identified language barrier in the main hindrance to mother-staff communication in unit. Two doctors mentioned:

"It is challenging to communicate with mothers who cannot speak English. We often involve hospital translators (who are rarely available) to relay medical information."

There is space limitation in the unit and the NICU staff are not able to communicate privately with the mothers. This inflict stress to some mothers who do not want the condition of their babies to be exposed to other people in the unit. Lastly, we identified that the technological environment in the NICU affects some mothers. Two nurses attested to this observation when they said:

Anticipated Outcome
At the end of our study, we expect to demonstrate the use of co-design in this context, and potentially contribute further understanding of the appropriate research methodologies that are suitable while working with mothers with young infants. We will demonstrate how these methodologies empower mothers to participate in the design process. Lastly, we expect the final prototype of the proposed intervention will support the communication between the NICU staff and mothers thus enabling the mother to have access to infant's health status as well as parental health education.

"Yes*, most mothers are frightened by the alarms which go off quite often."*

These mothers are not able to interpret the reading on the monitors connected to the infants, and they mostly switch off the alarm without consulting the NICU staff. This is risky and can cause the condition of the infant to deteriorate in case the child's condition needed immediate action from the NICU staff.

During our interactions with mothers, we confirmed that premature delivery and hospitalization are stressful events for mothers. The main cause of stress in this context are: 1. Uncertainty of infant health condition 2. Minimal communication with staff 3. Unfamiliar NICU environment 4. Lack of information 5. Sociocultural and socioeconomic factors. Most mothers rely on the information provided by the NICU staff but there is minimal communication between them thus aggravating stress related to premature birth. We are still analysing our data and we plan to have conclusive analysis in the next three weeks.

Future Work
In the next five phases, we plan to involve our participants in the design activities of the communication tool. We will use brainstorming, focus group and interview sessions to involve mothers and NICU staff in the design of the technological intervention. We focus on understanding factors that affect co-designing as we work with our participants and research methods that are efficient while working with this vulnerable group of participants.

Bio
Christine Mburu is a first-year Ph.D. candidate at the Department of Computer Science, University of Cape Town. She has broad interests in ICTD and HCI research in developing world context.

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