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Doctoral Thesis

Preemie Care: A Co-designed Digital Tool to Improve Communication Between Health Personnel and Parents of Preterm Infants.

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Declaration of Authorship

I, Christine Wanjiru MBURU, declare that this thesis titled, "Preemie Care: A Co-designed Digital Tool to Improve Communication Between Health Personnel and Parents of Preterm Infants." and the work presented in it are my own. I confirm that where I have collaborated with other researchers or included published work of others researcher this is clearly attributed and the researchers or quoted research materials are acknowledged or are explicitly referenced as appropriate.

This work is being submitted for the degree of Doctor of Philosophy in Computer Science at the University of Cape Town, South Africa. This thesis has not been submitted to any other university or institution for any other degree or examination.

Signed:

Christine Wanjiru Mburu

Date:

"A dream doesn't become reality through magic. It takes sweat, determination and hard work."

Colin Powell

Abstract

Communication between parents and health providers is essential in the Neonatal Intensive Care Unit (NICU) settings to ensure both parties collaborate in infant care. However, in most NICUs, the interaction between parents and NICU staff is strained, thus hindering communication. These communication challenges are due to language, medical vocabulary and cultural barriers between NICU staff and mothers. These challenges create communication gaps, which disempower parents and frustrate health staff. To bridge NICU communication gaps, several researchers have deployed digital health interventions. However, although the existing NICU technologies have effectively improved NICU communication, most parents struggle to interact with these interventions because they do not fit parents' technical and literacy capabilities. These design gaps arise because parents were not fully included in the design process of the existing NICU digital interventions.

In this research, we sought to address the communication gaps within the NICU environment by employing a co-design approach to develop a digital intervention that supports infant care journey in a low-resource NICU setting. The co-design process included six research phases that spanned over 32 months. We engaged mothers of premature infants and NICU staff throughout this process while focusing on identifying how best to involve NICU stakeholders in a co-design process to ensure that the final intervention was usable and useful. The co-design process led to the development of MoM connect workflow which was disqualified by mothers and NICU staff because it did not meet mothers' needs. We further engaged NICU stakeholders in the co-design process and agreed on developing Preemie Care (PMC) system, an educational resource tool that disseminated digital health videos in multiple languages and through multiple technologies to empower parents and NICU staff to work together and advocate for their preterm infants.

PMC system was deployed at Groote Schuur NICU for eight months where we interacted with users and monitored it usage logs to evaluate its efficacy. Our empirical evidence revealed that access to health information improved parents and their social networks medical vocabulary, thus empowering them to engage with their peers and NICU staff. We also learned that sharing health information in multiple languages does not resolve the language barriers among multilingual NICU parents. Instead, our results show that bilingual parents prefer accessing health information in multiple languages to improve their medical vocabulary and understandability, thus empowering them to engage in their infants' health care and decision-making. Hence, this research provides the design mechanisms for a NICU intervention to bridge communication gaps between bilingual parents and NICU staff.

This work contributes to the field of Human-Computer Interaction(HCI) by highlighting the ethical and methodological considerations to engage NICU stakeholders interacting in a sensitive NICU setting in a collaborative co-design process. We also contribute to HCI knowledge by providing design mechanisms for a NICU intervention meant to bridge communication gaps between bilingual parents and NICU staff in a low-resource setting and design features of a digital NICU intervention that enhance family-centred care in the NICU setting.

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List of Abbreviations

NICU	**N**eonatal **I**ntensive **C**are **U**nit
HCI	**H**uman-**C**omputer **I**nteraction
HCI4D	**H**uman-**C**omputer **I**nteraction for **D**evelopment
ICT	**I**nformation and **C**ommunication **T**echnology
ICTD	**I**nformation and **C**ommunication **T**echnology **D**evelopment
SMS	**S**hort **M**essaging **S**ervice
PMC	**P**ree**M**ie **C**are
SSID	**S**ervice **S**et **ID**entifier
KMC	**K**angaroo **M**other **C**are
GSH	**G**roote **S**chuur **H**ospital
FCC	**F**amily-Centered **C**are

Publications

1. Mburu, C., Joolay, Y. and Densmore, M. 2018. The NICU Design Toolbox: Co-design through Empathic Relationship Building In Proceedings of the Second Conference on Computing and Sustainable Societies (COMPASS 2019 Posters) July 3-5, 2019, Accra, Ghana. ACM, New York, NY, USA, 4 pages. https://dl.acm.org/citation.cfm?id=3314344

2. Mburu, C., Wardle, CJ., Joolay Y. and Melissa Densmore. 2018. Co-designing with Mothers and Neonatal Unit Staff: Use of Technology to Support Mothers of Preterm Infants. In Proceeding of Second African conference for Human-Computer Interaction (AfriCHI'18). ACM, New York, NY, USA, 10 pages. https://doi.org/10.1145/3283458.3283487

3. Mburu, C., Joolay, Y. and Densmore, M. 2018. Using Experience-Based Co-design Approach to Improve Communication between Mothers of Preterm Infants and NICU. In Proceeding of Human-Computer Interaction Across Borders Symposium (HCIXB'18) https://hcixb.org/papers_2018/hcixb18-final-15.pdf

This work is dedicated to my parents, Mr and Mrs. Mburu Wagacha and to my lovely daughter Wambui K.

Chapter 1

Introduction

Imagine a low-income mother caring for her premature baby in the Neonatal Intensive Care Unit (NICU). The unfamiliar NICU environment and the sight of her tiny baby in an incubator attached to cables and beeping machines traumatize her. She wished she could receive constant updates on her baby's health status. Unfortunately, the health personnel only share information occasionally with the lady, which she barely understands because she does not understand the medical jargon. Although she wishes to interact with the health personnel, she is afraid of initiating the conversation because she speaks a different language from the health personnel and the health personnel are often busy caring for sick infants. This situation causes stress for the mother because she needs information to help her understand the baby's health status and her role as the primary caregiver.

Literature shows that NICU staff and parents' communication is integral in supporting parents to partake in infant care. However, most NICU staff have a heavy workload, and they focus mainly on stabilizing infants' health, without fully involving parents in their infant care journey. Most NICUs in the developed world have adopted digital technologies which have successfully supported health personnel communication with parents. However, the development process of the existing NICU technologies only partially involved parents in the design process, thus limiting the replication of these interventions in other NICUs, especially those in low-resourced settings. Involving parents and NICU staff throughout the design process of these digital technologies is critical to ensure the interventions are useful, usable and adopted by users. Thus we pose this question: what place does Human-Computer Interaction (HCI) research have in the NICU scenario described above? The work reported in this thesis seeks to engage NICU stakeholders in a co-design process to uncover the design considerations for NICU communication tools that could bridge the communication gaps between NICU staff and parents in low-resourced NICU settings.

1.1 Background

Human-computer interaction (HCI) is a design field that focuses on studying how people interact with computers and to what extent computer interfaces can be improved to ensure successful interaction with human beings (Oulasvirta and Hornbæk, 2016). HCI is an interdisciplinary discipline that engages in developing technological solutions to solve problems in various application domains. Within the HCI community, there is an explosion of interest in Human-Computer Interaction for development (HCI4D) research that primarily examines how to apply user-centred design principles to design and evaluate Information and Communication Technologies (ICTs) for users in low-income contexts (Anokwa *et al.*, 2009; Wyche, 2011).

A review of older HCI4D literature revealed that older HCI studies focused mainly on low-income users living in rural areas with limited education levels (Ho *et al.*, 2009). Recently, in both developing and developed world contexts, a growing portion of HCI research has been conducted in sensitive settings with vulnerable participants who might be marginalized or at risk of health or social disadvantage. Waycott *et al.* (2015b) refers to design studies conducted in sensitive settings as "sensitive HCI" because researchers are required to tread carefully when engaging with participants to ensure that the research practices do not harm either the researchers or the researched. Sensitive HCI research primarily focuses on designing technologies to cater to vulnerable populations whose requirements are not considered within the traditional HCI literature. Examples of sensitive HCI research include those conducted in settings such as conflict zones (Talhouk *et al.*, 2017), with young children (Hervás *et al.*, 2014), older adults (Waycott *et al.*, 2012), the health sector (Poole, 2013), low literacy populations (Hussain, Sanders, and Steinert, 2012), among others.

Although sensitive HCI is an emerging area of interest, Anokwa *et al.* (2009), Waycott *et al.* (2015b) and Abdelnour-Nocera and Rangaswamy (2018) highlight the complexity of researching in these contexts due to technical, environmental and cultural challenges. Alongside these challenges, HCI researchers encounter complex ethical issues that are emergent, diverse and highly contextualized. Therefore, researchers must use design participation approaches that are sensitive to ethical concerns and emotional impact on both researchers and the participants. Also, researchers should be careful during the design process to ensure that the risk of the new design technologies does not exacerbate the vulnerability of participants. Regardless of the complex nature of conducting sensitive HCI studies, working with vulnerable participants has led to great design innovations and socio-economic development. For instance, Piper and Lazar (2018) , Tan and Szebeko (2009) and Nakarada-Kordic *et al.* (2017) provided design practices while engaging vulnerable participants in mental health issues, Peyton *et al.* (2014), Wardle *et al.* (2018) and Balaam *et al.* (2015) share design consideration for motherhood HCI and Fisher, Yefimova, and Yafi (2016) and Talhouk *et al.* (2017) for systems meant to support refugee.

Recently, a nascent body of research are exploring how digital technologies could be used to inform, empower, and support parents of premature infants in the NICU and afterwards. Premature birth (before 37 completed weeks of gestation) is the primary cause of neonatal deaths globally (Arnold *et al.*, 2013). The global burden of preterm birth is estimated to be 15 million, with substantially higher rates in developing countries (Steyn, Poggenpoel, and Myburgh, 2017; Blencowe *et al.*, 2013; Althabe *et al.*, 2012). As a result, many developing nations have an increasing focus on neonatal care, with tertiary level centres being established to provide neonatal training programs (Lloyd and Witt, 2013; Enlow *et al.*, 2017).

However, despite remarkable progress in neonatal care, little work has been done in supporting parents of premature infants as they take care of their infants. Parenting an infant in the NICU comes with many unique challenges that NICU parents are unaware of prior to their infant hospitalization.(Howe *et al.*, 2014). In addition, studies have reported that parents of preterm infants, especially the mothers, experience increased levels of stress in the neonatal period, which often leads to depression and anxiety (Guillaume *et al.*, 2013; Wigert, Blom, and Bry, 2014; Heidari, Hasanpour, and Fooladi, 2017). Therefore, parents' stress management is crucial during infant hospitalization.

Various studies recommend the Family-Centered Care (FCC) care model as the "best practice" in NICU in both developed and developing countries (Al-Motlaq and Shields, 2017; Rostami *et al.*, 2015). FCC involves holistic care and requires cooperation between parents and NICU staff in the care of hospitalized infants. However, a gap still exists concerning the holistic involvement of parents in premature infants' care. This is because most parents lack a complete understanding of their parental role in the NICU. Moreover, they feel their psychosocial needs are neglected. Thus, they experience anxiety due to the vulnerable state of their infant's health. In these cases, most parents rely on NICU staff for support during their infants' hospitalization. Therefore, health researchers recommend frequent communication between parents and NICU staff to ensure all NICU stakeholders are involved in the care of the admitted infant (Campos *et al.*, 2017; Wigert, Dellenmark, and Bry, 2013).

Although improvements in neonatal care have increased survival for preterm infants, current prevention research and knowledge have not reduced premature births. Interventions such as Baby CareLink (Gray *et al.*, 2000), My Preemie (Doron, Trenti-Paroli, and Linden, 2013), Estrellita (Hayes *et al.*, 2014), NICU-2-HOME (Garfield, Young, and Lee, 2014), Baby Talk (Mahamood and Reiter, 2011) and the internet-based program (Lindberg and Öhrling, 2012) have been designed and deployed in NICU settings to provide parents with health information related to premature birth. These interventions have demonstrated the potential of Information and Communication Technologies (ICTs) in supporting parents of premature infants while taking advantage of the ubiquity of the mobile phone. Although these interventions significantly improve parents' satisfaction, they require users to have a high-speed internet connection and accessibility to smartphones, which most families in low-income settings cannot afford.

For instance, Baby CareLink provided information to parents using both a website and videoconferencing system from the NICU (Gray *et al.*, 2000). The parents used a secure password to access their infants' health information. The MyPreemie application was initially available for iPhone users and parents were required to buy the application from the Apple iTunes store before they could use it (Doron, Trenti-Paroli, and Linden, 2013; *MyPreemie App by Graham's Foundation*). Later, they made the application available for android phone users who freely downloaded the app on Playstore. However, MyPreemie users required a good Internet connection to access health information. Estrellita includes two interfaces: a mobile application and a web-based clinical interface (Hayes *et al.*, 2014). The mobile application allows users to record Observations of Daily Living (ODLs) for the infant and caregiver which is visible to the clinical providers.

The website allowed healthcare providers to interact with the caregiver and keep abreast with the infant's health status.

The NICU interventions mentioned above effectively equipped parents with the necessary information required to care for their premature infants. However, these studies did not fully engage parents in the design of these interventions, thus adopting their designing considerations in low-resourced NICU settings may not be feasible since the sociocultural, technical and literacy levels differ from the developed world context according to Mars and Erasmus (2012) and Wamala and Augustine (2013).

Although involving parents of premature infants in the design process is essential in ensuring the final product meets their needs, Human-Computer Interaction (HCI) researchers have identified that it is challenging to design with new parents. For instance, according to Balaam *et al.* (2013), designing with new parents, especially mothers, brings new challenges for participatory design methods. Parents tend to focus more on their children rather than on design activities. Ignazio *et al.* (2016) involved a group of mothers and experts in the design process that focused on improving the design of breast pumps. They recognized that designing for the postpartum experience is complex and context-sensitive, as it sits at the intersection of numerous legal, political, social and cultural factors. Wardle *et al.* (2018) mention that mothers' availability during the co-design process is limited, and HCI researchers should consider appropriate research methods that allow mothers to participate in the process of designing their technologies fully.

Hence, HCI researchers need to understand how they can effectively engage participants in sensitive HCI studies to ensure the design of usable systems in sensitive contexts, such as the NICU. This design approach is necessary because parents of preterm infants are susceptible to stress, and researching with them requires the researchers to consider the topic's sensitivity. In addition, the NICU has a hierarchical infant care structure where the neonatal staff supervise and care for infant health with minimal parental involvement (Tang *et al.*, 2013; Umberger, Canvasser, and Hall, 2018). These hierarchical structures create power imbalances that requires careful methodological and ethical consideration before engaging parents in a co-design process. According to Waycott *et al.* (2015b), one challenge in HCI research related to sensitive personal issues is the need to conduct research ethically and generate credible data while protecting research participants against emotional risks. For this purpose, researchers have queried whether HCI researchers are capable of responding to the needs of vulnerable participants (Vines *et al.*, 2013). Chan, Teram, and Shaw (2017) recommend that researchers should consider (a) the effect of participation towards respondents and (b) the effects of research methods on participant disclosure rates, and the credibility of the information provided.

From literature, no work has recorded the full involvement of premature infants' parents in the co-design process of NICU technology meant to support parents.Hayes *et al.* (2014) highlights that the burden of caring for premature infants often prohibits parents from engaging in the design of supportive NICU technologies. In addition, lack of knowledge of the NICU environment and premature infant care also precludes parents from engaging in the design process of supportive NICU technologies (Singh and Ewer, 2013; Gatt *et al.*, 2009).

Therefore, in this research, we [1] have taken the interventionist approach to understand the subtle needs of NICU technology that could enhance staff-parents communication in the NICU context. This approach allowed us to commence the research without intervention in mind. Instead, we opted to examine the NICU environment to identify the appropriate co-design methods that can be used to involve low-income mothers of premature infants and NICU staff with limited design skills throughout the co-design process of a possible NICU communication intervention. We also focus on unearthing design considerations for communication intervention in a low-resourced context to inform future researchers who might wish to extend research in the NICU environment. In the next section, we share our research statement and questions guiding this study.

1.2 Research Statement

The research reported in this thesis seeks to explore the appropriate approach of involving NICU stakeholders in the design process of a possible communication intervention that could bridge communication gaps between parents and NICU staff. We focus on understanding the communication gaps in the low-income NICU context and design considerations for a possible intervention that could educate parents or caregivers on the NICU environment and their infants' health conditions to encourage them to interact with NICU staff and partake in the care and decision-making of their infants' health care. In health literature, we learned that parents rarely interact with NICU staff due to various reasons such as language barrier, low literacy, hierarchical NICU structures and lack of medical knowledge (Lupton and Fenwick, 2001; O'Brien and Warren, 2014; Fowlie and McHaffie, 2004). Instead, the NICU staff periodically interact with parents or caregivers to inform them of their infants' health status. In addition, NICU staff interact with parents— especially mothers, to educate them on breast milk expression and skin-to-skin care, commonly known as Kangaroo Mother Care (KMC) (Heidari, Hasanpour, and Fooladi, 2017). In most NICUs, these staff-parents interactions follow the traditional health system in which neonatal staff share infants' health status and provide instruction to parents who rarely engage in the conversation (Kredo *et al.*, 2019; Trombini *et al.*, 2008; Umberger, Canvasser, and Hall, 2018).

To understand and address the complex and multifaceted NICUs communication challenges, we employed a co-design approach, engaging mothers (the primary caregivers) and NICU staff in a design process of a possible technological intervention that could bridge the NICU communication gaps. In the early stages of this research, we volunteered to work at the NICU and focused on helping nurses to cup feed and clean infants. We used this opportunity to familiarize ourselves with the NICU environment and understand the challenges that both staff and mothers face. We later, through fieldwork and literature review, sought to identify the best research techniques that could engage both NICU staff and

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[1] Throughout this thesis I Wanjiru Muburu the author of this thesis will use "we" to refer to the collaborative work done by myself and my supervisors A/prof Melissa Densmore and Dr. Yaseen Joolay. I conducted the fieldwork while my supervisors provided research guidance throughout the research period.

mothers in constructive participation despite the existing hierarchy in NICU infant care. This study was conducted in six phases, namely: problem identification, ideation process, ideas specification, interactive prototyping, deployment and handover and evaluation.

The overarching research question guiding this study was: How can low-income mothers of premature infants be engaged in a productive co-design process that would encourage their interactions with NICU staff to achieve holistic infant care? The following specific research sub-questions were developed to answer the main question;

RQ1. What are the current communication interventions being used in the NICU?

  1.1. Do these interventions support staff-mother interaction?

  1.2. What challenges hinder existing communication interventions from achieving their roles in the NICU?

RQ2. What are the appropriate strategies for engaging multiple NICU stakeholders in a productive co-design process?

RQ3. What intervention or improvement to the current NICU communication mode can be employed to support staff-mother interaction?

  3.1. Which design considerations should be taken to ensure the designed intervention meets users' needs?

  3.2. What features should be reinforced in the designed intervention to support family-centred infant care?

The sub-questions listed above were answered in different phases of this study. The first question was addressed when we familiarized ourselves with the NICU environment and stakeholders. We analysed the qualitative data collected during the first phase of this research to identify the strengths and shortcomings of the existing communication intervention. Answers to sub-question one helped us to explore and discover the appropriate methods that encouraged NICU stakeholders to collaborate in the co-design process. After addressing sub-question one and two, we were able to uncover the design considerations for a feasible technological intervention that motivated parents and their families to engage with NICU staff in the care of their sick infants.

Based on work done to answer the three research questions listed above, we developed an offline android application, dubbed Preemie Care (PMC) system and deployed it in the NICU. The intervention aimed at bridging the communication barrier between the parents and NICU staff. We studied the use of the intervention over eight months, and based on the findings, we introduced research question four which mainly focuses on the usage trend of the co-designed intervention. The sub-questions listed below helped us to answer research question four; these are discussed in detail in section 7.2

RQ4. What are the usage consumption patterns for Preemie Care system users?

  4.1. Did the multiple channels increase the accessibility of videos to the users?

4.2. What did the video-watching pattern tell us about video design in the NICU context?

4.3. How did primary users (mothers) and secondary users (fathers, relatives and friends) engage with the PMC system?

4.4. What are the video design mechanisms for the multilingual NICU community?

4.5. What was the user experience on the PMC system and the main course of actions to enhance its usability?

1.3 Groote Schuur Hospital

This research was conducted at Groote Schuur hospital (GSH), a government-funded tertiary referral hospital that provides health care to sick and preterm infants in Cape Town, South Africa Western Cape Government, 2014. The 75-bed capacity neonatal unit admits approximately 2000 infants annually, a majority of whom are preterm infants. Most parents of these infants live in informal housing settlements on the periphery of the city where overcrowding, unemployment, and poverty are rife Thompson *et al.*, 1993.

Similar to other South African state-funded hospitals, the neonatal unit at GSH has staff shortages which indirectly contribute to suboptimal communication in the NICU Lala, Lala, and Dangor, 2017. Given their heavy workload, neonatal staff struggle to connect with the parents leaving them with little or no information regarding their infants' health status. Parents often rely on the information provided to them as staff discuss infants' health status during their daily ward rounds. However, this mode of interaction is ineffective because neonatal staff use medical jargon or a language that parents do not understand. In addition, some parents are unable to visit the unit either due to lack of transportation costs or the responsibilities of other older children at home. These parents have limited information about their ill infants thus exacerbating their stress level which directly has a negative impact on infant health.

To support NICU communication, the neonatal staff employ ICT interventions such as text messages and phone calls to share information with parents. Even so, these communication channels are hampered when parents lack mobile phones, share mobile phones in their household, have unreliable access to electricity or frequently change the phone number that is on file within the NICU. As a result, parents miss out on the opportunity to partake in the care of their infants as well as access important information about their infants' health. On the other hand, parents who call the unit complain that the process of reaching the unit call centre is cumbersome due to the delays caused by phone transfers at the hospital's main switchboard, increasing the cost of the call.

Given this setting, the goal of this research was and still is to engage low-income parents and neonatal staff in the co-design process of a low-cost communication intervention that provides parents with the necessary information they require to actively partake in the care of their infants.

1.4 Research Design and Approach

We employed a co-design approach, engaging participants (NICU staff and mothers) as active research participants throughout the design process. Co-design is a creative practice that allows participants to engage in the formulation of a possible solution throughout the design process to ensure the results meet their needs and are usable (Sanders and Stappers, 2008; Nilsson and Barton, 2016). Co-design acknowledges that the ability to design is innately human and everyone can engage in the transformation of their current scenario to ensure that the outcome meets their needs and expectations (Saunder and Westerlund, 2011; Sarmiento-Pelayo, 2015). In contrast to the traditional design practice where users are only engaged during the data collection and evaluation process, co-design is practised using a *design-with* mindset that allows the designers or design researchers to use the ideas generated by participants as sources of inspiration and innovation.

Within health care, co-design has been mainly employed as a way of designing better experiences for patients, carers, and staff (Piper and Lazar, 2018; Timmerman *et al.*, 2016; Ward *et al.*, 2018). Various researchers have emphasized the importance of using a co-design approach in the health system design process (Piper and Lazar, 2018; Timmerman *et al.*, 2016; Birnbaum *et al.*, 2015; Wolstenholme, Grindell, and Dearden, 2017; Robert *et al.*, 2015). They highlight that co-design encourages users' engagement through participatory and empathic methods (Piper and Lazar, 2018). Participatory methods embrace democracy during the design process, thus enabling all participants to play an active and influential part in decisions that affect their lives. On the other hand, empathic methods help the designer/researcher to deepen the understanding of the end-user in a way that intangible concepts such as feelings, emotions, aspirations and fears provide the designer/researcher with clues of how stakeholders see, understand and interact with the world around them (Sarmiento-Pelayo, 2015; Schneider, 2018). As a result, these clues inspire the design of a product with a better functional balance, which, in turn, provide better experiences of use to the end-users.

Based on the aspects mentioned above, I chose to employ a co-design approach in the NICU environment and focus on using it as an empowerment process. According to Schneider *et al.* (2018), co-design advocates the design and development of tools that people can use actively and creatively, thus empowering them. In health and HCI literature, we learned that the NICU is an under-researched environment with few existing studies in health and HCI literature focusing on using technological interventions to support parents. In addition, the existing studies did not fully engage parents in the design process of the NICU technologies, thus providing limited design considerations while developing NICU interventions. This being the case, we chose to go beyond adopting and testing the existing technologies. Instead, we sought to engage NICU stakeholders (mothers and NICU staff) as co-designers to understand their communication challenges, needs and design consideration for a solution that could meet their communication needs. This active participation follows human-centred design principles that focus on the needs, contexts, behaviours, and emotions of the people that the solutions will serve (Blandford *et al.*, 2018; Buchanan, 2001).

Consequently, this process could provide a sense of ownership among the participants because it enables them to tailor the intervention to their specific cultural needs and contexts. In addition, Verbiest *et al.* (2018) argue that this approach often contributes to better uptake of the health care system. In the following subsection, I describe this study's methods and approaches. Finally, I reflect on the challenges I faced and how they influenced my methodological selection and interactions with the participants.

1.4.1 Research Phases and Activities

Phase	**Duration**	**Participants**	**Methods**
Needs Assessment and Idea Generation	7 months Sept 2017-March 2018	15 mothers 15 NICU Staff	Observation Interviews
			Context mapping
Ideas Exploration	4 months Apr-Jul 2018	4 mothers 10 NICU Staff	Focus Groups Brainstorming Role-playing Scenarios
Ideas Evaluation	2 months Aug-Sept 2018	4 mothers 1 Nurse 1 project coordinator	Interviews Observation
Idea Generation and Prototyping	10 months Oct 2018- Jul 2019	6 mothers 6 NICU Staff	Focus Groups Sketching Generative techniques Emoji
System Deployment	4 months Aug- Nov 2019	30 mothers 10 NICU staff 6 fathers 5 relatives	Observation Interviews System Logs analysis
Handover	5 months Dec 2019-April 2020	8 NICU staff 7 mothers 2 fathers	Staff Training Brainstorming Interviews

TABLE 1.1

Overview of methods used, duration, and the number of participants involved in the 32 months study.

This study comprises six phases, which were conducted over 32 months. The first phase (reported in detail in chapter 3) ran for six months. In this phase, we focused on answering research question one. We engaged mothers of preterm infants—who had been discharged from the hospital for at least two months—and NICU staff to assess the communication needs and challenges in the NICU. We also sought to understand the strength and shortcomings of the current NICU communication tools. We used observation and interviews to understand the

NICU environment activities and communication challenges in depth. The observations were conducted in two parts. Firstly, we worked closely with NICU staff to understand the unit's workflow and interactions. Secondly part, we visited the unit twice a week (both during the day and night) to gain insights into the unit's activities from multiple perspectives.

As this study is a new and sensitive research environment, observation allowed us access to the explicit and observable aspects of the lives of the parents and NICU staff. Through the observation sessions, we learned that the NICU environment is stressful for both parents and staff who work round the clock to ensure that the health of infants is stabilized. Staff-parents communication is minimal and when it happens, it is unidirectional where staff are often sharing information with parents who rarely engage in the conversation. To further understand the NICU communication challenges and stakeholders' needs, we used one-on-one interviews and the *context mapping* (Offermans, Essen, and Eggen, 2014) techniques to understand participants' experiences and aspirations. We identified that parents fear NICU staff since they deem them superior in the care of their hospitalized infants. We also observed structural gaps, such as language, vocabulary and technology gaps that negatively influence NICU communication. The data collected in this phase were thematically analyzed using nVivo software. The identified themes, which we used as input information for subsequent phases, helped us to modify research design and methods in subsequent data collection phases to overcome the identified power imbalance and structural gaps. We did this to ensure the study adhered to design ethics without inflicting pain, fear or stress on the participants.

The second and third phases, discussed in chapter 3, ran for eight months. These phases were designated for design idea generation and design features exploration process. During this period, we focused on answering research questions two and three. We engaged mothers, doctors and nurses to identify and define possible interventions that could be adopted to solve the communication gaps identified in the first phase. We employed Marsden, Maunder, and Parker (2008) *empowered design* to enable participants with limited exposure to design technology solutions that met their NICU communication needs. To avoid the power imbalance identified among NICU stakeholders, we held separate focus groups with different stakeholders groups. We also used brainstorming and sketching methods to facilitate collaboration and creative design among the participants. We focused on exploring research methods that encouraged the participants to use their NICU experiences to model a solution that could suit their context. However, during these sessions, we encountered co-design dynamics such as power inequality, group thinking and disagreements that hindered some participants from engaging in the design ideas generation. To counter these co-design challenges, we include other methods such as *role-playing* (Lawson *et al.*, 2016), *card sorting* (Nakarada-Kordic *et al.*, 2017), *scenario* (Nardi, 2007) together with generative techniques such as *persona* (Miaskiewicz and Kozar, 2011), which enabled shy participants to engage in a constructive design discussion. With ethics considerations in mind, we paired methods and explored their effects on the information-sharing process and allowed the methods to reinforce and complement each other, enabling the triangulation of data.

Although pairing research methods helped us overcome co-design challenges, we learned that having separate focus groups limited collaboration when we held a joint focus group with multiple NICU stakeholders. This design approach did not encourage mutual learning among participants since each group had varying design ideas, which they were pushing through in the discussion. Doctors seemed to dominate the discussion due to their vast medical knowledge. This knowledge gap between stakeholders made nurses and mothers agree with doctors' decisions even though they did not follow their idiosyncratic interests. As a result, NICU stakeholders agreed to automate the communication mechanism of an existing project to ensure mothers who could not visit the NICU receive their infants' feeding information via text messages. To further understand the feasibility of the suggested intervention, we visited mothers in their communities to learn whether they were utilizing the breast milk delivery services that the hospital had offered. We learned that the proposed communication mechanism was not feasible since mothers preferred visiting their infants at the hospital instead of delivering their expressed breast milk via a motorbike rider. Based on these findings, we decided to change the strategy and have all stakeholders in joint brainstorming sessions in subsequent co-design activities.

In phase four, discussed in Chapter 4, we focused on answering research questions two and three. We engaged mothers and NICU staff in a joint brainstorming session where they collaborated in tailoring health information and sketching the final prototype of the proposed solution. Unlike in phase two, where we held separate sessions with different stakeholders, we chose to have one focus group with multiple stakeholders to foster relationships and build trust. During the focus group session, we used a *series of unanswered questions* and *images*(Nakarada-Kordic *et al.*, 2017). We asked participants to use their NICU experiences to expound and simplify the information suggested in previous phases. To encourage NICU staff and mothers' interaction, we hired interpreters who assisted mothers who could not communicate in English. After tailoring health information successfully, we engaged participants in a collaborative prototyping session to visualize the suggested information in a simple format that mothers could easily access on a mobile phone interface. This co-design approach encouraged the participants to share their NICU experiences and explore the most viable communication intervention in the NICU context. It also supported mutual learning and empathy-building among participants. Relationships and trust among participants were boosted during the discussion, fostering creativity and ideas sharing. This collaboration was achieved due to design activities being entirely led by the participants under our facilitation. As facilitators, we acknowledged that the participants had vast NICU experience, thus granting them privileges in shaping the design ideas. Our role was to support the participants' design activities as we visualize their views on a workflow. We also facilitated the collaborative sketching sessions, ensuring that participants had access to all the materials required to actualize their ideas. We coined and advocate scaffolding co-design, as the appropriate method when working with different stakeholders in co-design activities. We argue that the process allows researchers to build co-design activities based on the design ideas raised in previous co-design sessions with different participants to ensure a meaningful co-design process when new participants engage in consecutive design activities.

This approach influenced changes in design and workflows developed in previous phases. Participants devised the best ways of accessing and sharing information in a resource-constrained environment in a manner that fits within the stressful NICU context (see Chapter 4). They co-designed an offline android application, dubbed Preemie Care (PMC) system, to ensure that mothers did not incur any cost to access health information. They further asked us to develop the application in the three languages(English, isiXhosa and Afrikaans) commonly used in the unit. We developed the proposed mobile application and configured the PMC system with multiple access channels, such as television display, PreemieTube (offline video streaming service) and PreemieChat (offline chat service), to ensure that mothers, with and without mobile phones, could access health information. We later evaluated the PreemieCare system usability and stability before deploying it at the hospital.

In August 2019, we deployed the intervention in the NICU and evaluated its effect on the communication between mothers and the NICU staff. We worked in the unit for two weeks to train, monitor and support mothers and NICU staff as they interacted with the system. We used observations, cognitive walkthroughs and follow-up interviews to evaluate participants' interactions and experiences with the deployed intervention. I further logged usage of the tool and conducted an analysis, which is conveyed in detail in Chapter 5). to answer research question four, we learned that parents used the information shared on the PMC system to improve their medical vocabulary, thus enabling them to interact with NICU staff. Although the system was designed for mothers of premature infants, we learned that the information shared was also relevant to their social circles, who used the system to support mothers as they cared for their hospitalized infants.

After deploying the PMC system for four months, we organized a workshop with NICU stakeholders to discuss the sustainability plan of the PMC system after it was handed over to the unit. Before the workshop, we trained the nurses and one NICU secretary to operate and manage the system. During the workshop, we used the brainstorming method to discuss ways in which the NICU staff could encourage parents to adopt the system as they take care of their sick infants. We also discussed how the system could be reinforced to promote staff uptake as they supported parents in the NICU. After the workshop, we continued monitoring the system and offered technical support to PMC system users. We also continued observing and analyzing the system usage logs before engaging users in semi-structured interviews to understand the positive and negative outcomes of the project and strategies for improving usability. We use the findings of this phase to provide design considerations for a sustainable NICU communication tool. We hope that these findings will inform and guide future HCI researchers who may wish to further this study in a low-income NICU context.

1.5 Research Contribution

In addressing the research questions above, this research makes two major contributions to Human-Computer Interaction for Development (HCI4D) knowledge.

1. The study contributes towards the growing field of "sensitive HCI" knowledge by providing a methodological process for designing with and for NICU stakeholders. We provide a thick description of the co-design process we conducted and highlight the challenges and methodological pitfalls we encountered as we engaged NICU stakeholders in the co-design process. We describe the power inequality among NICU stakeholders and discuss the importance of using creative, generative techniques, which encourage participants with limited design skills to collaborate in the design of an intervention that meets their needs. We recommend *scaffolding co-design approach* to future HCI researchers who may wish to interact with NICU stakeholders in a low-resource context. The approach recognizes the volatile nature of the NICU environment where there are different participants with different design views at every step of co-design. Therefore, the researchers should consider research methods that acknowledge all participants' views as they negotiate the final design needs for the digital intervention.

2. The study also contributes towards design considerations for multilingual communities in the health context. We share the design features for a communication intervention meant to bridge the communication gap in the health context and highlight that having health information in different languages does not bridge the language barriers in the health sector. Instead, we show that annotating health videos with a different language than the narration encourages multilingual users to code-switch between the two languages to comprehend the health information shared. We discuss how it is vital to incorporate the stop and pause feature in health videos to encourage users to code-switch from one language to another while accessing health information. We also show that sharing information using multiple access channels allows users to explore the affordances of each channel before they adopt the one that meets their technical needs.

1.6 Thesis Outline

The rest of this dissertation is structured as follows:

In Chapter 2, we examine the relevant literature, which provides premature birth statistics, challenges that mothers of premature infants face, the communication challenges in the NICU and the current technological interventions used to support parents of premature infants. We uncover the design gaps within the design of NICU technologies and share recommendations provided by other researchers who have researched in similar sensitive settings. In addition, we discuss the study context providing a rationale for conducting our study in a South Africa tertiary hospital.

Chapter 3 describes the methods in detail and our experiences interacting with NICU staff and mothers to identify the communication challenges in the NICU. We further engaged them in the co-design process to explore their design views for a feasible NICU communication intervention. We explored numerous design ideas and decided to automate the communication mechanism of an existing project deployed at the unit. We developed a workflow of the proposed communication mechanism and visited mothers in their homes to evaluate its feasibility. Through these co-design activities, we demonstrate the importance of prioritizing participants' voices in the design process by discussing the research techniques that worked and those that did not. The chapter concludes by presenting the findings and discussions of this study's first, second, and third phases.

Chapter 4 presents the co-design process where we further involved NICU stakeholders in ideation and prototyping activities. We describe the methods we used to bridge the knowledge gap between NICU staff and mothers as they tailored health information that should be shared with mothers. We highlight how creative methods that encourage mutual learning are suitable to mediate NICU stakeholders' interactions. We show how these methods disentangled NICU stakeholders' dialogue and mothers who previously feared NICU staff were empowered to raise their design views based on their lived NICU experiences. The chapter also discusses the therapeutic experiences that participants encountered during the session, emphasizing the techniques that promoted this experience. We share the co-tailored (collaborative tailoring of information) health information and high-fidelity prototype of the proposed NICU communication intervention. We conclude the chapter by discussing the results collected during the co-design process.

Chapter 5 starts by describing the system development and testing process. We explain in detail our experiences during the eight months of deployment and the system handover process. We discuss the evaluation process and the approaches used to elicit feedback from the staff and mothers. The chapter concludes with a discussion of the lessons learned after analyzing the usage log and qualitative data collected from the system users.

Chapter 6 discusses our reflections on our experiences during this study. We use Interpretative phenomenological analysis (IPA) method to provide detailed author reflection on their research journey in emotional laden NICu setting. We use IPA method to present the methodological and ethical challenges we encountered as we engaged multiple stakeholders in sensitive research.

Chapter 7 revisits the research questions guiding this study and provides detailed answers to these questions based on the findings collected and analyzed throughout the study. It also summarises the contributions, limitations of this research and ideas for future work.

Chapter 2

Literature Review

2.1 Introduction

The previous chapter introduced the purpose and motivation for this research. This chapter describes the communication challenges in the NICU and how they affect parents' collaboration with NICU staff in infant care and the decision-making process. We discuss the design process of existing NICU communication interventions to improve parent-staff interaction and analyze their efficacy in a low-income NICU context. Our analysis aims to identify the appropriate methods and techniques for engaging parents in a co-design process of a possible NICU intervention that could alleviate NICU communication challenges. There is an emphasis in this chapter on the significance of engaging both NICU staff and parents in the design process to ensure that the final design meets all users' needs. We conclude the chapter by discussing factors that could affect participatory design in the NICU context, thus highlighting the design gap that we focus on filling using this study.

2.2 Premature Birth

Premature birth is defined as birth before 37 weeks of gestation (World Health Organization, 2015). According to Lancet report on preterm births, an estimated of 15 million births, or 11 per cent of all births worldwide, occur prematurely (Blencowe *et al.*, 2012). Globally, preterm birth is a major cause of neonatal deaths (death under 28 days of age) (Morisaki *et al.*, 2014). Although significant progress has been made over the last decade to improve the care of preterm infants, the reduction of neonatal mortality has been much slower, accounting for 45 per cent of the global neonatal deaths (Lee, Blencowe, and Lawn, 2019). The majority of these deaths are in developing countries, particularly in Africa and South Asian regions (Koenraads *et al.*, 2017). Also, preterm birth has lifelong effects on infants neuro-developmental functioning, such as the increased risk of cerebral palsy, difficulty in learning and poor eyesight, and possibility of chronic diseases (The Lancet, 2008).

The health problems associated with preterm birth is accompanied by the high costs in terms of NICU health care and lifelong physical, neurological and educational disability needs (Behrman and Butler, 2007). These costs impose a considerable burden on limited health care resources, especially in low-income countries. The emotional price is also high, with many parents experiencing the sudden death of a preterm baby or a stressful hospital stay (Blencowe *et al.*, 2012). In the next subsection, we discuss the stress related to premature birth.

2.2.1 Stress Related to Premature Birth

Premature birth and infant hospitalization are stressful events for parents, especially mothers who are the primary caregivers (McGrath *et al.*, 2013). The experiences of parents during their infants' NICU hospitalization are well-documented in the literature (Steyn, Poggenpoel, and Myburgh, 2017; Franck and Spencer, 2003; Turner, Chur-Hansen, and Winefield, 2015). Giving birth unexpectedly and subsequent separation from their newborn is worrying to parents who are often overwhelmed with grief and fear, making them feel helpless and uncertain of their infants' health outcome (Blencowe *et al.*, 2012).

Despite their availability in the hospital, parents lack the critical skills required to partake in the care of their sick infants. They rely on the instructions provided by the NICU staff to engage in their infants' care. Parents, especially mothers, are forced to make significant life adjustments to facilitate their involvement in infant care. For instance, they have to travel to the hospital regularly as well as balance other aspects of family life, which creates complexities in their daily life (Heidari, Hasanpour, and Fooladi, 2015). Even worse is the possibility that these infants may need to spend a prolonged time in the NICU. Furthermore, parents are overwhelmed by the technological environment with unfamiliar equipment, displays, blinking lights, and noise which make them feel uncertain and insecure about their infants' life outside that environment (Ionio *et al.*, 2016).

Previous studies show that most parents in the NICU have shattered confidence and they avoid touching their infants through fear of giving them a harmful infection (Arnold *et al.*, 2013; Ionio *et al.*, 2016; Heidari, Hasanpour, and Fooladi, 2015). As a result, they turn into mere spectators as NICU staff perform procedures on their infants (Araújo and Rodrigues, 2010). This care arrangement excludes parents from full involvement in infant care, making them feel guilty for not knowing how to take care of their infants. Hence, this situation causes parents to develop negative feelings toward NICU staff. As a result, they distance themselves from NICU staff, limiting the much-needed communication.

NICU staff are best placed to provide support to parents because they come into daily contact with them (Orzalesi and Aite, 2011; Enlow *et al.*, 2017; Mok and Leung, 2006). However, NICU staff are overwhelmed with immense duties in the unit. Consequently, they prioritize the infants' well-being, and do not fully involve mothers in the care of their infants. (Kadivar *et al.*, 2017). To reduce stress related to premature birth, parents desire more support from NICU staff, particularly in the area of supportive communication and access to infants' health information (Enke *et al.*, 2017). Addressing parents' psychological needs is essential to reduce stress related to premature births. Parents' psychological support can be achieved by incorporating interventions that focus on enhancing communication between NICU staff and the parents. However, NICU communication is faced with numerous challenges, thus making effective NICU staff-parents interaction unachievable. In the next section, we discuss barriers to effective NICU communication.

2.3 NICU Communication Challenges

Previous literature has shown that communication between NICU staff and parents of hospitalized infants is faced with numerous challenges (Shirazi *et al.*, 2015; Campos *et al.*, 2017; Enke *et al.*, 2017; Fowlie and Jackson, 2007). Many of the ethical and medical issues encountered routinely in the NICU are highly complex.(Enke *et al.*, 2017). NICU staff are expected to communicate empathetically and give appropriate and timely information to parents (Campos *et al.*, 2017). According to Mercer and Reynolds (2002), empathetic communication in hospital involves four components : "1. the ability to experience another's feelings (emotive) subjectively, 2. a compassionate force that motivates empathetic practice (moral), 3. an understanding of the other person's perspective (cognitive) and 4. the ability to act in a helpful way that is based on a validated understanding (behavioural)". However, Campos *et al.* (2017) and Weis, Zoffmann, and Egerod (2014) highlight that NICU staff are not well equipped to share sensitive information with the already stressed parents, which is attributed to a lack of specific training in communication skills.

As such, most NICUs, especially in the developing world context, still follow the traditional NICU system where infants are under the supervision of NICU staff only, with limited parental involvement (Sankar *et al.*, 2017). This system creates a hierarchical care structure that hinders effective parent-staff communication (Jones, Woodhouse, and Rowe, 2007; Brock, 2015; Kowalski *et al.*, 2006; Bramwell and Weindling, 2005). The parents are given updates on their infants' mostly during ward rounds and counselling sessions. Miscommunication, inadequate explanations of medical terms and conflicting information from the NICU staff have been reported as some of the communication barriers in the NICU (Wigert, Dellenmark, and Bry, 2013; Coats *et al.*, 2018; Russell *et al.*, 2014). In addition, the unfamiliar technical NICU environment and cultural factors hinder effective NICU communication (Heidari, Hasanpour, and Fooladi, 2017; Rostami *et al.*, 2015; Ramezani *et al.*, 2014). In the next section, we describe how these factors affect NICU communication in detail.

2.3.1 NICU Hierarchical Structure

Most health environments have a hierarchical structure, which creates a power imbalance between health personnel and patients or caregivers (Henderson, 2003; McDonald, Jayasuriya, and Harris, 2012; Molina-Mula, Gallo-Estrada, and Perelló-Campaner, 2018; Tang *et al.*, 2013). Power can be described as the relationships between two or more entities where one entity's behaviour may affect the other (Bristowe and Harris, 2014). Power imbalance often emerges due to differences in social, cultural and professional differences between health personnel and the patients or caregivers (Tang *et al.*, 2013; Rothmann *et al.*, 2016). In the hierarchy of health professions, doctors have often uphold their professional autonomy, and independence in their relationships with other health personnel. Moreover, health personnel do not efficiently share their knowledge and decision-making role with patients or caregivers (Henderson, 2003). Instead, they tend to control patients'/caregivers' input, thus hindering them from contributing to their health care.

Within sociology, the work of Michel Foucault has supplied an understanding of medical profession function in clinical settings (Powers, 2003; Molina-Mula, Gallo-Estrada, and Perelló-Campaner, 2018; Bristowe and Harris, 2014). Foucault's empirical analyses of power call attention to the notion that patients who lack medical knowledge are placed in a position of the vulnerable supplicant when they seek consultation from health personnel. In return, health personnel exert their power on patients through different manipulations, thus giving patients or their caregivers little opportunity to challenge their decisions (Molina-Mula, Gallo-Estrada, and Perelló-Campaner, 2018; Powers, 2003).

In a NICU context, literature shows that the staff predominantly take care of hospitalized infants, thus limiting the parental role to merely instruction receivers (Jones, Woodhouse, and Rowe, 2007; Obeidat, Bond, and Callister, 2009; Heidari, Hasanpour, and Fooladi, 2015). The power inequality in a NICU hinders parents from expressing their views or making decisions about their infants' health in the presence of the NICU staff (Jones, Woodhouse, and Rowe, 2007; Van McCrary *et al.*, 2014; Obeidat, Bond, and Callister, 2009; Wigert, Blom, and Bry, 2014). As a result, Ionio *et al.* (2016) research delineates that NICU parents feel powerless, hopeless and alienated within the NICU environment mainly because they lack the information required to involve them in their infants' health decision-making.

In addition, Wigert *et al.* (2012) identified that doctors sometimes do not directly share information with parents. Instead, they relay the information through the nurses. This limits parents' interactions with the doctors who hold a vital medical diagnosis of the hospitalized infants. Desai *et al.* (2017) also identified that the nurse-doctor hierarchical relationship attributes to poor teamwork and communication, which eventually contributes to miscommunication or reporting errors when interacting with parents. Doctors possess greater power in decision-making which causes them to have lesser interest in collaborating with the nurses. Consequently, this leads to ambiguous communication between doctors and nurses, affecting their interaction with parents.

A study by Rosenstein (2002) on the perception of NICU staff team towards their working relationship showed that nurses often call doctors to check on the infants without sufficient health information about the infants. This unclear communication affects nurses-doctors working relationships thus causing nurses to leave the profession (Chiswick and Roberton, 1987). This duty withdrawal results in the staff shortage in NICUs, which is critical to effective and efficient communication with parents. Chiswick and Roberton (1987) suggest that it is essential to integrate nurses into the medical care team to ensure that they have accurate and adequate information to share with the parents.

In a South African context, Honikman, Field, and Cooper (2020) show that maternity care nurses often abuse mothers because they see themselves as subordinate to doctors. The intertwined histories of apartheid and the nursing profession in South Africa facilitated a specific scrutiny of the negative interpersonal interactions between health care providers and women in public health sectors (Jewkes, Abrahams, and Mvo, 1998). Mannava *et al.* (2015) metadata review indicates that women seeking maternal care often reported negative behaviours such as verbal abuse—specifically shouting and scolding, as they sorted care during antenatal care, child birth and postnatal care. These negative attitudes limits women-health personnel interactions, thus making women feel abandoned during consultations or in critical situations where they need assistance. Kredo *et al.* (2019) work evidence that South African health personnel indeed work under very trying circumstances. However, the challenges they face do not justify the abuse of patients. Hence, White, Phakoe, and Rispel (2015) advocate continuous ethics education and management of health system deficiencies to enhance health caregivers' professional development and their ethical decision-making and practice so that health personnel can build empathy with patients.

2.3.2 Inadequate Communication

In the NICU context, the ethical and medical issues encountered routinely are highly complex and need to be communicated to stressed parents in an effective manner (Enke *et al.*, 2017). However, several studies have reported miscommunication, inadequate explanations of medical terms and conflicting information as some of the barriers that hinder parental education and parents' ability to actively partake in their infant's health care decision-making (Musabirema, Brysiewicz, and Chipps, 2015; Fleck, 2016; Spiridonov, 2017; Weis, Zoffmann, and Egerod, 2015). As a result, poor and inadequate communication results in patients' dissatisfaction, increased complaints and litigation.

For instance, according to Wigert, Dellenmark, and Bry (2013) and Mok and Leung (2006) studies, parents mentioned they did not receive emotional support and adequate information to involve them in the decision-making of their infants' health, thus exacerbating their stress levels. To further understand the inefficient NICU communication, Makworo, Bwibo, and Omoni (2016) identified that lack of space, language barriers, staffing and time limitation hindered health personnel from providing parents with individualized care. Due to the lack of essential facilities in the public hospitals, most parents opt not to stay with their infants in the NICU, thus eliminating them from the infants' care team.

With the health of hospitalized infants at stake, learning to communicate effectively and efficiently with all patient-care team members is critical. Shields (2015) recommends holistic care where parents are equipped with relevant information to promote their partnership with NICU staff in the care of preterm infants. However, implementing this patient-care team is challenging, especially in developing countries, because nurse-to-patient ratios are high. To make it work, health services managers should amend the hospital policies to ensure that all those concerned with the care of children are equipped with the relevant information.

2.3.3 NICU Technical Environment

Giving birth to a premature infant that requires admission to the NICU increases parents' responsibility (Barkin *et al.*, 2010). Parents are required to visit and take care of their sick infants in a highly technological NICU environment with unfamiliar equipment, displays, blinking lights and noise (Heidari, Hasanpour, and

Fooladi, 2017). This environment frightens and overwhelms parents who cannot interpret the information on the monitor displays or respond to the alarms. The sight of their infants with monitor wires, feeding tubes and oxygen attached to them often causes stress and panic.

This environment significantly impacts parents (Williams *et al.*, 2018). They need to know what the machines, wires and alarms do and the rules for touching their infants who are cared for in a controlled environment. Unfortunately, this information is not readily available (Kim, Garfield, and Lee, 2015). NICU staff required to prepare a supportive environment for parents mainly focus on stabilizing infants' health with limited time to orient parents to the unit environment and activities. That being the case, most parents become spectators with little interaction with their infants. They feel a loss of their parental role and watching their infants struggling to live exacerbates their stress levels. Arnold *et al.* (2013) and O'Brien and Warren (2014) studies show that these parents do not touch their infants in fear of disconnecting the wires attached to the infants.

Consequently, limited parents-infants interaction interrupts and delays their bonding and attachment, influencing the quality of care offered by parents (Heidari, Hasanpour, and Fooladi, 2017). Several studies found that parents in the NICU not only need information about their infants' health but also orientation to the NICU environment (Heidarzadeh *et al.*, 2016; Silva, Silva, and Christoffel, 2009; Heidari, Hasanpour, and Fooladi, 2015). Therefore, there is a need for supporting parents to cope with the NICU environment to enable them to participate fully in the care of their infants. Increased information about the NICU environment and specific aspects that cause stress to parents may allow NICU staff to identify parents at risk and plan interventions to reduce parent stress and promote parents-infants bonding. Prior studies have identified that the scale-up of technology and cost-effective interventions such as family-based care and peer support could support parents to cope in the NICU. In addition, these interventions empower parents to be involved in the care and decision-making of infants care, which eventually restore their parental role (Pas, 2017; Ramezani *et al.*, 2014; Mendelson *et al.*, 2017). In the next section, we discuss these interventions and analyze issues that affect them.

2.4 Programs Used to Enhance NICU Communication

To complement staff-parents face-to-face communication, researchers have explored various approaches to equip parents with relevant NICU-related information. These interventions include the baby diary, which allowed doctors to update infants' progress and parents to write memories, notes and questions or concerns for staff to address during face-to-face communication (Vijver and Evans, 2015). However, staff shortages, frequent change of staff shifts and language barriers hindered the regularity of staff documentation and parents participation. In the following subsection, we discuss other programs used to support NICU parents.

2.4.1 Family-Centered Care in the NICU

Family-Centred Care (FCC) is holistic care that promotes cooperation between parents and NICU staff in the care of preterm infants (Al-Motlaq and Shields, 2017; Shields, 2015; Ramezani *et al.*, 2014). This approach ensures parents are central to their infants' well-being by involving them in the planning, delivering, and evaluating infants' health care. Consistent communication, information sharing, psychological support and education on NICU environment improve parental satisfaction, lower their stress levels and develop a good relationship between parents and NICU staff (Ramezani *et al.*, 2014; Al-Motlaq and Shields, 2017). FCC also has a positive impact on sick infants by ensuring they improve their breastfeeding rate and gain the desired weight, which consequently shorten their hospital stay (Sankar *et al.*, 2017). For this reason, parents incur minimal hospital expenses and achieve optimal quality of their infants' care (Ramezani *et al.*, 2014).

Despite the emphasis on using FCC in NICUs, previous studies have reported challenges in its implementation (Shields, 2015; Al-Motlaq and Shields, 2017; Makworo, Bwibo, and Omoni, 2016). FCC is considered a complex concept where various economic, social, cultural and behavioural factors influence its application (Ramezani *et al.*, 2014). Coats *et al.* (2018) study expressed the difficulty of implementing FCC due to the human factors that influence the relationships between NICU staff and parents. Instead, most NICUs employ the traditional system where infants are supervised and cared for by NICU staff with limited involvement of parents. A study by Lupton and Fenwick (2001) observed that NICU staff were reluctant to become involved with parents to avoid additional NICU obligations. Consequently, parents feel their need for communication are neglected and staff may not be aware of communication problems in the same way as parents (Weis, Zoffmann, and Egerod, 2014; Coats *et al.*, 2018).

This situation is prevalent in low-income countries (Makworo, Bwibo, and Omoni, 2016; Oulton *et al.*, 2011; Russell *et al.*, 2014). There is a paucity of literature discussing the application of FCC in NICUs in these countries. Al-Motlaq and Shields (2017) stated that poorly-resourced NICUs consider FCC as a luxury. Researchers identified factors, such as staff shortages, parents' inability to visit the unit, lack of support from hospital management and absence of FCC in the paediatric training programme as the major hindrance to FCC implementation in low-resourced NICUs (Rostami *et al.*, 2015; Al-Motlaq and Shields, 2017; Makworo, Bwibo, and Omoni, 2016). NICU management needs to identify interventions that will enhance parents-NICU staff communication and evaluate how they establish parents' satisfaction to overcome these shortcomings. Considering the challenges mentioned above that are common in a low-resourced NICU context, this study explores how to promote FCC using a technological intervention.

2.4.2 Peer-to-peer Support Program

Peer-to-peer support is a popular program for improving outcomes of the health of people with a wide range of risk factors and diagnoses (Humphreys *et al.*, 2004; Dixon *et al.*, 2014). In a NICU setting, the peer-to-peer support program has been used to support parents. Peer support can be provided through phone calls, in-person conversations or even through internet-based websites (Hall *et al.*, 2015a). Another model is parent support groups, which are often co-led by veteran parents and NICU staff (Hall, 2016; Hall *et al.*, 2015b).

Peer-to-peer support is advocated in the NICU setting because it allows parents to provide support to each other in a way that NICU staff cannot. Parents are free with each other, enabling them to share feelings they may not express to the NICU staff. By virtue of shared experience, parents have access to practical advice which helps them to partake in their infants' care. In cases where parents do not have the privilege of having their families with them in the unit, other parents serve as friends and family, thus reducing isolation.

In low-income NICU settings with staff shortages, peer-to-peer support programs serve an essential role in disseminating health information. For instance, in parent support groups, the health personnel share the information shared among parents in a simple language that parents can easily understand. Literature has shown that parents who engage in peer-to-peer support programs become more optimistic, confident and accepting of their situation(Hall *et al.*, 2015a; Sorkin and Tracy, 2016). As a result, parental depression and anxiety rates reduce to a level where parents can partake in their infants' care with greater feelings of empowerment.

Despite the numerous benefits associated with this program, literature has shown that low-resourced NICUs are unable to implement it due to language barriers, limited space and cultural factors (Hall *et al.*, 2015b). In addition, low-resourced NICUs lack the proper structures required to plan the recruitment and training of mentor parents. Even when peer support programs are available, these NICUs lack resources to support volunteers and health personnel that provide educational services. Hall *et al.* (2015a) reported that staff are often sceptical that parents can meet other parents' needs.

On the other hand, parents cannot participate in these programs due to lack of transportation to the health facilities or other family responsibilities at work or home (Wigert, Blom, and Bry, 2014; Petrou, Sach, and Davidson, 2001). In such cases, telephonic and internet-based peer support are suitable because they are easily accessible regardless of the geographic location (Globus *et al.*, 2016; McNutt, 2017).

However, one of the drawbacks of Internet-based support is the need for internet access, which is a significant challenge among low-income families. Considering parents' socioeconomic status, this study focuses on investigating viable approaches of using digital interventions to provide peer support and encourage interaction between parents and NICU staff. In the next section, we discuss different approaches where technology has been used to enhance NICU communication.

2.5 Technology Used to Enhance NICU Communication

We conducted a literature review to understand how technological interventions have been used to improve NICU communication. We identified that most technologies, mainly deployed in developed countries' NICUs, had efficiently furnished parents of premature infants with information that enabled them to interact with NICU staff (Hayes *et al.*, 2014; Doron, Trenti-Paroli, and Linden, 2013; Gray *et al.*, 2000; Globus *et al.*, 2016; Mahamood and Reiter, 2011; Weems *et al.*, 2016). Most of these technological interventions provide parents with a continuous update on their infants' health status, explanation of common medical terms used in the NICU and information on parental roles in the NICU and after infants are discharged from the NICU (Mahamood and Reiter, 2011; Hayes *et al.*, 2014; Globus *et al.*, 2016). We further analyzed the existing technological interventions to understand their strength, challenges and replicability in other NICU contexts. We focused on identifying the purpose of the interventions, how they were implemented and their impact at the end of the study. We identified three categories of NICU interventions. These are communication technologies used to provide 1. neonatal status; 2. ad-hoc communication services; and 3. parental education. These categories of interventions are discussed in the following sub-sections.

2.5.1 Communication Technologies used to Provide Neonatal Information

To provide parents with a continuous update on infants' health status, we identified that video-conferencing tools and Natural Language Generation (NLG) systems are mainly used based on their security-enhanced features that allow NICUs to enhance health information confidentiality when sharing infants' images and medical reports with parents. Furthermore, researchers advocate these technologies because they allow parents to access information even when away from the hospital.

Video-Conferencing Systems: Virtual and online support systems are currently being used in the NICU to provide technical information regarding the care of the hospitalized infant, prognoses of these infants and the role and skills expected of parents at discharge (Joshi *et al.*, 2016; Luu *et al.*, 2017; Yang *et al.*, 2014). These systems provide a portal that allows care givers to access tailored information pertinent to their newborn infants' care. For instance, Gray *et al.* (2000) deployed the Baby CareLink telemedicine application: a tool that provided information to parents using both a website and video-conferencing system. Their deployment findings show that the application supported the educational and emotional needs of families. However, many parents had Internet access challenges, which limited the adoption of the Baby Carelink system. These findings are similar to Lindberg and Öhrling (2012), who deployed a video-conferencing system to support parents who were unable to visit the NICU. In addition, Gund *et al.* (2013) identified that health personnel were reluctant to adopt a video-conferencing system since they added extra responsibilities to their roles.

The government of Canada invested three million Canadian dollars in implementing the ChezNICU Home system to maintain virtual contact between parents and their infants (McNutt, 2017). The system strengthens staff-parent relationships and augments the care provided by enhancing communication and providing accessible, up-to-date, standardized education materials to parents. Similarly, Joshi *et al.* (2016) offered webcam cameras to parents of preterm infants and used them for communication between staff and parents. However, these studies reported that the web camera increased nurses' workload and stress, which as a result had adverse effect on providing quality care. In addition, some parents did not embrace the webcam intervention due to cultural and economic factors. Some families (Amish, Mennonites and Hmong) preferred not to use the camera because it was against their cultures. Some families living close to the hospital also preferred visiting infants at the hospital rather than using camera services since it was economical.

We established that video-conferencing systems are viable tools for disseminating or accessing information in cases where parents cannot visit the NICU. This intervention enables parents to interact with NICU staff when they need educational and emotional support. Feedback from NICU staff enhanced parents' confidence, thus encouraging them to partake in their infants' care. For instance, according to Joshi *et al.* (2016), some mothers reported increased breast milk volume as they observed their infants on camera. Nevertheless, the necessity of Internet access and expensive devices hindered some parents from enjoying the benefits of video-conferencing systems. Supportive NICU intervention should focus on limiting infant care costs, bearing in mind that NICU care is expensive. Alternatively, parents ignored the intervention and chose to visit their infants in the NICU.

Therefore, it is essential for researchers to emphasize that video-conferencing tools are not intended to replace parental presence in the NICU but to bridge it. In addition, consideration should be made to ensure that intervention does not increase health personnel workload but instead support them as they interact with their parents. These considerations can be articulated at the project's onset by engaging parents and NICU staff in a collaborative discussion to voice the design ideas to ensure the final intervention meets their needs.

Natural Language Generation (NLG) Systems: NLG systems have increasingly been used to develop e-Health systems (Hueske-kraus and Kraus, 2003; Pauws *et al.*, 2018; Lindahl, 2005). Within healthcare, health personnel store increasing amounts of patient data within computerized health databases. This information is stored in patients' records which also includes drug databases and description of common medical terminology. Besides helping to provide information support to clinicians, NLG systems play a more significant role in providing patients with access to personalized health information.

In the NICU setting, BabyTalk family systems are being used to communicate medical information summaries for parents of preterm neonatal infants (Mahamood and Reiter, 2011). These interventions include the BT-45 system that automatically summarizes 45 minutes of continuous and discrete data in four stages to assist parents in real-time decision making (Gatt *et al.*, 2009). BT-Nurse provided summaries for nurses to assist in shift handover, thus allowing nurses to provide correct information to the parents that do not conflict with nurses in previous shifts (Hunter *et al.*, 2011).

The research and improvement of the BT-family system are still in progress and researchers are currently exploring the use of representing information in an emotion-sensitive manner. This development has led to the creation of 'Affective' NLG (ANLG), which takes into account parents' emotional aspects and modifies its textual output (Mahamood and Reiter, 2011). After evaluating the system, they found that such effective strategies may be appropriate, especially when communicating sensitive, emotional information to parents with little knowledge about technology.

While many NLG applications have been deployed in high-income countries' contexts, low-resource settings remain relatively nascent. Among the few emerging systems in low-resourced countries are those used in the health domain to generate and analyze clinical text in languages other than English (Byamugisha, Keet, and DeRenzi, 2017; Wahl *et al.*, 2018). These systems show promising outcomes by allowing patients/caregivers to access health information in a simple language that they can easily understand. Accessing health information in simple language is essential in a low-resource context where the language barrier hampers health communication with patients. Also, healthcare personnel use these systems to obtain and communicate relevant information on patients and their treatment.

Although NLGs promise to transform healthcare services in a low-resource context, various hurdles limit their implementation. NLGs are often data-intensive to train, which makes them expensive to develop. Health records in low-resource countries are maintained in hand-written records in local languages. Lack of internet access and Information and Communication Technologies (ICTs) infrastructure hinders low-resource hospitals from implementing electronic health records. For this reason, Hunt and Hartman (2018) highlight that there is limited text available for low-resource languages and dialects. As such, developers need tools and innovative learning techniques to expand the corpora for these languages, which is often difficult and time-consuming (Agaronnik *et al.*, 2020; Mi *et al.*, 2019).

Therefore, for NLGs to benefit users in low-resource settings, these challenges need to be considered in the design process. These design considerations can be achieved using a human-centred design where patients and health personnel design and implement new NLG systems. Despite the potential of NLG systems in low-resource NICUs, their application is out of scope in this research because we are dealing with multilingual NICU parents from varying cultures and socioeconomic statuses.

2.5.2 Ad-hoc day-to-day Communication Interventions

Frequent NICU communication is essential to keep parents and NICU staff abreast with infant health status. An infant's medical issues encountered routinely in the neonatal unit need to be communicated to parents as soon as they occur. Considering the sensitivity of infants' health information, most NICUs use Short Messages Services (SMS) (Globus *et al.*, 2016) and phone calls (Keraan *et al.*, 2017; University of Rochester medical School, 2019) to share personalized information with parents. These communication channels are widely used in a low-resource context because patients/caregivers do not require high-specification phones to access information.

With regard to broader literature about SMS, numerous studies have showcased the efficacy of SMS notification in the health domain (DeRenzi *et al.*, 2012; Densmore *et al.*, 2013; Perrier, 2019; Castillo, 2017). SMS have been widely used as reminders (DeRenzi *et al.*, 2012; Castillo, 2017), to alert the community of outbreaks in their community(Bradley, Johnston, and Smyth, 2014; Toda *et al.*, 2016), to share patients' health information (Perrier, 2019; Globus *et al.*, 2016) and for communication purposes(Densmore *et al.*, 2013). SMS are a cheap and easy way to disseminate health information. However, delays in information delivery have been reported as the main challenges of using SMS(DeRenzi *et al.*, 2012; Perrier, 2019). This limitation may affect patients' or caregivers' actions toward healthcare which may be detrimental if an immediate response is required. Also, SMS in health education does not guarantee health information confidentiality since the text is not encrypted.

Taking this into account, parents' use of SMS in NICU needs to ensure that secure health information is accessible by parents in real-time. Real-time information access enables parents to make an immediate decision on their infants' health when their input is required during infants' care. Although Globus *et al.* (2016) reported improved NICU staff-parents interaction after using the SMS platform, further study is necessary to investigate the confidentiality and ways of ensuring parents' understanding of medical jargon used in the NICU context. Understanding the format of sharing information and modes of delivery are salient to NICU parents.

In this study case, the unit is already using phone calls to remind parents to visit their infants. However, SMS platforms are not feasible since the NICU does not permit the sharing of infants' health information. Another reason we are opposed to SMS utilization in this context is that the unit works with parents from a multilingual community and the design of an SMS platform for the various languages used is not viable.

2.5.3 Parental Education Systems

The wide usage of smartphones and affordable prices of wireless technologies have led to the explosion of mobile application developments. The increasing number of preterm infants being born globally, the high cost of caring for these infants and the need for frequent NICU communication push healthcare providers and system designers to create web and mobile applications that can be used to provide parental education. These tools aim to complement staff-parents communication.

For instance, NICU-2-Home (Garfield, Young, and Lee, 2014) and MyPreemie (Doron, Trenti-Paroli, and Linden, 2013) are mobile applications used to provide parental education, monitoring of infants' progress and encouragement to parents of preterm infants. The applications proved that they could ease stress among parents and avoid the need for NICU staff from repeating information to them. They argued that smartphone applications are practical for NICU parents commuting for months between work, home and the hospital with a desire for personalized and synchronized information.

The Creating Opportunities for Parent Empowerment (COPE) is a four-phased educational-behavioural intervention program that offers parents an audiotape and written materials to educate them on what to expect from their preterm infants during the NICU stay and for nine months after discharge (Melnyk *et al.*, 2004). Melnyk *et al.* (2006) evaluated the program with 260 families with preterm infants and identified that parents had less parental stress because they understood their infants' behavioural cues, and how to care for and bond with them. With NICU staff support, parents gradually gained confidence in their parental role. This experience is similar to Vijver and Evans (2015) research that used the diary to improve parents-NICU staff communication. Although these interventions were effective, they limited parents-NICU staff face-to-face interaction. Instead, they communicated through written materials. According to Toyama (2011), technology should be an enabler that does not replace the need for human interaction.

Estrellita (Hayes *et al.*, 2014) and fitbaby (Hayes *et al.*, 2010) included two interfaces: a mobile application and a web-based clinical interface. The mobile application allows users to record Observations of Daily Living (ODLs) for the infant and caregiver which is visible to the clinical providers. The website allowed healthcare providers to interact with the caregiver and keep abreast with the infant's health status. The system evaluation showed that the systems were usable by parents with minimal training.

However, some of these aforementioned web and mobile applications for NICU require parents to own expensive devices and high broadband internet to access educational content. Most parents in these studies mentioned that lack of Internet access hindered them from accessing parental information. According to Enweronu-Laryea *et al.* (2018), the economic cost of hospitalized infants is high and available interventions required to support parents should be cost-effective. This consideration is paramount in the low-resource NICU context where socioeconomic factors are a major hindrance to parents involvement in their infants care (Makworo, Bwibo, and Omoni, 2016; Al-Motlaq and Shields, 2017).

Therefore, there is a potential for using these interventions to support NICU parents, pegging on the proliferation of mobile for health (mhealth) applications in low-resource countries. However, the design process of the technological intervention mentioned above partially involved parents in the design process. Thus their adaptation in other NICU settings, especially in low-resourced NICUs, where parents have limited access to the Internet and advanced devices, might be limited since the needs of parents in low-income settings differ from those in the developed world. Hence, there is an opportunity to study some of the novel design considerations for NICU technological intervention that could educate and encourage parents to interact with the NICU staff in the care of premature infants. The design process of NICU intervention is achievable if parents and NICU staff are involved throughout the design process to ensure the final product is usable and sustainable in a low-income NICU context. In the next section, we discuss the methodology used to design the existing NICU technologies, highlighting the strengths and challenges of the NICU intervention design process.

2.6 Design Process for NICU Interventions

Implementing technological intervention in the NICU setting requires intense cooperation from parents and NICU staff to identify interventions design ideas that meet their needs. Despite the deployment of various NICU technological interventions that have been discussed in previous subsections, none involved parents throughout the design process. For instance, Hayes *et al.* (2014) used User-Centred Design (UCD) methodology in the design process of the Estrellita system. However, they partially involved parents in the design process. Parents were interviewed in the initial stage of the design process to identify their communication needs. However, due to other parental roles, parents had limited time to engage in the design process. Instead, designers and NICU staff collaborated in articulating approaches that the system would support parents. They used brainstorming and paper prototyping methods to develop the Android design prototype. After developing the mobile application, some parents were involved in pilot testing to provide feedback on the system usability.

Similarly, Garfield, Young, and Lee (2014) conducted semi-structured interviews with parents to identify devices that parents owned and parents' information needs. The study did not provide details on the design process of the NICU-2-Home system. Instead, they explained how parents were included in two randomized group studies to evaluate the effectiveness of the information provided and system usage. Each parent in the intervention group was given a smartphone with the NICU-2-Home application, mobile phone service, and a data plan.

Doron, Trenti-Paroli, and Linden (2013) used their experiences as neonatologists and mothers of preterm mothers to articulate the features and content of myPreemie mobile application. They shared their app requirements with system developers who built the tools and parents were only included during the evaluation process. On the other hand, Lindberg and Öhrling (2012) included only two nurses in the design phase of the Baby Carelink system and parents were included during the system evaluation process. Even so, parents did not fully participate in the evaluation process because they lacked the required technological device. The other NICU systems discussed in section 2.5 do not provide information on the design process of NICU systems. Instead, researchers provided feedback on system effectiveness after parents had utilized them. The lack of design criteria for existing NICU systems limits the reproducibility of similar systems.

Based on the analysis of the NICU systems design process discussed in this subsection, it is essential to consider NICU power inequity, parents' technical knowledge, and socio-economic and cultural status before engaging NICU stakeholders in a collaborative design process. In summary, we identified various factors that hamper parents' involvement in the NICU system design process. These factors include unavailability of parents due to other parental roles (Hayes *et al.*, 2014), limited technical knowledge (Mahamood and Reiter, 2011; Gray *et al.*, 2000) and the sensitivity of the design topic(Hayes *et al.*, 2014; Gray *et al.*, 2000). In the following subsections, we expound on how the factors mentioned above affect the design process of NICU intervention and recommend possible strategies for bypassing them.

2.6.1 Power Relations in Participatory Design

Participatory design (PD) (also referred to as co-design) is an iterative approach to design that actively involve all stakeholders in the design process to ensure the final solution meets their needs and is usable (Sanders, Brandt, and Binder, 2010). In the health environment, PD is recommended to empower patients/caregivers and health personnel to engage equally in the design of technological solutions (Piper and Lazar, 2018). PD differs from other traditional design approaches, such as user-centred design and contextual design because it helps stakeholders to interact and learn from each other, thus ensuring that the voice of all users is heard (Hussain, Sanders, and Steinert, 2012).

However, these interactions are often affected by the power imbalance among healthcare stakeholders. Health personnel have expertise in health care, while patients' or caregivers' experiences are valuable resources to the healthcare system design. The disparity in health knowledge between health personnel and patients/caregivers may hinder the latter from participating in design dialogue. Researchers such as Guo and Hoe-Lian (2014), Hampshire, Hills, and Iqbal (2015) and Farr (2017) have used Foucauldian lenses (discussed in section 2.3.1) to understand power relations in PD health projects. Hampshire, Hills, and Iqbal (2015) identified that power inequality is manifested when participants have different knowledge capacities, agendas and positions of power. This finding is similar to Molina-Mula, Gallo-Estrada, and Perelló-Campaner (2018) analysis that shows patients are limited from making an autonomous decisions about their health because they fear interacting with health personnel.

In the NICU context, parents feel powerless and alienated within the NICU environment, making it difficult for them to express their views and decision-making over their infants' health (Obeidat, Bond, and Callister, 2009; Wigert, Blom, and Bry, 2014; Ionio *et al.*, 2016). Although few researchers reported using participatory methods in NICU technology design, we identified limited participation from parents. Several barriers to effective interaction between NICU staff and parents include inadequate or conflicting information, cultural influences and power inequality in infant's health decision-making (Jones, Woodhouse, and Rowe, 2007; Van McCrary *et al.*, 2014).

To avoid these limitations, NICU staff need to create a rapport with the parent to empower them to participate in health conversations. Although this is a challenging practice in NICUs considering NICU stakeholders' disparity in knowledge, socioeconomic and cultural status, Wilson *et al.* (2015) suggests the use of various mediating techniques to establish strategies of encouraging participation. This participatory design process is achievable through continuous iterative interactions, which gradually support mutual learning that allows a power shift to parents (Hampshire, Hills, and Iqbal, 2015). However, this iterative process is time-consuming. Therefore, in this study, we focus on identifying ways of involving NICU stakeholders, with limited time, throughout the design process and ways we could combat power inequality to improve participation.

2.6.2 Parents Unavailability in the NICU

As discussed in subsection 2.5.1, NICU technological interventions have proven beneficial to parents of preterm infants. However, parents experience some challenges while using them, which could have been avoided if they were included in the design process. However, according to Balaam *et al.* (2013), designing with new parents bring new challenges for participatory design methods. Parents, especially mothers, tend to focus more on their children rather than on the design activities. As such, researchers need to consider sensitive methods for engaging new parents, ensuring they consider the cognitive, emotional, and physical limitations of their new parental role.

For instance, Ignazio *et al.* (2016) involved a group of mothers and experts in a brainstorming design session that focused on improving the design of breast pumps. They identified the limitation of having mothers attending design sessions and instead chose to use the crowdsourcing process to solicit information through email and social media sites. Similarly, Balaam *et al.* (2015) and Wardle *et al.* (2018) engaged new mothers in the design process of mobile applications to support lactating mothers and learned that mothers with young infants have limited time to engage in the design process. Wardle *et al.* (2018) recommend using surveys over probes and workshop methods since mothers could share their design views remotely and at any time. In summary, we gather that design methods for new parents need to be flexible, quick and undemanding to allow them to participate fully.

2.6.3 Participatory Design in Sensitive Research

Dickson-Swift, James, and Liamputtong (2008) define sensitive research as those that involve participants who might be marginalized or at risk of health, social, or political disadvantage. The fields of health and social science research often deal with sensitive issues that may evoke participants' emotions (Decker *et al.*, 2011). Studies such as end-of-life care (Borgstrom and Barclay, 2017), bereavement support (Massimi, 2013) and design for mental health issues (Wilson *et al.*, 2015; Thieme *et al.*, 2013) fit in the sensitive research category.

Although PD methods are recommended in sensitive settings to uncover people's behaviours, motivations and goals, this methodology poses more challenges for researchers, such as difficulty in 1) building rapport with participants, 2) maintaining research boundaries and 3) protecting participants' vulnerability (Dickson-Swift, James, and Liamputtong, 2008; Waycott *et al.*, 2015a). Despite planning and covering anticipated risks in formal ethics approval, researchers may inadvertently heighten participants' sensitivity to the issues discussed, deterring them from engaging in the study(Waycott *et al.*, 2015a). This design challenge may prevent potential participants from engaging in the design process.

These challenges are severe in the developing world context mainly due to language barriers, low literacy levels and socio-economic and cultural barriers (Hussain, Sanders, and Steinert, 2012; Wadley, 2016; Garzotto and Schelhowe, 2008).

Therefore, few studies have addressed the real-life challenges of doing sensitive studies in the developing world or how participatory design methods have to be adapted in such settings (Winschiers-Theophilus *et al.*, 2010; Oyugi *et al.*, 2008). For instance, Hussain, Sanders, and Steinert (2012) identified that participants were hesitant to participate in the design process due to cultural factors that hindered children from communicating in the presence of their elders. Participants in Wadley (2016) study avoided participating in the design process because they feared facing stigmatization due to the sensitivity of mental health illness. On these accounts, Munteanu *et al.* (2015) emphasize that it is essential for researchers to adjust their research methods to accommodate participants' needs and their socio-culture status.

However, the literature regarding appropriate participatory methods for sensitive research topics is ambivalent. PD has its methodological orientations, methods and techniques which might be incompatible with participants' standards or culture, thus limiting them from engaging in the research (Oyugi *et al.*, 2008). Research methods such as interviews and focus groups might be evasive, making the participants divert the study and follow an alternative course (Dempsey *et al.*, 2016; Jordan *et al.*, 2007). Although these methods have successfully been applied to acquire sensitive information from participants, Danaher *et al.* (2013) argues that these methods cannot be replicated from one project to another.

To that end, researchers need to plan their study and identify appropriate methods or techniques for communicating abstract ideas to participants to enable them to express their needs while at the same time feeling safe and at ease when discussing their sensitive experiences. Also, Dearden and Rizvi (2008) and Winschiers (2006) emphasize that researchers should assess research methods to ensure they are culturally acceptable for the participants. In addition, the selected research methods should consider the sensitivity of participants' cultures by encouraging designer empathy and empowering marginalized individuals (Mattson, A., and Wood, 2014; Dearden and Kleine, 2018). These design considerations are achievable if researchers purposefully familiarize themselves with the local people and their culture at the onset of their study (Hussain, Sanders, and Steinert, 2012; Winschiers, 2006).

Nevertheless, Maunder *et al.* (2007) ascertain PD as a problematic methodology for engaging marginalized participants in technology design. These participants have limited technology literacy and they need sufficient time and space to explore feasible ways of applying technologies in their lives. Marsden (2008) advocates an *empowered design* concept that allows participants to explore high-level technology and understand how they can modify it to fit their own needs. Unfortunately, this approach may not be suitable for under-researched sensitive agendas, such as the communication challenges in low-resourced NICUs that require a greater degree of novelty.

Therefore, Winschiers-Theophilus *et al.* (2010) contend that researchers and participants need to collaborate in PD in a way that allows participants to acquire technological knowledge gradually. Yet, PD and research ethics literature offers little practical, sensitive research guidance to assist researchers in low-income settings understand how to combine different design approaches to safeguard participants' vulnerability. Given the uncertainty regarding the appropriate research methods in sensitive studies, there is still a need for more in-depth analyses of case studies exploring both challenges and opportunities for conducting

PD projects for marginalized people in developing countries.

In this research, we focus on engaging South African low-resource parents of premature infants in the design process of a possible technological intervention that could augment NICU communication. According to our knowledge, no previous research has explored the design of NICU technological intervention in a low-resource context. This design gap provides an excellent opportunity to investigate how NICUs in a low-resource context are currently using technologies to support communication, the challenges they encounter while using these interventions and the appropriate PD approach required to engage this vulnerable group of participants in a design process of a possible intervention that will meet their NICU communication needs. There is an opportunity for understanding parents who have experienced stressful events at NICUs as co-designers and how the design process empowered them using participatory techniques. The participatory methods, techniques and design considerations identified in this case study build testable research strategies based on the real experiences of all stakeholders involved in the design process. We hope that these findings will offer practical design considerations for future researchers in the low-resource NICU context.

2.7 Chapter Summary

In this chapter, we discussed preterm birth statistics and their associated stress and financial burden. We reviewed technologies and programs used to support NICU communication, focusing on analyzing their strengths and challenges. We identified that existing NICU technologies, mainly deployed in developed countries, did not fully engage parents in the design process, thus leaving a design gap in how to engage both parents of premature infants and NICU staff in a collaborative design process of NICU communication intervention. Therefore, in this study, we focus on identifying the appropriate approach to engage low-income, multilingual parents with limited design skills in a design process of a NICU communication tool that may encourage parent-NICU staff interaction. We hope to uncover the design mechanisms for the communication intervention during the design process to inform future researchers of design considerations that they need to focus on while conducting similar research in a low-income context.

Chapter 3

Co-ideation: Exploring Communication Challenges with NICU Stakeholders

3.1 Introduction

In this chapter, we describe the initial co-ideation process of a possible NICU communication intervention. Co-ideation is part of the co-design process and it refers to the process where stakeholders are engaged in the process of identifying a problem and generating design ideas that could solve the problem. The co-ideation process in this chapter comprises three phases: 1) needs assessment and idea generation, 2) idea exploration and 3) idea evaluation followed to identify NICU communication challenges and feasible solutions to alleviate mother-NICU staff interaction. These phases focus on answering research questions one and two. In the following sections, we discuss the co-design activities conducted with NICU stakeholders, articulate what we learned about co-design in the NICU setting and design considerations for low-resource NICU communication interventions. We argue that although our methodology helped us uncover NICU communication challenges, it did not include mothers' voices due to power imbalances and limited design skills among NICU stakeholders. Therefore, we suggest that it is crucial to evaluate the co-designed high-level prototype with end-users to understand the constraints apparent to the prototype and find ways of fixing them to ensure the final prototype meets users' needs.

3.2 Related Work

Ongoing studies in the health context have identified that hierarchies and distinctive roles of health personnel and patients or caregivers affect the co-design process of health technologies (Waycott *et al.*, 2015b; Rothmann *et al.*, 2016). Thieme *et al.* (2014) and Slattery, Saeri, and Bragge (2020) indicate that the co-design approach in the health sector is often unsuccessful because HCI researchers are not familiar with specific health contexts. Also, HCI researchers are unaware of the "emotional labour" involved in researching sensitive health settings (Waycott *et al.*, 2015b). Winschiers-Theophilus, Bidwell, and Blake (2012) highlight that designers in unfamiliar contexts, such as the health sector, need to renegotiate their design approaches to enable them to facilitate or respond appropriately in a sensitive situation. For instance, Piper and Lazar (2018) highlight that to democratize the co-design process, researchers should adopt design approaches that encourage all participants to express their health-related needs and feelings using multiple ways to discover and respond to health issues that affect them. On the other hand, Nakarada-Kordic *et al.* (2017) argue that the use of flexible and adaptive creative activities during the co-design process may encourage engagement among participants. Hussain, Sanders, and Steinert (2012) and Winschiers-Theophilus and Bidwell (2013) emphasize that researchers should understand the local culture of participants to help them learn how to facilitate the design process with respect and following participants' culture and beliefs. In the health sector, Green (2016) recommend a co-design process that encourages health personnel, who have vast knowledge in the health sector, to support patients as they drive and shape the digital health intervention that will improve their health outcome.

This patient-centred co-design approach empowers patients or caregivers with limited knowledge in the health context to voice and articulate their health-related needs. Although health personnel-patients engagement is often hampered by language or culture disparities, Thieme *et al.* (2014) encourages researchers and health personnel to employ methods that enable emphatic engagement to gain design insights from the participants' life experiences. They argue that when researchers and clinicians empathize with patients, patients feel valued and empowered, thus encouraging them to share more details about themselves.

This chapter builds upon and contributes to this body of knowledge that focuses on providing a practical understanding of methodological considerations while interacting with NICU stakeholders in an emotionally laden design process. We highlight that having separate homogeneous focus groups before merging them into a joint group does not eliminate power inequity. Instead, it exacerbates the knowledge gap between health personnel and patients, thus hindering patients from voicing their design ideas. Therefore, we argue that HCI researchers working with multiple stakeholders in the health sector should devise methods that encourage collaboration in the design process.

3.3 Participant Recruitment

In this study, we included doctors, nurses and mothers in the co-design process. Although researchers such as Peyton and Wisniewski (2019), Fletcher *et al.* (2018) and Ammari and Schoenebeck (2015) advocate the inclusion of both parents in the design of technologies that support maternal and child health, in this sensitive research, we assessed the possibilities of including both parents and identified that mothers are the main caregivers in the NICU. In addition, we learned that in South Africa, most children have absent fathers, thus leaving mothers as the main caregiver (Richter, Chikovore, and Makusha, 2010; Sonke Gender Justice and Human Sciences Research Council, 2018). To ensure that we do not eliminate single mothers in this study or make them feel uncomfortable as they engage with married parents, we opted to involve mothers only and not both parents.

According to Patino and Ferreira (2018), researchers should ensure that participants are not subjected to unnecessary risk, which could have been avoided if they were included in the exclusion criteria.

During the interview sessions, we visited the NICU and recruited ten nurses (from both the day and night shifts) and five doctors we interacted with during our observation sessions. We also recruited 15 mothers of discharged infants who were attending their infants' follow-up appointments at Mowbray Hospital [1]. We engaged mothers whose infants had been discharged from the hospital for at least one month to ensure that the interview sessions did not impose any emotional harm on them. Unfortunately, we excluded mothers who could not communicate in English since we were not conversant in South African languages.

We used this sample size after attaining saturation. In qualitative research, saturation is reached at the point where collecting additional data will yield similar responses to those obtained earlier; thus, further data collection is not required (Morse, 2000; Malterud, Siersma, and Guassora, 2016). Although (Braun and Clarke, 2014) strongly oppose saturation point in thematic analysis, we argue that when and how saturation may be judged to have been reached differ depending on the type of study. writing from grounded theory standpoint, we defines saturation as: 'the point in coding when you find that no new codes occur in the data (Saunders *et al.*, 2018). In addition saturation is achieved during data collection when new data tend to be redundant of data already collected. When the researcher begins to hear the same comments again and again, data saturation is being reached and it is then time to stop collecting information and to start analysing what has been collected.

Table 3.1 summarizes the co-design activities discussed in this chapter

Phase	**Duration**	**Participants**	**Methods**
Needs Assessment and Idea Generation	7 months Sept 2017-March 2018	15 mothers 15 NICU Staff	Observation Interviews
			Context mapping
Ideas Exploration	4 months Apr-Jul 2018	4 mothers 10 NICU Staff	Focus Groups Brainstorming Role-playing Scenarios
Ideas Evaluation	2 months Aug-Sept 2018	4 mothers 1 Nurse 1 project coordinator	Interviews Observation

TABLE 3.1

Overview of methods used, duration, and the number of participants involved in the three co-design phases.

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[1] A nearby secondary referral maternity hospital where mothers attend their infants' development check-up once they have been discharged from GSH.

3.4 Phase 1: Needs Assessment and Idea Generation (Sept 2017- Feb 2018)

The essence of this phase was to engage NICU stakeholders in identifying the common NICU communication challenges and suggestions for a possible solution that could enhance NICU communication (RQ1). Before engaging NICU stakeholders in the co-design process, we developed the research protocol and submitted it to the University of Cape Town's Faculty of Health Sciences Ethics Review Board, for ethics clearance. While we waited for the approval, we took an online maternal and childcare course to learn how to respond to stakeholders' needs and emotional reactions sensitively. We also volunteered to work in the NICU setting to familiarize ourselves with the environment. Upon receiving approval, we used observation and semi-structured interview methods to engage NICU stakeholders and understand the communication challenges they face as they collaborate in infant care. In the next subsections, we discuss in detail the co-design activities with stakeholders.

3.4.1 Observation

I [2] conducted NICU observations in two parts. In the first part, I registered with the Groote Schuur Hospital's (GSH) Benevolence Department to work as a volunteer in the NICU. GSH NICU admits approximately 2000 infants annually. The wards provide a range of levels of care: the neonatal intensive care unit (NICU) (20 babies); high care (30 babies); pre-KMC (20 babies); and KMC (10 mothers with babies). Other significant features include breastfeeding spaces, sterile milk kitchens, and parent support facilities. For the volunteer work, I was allocated to the KMC section, which admits infants with stable health that are being monitored before they are discharged. KMC section has at least three nurses and one doctor per day. The neonatologist, who is the unit contact person and co-supervisor for this study, introduced me to KMC section nurses who allocated duties to me that did not require medical expertise. For three months, I visited the KMC section once a week for at least two hours and helped nurses to cup feed and clean infants. I also helped mothers to dress their infants whenever they requested my assistance. I built trust and working relationships with NICU stakeholders through these activities as I familiarized myself with the NICU environment.

In the second part of the observation, I conducted observations in all unit sections to gather more facts about the NICU environment and stakeholders. Before commencing with the observations, I scheduled a meeting with the nurse supervisor and discussed my observation objectives and how I planned to achieve them. The nurse supervisor oriented me to all NICU sections and asked nurses to support me as I conduct our study. I also attended the doctors' weekly meeting, where our NICU contact person shared our research objective and asked doctors to collaborate with us as we work in the unit. This exercise was essential to ensure

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[2] In this chapter, I will use the first-person point of view to represent my (the author of this thesis) to discuss the activity I conducted without engaging my supervisors

the NICU staff recognized our intention in the unit, which was only restricted to infants' families.

Over one month, I conducted nine observation sessions. Each session lasted for approximately 45-60 minutes. I visited the NICU at different times of the day—in the morning, during the day and at night, to gather comprehensive details of the NICU activities. Attention was paid to understanding the NICU staff's roles and how they interacted with mothers. I also focused on learning the NICU practices in using technology to support staff-mothers communication. Field notes were recorded in writing during all observations to help us record the behaviours, activities, events, and other observation features. I transcribed the data collected during observation and used NVivo software to conduct a thematic analysis. We used the inductive approach allowing the data to determine the emerging themes. The themes identified were used to shape the interview sessions discussed in the following subsection.

3.4.2 One-on-One Interviews with NICU Stakeholders

After conducting observations for four months, we carried out one-on-one interviews with NICU stakeholders to clarify the information collected during the observation sessions. After recruiting 30 participants, 15 NICU staff and 15 mothers, we opted to conduct interviews with NICU staff before engaging mothers. Since the staff were readily available in the NICU, unlike the mothers who were only available during infants' clinic appointments, the engagement with NICU staff would help us understand NICU communication patterns in totality, making it easier to interact with mothers who were in the unit for a short period. Interviews with NICU staff were conducted at GSH NICU. We shared a written consent form with each participant and gave them time to read through and ask us questions pertaining to the participation or research before they could sign the form. After signing the forms, we interacted with staff from different sections of the unit. We focused on understanding their daily roles in the unit, the communication challenges they faced in the line of work, and their perceptions of how technology could support their interaction with mothers.

After interviewing the NICU staff, the nurse supervisor gave us a list of mothers who had follow-up appointments scheduled at Mowbray Hospital. We called the mothers before the clinic appointments to introduce ourselves and our research objectives. Every Wednesday, we visited the clinic and recruited mothers waiting for the doctor to examine their infants. The recruitment process was challenging because mothers preferred to leave the clinic immediately after their appointment to attend to their household chores. Consequently, the doctor in charge of the clinic decided to introduce us to the mothers seated at the waiting bay before their check-up sessions and explained the objective of our study. Following the introduction, we approached mothers and requested them to voluntarily participate in one-on-one interviews, informing them that the session would not take more than 30 minutes. We volunteered to dress infants after they were weighed by the nurse, thus giving mothers uninterrupted sessions with the doctor as they discussed infants' development goals and nutrition.

In four weeks, we managed to recruit 15 mothers (3-4 mothers per week). After attending their infants' appointments, we ushered mothers to a private room that the hospital provided to ensure privacy during the interviews. During the interview sessions, we focused on understanding the challenges mothers faced during their infants' hospitalization, their communication with NICU staff, how they used technology to access information and suggestions on how technology could help them access their infants' health information. We used open-ended interview questions to encourage mothers to provide additional information, including their feelings, attitude and understanding of the research objectives.

All the interview sessions were emotional, affecting both the mothers and the researcher. In such cases, we diverted the interview to social discussions to help us recollect ourselves before resuming the interview. In cases where mothers were overwhelmed with emotions, we referred them to the clinic counselors who offered psychological support. We did not take photos during these sessions to ascertain the participants' anonymity. Instead, we audio-recorded conversations and took field notes on participants' approval. All the audio data was distorted and deleted after transcription. At the end of each session, we gave mothers picture books as an honorarium. We chose to provide them with picture books because doctors recommend them to help infants' brain development, yet most mothers could not afford them. After the interview sessions, we transcribed the observation and interview data. We later used NVivo software to identify emerging themes we used as input for the phase two co-design process discussed in the next section.

Figure 3.1. Picture books given to mothers as honorariums.

3.5 Phase Two: Idea Exploration (Apr- Jul 2018)

After analyzing the data collected in phase one, we identified unique structural, cultural and socioeconomic factors that affected mother-staff interactions. To demystify how the aforementioned factors influenced NICU communication, we decided to include three doctors, three nurses and four mothers who were interviewed in the first phase. In addition, we recruited two nurses and two mothers to gather new ideas that could help us clarify the findings collected in the previous phase. We used focus groups and brainstorming sessions to generate design ideas and uncover viable areas of innovation in this context. We held three separate sessions with doctors, nurses and mothers before having a joint focus group that included all NICU stakeholders. This co-design approach was adopted to mitigate the power imbalance among NICU stakeholders that we uncovered in the first phase.

In each focus group session, we shared the research objectives and required written consent from each participant before the focus group commenced. We audio-recorded the discussions and took field notes to document our findings. After the session, we offered a chocolate bar to each NICU staff as an honorarium and mothers were offered 100 South African Rands (7 USD) as compensation for lunch and transport. In the following subsection, we discuss our co-design process, describing the research methods applied in each session.

3.5.1 Doctors' Focus Group

From the five doctors we interviewed in phase one, we involved three (two ladies and one male) in the focus group session that lasted between 45-60 minutes. We presented the outcome of phase one and introduced the emergent factors that influenced NICU communication. Based on their NICU experiences, we asked doctors to discuss their challenges while interacting with mothers and viable solutions to these issues. Unfortunately, doctors' interactions led to a disagreement because their ideas towards enhancing staff-mother collaboration in infant care differed. One doctor was fixated on their suggested ideas, thus complicating the idea negotiation process with other participants. During their discussion, we identified they were using an *"Imagine you are a mother and.."* statement to situate mothers' scenarios in the NICU. To ensure conflicts were transcended and translated into meaningful design concepts, we developed two scenarios (described below) based on mothers' narration during prior interview sessions. We then asked two doctors to role-play as mothers and the third doctor took up the doctor's role.

Scenario 1: A mother has a child with a chronic breathing problem. The baby is on and off oxygen. The doctor has tried different methods of administering oxygen to support the infant's breathing. The mother does not understand why her infant's breathing problem is not improving. She takes the infant report book and asks the doctor to explain the medical terms, the state of the infant and the possibility of her infant's health improving.

Scenario 2: A mother in the unit is crying because her infant, whose health was stabilizing, is transferred to the Intensive Care Unit (ICU2) after the doctor conducts some procedures. The doctor tries to explain the condition of the infant, but the mother cannot communicate in English.

After the performance of each scenario, we asked doctors to discuss and clarify the NICU communication needs and solutions emerging from the skit. This co-design approach helped doctors to streamline their ideas, thus enabling them to engage effectively. We later shared a list of technologies suggested during interview sessions and asked doctors to discuss the feasibility and sustainability plan of the solutions. We provided design materials, such as flip charts, sticky notes, pens and pencils. We asked the doctors to take the lead in unveiling possible solutions that could support mothers from low-income settings. They used scenario techniques to showcase how technology could be used to disseminate information. In addition, they listed design ideas on a flip chart before sketching a system workflow to visualize their ideas.

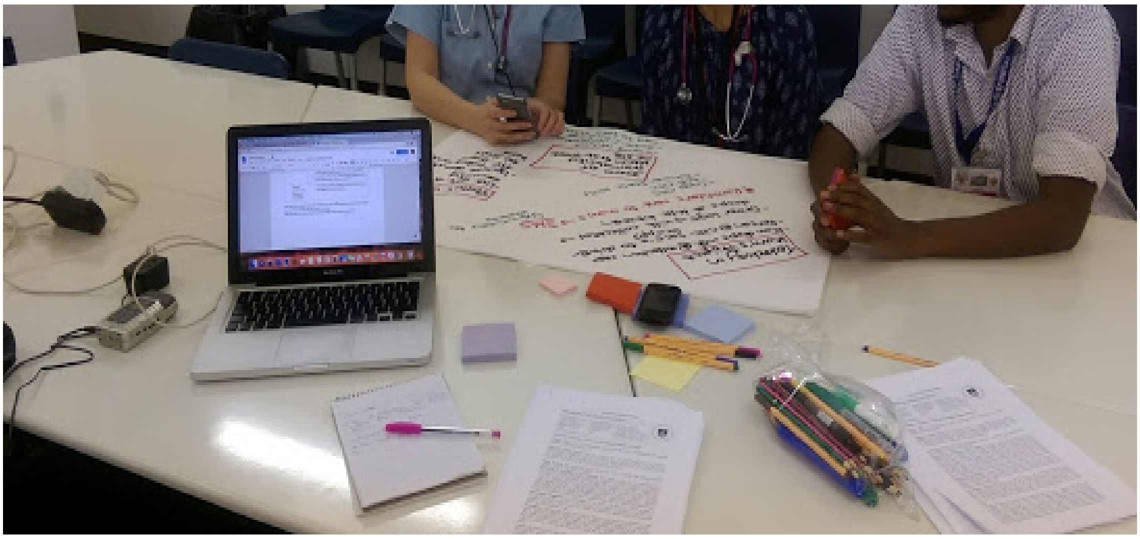


Figure 3.2. Doctors sketching and visualizing their ideas.

3.5.2 Nurses' Focus Group

Two days after conducting a focus group with doctors, we held a focus group with five nurses, of which three participated were included during interview sessions. Among the two newly recruited participants was a nurse supervisor who represents the unit management team. We scheduled the meeting during the nurses' tea break to ensure the section they were allocated in the unit was covered despite their absence. The focus group lasted between 30- 45 minutes. Similar to the doctors' session, we requested nurses to share communication challenges in their line of duty. We focused on understanding how structural and socio-cultural factors hindered their communication with mothers and how they overcame them. In addition, we provided them with a list of technologies suggested in phase one and asked them to discuss the feasibility of these technologies in the GSH NICU context.

Unfortunately, the junior nurses were not free to share or criticize each other's ideas in the presence of their supervisor. As such, the nurse supervisor was dominating the discussion with limited contributions from junior nurses. To mitigate power inequality in the discussion and allow junior nurses to voice their ideas, we asked nurses to individually write their ideas on sticky notes and stick them on a flip chart hanging on the wall. Afterwards, we asked each nurse to expound on their written ideas and use the *card sorting* (Robert *et al.*, 2015) method to organize similar design ideas together. This activity motivated nurses to interact with each other, encouraging them to improve or criticize each other's ideas. We hung a flip chart on the wall with three information categories suggested in phase one and asked nurses to discuss the feasibility of technologies listed in each category. We also asked them to propose more solutions that could meet communication needs in a low-resource NICU context. They wrote their suggestions on sticky notes and stuck them under each information category as shown in Figure 3.3. This activity led to a constructive discussion that allowed the nurses to reach a consensus on viable solutions that could be used to enhance NICU communication.

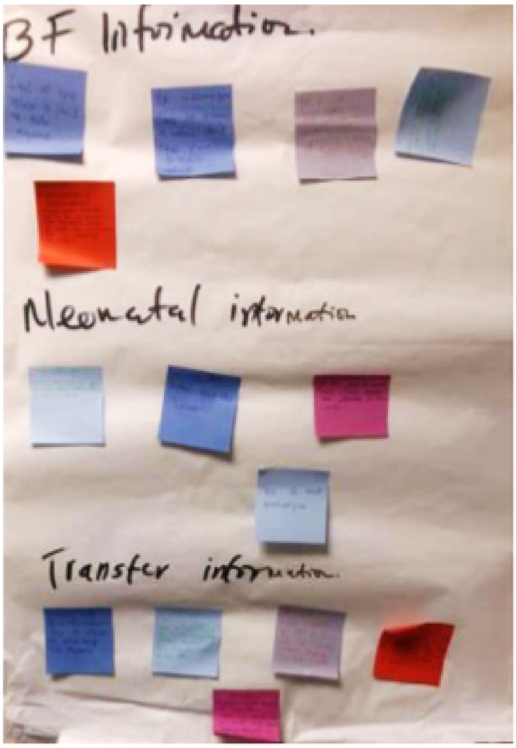


Figure 3.3. Using card sorting methods to categorise the design ideas shared by nurses.

3.5.3 Mothers' Focus Group

We visited Mowbray hospital and recruited seven mothers who agreed to attend the meeting at GSH. Unfortunately, the first two attempts to hold the meetings were unsuccessful, and only two mothers attended the third attempt for the focus group. The unavailability of participants prompted us to include two mothers in the meeting via phone calls. During the meeting, we focused on understanding how power imbalances and socio-cultural factors affected mothers' interactions with NICU staff. In addition, we were interested in understanding how mothers interact with technologies they possess or those available in their households to access infant care information. Thereupon, we engaged them in a brainstorming session where mothers were asked to discuss how they preferred to access their infants' health information while they were admitted to the NICU.

Unfortunately, we had to stop the meeting several times as the mothers received calls from their family members. In addition, one mother who was on the phone dropped the call to feed her infant. After resuming the meeting, the mothers were silent. To stimulate their design thinking, we opted to use *scenarios* (Millen, 2000) based on the information we received while interviewing mothers in phase one. This method helped the mothers to share their challenging experiences in the unit and how they affected them. Eventually, one mother suggested that she would prefer technology to support breastfeeding mothers. Although we expected other mothers to share various design ideas, all mothers chose to endorse the ideas shared by the first mother without further discussing how the suggested technology could be improved.

3.5.4 Joint Focus Group

Shortly after the mothers' focus group, we convened the doctors, nurses and mothers from the separate focus group in a boardroom to discuss the findings and suggestions of each group. We asked NICU stakeholders to use the card sorting method to group similar ideas that emerged from their separate sessions and realign them to design ideas that would support NICU communication. This session aimed at allowing the stakeholders to negotiate their design ideas before arriving at the most viable design idea. We hung flip charts with each group's solution on the wall for stakeholders to refer to their solutions during the brainstorming session. We also provided them with pens and papers to encourage collaborative sketching of a conceptual workflow of a possible intervention that could enhance communication between NICU staff and mothers.

NICU staff emphasized that they were facing major communication challenges with mothers who were unable to visit their infants at the NICU. They reiterated the need for a solution that would help them support this category of mothers who irregularly visited their infants in the NICU. The staff suggested that instead of coming up with an entirely new system, they could enhance the existing NICU projects that supported communication with mothers who could visit the NICU frequently. They recommended an existing NICU project called Mom's Milk on the Move (MoM). MoM project is a project that motivates mothers to express and deliver their breast milk in the local healthcare facility in their neighbourhood where it is collected by scooter drivers and delivered to the GSH NICU kitchen (Relate, 2017). They argued that automating the MoM project's communication mechanism would support mothers who were unable to visit the NICU frequently by motivating them to use the motorbike transportation system established by the NICU to deliver their expressed breast milk to the unit. They also suggested that the system should also share infants' feeding schedules and supportive educational information from NICU staff.

Figure 3.4. Joint focus group with nurses, doctors and mothers.

3.6 Phase Three: Co-design Idea Evaluation (Aug- Sept 2018)

In phase two, the key takeaway was a conceptual workflow to enhance the communication workflow of the MoM project. During phase three, we aimed at gaining an in-depth understanding of the suggested workflow (RQ3). We decided to have interview sessions with the MoM project coordinator, the local facility nurse who managed the project and mothers enrolled in the project. All participants had to sign a consent form before the interview session. We recorded the sessions and took field notes when observing the environs. Mothers requested us not to take pictures in their neighbourhoods or homes to avoid attracting attention from the community. In these interview sessions, we did not compensate the participants since we engaged them in their home area. In the following subsection, we discuss the interview sessions with the MoM project coordinator, mothers and nurses in detail.

3.6.1 Interview with Project Coordinator

We visited the project coordinator's office based at GSH NICU and conducted a semi-structured interview to get a holistic view of the project's objective. We also went through the project's documentation to understand the project operation, enrolment process and impact on infant care. We also presented the communication mechanism workflow proposed during the joint focus group to gain insights into its feasibility.

After the interview session, the coordinator shared with us seven mothers who had enrolled on the project and asked us to get their views on the initiative.

Before we engaged with the mothers, the project coordinator sent text messages to the mothers informing them about our study and the possibility of us contacting them to participate in the study. This procedure was essential to build trust with the mothers during the recruitment process.

3.6.2 Interview with Mothers

We recruited six mothers via phone calls and scheduled home visits with them. They provided direction to their communities and suitable visit times. Three days before our visit, we sent reminder messages to inform the mothers about our scheduled meeting. However, on the day of the visit, two mothers did not answer our phone call. We only visited four mothers. Prior to the visits, we considered our safety in the communities by ensuring we dressed low-key. We also did not carry any devices except for a small phone which we used as a voice recorder.

We visited four mothers over three weeks in different suburbs of Cape Town, spending half a day on each visit. We encouraged open conversation during the interview sessions and mothers shared personal stories about past NICU experiences and the procedure they followed to ensure their expressed breast milk was delivered to the NICU. The next step was to present the communication mechanism workflow proposed during the joint focus group to gain insights on its feasibility.

To make them comfortable, we once again encouraged open conversation for mothers to share personal stories about past experiences and embraced the silence to reflect on what they said previously.

3.6.3 Interview with a Nurse

During the mothers' visits, one mother introduced us to a nurse at the local health facility where she delivered her expressed milk. We interviewed one nurse to understand the breast milk delivery processes and their perception of automating the communication process of the project. We walked through the milk delivery process to learn how nurses interact with mothers. After conducting the fieldwork, we held a brief meeting with the project coordinator to share the mothers' and the community health personnel's feedback.

3.7 Data Analysis

We transcribed all the data collected during our interaction with NICU stakeholders and included the non-verbal expression in our final transcripts. We later used Nvivo software to analyze the qualitative data. We used the inductive data analysis approach. We subjected the data to a three-stage analysis method: data reduction, data display and conclusion drawing (Bottoman, 2004). during the data reduction stage, we read the raw data in detail and summarise it in summary format. We then established a clear link between the summary findings and the research objectives. Open coding was used to look for recurring themes in the data. Using Nvivo, we could easily identify the relationships between themes and figure out underlying ideas and meanings among them. We merged the various themes and came up with three major themes that represented the participants' feedback.

3.8 Findings

In the next sub-section, we present the identified research themes listed in the data analysis section above. In particular, we reveal the NICU communication workflow, factors that hinder effective communication and the perception of NICU stakeholders towards using technology to enhance communication in the NICU.

3.8.1 NICU Communication Workflow

Figure 3.5 provides an overview of the NICU communication workflow that we identified during our interactions with NICU stakeholders.

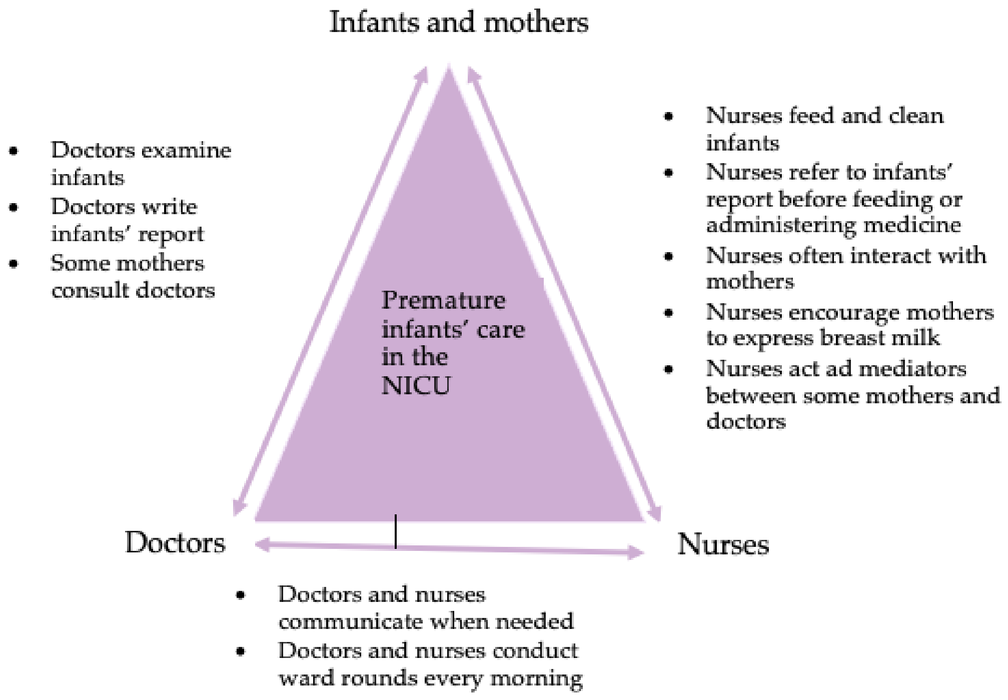


Figure 3.5. Groote Schuur Hospital NICU Communication Workflow.

We learned that doctors and nurses often interact when conducting medical procedures on infants. They work together to ensure they are on the same page regarding the infants' condition and treatment. Nurses consult doctors before administering medication, discharging or moving an infant from one section of the unit to another. Moreover, doctors consult each other while attending to the infants. They sometimes use neonatal medical books or smartphones to access online medical information when conducting procedures and writing medical reports.

However, there is minimal communication between the NICU staff and mothers. Doctors interact with mothers mostly during the ward round, which happen in the morning hours. On the other hand, nurses interact with mothers to educate them on breast milk expression, cup feeding and skin-to-skin care. However, these interactions are brief, and mothers said they needed additional support from staff to help them cope with NICU adversity. From our data analysis, we identified three main categories of gaps that influenced communication amongst NICU stakeholders. These include 1) Relational and Trust Gaps, 2) Structural Gaps and 3) Cultural gaps. We discuss these communication gaps below.

3.8.2 Factors Hindering NICU Communication

Relational and Trust Gaps

We observed and identified interaction challenges during interactions between the neonatal staff and parents. During the ward rounds, doctors share updates on the infants' health status with their parents. The interactions were unidirectional, with parents nodding their heads to indicate they understood the information and instructions given to them. These observations were further unpacked during the interview sessions. We identified that mothers feared initiating a conversation with doctors because they viewed them as superior in infant care. As such, mothers reserved their comments or dissatisfaction and opted to follow all the instructions given to conform to the responsible mother's label framed by the neonatal staff. For instance, one mother recounted her NICU experience and said: *"The doctors and nurses knew what was best for my child. I did what I was asked to make sure my child's health got better."* –Mother 1, Interview

We also learned mothers had a strained relationship with NICU staff because they felt NICU staff had taken over their maternal role. Five mothers said they were dissatisfied with the fact that the NICU staff did not involve them in their infants' health decision-making process. Mothers made these comments during the interview sessions:

"I was still in the labour ward, I went downstairs to visit my baby and found my child drinking formula... no one had asked me for my breast milk. I was so angry, but I did not know what to do" –Mother 2, Interview

"Nurses did not tell me they had moved my child from ICU2 to HC1. I was scared something wrong had happened ...you understand? At least I found her, but that was a bad feeling." –Mother 3, Interview

To help them understand their infants' health condition, mothers said they needed educational and infants health information from NICU staff. In particular, they emphasized that they needed to be informed and educated about the NICU procedures conducted on their infants to help them manage the stress related to painful situations that the infants went through. For instance, two mothers mentioned that they witnessed doctors conducting procedures on their infants and were unaware of why the procedures were being performed.

"Doctors had put my baby on a table and did not tell me what they were doing to my child. He was crying so much, and I felt helpless because I could not protect him from pain" –Mother 4, Interview

"My baby cried a lot when they removed blood with a needle from her head. I did not know what the test was all about." –Mother 5, Interview

From our initial engagements, the power imbalances amongst stakeholders became quite apparent. As a result, we chose to have separate focus groups during the ideation process to ensure participants were comfortable in their various groups before engaging with other stakeholders in a joint focus group. We followed up with staff to understand their working relationship with mothers. Nurses mentioned that although they try to collaborate with mothers in infant care, some mothers do not comply with the advice provided. For that reason, nurses are sometimes demanded to be tough on mothers to ensure they cooperate in infant care. We confirmed this during our observation sessions when we observed a mother being scolded by a nurse because she had not delivered expressed milk for her baby. The nurse said:

"Your baby is sick and vomiting because you don't want to express milk. Formula milk is not good for your baby, and you are not putting any effort to help her" –Observation

As a result, mothers fear nurses and comply with their requests to avoid being rebuked. Explaining the situation in the NICU, one mother said: *"The woman sitting next to me did not like the way the nurse handled her baby, but she couldn't tell her. She told her husband, who wanted to report the nurse to the supervisor, but she stopped him because she feared the nurse would mistreat her baby. Sadly, the baby died that night, and the lady felt guilty for not fighting for her baby"*–Mother 6, Interview

On the other hand, doctors said they do not involve mothers during NICU procedures because the process is intensive and emotionally overwhelming for mothers. Instead, they chose to provide mothers with infants' health progress during the ward round.

"We use simple language to inform mothers about the procedures, but they seem not to understand." –Doctor 1, Doctors' Focus group

Moreover, doctors acknowledged that infants' health fluctuates rapidly, and they prefer having irregular meetings with mothers to avoid giving them false hope. To support the notion of intermittent interaction, doctors said they have limited time to provide psychological support due to their heavy workload in the unit. Nurses reiterated the same sentiment arguing that staff shortage in the unit limited them from interacting with mothers.

During the focus group sessions, NICU stakeholders articulated their NICU communication needs in their separate focus groups. However, power inequality effects were recognizable during the joint focus group. There was tension during the session, which limited mothers from voicing their design ideas. Instead, they conformed to the views raised by neonatal staff. Eventually, mothers endorsed MoM's project workflow (discussed in detail in subsection 3.8.3) proposed by NICU staff, even though they did not know about the project. During the field visit, we learned that mothers enrolled in the project even though they did not fully understand how it operated.

"I did not understand how the project operates. I preferred taking my expressed milk to the hospital whenever I had transport money."–Mother 1, Field visit

Despite discussing the project with the project coordinator during the enrolment process, all mothers confirmed they did not comprehend the communication mechanism involved in the project. They said the enrolment process took place when their infants were still in the hospital, and they feared turning down the enrolment request from the nurses and project coordinator. It was clear that mothers' relationship with NICU staff was strained.

Structural Gaps

Our initial engagement with NICU stakeholders revealed organizational factors, such as language, vocabulary, and technological barriers hindering effective mother-staff interaction.

1. Language barriers: We had first-hand experience with this challenge while recruiting mothers for interviews as mentioned in the recruitment process in subsection 3.3. We realized that most mothers were not proficient in English—which is often used by NICU staff. As such, NICU staff found it challenging to interact and discuss infant health conditions with these mothers. Although the hospital has hired interpreters to support mothers, they are rarely in the unit because they have to attend to interpretation needs in other wards. Nurses who were conversant in the mothers' home language mentioned that they sometimes play the interpreter's role and share information in a language that mothers could comprehend. Therefore, mothers focus on cultivating good relationships with nurses to access updates on their infants' health. This arrangement excluded mothers (mostly foreigners) who did not understand common South African languages. One nurse summed up this situation:

"We deal with different parents in the unit. Some of them don't follow our instructions and it is even challenging when we deal with foreigners who do not understand South African languages." –Nurse 2, Interview.

We then sought to understand how such mothers accessed information and learned that the unit designed pamphlets in various languages to support all South African and foreign languages. However, NICU staff confirmed that parents rarely use the pamphlets because they do not understand some medical terms described in their home language. Such mothers depend on their social circles, who hardly visited the unit, to access information from the NICU staff.

2. Vocabulary barriers: Unfamiliar medical terms used in the NICU create additional barriers between mothers and NICU staff. NICU staff said that language barriers and time constraints made it difficult for them to explain terminology to the mothers. In addition, nurses interpreting information for mothers highlighted that most medical terms could not be translated directly from English into the mothers' home language. To support mothers' understanding of their infants' health conditions, doctors said they used simple language. Even so, mothers nodded their heads in agreement despite not understanding the medical terms used by doctors.

To gauge mothers' understanding of their infants' health status, the doctors often ask mothers to reiterate the information they share with them. Unfortunately, mothers remain silent, indicating they did not understand doctors' explanations. We followed up on this issue during the doctors' focus group. Two doctors emphasized that nurses are better positioned to share health information with mothers because they can engage mothers in their home language. This discussion resulted in disagreements because the third doctor was adamant that it was the doctors' role to ensure mothers understand their infants' health status.

"As doctors, we should find means and ways of sharing detailed information about infants' health status. Imagine you are a mother and you do not know what is happening to your child."–Doctor 1, Doctors' focus group

Each doctor stood firm on their initial decision making it difficult for them to negotiate favourable strategies to support mothers in the NICU. However, after performing the skit for the scenarios discussed in 3.5.1, doctors' attitudes towards their initial ideas gradually changed. This change of attitude led to a lengthy discussion, and the doctors agreed that their information-sharing role in the NICU was critical because they better understood the infants' health progress better than the nurses. Overall, during the joint focus group, NICU stakeholders emphasized the importance of using technology to share an explanation of common medical terms used in the NICU.

3. Technological barrier: The neonatal staff use phone calls and text messages to contact mothers who miss unit visits for more than three days. The nurses call these mothers not to provide any health information related to their infants but to remind them to visit their infants and deliver expressed breast milk. We learned that these modes of communication were not effective. Nurses mentioned that most parents are unreachable either because their phones are off or they have changed their mobile phone numbers.

"Mothers change their phone number quite often thus it is hard to get hold of them when we call them using the units landline phone"–Nurse 3, Interview

When asked, some mothers said they own several sim cards from different mobile network operators to take advantage of services such as bulk SMS, data bundles, talk time etc. which are offered at different rates by various service providers. They keep interchanging sim cards, which is among the contributory factors leading to their fractured availability. Others said they shared mobile phones in their households, thus making them unreachable. Moreover, parents confirmed that they ignored calls from unknown callers to avoid being tricked by con men who use different phone numbers to solicit funds. For instance, one mother commented: *"Con men are clever, they use different numbers to trick you. They will call you and SMS you many times. That is why I ignore calls and messages from unknown callers."* —Mother 4, Mothers focus group.

These allegations were evident during the field visits. Mothers did not trust us when we called them. As such, they chose not to meet us in their homes but rather in a public area. One mother said:

"These days you cannot trust people. There is so much crime in this neighborhood, so I wanted to make sure you are genuinely from the hospital." –Mother 1, Field visit

In addition, mothers mentioned it was expensive to call the hospital because their calls had to be redirected from the hospital switchboard to the unit line. This deterred them from seeking their infants' medical status using a phone call. Mothers explained this situation by saying:

"....you could wait for up to 20 minutes before you speak to nurses in the NICU. I tried once and said never again." – Mother 7, Interview

During the field visits, mothers mentioned that phone calls used by the project coordinator were not well-scheduled. Two mothers commented:

"I received random calls from the nurses even when I was at the hospital to visit my child. It was not clear when the hospital people would call us, and most time, I found missed calls from them."-Mother 2, Field visit

"I did not have a phone and the project coordinator would call my husband even when I was visiting my child at the hospital. Such calls frightened my husband." –Mother 3, Field visit

This comment validated the project coordinator's statement that most mothers did not answer her phone calls whenever she wanted to remind them to deliver their expressed breast milk. Further investigation with the mothers revealed that, among other factors, improper NICU communication channels hindered mothers from adopting the MoM's Project initiative. Considering these technological challenges, it was clear that the technological interventions used in the unit were not effective. Thus, we engaged our participants in an ideation process to identify potential cost-effective strategies for bridging communication gaps in the NICU.

Cultural gaps

11 out of 15 interviewed mothers associated their premature birth and hospitalization with various cultural beliefs during the interview sessions. Separation and reduced opportunities to interact with their infants are against their culture and they felt they were not fulfilling their maternal role. Some mothers attributed premature birth to specific cultural practices they failed to conform to while pregnant. In addition, religion and spiritual practices served as a background to explain the present condition of their infants. However, some staff did not understand these practices, dismissing them as uncouth. As such, mothers felt isolated because their cultural practices were neglected as part of infant care.

"I invited an Imam to pray for my baby, but the security guard did not allow him in the unit even though I had requested a nurse who was my friend. To allow the Imam to visit us. This is so stressful that mothers are not allowed to conduct their religious beliefs in the unit" –Mother 4, Interview

"I wanted the pastor to hold my baby and apply holy water on her forehead, but the nurse said we could not remove the baby from the incubator. This was devastating, and I felt less of a mother since I could not make any decision with regards to my baby" –Mother 8, Interview

In response to these comments, NICU staff mentioned that they upheld these restrictions to avoid infants' infections. Due to these restrictions, mothers avoid sharing their views with staff who do not understand their cultural practices. Instead, they looked forward to engaging with staff who were conversant with their cultural belief.

"I liked going there over the weekend because there was a nurse who understood my traditions and what I believed about my child. She always supported me...." – Mother 9, Interview

Mothers emphasized the importance of having culturally concordant NICU staff to connect with on matters related to their NICU stay. They said this would help mother express their needs from their cultural background, thus improving NICU communication. In consensus, during the joint focus group, stakeholders agreed that mothers should be educated on the unit's policies to avoid conflicts between staff and mothers. In addition, all participants agreed that the final design should consider the different cultural practices and languages in South Africa to support the specific needs of mothers in the NICU. In the next section, we discuss stakeholders' perspectives towards the use of technology in the NICU.

3.8.3 Participants' Perceptions Towards the Use of Technology in NICUs

During the interview sessions, we learned that mothers owned mobile phones, which they often used to communicate with their families and friends. Eleven mothers owned smartphones, which they used to access social media such as WhatsApp and Facebook. They also used their phones to take photos of their infants and keep an album to track their infants' development. However, mothers rarely use technology to access information related to their infants' health. The high cost of data deterred them from using the Internet to access online health information.

"Internet is expensive. We only buy it when we need to send important messages to friends and families" –Mother 4, Interview

Twelve mothers reported using the Internet (either using WIFI provided at work or mobile data) during their pregnancy to access pregnancy and motherhood information. However, while in the unit, only three mothers used the Internet to access premature birth-related information. They said that online information was contradicting, thus making them solely rely on NICU staff for support.

TABLE 3.2

Analysis of the suggested communication technologies

Information	**Suggested Technologies**	**Pros**	**Cons**
Breastfeeding information	Digital video	Digital video will be displayed in the unit	Most mothers’ phones have limited capacity to store videos
	Text messages	Mothers with both featured and smartphone can access the information Mother can retrieve the message and read it again	It is hard to reach mothers when they provide incorrect phone numbers
	Interactive website	Mothers with both low-end and high-end smartphones can access information	Requires internet access Only mothers with smart phones can access
Neonatal information	Text messages	Mothers with both featured and smartphones can access the information Easy to use	It is unethical to share patients’ data via text messages due to confidentiality issues
	Toll-free number	Support mothers who cannot afford transport and airtime costs Supports mothers who do not own phones	Some mothers share a phone in their household thus this may lead to a breach of confidentiality
	Digital video	Common conditions which are related to premature birth can be displayed in the NICU.	Expensive approach and requires additional personnel to operate the system Mothers phones have low capacity and cannot store video with large data
Inter-section transfer information	Text message	Easy to use Mothers with both featured and smartphones can access the information	The unit transfer message might give the mothers false hope since infants’ health changes drastically It is hard to reach mothers when they provide incorrect phone numbers

“The Internet information is confusing.... Aaah, I decided to listen to the doctor and nurses advice” –Mother 5, Interview

We further investigated NICU stakeholders’ views on the feasibility of technology as a communication enhancer. Our thematic analysis identified three categories of information that both NICU staff and mothers preferred to share via technological intervention. These are 1) breastfeeding information, 2) infants’ health status and 3) intersection transfer and hospital discharge information. 3.2 summarizes the information categories and possible technology suggested during interview sessions and analysis of each intervention’s pros and cons, as discussed during the ideation process.

During the interview sessions, we learned that mothers of premature infants experience numerous lactating challenges. They needed educational information that could support them as they endeavored to breastfeed their infants exclusively. Also, nurses also suggested that mothers needed to be educated about breast milk donation— a concept supported in the unit to aid infants whose mothers were unable to breastfeed their infants. These statements confirm their suggestions:

"We can use text messages to educate mothers on the benefits of breastfeeding and how they could donate their surplus expressed breast milk." –Nurse 4, Interview

"First-time mothers and teenage mothers have lactation issues and they require regular support. With the availability of mobile phones, they can easily access lactation information." –Nurse 5, Nurses' Focus group

Further discussions with NICU stakeholders revealed that lactation information could be disseminated in three modes, namely digital videos, text messages and interactive websites. However, they agreed that the generated digital video should not feature mothers and infants but should only include only text and voice. In terms of neonatal health information, mothers mentioned that they needed frequent updates on their infants' health status. Mothers and NICU staff suggested that text messages, a toll-free number and digital videos could be used to disseminate this sensitive information. Furthermore, mothers wanted the unit to provide information about their infants' inter-section and hospital transfers. Mothers used their NICU experience to justify the necessity of this information category. For example, one mother said:

"I visited the unit and found they had moved my baby from the section I had left her. They did not inform me about it and I had to move around the NICU to look for her." –Mother 3, Interview

However, during the joint ideation process, NICU stakeholders acknowledged that neonatal and infant transfer information was sensitive and that disseminating this information via phone would breach the confidentiality of patients' information. To adhere to South African National Law, they agreed that the unit should refrain from sharing information that contains patient health information. Upon understanding the critical nature of infants' health information, mothers provided further information that justified the exclusion of these categories of information. They said a frequent update on infants' health information would cause anxiety, especially if the mother is not in the unit.

"I would not like to receive my child's health condition via SMS, it is traumatizing. There is a time my child was transferred between ICU and high care several times. I was scared every time I received a call from the hospital. At some point, I asked the doctor to keep him in ICU because he was OK while there. Every time he left ICU, he got sick" –Mother 1, Joint focus group

Eventually, during the joint focus group, NICU stakeholders (mothers, Doctors and Nurses) unanimously agreed that technology intervention could only disseminate breastfeeding information and simple explanations of common medical terms used to describe infants' health conditions. They decided that access to this information would encourage mothers to engage with NICU staff because they would be aware of the importance of breast milk in infant care and understand the medical terms used by doctors during the ward rounds. In their discussion, they considered the feasibility of various technological interventions and suggested that educational videos could be displayed on the televisions in the NICU.

Further discussions on breastfeeding information revealed that mothers who could visit the unit needed the motivation to continue expressing breast milk for their hospitalized infants. Doctors and nurses emphasized that mothers' breast milk determines the health progress of sick infants since it did not have side effects like formula milk. While discussing their design ideas, doctors mentioned that the unit, in partnership with other non-profit organizations, had launched the Mom's Milk on the Move (MoM) Project to support mothers who could visit the unit, either due to financial challenges or demands from their household duties. The MoM project included a motorbike rider who collected expressed breast milk from local health facilities close to the enrolled mothers' homes. The breast milk was delivered to the unit upon collection, but mothers were not notified about it. Moreover, mothers were not informed whether the delivered breast milk was fed to their hospitalized infants.

To support this initiative, doctors suggested that the MoM project workflow be automated to ensure mothers received notification once their breast milk was collected from the local health facility and when it arrives at the unit. In addition, the system could send motivational messages to encourage mothers to continue expressing breast milk for their infants. The nurses' design idea was in line with the doctors' suggestions. They proposed a system that automated the unit's recording of breast milk delivered by the mothers (those within the NICU and those who could visit the unit) in the unit's kitchen. Upon delivery, the system sends scheduled messages to the mothers, informing them of the amount of breast milk fed to their infants and when they needed to deliver more breast milk.

Unfortunately, the mothers did not have much knowledge about the unit processes that involved expressed breast milk delivery. Their suggestions focused on using text messages to educate mothers on lactating diets and infants' feeding schedules. The NICU stakeholders discussed and negotiated their design ideas with minimal input from the mothers. Nurses used this opportunity to describe the MoM project to help mothers understand its processes. NICU staff endorsed a mashup of the three design ideas to encapsulate all their design ideas. The final design ideas were inclined towards the doctors' initial design with a touch of the nurses' and mothers' suggestions. Nurses sought the mothers' views on the feasibility of the system, and without critical scrutiny, the mothers adopted it. Hence, the doctors sketched the suggested MoM project workflow and added details as requested by the nurses. The mothers did not provide any suggestions. Instead, they silently watched as NICU staff collaborated in developing the project's communication workflow. The final MoM project's communication mechanism workflow is presented in Figure 3.6.

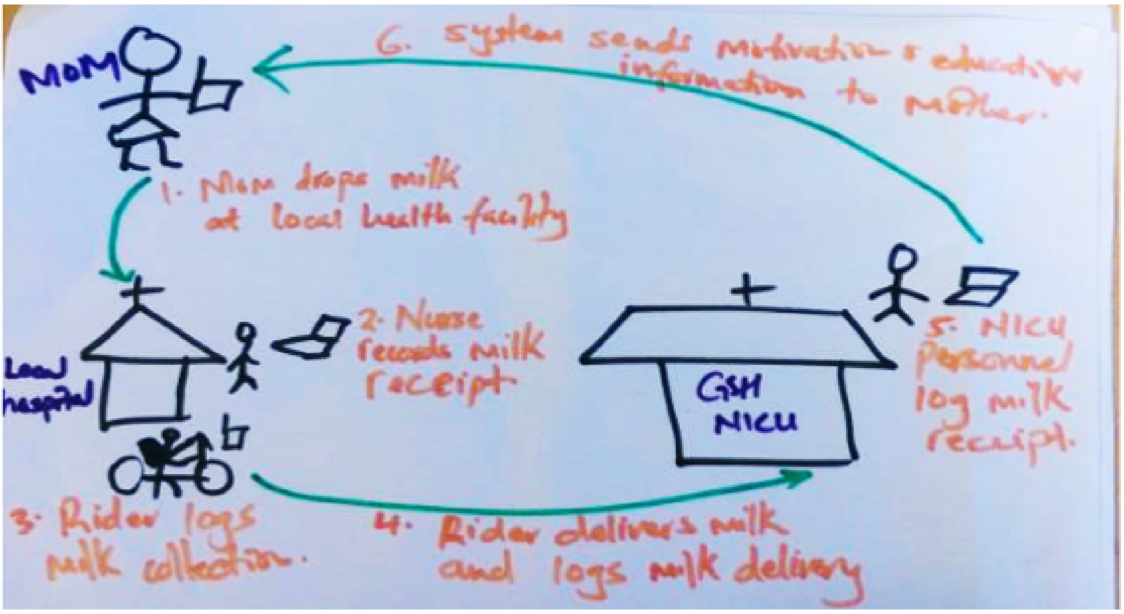


Figure 3.6. Proposed MoM project communication mechanism workflow.

Objection to MoM Project Workflow

Although our home visits were meant to help us understand mothers' households and the processes they took to deliver their expressed breast milk to their infants, all mothers chose to meet us in public spaces such as the hospital (Mother 1), police station (mother 2) and shops near taxi ranks (Mothers 3 and 4). They mentioned that they felt it was safer to meet us in public spaces to prevent security issues with strangers, which were prevalent in their communities. We adapted to the new environments proposed by the mothers to gain their confidence. We then presented our identity cards to ensure the mothers felt safe during our interactions. We also presented our school identity card to justify our position as researchers at GSH. This interaction approach helped mothers to engage in the interview sessions comfortably.

The interview sessions gave us a new view of MoM project services in the communities. While the project aimed to enable low-income mothers to deliver their expressed breast milk to the unit, all mothers confirmed that they did not fully utilize MoM project services. Despite discussing the project with the project coordinator during the enrolment process, all the mothers confirmed they did not comprehend the communication mechanism involved in the MoM project. They said they enrolled in the project, although they were not interested in it.

".... let me tell you when you have a sick child, you say yes to everything told by doctors and nurses even when you don't understand what it is all about. As long as it is good for your child, you go with it." –Mother 1, Field visit

When we presented the proposed workflow to the mothers, they disapproved of it because they rarely used the initiative's services. Further investigation revealed that the MoM project implementation did not consider the mothers' transportation challenges. The mothers said the health facilities designated for milk collection were not in their neighborhood and they were required to incur transportation costs to deliver their expressed breast milk. Due to this, mothers did not see the need of using the project. Instead, they preferred visiting the NICU since they could bond with their infants.

"The closest health facility is in Mitchell's Plain. To get there, I have to take a taxi or a bus which will charge me nine rands. The cost of going to Groote Schuur is 15 rands. So, you see it is better I go to the hospital and see my child." –Mother 3, Field visit

"The health facility is so far and we need to incur additional transport costs. I could have used the rides if they used the local health facilities in our communities." –Mother 4, Field visit

We presented the mothers' views to the project coordinator and asked whether it was possible to include local health facilities close to their mothers' neighborhoods in the project. She mentioned that they had chosen three local health facilities because they met the standards (availability of refrigerator and backup power generator in case of a power outage) required by the South African Ministry of Health to store expressed breast milk. Therefore, the mothers' request for having the milk depot relocated to the health facilities in their neighborhood was only possible if more mothers enrolled in the project to justify the need for an additional breast milk depot. From the document analysis, we identified that only seven mothers had enrolled on the project. In consensus with the MoM project team, we agreed that automation of the MoM project communication mechanism was not feasible since the project was serving too few mothers (seven mothers) who were not using its services. The project adoption was slow and the coordinator acknowledged that they needed to discuss the project challenges with GSH management to identify a better approach to supporting low-income mothers.

3.9 Discussion

This section discusses the lessons learned as we engaged NICU stakeholders in a co-design process of a viable communication intervention. We focus on discussing 1) co-design readiness among NICU stakeholders, 2) factors to consider while engaging NICU stakeholders in the co-design process and 3) design consideration for a possible NICU communication intervention for a low-resourced NICU context.

3.9.1 Understanding Co-design Readiness— Scaffolding Partnership

When working in the NICU environment, it is vital to recognize parental sensitivity and power imbalance among stakeholders. At the onset of this study, we identified there was a power imbalance between parents and neonatal staff. This realization informed our decision for having separate homogeneous focus groups to encourage collaboration in the joint focus group. We assumed that having separate focus groups with different stakeholders would allow each stakeholder group to generate their ideas, thus eliminating power dynamics when they engage in a joint focus group.

However, our design approach failed to encourage collaboration during the joint focus group despite using various participatory methods. Instead, the NICU staff dominated the discussion with limited contribution from the mothers. Moreover, the NICU staff recommended the MoM project workflow as a feasible communication intervention even though mothers had no previous knowledge about the NICU initiative and processes. Although the focus group sessions uncovered communication challenges in the NICU, we realized that having separate focus group sessions did not encourage collaboration. Instead, it limited parents, who are the beneficiaries of the final intervention, from voicing their ideas since they did not have the same technical and medical expertise as the neonatal staff. Thus, similar to Dourish *et al.* (2020), we learnt from our failed experience that it is useful to restructure participatory methods to improve stakeholders' working relations. Having failed to achieve the required result in these separate focus group sessions, we chose to engage mothers in an environment where they felt comfortable sharing their views on the proposed MoM project workflow. These interactions shifted power from the NICU staff to the mothers by allowing them to highlight the project's shortcomings and the infeasibility of the workflow proposed by the NICU staff. Similar to Molapo (2017), we echo the importance of improving the mothers' *co-design readiness* to enable them to articulate and negotiate their design ideas in a co-design process. The mothers' co-design readiness was beneficial to our design process and the MoM project management team, whom we furnished with structural challenges suggested by the mothers as the main hindrance to the project adoption. We, therefore, argue that HCI researchers working with multiple stakeholders with power inequality need to iteratively explore appropriate approaches to establish participants' co-design readiness to ensure the co-design process successfully brings all participants' voices to the table.

3.9.2 Consideration of NICU Stakeholders as Co-designers

Co-design with NICU stakeholders is a rarity due to the sensitivity of the infant care topic and NICU stakeholders' unavailability. Our approach to understanding the appropriate way to engage with NICU stakeholders was to embed ourselves in the NICU environment and familiarize ourselves with the unit's communication workflow and stakeholders' role before delving into co-design activities. In the three co-design phases reported in this chapter, we identify three factors that researchers conducting co-design in NICU should consider while planning their research design. These factors include 1) NICU-related emotions, 2) co-design approach with multiple stakeholders and 3) participants' time. In the following subsections, we discuss these factors in detail.

NICU Related Emotions: The NICU environment is intimidating and has an emotional effect on both the researchers and the research subjects. Throughout the co-design process, we identified that our interactions with the mothers were emotionally laden. Although our interaction with mothers during observation sessions was minimal, we realized that the sight of sick infants surrounded by machines affected us emotionally. In addition, the negative feelings displayed by the mothers occasionally transferred to us as we supported them with infant care. We sought nurses' support which was beneficial in helping us overcome the adverse effect. We assumed that the therapy sessions with nurses would enable us to support mothers in our subsequent interactions since we had a shared NICU experience with them.

Yes, the shared NICU experience with the mothers facilitated rapport and trust-building during interview sessions since we provided them with deep validation of their experiences. However, we were not in a position to give counselling support to them. Instead, the in-depth discussion of the mothers' experiences with hospitalized infants aroused emotions that affected both mothers and us. Borrowing from the skills learned from the online maternal and child health course we pursued, we decided to divert the discussion to general topics to clear the emotional atmosphere. We used the audio and picture books offered to the mothers as an honorarium to play with the children during this break time. The children enjoyed the interactions with these books, which subsequently made the mothers divert their attention to their infants.

We realized these approaches to handling emotional engagement were effective for both the mothers and us. In some cases, the mothers were willing to proceed with the interview sessions. We connected with mothers who could continue with the engagement with hospital nurses who offered counselling support to them. We also provided them with our research phone number to communicate with us whenever they needed emotional support. With the availability of our contact details, the mothers used us as their mediators with the doctors whenever they needed information concerning their infants' health and milestone development.

Despite ensuring mothers were accorded sufficient emotional support, we neglected the exhaustion and emotional impact of the interactions on us. The mediator role took up a lot of our research time since we had to ensure mothers were connected with NICU doctors whenever they needed information. Although these interactions helped us understand communication challenges in the context of the NICU, they were demanding and out of our research scope. However, we could not ignore mothers who trusted us as their mediators.

From these NICU co-design experiences, we drew two conclusions. Firstly, researchers need to analyze the potential emotional effect during their research design plan and establish guidelines for managing them. Although the ethical guidelines used to develop study protocol may not cover all the "emotional triggers" in the study, we recommend the situational ethics approach of Munteanu *et al.* (2015) if such emotional issues are encountered during the study to enable the researchers to adapt to unexpected conditions that may arise after the research design and ethics protocol are in place.

Secondly, researchers should protect themselves from over-engaging with participants' day-to-day emotional management. Nevertheless, this should not impede researchers from enabling empathy with their participants. Instead, they should direct emotional participants to professional counselors to ensure they receive proper care and support. One approach to guaranteeing efficient care of participants is by considering the inclusion of counselors as part of the research team from the onset of the study. The counselors can join the engagement sessions with participants to ensure they handle the emotional issues as they arise and continue providing support to the participants throughout the study. This approach is in line with Hubbard, Backett-Milburn, and Kemmer (2001), who argue that researchers should not manage the emotional impacts of sensitive studies on their own but instead rely on the research team to provide support and advice on effective ways of engaging participants.

Co-designing with Multiple Stakeholders: Co-designing with multiple stakeholders is challenging due to the different stakeholders' backgrounds and areas of expertise. It is even more daunting when working on a sensitive topic. In this study, we engaged NICU stakeholders to identify communication needs and feasible approaches to overcoming these challenges from multiple stakeholders' views. To echo Honikman, Field, and Cooper (2020) study, we identified that NICU staff's social superiority over mothers was pronounced in the NICU setting thus affecting stakeholders' engagement. We experienced co-design dynamics, such as conflicts, power inequality and group thinking that impeded stakeholders from generating diverse ideas.

To orchestrate the group discussions and ensure they translated into meaningful design ideas, we paired and localized participatory methods from our list of participatory methods—which we refer to as the *"basket of methods"*, to find balance in the groups and progressivity in collaborative design. In our basket, we had methods and techniques such as card-sorting, role-playing, scenarios, emojis, brainstorming, sketching and brain dumping that we were ready to experiment with when one option failed. Methods such as observation, role-playing, scenarios and brainstorming were meant to encourage conversation among the participants. emojis, brain dumping, card sorting and sketching aimed at encouraging individuals to share their ideas either when there was silence in the group, if some participants were dominating the sessions or when we wanted groups of participants to share their ideas with other groups. The aforementioned set of methods could either be paired to optimize engagement in the sessions. The method pairing was determined by the co-design dynamic experienced, while method localization was based on the NICU experienced scenarios emanating from the participants' discussions. For instance, in the nurses' focus group, we had to allow individuals to develop their design ideas based on the different NICU experiences before engaging others to avoid power inequality.

In line with Winschiers-Theophilus and Bidwell (2013) methods, localization is necessary for a sensitive research context to ensure participants align their design ideas with their practices and environments. Therefore, researchers working with vulnerable participants should realize their core role as facilitators is not only to establish stakeholders' collaboration, but they should mainly focus on empowering stakeholders through the co-design process. From our experiences, we learned that to achieve favourable co-design results, researchers need to understand the dynamics affecting participants' collaboration to ensure the selected methods empower participants as they collaborated in the design process.

However, researchers should recognize that unforeseen aspects could hamper this facilitation approach. For instance, during the mothers' and joint focus group sessions, our empowering approach did not succeed due to the unavailability of participants in one venue and numerous interruptions from infants' needing attention during the mothers' discussion and the lack of knowledge on NICU communication processes among the mothers during the joint focus group. To ensure the mothers' voices were included in the design process, we decided to visit them in environments convenient for them. This approach empowered mothers who objected to the idea of automating the MoM project communication mechanism. Therefore, we argue, that the ability of the facilitator to determine participant empowerment is crucial to ensure all stakeholders' voices are included in the final design decision. We recommend that researchers should have a proactive attitude embedded in their design process to help them respond to the participants' empowerment process.

NICU Stakeholders' Time Consideration: Researchers working in the NICU environment should factor in stakeholders' time limitations as they plan the co-design process. The NICU's heavy workload, staff shortages and mothers' unavailability may inhibit stakeholders from engaging in the co-design process. In this study, we needed to adjust our co-design activity according to stakeholders' availability. During the nurses' focus group session, we engaged nurses during their tea break to ensure their allocated area of work was covered while they were away. The mothers' focus group was rescheduled thrice to ensure we had a quorum. Unfortunately, most mothers were unavailable. Thus, we had to restructure our co-design approach to include mothers via the telephone. Even so, the discussion was not effective due to the numerous interruptions of infants needing attention, which mothers had to attend to. Similar to Balaam *et al.* (2015), we realized that we needed to make the session flexible to allow mothers to attend to their infants' needs. In addition, we noticed that engagement with NICU stakeholders needed to be short and precise to ensure the availability of participants.

3.9.3 NICU Communication Tool Requirements

There are several design implications for NICU communication interventions in a low-income context. First of all, it is essential to understand the sensitivity of infant care. Although parents may require frequent updates on their infants' health status, researchers should refrain from disseminating infants' personal health information while using a technological intervention. We learned that infants' health status often fluctuates and sharing health status as they happen may exacerbate parents' uncertainty and emotional stress. As such, using technology, in this case, can have adverse effects on parents, thus deterring them from adopting the intervention. In addition, health technologies pose significant privacy and security risks for health information. Despite efforts to create secure health applications, Langarizadeh, Moghbeli, and Aliabadi (2017) argues that many contain serious flaws that increase the threat to the security of information. These security threats are critical in a low-resourced context like our case that shows household phones being shared. This may breach the confidentiality of infants' health information if accessed by an unauthorized family member. Therefore, researchers should focus on sharing supportive and educative information via health technology to empower them to understand their role as caregivers in the NICU.

Secondly, infant care involves the use of unfamiliar medical terms that parents may fail to understand. This challenge is a bigger concern to parents with low proficiency in the language used to disseminate information. Our findings indicate that language and vocabulary barriers limit effective communication in the NICU. Parents rely on NICU staff who understand their home language to access information to partake in the holistic care of their infants. Therefore, researchers should consider parents' multilingualism as they design health information. The participants' languages should not be isolated from their culture. Most parents associate infants' illness and care with their cultural practices. As such, they expect information to be relayed in a manner that respects their beliefs. Thus, we recommend the involvement of health personnel conversant with parents' cultures and languages in tailoring information shared via health technologies to ensure it is medically and culturally fit for parents' consumption.

Lastly, we learned that although most mothers owned or shared a smartphone in their household, they had challenges accessing the Internet due to the high cost of data. They said that their phones were low-end, with small screens and limited space, and they mainly used them for communication (text messages and phone calls) purposes. Therefore, NICU communication applications should not require data access. Instead, researchers should investigate a feasible approach to disseminating health information.

3.10 Chapter Summary

This chapter presents our initial interaction with NICU stakeholders. We focused on identifying NICU communication challenges and feasible technological interventions that could be used to bridge these challenges in a low-resourced NICU context. We used observation, one-on-one interviews and focus group methods to engage NICU stakeholders in a co-design process. Our results show that there are various structural, relational and cultural gaps that affect mother-staff communication. We also uncovered categories of information that mothers' need to partake in their infants care and viable technological interventions that could disseminate the identified information. Based on this information, we engaged NICU stakeholders in a collaborative ideation process. We realized that the sensitivity of the researched topic and power inequality among the NICU stakeholders affected the co-design process. We paired and localized various participatory methods to encourage stakeholders' collaboration. Even so, the NICU staff dominated the discussion, thus hindering mothers from voicing their design views. To empower mothers in this process, we visited them in their community to evaluate the feasibility of the system proposed by the NICU staff and identified that the proposed technology did not meet the mothers' needs. Through this co-design process, we learned that researchers need to acknowledge the challenges of working with multiple stakeholders to inform their research design plan. We recommend that researchers conducting sensitive studies should keep their co-design approach flexible to ensure they can adjust the co-design process whenever they encounter group dynamics, ensuring that all stakeholders' voices are included in the final design decision.

Chapter 4

Co-design: Bridging Stakeholders' Relational Gaps through Mediated Ideation and Cooperative Prototyping

4.1 Introduction

In this chapter, we aim at answering research question three. We discuss the extended ideation and collaborative prototyping sessions that we conducted with NICU stakeholders after identifying the proposed communication mechanism for the MoM project, discussed in Chapter 3, which was not feasible in the Groote Schuur Hospital (GSH) NICU context. We focus on identifying the co-design strategies that encouraged cooperation between different stakeholders to ensure that the final prototype incorporates all stakeholders' design views. Unlike in the co-design process discussed in Chapter 3, where we held separate stakeholders' focus groups, in this chapter, we lay out the importance of having a joint multiple stakeholders' session. We demonstrate how generative co-design techniques effectively mediate and motivate stakeholders to collaborate to design a feasible prototype that considered NICU communication protocol and mothers' technical capacities. Mutual learning during stakeholders' engagement opened a new avenue for the stakeholders to express their design ideas and tailor health information in six categories that were included in the final co-designed NICU communication system. We provide evidence that when empowered, stakeholders with limited design skills can design a suitable intervention that meets their needs. We start by discussing prior work that is related to the co-design process discussed in this chapter. Then we discuss the methods we used to engage stakeholders in tailoring health information and prototyping the interface of the final intervention they decided on. We discuss the information translation and system development process we undertook and lastly, we share our results and results' discussion.

4.2 Related Work

Ongoing studies in the health context have identified that hierarchies and distinctive roles of health personnel and patients or caregivers affect the co-design process of health technologies (Waycott *et al.*, 2015b; Rothmann *et al.*, 2016). In addition, Thieme *et al.* (2014) and Slattery, Saeri, and Bragge (2020) indicate that the co-design approach in the health sector is often unsuccessful because HCI researchers are not familiar with specific health contexts, thus limiting them from facilitating or responding appropriately in a sensitive situation. To overcome these limitations, Piper and Lazar (2018) highlights that researchers should do away with conventional ways of practising co-design and adopt an art therapy design approach that encourages participants to express their health-related needs and feelings through artworks. The art therapy design approach acknowledges that there is more than one right way of engaging in the co-design process. Instead, the approach emphasizes that participants should use multiple ways to discover and respond to health issues that affect them. On the other hand, Nakarada-Kordic *et al.* (2017) argue that the use of flexible and adaptive creative activities during the co-design process may encourage engagement among participants. They emphasize that researchers facilitating the co-design process should encourage clinicians; who have vast knowledge in the health sector, to support patients as they drive and shape the digital health intervention that will improve their health outcomes. This patient-centred co-design approach empowers patients with limited knowledge in the health context to voice and articulate their health-related needs. Although clinicians-patient engagement is often hampered by language or culture disparities, Thieme *et al.* (2014) encourages researchers and health personnel to employ methods that enable emphatic engagement to gain design insights from the participants' life experiences. They argue that when researchers and clinicians empathize with patients, they feel valued, thus encouraging them to share more details about themselves.

This chapter builds upon and contributes to this body of knowledge that focuses on providing a practical understanding of methodological considerations while conducting co-design in the health context. Unlike in Chapter 3 where we held separate co-design sessions with various NICU stakeholders, in this chapter we demonstrate that generative co-design techniques leverage power inequality between NICU staff and mothers, thus encouraging them to collaborate in the design process. that encourages mutual learning multiple stakeholders can engage in a meaningful co-design process. We recommend the use of creative methods to promote mutual learning among multiple stakeholders. We argue that when mothers with limited design skills and knowledge of medical terminologies are empowered with knowledge related to their infants' health, they can interact with NICU staff and collaborate in co-creating health interventions that would encourage staff-mother interaction in the NICU. We also highlight the challenges of co-designing in and for multilingual communities, showcasing the complexity of translating health information into multiple languages.

4.3 Co-design Process

In this ongoing ideation process, we involved 12 NICU stakeholders in two-day workshops at GSH. These workshops aimed to create a space where NICU stakeholders could cooperate and contribute to co-creating health information that was easy to understand and interfaces a viable technological intervention that could disseminate the co-tailored health information. In the first workshop, we engaged stakeholders in co-tailoring health information that would educate and encourage mothers to partake in their infants' health care. In the second workshop, stakeholders collaborated in designing a high-level prototype of the intervention that would disseminate the information generated in the brainstorming session. After compiling the findings of the two workshops, we presented the co-designed health information and NICU communication prototype to a senior neonatologist at the unit who evaluated the information and the high-level prototype of the proposed intervention to ensure it was usable in the NICU context. The neonatologist recommended that the information required editing into simple language that mothers could easily understand. He allocated three NICU staff members, whom we worked with in editing and translating health information into three languages to enable the multilingual users to access the co-tailored health information in their preferred language. We later hired three narrators to help us develop digital health videos in the three languages. We describe the participant recruitment process and the methods applied in the two workshops in the next subsection.

4.3.1 Participant Recruitment

Before the workshops, we visited the unit every Monday for three weeks to recruit mothers of premature infants attending their infants' eye check-up appointments after being discharged from the hospital. We shared the research objectives with the mothers during these visits and sought their views on using technology to enhance NICU communication. We recruited five mothers who volunteered to participate in the co-design sessions scheduled one week after the recruitment process. We also recruited three doctors and three nurses, of whom two doctors and two nurses participated in the idea generation process reported in Chapter 3. In addition, we opted to include new NICU staff to gather new design insights and validate information collected in the initial ideation process.

Unfortunately, on the day set for the focus group design session, only two mothers showed up. We could not reach the other three mothers on their phones. Therefore, we sought advice from the NICU contact person who recommended the recruitment of mothers in the Kangaroo Mother Care (KMC) section. KMC is the NICU section that admits infants whose health is stable and awaiting discharge. We considered the emotional risks involved in engaging these mothers and decided to recruit mothers who had been in the unit for at least three weeks to ensure they had acclimatized to the NICU environment and had vast NICU experience. To bridge the communication gap between the mothers and the NICU staff, we hired an interpreter to support mothers who could not communicate in English during the sessions. Before commencing with the scheduled design sessions, we followed the consent procedures by reading the consent form details and explaining our research work and giving participants a chance to sign the consent form. The interpreter explained the form content to two mothers who did not understand English in their home languages before asking them to sign the form.

4.3.2 Brainstorming Session

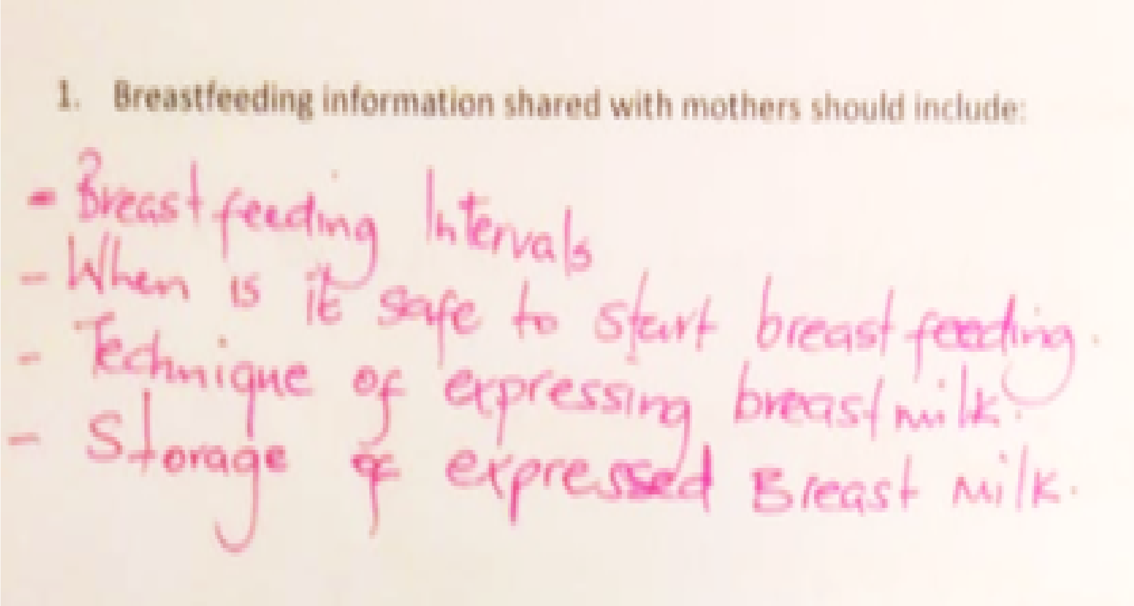
We involved the 12 NICU stakeholders in an hour-long brainstorming session. The session took place in one of the boardrooms in the hospital, which was central for the NICU staff and the mothers attending their infants' eye check-up appointments at the hospital. The session started with a brief introduction to the study and instructions on the co-design process. Then, we put the flip charts with sorted cards, workflows and sketches developed in previous design sessions on the wall to create a design room that encouraged imagination among participants (Nakarada-Kordic *et al.*, 2017).

We later grouped participants into three groups to promote participant interaction. Each group had one doctor, one nurse, and two mothers. We decided to have heterogeneous groups to ensure participants with different NICU knowledge learned from one another and completed design tasks in cooperation. As an icebreaker, we developed an activity where each participant shared their best and worst experiences in the NICU. This approach is referred to as Experienced Based Co-design (EBCD) (Mulvale *et al.*, 2016; Borgstrom and Barclay, 2017). EBCD encourages participants to use their experiences to identify the requirements of the designed intervention that could improve participants' experience in healthcare. NICU staff had a chance to ask the mothers questions and provide advice and supportive information. On the other hand, mothers got an opportunity to ask the NICU staff questions related to their infants' health conditions. They also voiced some of the challenges they faced while interacting with NICU staff. In response, the NICU staff shared the health information requested by the mothers and explained their day-to-day activities in the NICU and the factors that hindered their much-needed interaction with mothers.

After the ice-breaking session, we shared design materials coloured pens, pencils, erasers, a list of information categories suggested in previous ideation sessions and plain papers. First, we allowed each group to go through the two information categories (breastfeeding and medical terms) suggested in the joint focus group (discussed in Chapter 3). Then, we shared a series of incomplete sentences (sample shown in Figure 4.1) with information that emulated the breastfeeding and medical terms information categories suggested in Chapter 3. We used the incomplete sentence technique to mediate the ideation process and encouraged each group to provide suggestions on relevant content that could be included in the NICU communication tool.

After completing the task, we merged the groups and discussed the information suggestions generated by the three groups. Next, we filled in a new sheet of incomplete sentences with combined answers suggested by the three groups. Finally, distinctive answers from the suggested information were discussed further and only those that participants agreed upon were included in the new list of information.

We later asked participants to group the co-tailored information into different categories and subcategories. First, they discussed the main information categories and wrote them on separate flip charts. Then, they wrote the health information on sticky notes and stuck them on the flip chart that fitted the information category. Finally, participants used the *Card-sorting* method (Nurmuliani,



1. Breastfeeding information shared with mothers should include:

- Breast feeding Intervals
- When is it safe to start breast feeding.
- Technique of expressing breast milk.
- Storage of expressed Breast milk.

Figure 4.1. Sample of incomplete sentences used to mediate the ideation process.

Zowghi, and Williams, 2004) to group the information in each category into subcategories and ranked the subcategories in the order that they would be represented in the final application.

Eventually, we tailored six information categories that incorporated all participants' opinions. While discussing the appropriate media that would share the co-tailored health information with mothers, participants agreed that a mobile application was an appropriate medium since most mothers in the NICU owned smartphones. However, they emphasized that the mobile application should be offline since most mothers had limited Internet access. Therefore, we scheduled a meeting to continue designing the mobile application interfaces that mothers would use to interact with the co-tailored health information.

4.3.3 Cooperative Prototyping Session

A day after the brainstorming session, we met at the same venue with the same participants who attended the brainstorming session. We held the two meetings back-to-back to ensure mothers whose infants were soon going to be discharged from the hospital were still available to participate in the design process.

This session focused on exploring better ways of representing the information tailored during the brainstorming session in a simple layout that mothers could easily understand and access on a mobile phone. We asked participants to break out into three groups where they worked with different group members other than those in the brainstorming session. We shared design materials (sticky notes, android phone wireframe, plain papers, sticky emoji cards and colored pens) among the groups. We then asked them to collaborate in sketching and visualizing information layout on mobile phone interface and screen transitions from one category of information to another and from the main information category to the subcategories.

To evaluate the design prototypes, we asked participants to use *emoji cards* (Alismail and Zhang, 2018) to express their satisfaction or dissatisfaction with the prototype ideas shared by group members. The participants had to place a "happy" emoji when they approved the design idea or a "sad" emoji when they disapproved of the raised design ideas. These techniques were used to encourage reserved participants to share their design views by placing the emoji card in the middle of the table or next to the proposed design. This co-design technique prompted group members to engage in discussions and negotiate the appropriate way of representing the co-tailored health information in the android wireframes.

Figure 4.2. Emoji cards used to evaluate the interfaces of the designed prototypes.

At the end of the session, we merged all the groups and asked each group to present their high-fidelity prototypes. The three prototypes included the order in which the information categories were organized and the interface transition from one category to another and from the main information categories to the subcategories.

We used the *cognitive walkthrough* (Heuwing, Mandl, and Womser-Hacker, 2014) to evaluate the usability of the sketched interfaces. We chose two mothers and asked them to talk through the steps to access two information categories (proposed during the brainstorming section) on the three prototypes. They used emoji cards to express their decisions towards the content included in the prototypes and the step taken to access information. They stuck the "sad" or "happy" emoji card next to the prototypes and explained their feeling towards the proposed low-fidelity prototypes. The prototype with the most "feel good" emoji cards were chosen and some aspects of the other two prototypes were incorporated into it. At the end of the session, we gave each mother an honorarium of 100 ZAR (7 USD) to cater for their lunch and transport cost. Each NICU staff was given a bar of chocolate to show appreciation for their time and design insights.

4.3.4 Prototype Evaluation

One week after engaging the NICU stakeholders in a cooperative prototyping session, we approached one senior neonatologist to help us to evaluate the co-tailored health information and co-designed the high-fidelity prototype. This evaluation process aimed to gain feedback on the clarity of medical information, interface flexibility, ease-of-use and presentation of health information on the final prototype.

We presented the three suggested prototypes and explained the criteria used to settle on the final prototype. The neonatologist verified the suggested information to ensure it was fit to share with mothers of hospitalized infants. He emphasized that the co-tailored medical information needed to be simplified further to ensure mothers comprehended the information. He shared a booklet used in neonatal care and recommended two reliable websites (KidsHealth by Nemours [1] and Healthy Children [2]) that we could use to verify and edit the medical information tailored by NICU stakeholders.

To help us edit the information, he introduced us to a doctor and two nurses who assisted us in editing health information. The nurses also helped us to translate English medical information into isiXhosa and Afrikaans languages as requested by NICU stakeholders during the brainstorming session. These are the common South African languages spoken in Cape Town (Alexander, 2018; Levin, 2006). The neonatologist further tested the usability of the final prototype and certified it as easy and appropriate for mother usage.

4.4 Health Information Translation

In February 2019, we worked with the appointed doctor to define and elaborate the meaning of the common NICU medical terminologies in a simplified language. This process ran for three weeks. To assist us with the translation process, we used the NICU booklets and two reliable websites recommended by the neonatologist.

After developing the English version of health information, we scheduled a meeting with the nurses appointed to assist us with the isiXhosa and Afrikaans translations. We shared hard copies and soft copies (google word documents) of the English health information with the nurse to enable online collaboration whenever they needed further information. Unfortunately, the Xhosa nurse went on leave for three weeks and when she resumed work, she was transferred to the labour ward. Since she could not help us translate the information, she asked us to hire someone to do the translation and she would assist us in verifying the

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[1] Link to KidsHealth website https://kidshealth.org/

[2] Link to Healthy Children website https://www.healthychildren.org/

clarity of the translated information. The Afrikaans nurse also informed us that she was not willing to continue supporting us with the translation process.

To expedite the translation process, which took longer than expected, we hired Afrikaans and isiXhosa translators. The Afrikaans translator was professional and previously a mother of premature babies. Two translators did the IsiXhosa translation; a Xhosa postgraduate student and a senior medical student fluent in isiXhosa. We collaborated with the translators on Google Drive to ensure timely responses before meeting with them in person to discuss the final translated information.

After the translation process was completed, we shared the translated information with the nurses who evaluated them before we shared them with the neonatologist for approval. Once the neonatologist approved the information to be fit for sharing with mothers, he asked us to proceed with the health video and mobile application development in three language versions.

4.5 Data Analysis

We used the inductive data analysis approach. We subjected the data to a three-stage analysis method: data reduction, data display and conclusion drawing (Bottoman, 2004). during data reduction stage we read the raw data in detail and summarise in summary format. We then established a clear link between the summary findings and the research objectives. Open coding was used to look for recurring themes in the data. Using Nvivo, we could easily identify the relationships between themes and figure out underlying ideas and meanings among them. In the next section, we discuss the identified themes that emerged from our data.

4.6 Results

This section describes the experiences around the cooperative brainstorming and prototyping sessions with NICU stakeholders and the health information translation process. We focus on reporting the co-design methods and techniques that fostered collaboration and how NICU stakeholders used simple design techniques to design NICU digital interventions that would enable them to access health information. Using the challenges mothers face in the NICU and their devices' capabilities, mothers raised design considerations for the final prototype to enhance its usability. We also highlight the challenges encountered in the translation process of health information.

4.6.1 Productive Interaction through Mutual Learning

Similar to the co-design process discussed in detail in Chapter 3, there was tension at the beginning of the brainstorming session. The mothers did not engage in the discussion, which doctors dominated. Instead, they nodded in agreement to every decision made by doctors. The icebreaker exercise played a significant role in enhancing participation during the discussion. NICU staff were fascinated to learn about distinct challenges that affected mothers' participation in their hospitalized infants' care. For instance, the mothers complained that nurses' explanations of infants' health conditions differed from doctors' and wished that NICU staff would streamline information sharing to avoid contradictions. Also, the mothers informed NICU staff that they needed frequent updates on their infants' health information. They said the doctors should use simple language to enable them to comprehend their infants' health progress. This suggestion led to a discussion where the participants decided that it would be prudent to share health information in three languages, that is English, Afrikaans and isiXhosa, to enable mothers to comprehend health information. Mothers argued that they felt comfortable talking to nurses who communicated in their home language to clarify health information received from doctors during the ward rounds.

"I always ask the nurse to explain my baby's status in isiXhosa because doctors use hard English ."–Mother 1, Brainstorming session

On the other hand, the mothers learned more about the NICU staff's daily schedule, thus helping them understand why the staff did not interact with them as often as they wished. Mothers also learned the communication protocol used in the NICU, thus allowing them to understand why the unit does not share infants' health information via phone calls or text messages. From these interactions, two NICU communication aspirations emerged 1) mothers expected the discussion outcomes to help their need for the necessary information that could support them as they take care of their infants during and after hospitalisation, and 2) the NICU staff expected mothers to express their information needs to share knowledge and work with mothers in moulding supportive health information.

During the brainstorming session, the incomplete sentences technique and the information shared in previous design sessions mediated the participants' interaction. These design approaches encouraged participants to translate their knowledge into health information ideas. The others used their NICU experience to express their information needs. Although they had limited understanding of medical terms used in the NICU, the NICU staff educated them on these terminologies by explaining the common medical conditions and procedures carried out in the unit. This interaction motivated the mothers to share more intimate concerns, feelings and challenges they faced in the NICU. They were confident to air their challenges because they could relate them to challenges listed by other mothers in previous co-design sessions' materials. The mother-NICU staff interaction while they filled in the incomplete sentences also encouraged mutual learning between them. The mothers gradually gained the confidence to ask questions related to premature birth, which NICU staff answered in simple language for the mothers to understand. For instance, in one group, a mother asked the doctor:

"We see you are always busy in the unit, when is the appropriate time to approach you when we have questions?"—Mother 1, Brainstorming session

In response, the doctor briefly described their schedule in the unit mentioning that they are always available during ward rounds and in the afternoon when their workload is lighter. We observed similar interactions when participants were discussing the health conditions that affected premature infants. NICU staff used simple language to help the mothers understand the health conditions and procedures used to treat the conditions. We identified that these interactions encouraged the mothers to share personal information, such as their struggle with breast milk expression, challenges they faced in their households and uncertainties about their infants' health.

Although such engagements were emotional, group members were empathetic with each other. The NICU staff also used their counselling skills to support the mothers by sharing similar experiences (to those shared by the mothers) they had encountered with other mothers in the NICU to advise and encourage mothers whose infants were still admitted to the unit. For instance, one mother whose infant had breathing complications mentioned that her infant was on and off oxygen support and she was scared that her infant's health was not improving. The doctor encouraged the mother saying:

"Your daughter will be fine, I have treated similar kids who recovered and were discharged from hospitals."–Doctor 1, Brainstorming session

Such intimate interactions bridged the relational and trust gap among NICU stakeholders. The more supportive the information the mothers got, the more they were comfortable in engaging in the brainstorming session. For instance, three mothers mentioned that lack of enough breast milk supply stressed them as they took care of their hospitalized infants. They said:

"When my child was admitted to the NICU, I did not have enough milk for my child. The nurses told me that my child's health will get worse if they do not feed her with my breast milk. This was stressful, but even doing my best, I could not produce enough milk. "–Mother 2, Brainstorming session

"I struggled with using my hands to express milk, it is hard. You have to care about storage, cleanliness.. yhoo! "–Mother 3, Brainstorming session

"When I came to the nursery, I noticed nurses were giving my baby formula milk at different times from other babies. Why is it so?"—Mother 4, Brainstorming session

These comments stimulated a discussion on the importance of including breastfeeding information in the application. Mothers were curious to understand the benefits of breastfeeding over formula milk, the varying feeding times for infants and the proper ways of storing expressed breast milk. Nurses shared the requested information with the mothers helping them to understand why they should purpose to breastfeed their infants rather than giving them formula.

In another group, mothers mentioned that they did not interact with NICU staff because they did not understand the medical terminologies used by the doctor. They mentioned some of the health conditions that their infants had and requested doctors to explain them. In addition to explaining infants' health conditions, doctors and nurses educated the mothers on potential infant developmental delays related to prematurity. Mothers actively engaged with questions as they sought clarity on some of the conditions shared by the NICU staff. For instance, the doctor mentioned that most premature infants need special care after being discharged from the hospital. To clarify this information, one mother asked,

> *"What are the chances that my child will not develop complications after we are discharged from the hospital ?"*–Mother 5, Brainstorming session

Both doctors and nurses engaged with the mothers to explain the health complications that can result in infant development delays. They urged mothers to attend scheduled clinic appointments after hospital discharge to ensure their infants' health and growth are monitored.

The working relationship built during the brainstorming session extended through the prototyping session. Despite participants working with different group members than those in the brainstorming session, they could map their design ideas for a viable prototype of the NICU communication tool. Participants mentioned that a deep understanding of the design problem during the brainstorming session and the availability of various design materials enabled them to learn from each other as they exploited their creativity. At the end of the prototyping session, we identified that NICU staff and mothers could freely interact. Soon after the group discussion, one mother approached the researcher and confided:

> *"I feel less stressed after talking to doctors. We should have these discussions often. They are therapeutic. "*–Mother 2, Prototyping session

4.6.2 Creative Techniques Enhanced Democratic Participation

We realized that generative co-design techniques leveraged the power inequality between the NICU staff and mothers. These techniques guided the co-design process, allowing all group members to voice their design ideas. The incomplete sentences used in the brainstorming session considered all stakeholders as equal partners in the design process by valuing and incorporating their disparate NICU experiences in the design process. We identified that the mothers' experiences' were steering the design process and the NICU staff focused on providing educational support to enable mothers to articulate their design needs. This engagement approach encouraged participants to negotiate their design ideas before including them in their final list of health information topics.

During the joint brainstorming session, participants analyzed and grouped similar information generated by the three groups. Participants discussed the relevance of new information that arose from each group and negotiated whether it was necessary to include them in the application. We identified mothers who had gained the courage to push their design concerns during this process by using their NICU experiences to disprove some NICU staff ideas. For instance, nurses and mothers differed on the appropriate diet to boost mothers' breast milk production. Nurses shared a diet list approved by the hospital to ensure mothers have enough breast milk for their hospitalized infants. However, one mother interjected and said:

"The diet provided by nurses is expensive and some mothers cannot afford it. I mainly use local meals such as oats and soup to increase my milk production."–Mother 3, Joint brainstorming session

This comment prompted a discussion where the mothers shared different diets that their communities used. This discussion was a learning opportunity for the NICU staff who were not aware of these diets. For those that were not clinically acceptable, the nurses discouraged mothers from using them by explaining their effect on the mother's and infant's health.

On the other hand, reserved mothers who could not confront NICU staff used the card sorting technique to raise and negotiate their concerns on the suggested health information. While grouping information into categories, mothers wrote notes on the sticky notes indicating the need to access the common conditions related to premature birth. They said that NICU staff only shared the current state of their infants but never informed them of other conditions or development delays related to these conditions

"The doctors don't tell you what will happen when your baby is discharged. My baby had breathing problems and I heard from other mothers that babies with breathing problems could get asthma. We need to know this so that we can prepare." -—Mother 4, brainstorming session

The NICU stakeholders discussed and agreed to include common health conditions that affect premature infants, the procedures conducted to treat the discussed health conditions and possible developmental delays related to the conditions. The NICU staff also suggested the inclusion of information that families of premature infants need to enable them to prepare their homes before their infants are discharged from the hospital. At the end of the session, NICU stakeholders co-tailored six information categories. Table 4.1 describes the content of each information category discussed during the cooperative co-design session.

Moreover, during the prototyping session, we identified that the use of the emoji cards technique empowered NICU stakeholders to voice their views during the evaluation of the final prototype. Mothers expressed their design opinions using sad or happy emoji cards. However, we identified that the mothers sometimes used emoji cards but did not have any valid reason for criticizing the designs. This situation created an awkward atmosphere because the other participants did not know whether to factor these decisions into the final outcome. For instance, during the walkthrough activity, one mother placed sad emoji cards on one prototype and said:

" I feel like it is hard to find data using this app" –Mother 2, Prototyping session

Although the mother had completed the information access process without any challenge, it was not clear how to address her decision which was purely based on her feelings. Overall, these techniques allowed participants to engage in a constructive discussion that led to the improvement of the final prototype designed in their groups.

TABLE 4.1

Co-created Information Categories and their content

Information Category	Content
Breastfeeding information	Provides breastfeeding information such as: -Benefits of breastfeeding -Breastfeeding Schedule -Breast milk expression -Breast milk storage -Food to eat while breastfeeding
Health Problems	Describes common health problems such as; -Breathing problems -Tummy Problems -Brain Problems -Infections -Eye problems
Medical terms	Describes common medical terms such as: -NICU procedures - Health Conditions -Medication
Life After NICU	Explains information that mothers requires once their infants are discharged from the NICU. For example: - Importance of Kangaroo Mother care - Health problems that may affect infants -Development delays - Services that infants need -Things they should do in their households
Peer support	Encouragement video from veteran mothers of premature infants
NICU equipment	Description of NICU equipment

4.6.3 Health Education Through Imagery

We identified that NICU stakeholders were using images to enhance their health information discussion throughout the brainstorming session. NICU staff used pictures to explain tough health conditions that mothers did not understand. The doctor either used their mobile phone to search online images from reliable health websites or images on pamphlets used in the NICU to help mothers understand health information. For instance, in one group, we observed a doctor explaining the importance of breastfeeding and the effects of formula milk feeding on premature infants. He used his phone to show mothers an infant's image with Necrotizing Enterocolitis (NEC), a condition that makes formula-fed infant's tummy swell. Although the image helped mothers understand the health risk of formula feeding, it also instilled fear in mothers, which was visible from their facial expressions and body language. The fear prompted one mother to ask:

" What happens to babies whose parents do not visit in the NICU? Where do you get breastmilk for them?"—Mother 4, Brainstorming session

The nurse in the group said that they often feed the babies with donated breast milk until they gain 2.5kilo grams before they are fed formula milk. In another group, doctors showed group members images of some of the health procedures conducted on infants. Mothers also used photos of their infants to seek information from doctors. For instance, one mother used her mobile phone to show the group a picture of her infant with a syringe on the head.

"When my child was in ICU1, I saw a doctor put a needle on my child's head. So this is the same procedure you are talking about?" –Mother 5, Brainstorming session

The doctor explained why the procedure was conducted, thus helping the mother understand why the doctors had to draw blood from her infant's head veins. In the same group, mothers were curious to learn the role of NICU equipment in infant care. The doctor used the image in Figure 4.3, which they use while teaching medical students to explain the role of NICU devices in infant care.

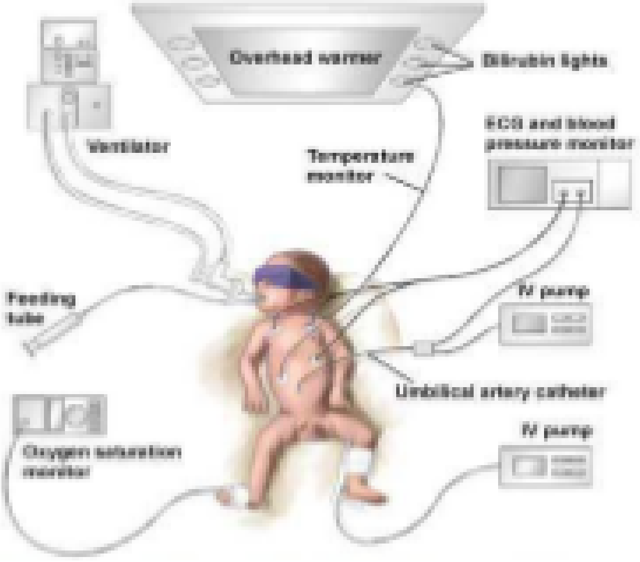


Figure 4.3. NICU equipment source: Mayo Foundation for Medical Education and Research by Mayo Clinic. Retrieved from https://bit.ly/3pbnW3E, 5th August, 2018.

We realized that imagery grabbed mothers' attention, thus helping them to participate in the discussion actively. They requested interpreter's services whenever they were unable to relay information effectively. They also provided scenarios and photos of their admitted infants to gather clarification or compare the discussed medical condition with their infants' condition. As a result, during the joint prototyping session, mothers mentioned that imagery helped them understand some complex health conditions that could not be understood only through explanation or description. They emphasized that videos; with similar images and voice-overs should relay health information instead of a chunk of words.

They mentioned that accessing information in video format was better since they often watch videos on their phone when conducting skin-to-skin infant care.

"Scrolling through information on the phone is hard, especially when holding a baby, I prefer listening to video songs because I don't need to hold the phone with both hands." –Mother 3, Prototyping session

In addition, they emphasized that the information should be disseminated in Afrikaans and isiXhosa, which are the common language used in Cape Town, to help mothers who are not proficient in English. In consensus, the NICU staff and mothers assented to represent health information in video format. However, they highlighted that images of mothers and infants in the NICU should not be used in the videos. For instance, while discussing peer support content, one nurse said that veteran mothers should be recorded live as they shared encouraging information. Mothers rebutted the nurse's suggestion and said:

"Being a mother of a premature baby is traumatizing and I wouldn't like to be live recorded"—Mother 6, Prototyping Session

Instead, they mentioned that animation and mothers' audio records should be used to offer peer support to mothers in the NICU.

4.6.4 Simplicity in Design

During the collaborative prototyping session, NICU stakeholders said they had a deep understanding of the problem they were solving after a productive engagement in the brainstorming session. We observed them draw design inspirations from simple design materials such as colored sticky notes and plain paper. Participants reported that it was easy to represent their design ideas in sticky notes of different colors (shown in Figure 4.4) before transferring them to the mobile phone wireframes provided.

In another group, participants chose to sketch their design using colored pens before exporting their design ideas to the wireframe. Participants could constructively criticize their group members' ideas throughout the prototyping sessions to ensure the final prototype included all the necessary information discussed during the brainstorming session. For instance, one nurse said:

"We should ensure the mobile application is easy to operate, especially for mothers who have limited technical skills. All the information categories should be on one page to ensure they don't struggle to access health information"—Nurse 1, Prototyping session

All participants agreed that grouping information into categories and placing them on the first page of the application would make it easy for mothers to find information. In addition, they said that information categories should have indicative labels for easy access. The participants' maintained design simplicity in the initial prototyping part, ensuring that they included all the necessary features and functionalities before working on the application aesthetics. The use of emoji cards helped the participants, especially the mothers and nurses, express

Figure 4.4. Mothers used sticky notes to represent their design ideas.

their perceptions of the jointly developed prototype. This technique gave them a chance to voice their ideas and critique the aesthetic features they disapproved. For example, one nurse disapproved of the different colors used in the prototype her group had designed. She put the "sad" emoji card next to the wireframe and said:

"This design has numerous colors that are conflicting. The interface appearance should be simplified and have only one color. Purple is the color that represents prematurity." –Nurse 2, Prototyping session

In consensus, the participants agreed that the application should have only one color, which is the color purple. They also suggested *Preemie Care* as the appropriate name for the application because the name was suggestive of the care that it was meant to provide to premature infants.

"Preemie Care is a good name, it shows the app is for helping mothers of premature babies." -—Nurse 2, Prototyping session

Overall, participants illustrated a deep understanding of prototype design features that mothers– who are the primary beneficiaries, would appreciate. Mothers felt privileged and empowered to share design ideas with NICU staff they deemed their seniors in NICU infant care. This realization can be confirmed by this comment made jointly by three mothers,

"This event has allowed us to talk to doctors who are always busy in the NICU. We feel comfortable approaching them now."— Mothers 1, 4 and 6, Prototyping session

Finally, NICU stakeholders jointly developed prototypes of the NICU communication intervention. Figure 4.5 has some of the final prototypes generated.

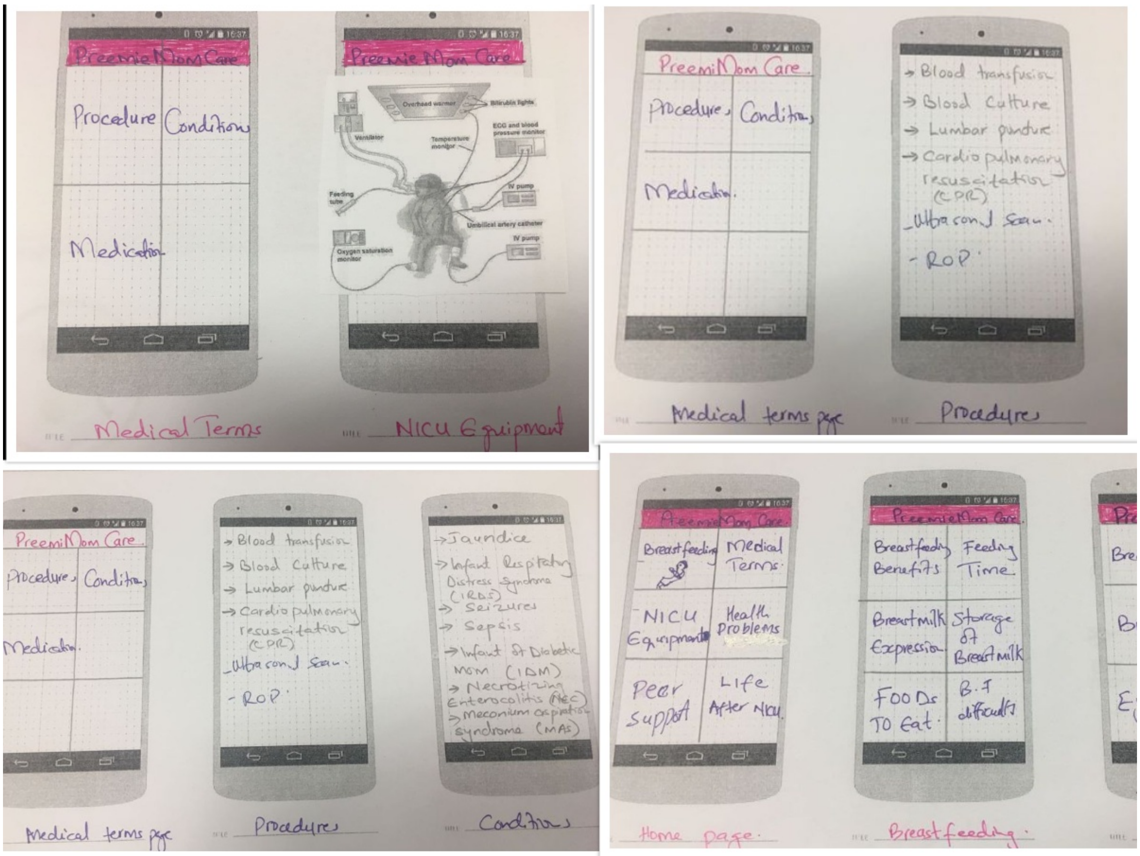


Figure 4.5. Prototypes co-designed by mothers and NICU staff.

4.6.5 Design Considerations for Low-income NICU Communication Intervention

During the collaborative prototyping, participants focused on co-designing an application that was easy to use by novice mothers in the unit. They factored in technical and NICU challenges that mothers experienced, such as language barriers, phone screen size, phone storage capacity, cost, mothers' limited technological knowledge and privacy. To counter these challenges, participants made these design suggestions to enhance the usability of the final prototype:

1. Language barriers: Develop the application in three official South African official languages that are mainly used in Cape Town to ensure all mothers have access to and understand the shared health information.

2. Phone screen size: Have all the information categories on one page to ensure easy access of information for mothers. In addition, participants agreed that the health information should be disseminated in video mode instead of a chunk of words to avoid scrolling down the small screen to access information

3. Phone storage capacity: The mobile application should be small in size for mothers who are using low-end android phones with limited storage space

4. Cost: The application should be available offline to avoid users from incurring additional financial costs to access health information.
5. Limited technological skills: Use indicative information titles to help mothers locate the information easily in the language of their preference
6. Privacy: Use animation instead of live recordings of infants and mentor mothers.

4.6.6 Complex Health Information Translation

We learned that it was challenging to work with NICU health personnel during the health information translation process. Two weeks after sharing health information documents with the nurses, we meet with them, but they had not worked on the information translation due to the heavy workload in the unit. After a month, we followed up on the translation process, but the nurses had not finished working on the translation yet. They said they were too busy in the unit and could not find time to work on the translation. Even when we suggested paying them for translation services during their off days, they declined. They indicated that they wished to spend off days with their families instead of doing extra work.

"Give us this week and see what we can do"— Nurses

One week later, we visited the unit to check on the translation progress and still, the nurses had not worked on the translation. We realized that the nurses were not conversant with working online. Every time we visited the hospital, they scribbled on the hard copy documents with a pencil. They mentioned that the translation process was challenging in the NICU setting since their supervisors expected them to care for the sick infants throughout the day except during their tea or lunch breaks.

After this realization, we opted to hire postgraduate students to help us with the translation process. Unfortunately, the first student, fluent in isiXhosa, did a direct translation the health information, thus losing the medical meaning of the co-designed health information. The Xhosa nurse informed us that the student had code-switched (mixing isiXhosa and isiZulu languages) while translating the health information and it would be hard for any mother to understand the health information. She said

"This is not pure isiXhosa. She has used her local dialect, where they mix isiXhosa and isiZulu. This is confusing for mothers who do not understand this dialect." -—Xhosa Nurse

The nurse provided suggestions on ways that the information could be edited to ensure mothers understood it. Despite several revisions based on the nurse's suggestions, the translated information was still not satisfactory to share with mothers of premature infants. As an alternative, the nurse suggested that we hire a postgraduate medical student to assist us with the translation. The medical student revised the information twice and the nurse approved it as fit for mothers' use.

To avoid such challenges while translating health information into Afrikaans, we decided to hire a professional translator who had NICU experience to help us with the translation process. The Afrikaans translation was reviewed by a neonatologist who did minor revisions before approving the information.

4.7 Discussion

The design and development of the co-designed NICU intervention uncovered some insights into design practices and system specification considerations when developing digital interventions for a low-income NICU. These findings can serve as guidelines for the design of future applications. This section discusses various lessons learned and design implications for NICU communication tools while we engaged NICU staff and mothers in the co-design process.

4.7.1 Bridging Knowledge Gaps Bridges Relationships

Our co-design approach offered a safer space for mothers to share their experiences, engage in a constructive discussion with NICU staff and ultimately tailor health information and technological intervention relevant to mothers in the NICU. Similar to (Donetto *et al.*, 2015), we identified to implement co-design in the health sector is complex because it involves multiple stakeholders with varying roles and expectations. We learned that asking participants questions or giving them tasks to generate information from scratch, was not an ideal approach to engage participants in a group with power inequity. Instead, we incorporated the icebreaker exercise and generative techniques to engage all participants as equal partners in the co-design process. Although mothers were initially reserved to share their experiences, the NICU staff provided supportive information, which encouraged mothers to collaborate in gathering insights and means to partake in their infants' care.

This collaborative design approach encouraged participants' autonomy; the mothers opened up and shared their emotions and NICU experiences to articulate their design ideas. Steadily, the interaction between NICU staff and mothers enhanced their working relationship since reserved mothers had gained the courage and confidence to engage NICU staff for support. We identified that the co-design process increased mothers' influence and position in the design process, thus empowering them to negotiate design ideas based on their experiences. In line with Ertner, Kragelund, and Malmborg (2010) and Schneider (2018), we identified that the co-design process increased the mothers' influence and position in the design process, thus empowering them to negotiate design ideas based on their experiences.

Despite mothers-NICU staff collaboration in the design process, we acknowledge that the mothers' ability to negotiate was dependent on the medical feedback received from NICU staff. This was proof that the NICU staff had the upper hand in the discussion. Therefore, unlike (Ertner, Kragelund, and Malmborg, 2010), (Zimmerman, 1995) and (Torretta and Pakbeen, 2012) who recommend power equalization in the co-design process, our study demonstrates that HCI researchers should not entirely focus on equalizing power since it is not a quantifiable unit that can be divided among participants. Instead, researchers should seek to re-configure participants' relationships to promote self-confidence, trust, collaboration and a new relationship among participants. Our experience shows that participants' empowerment is achievable by incorporating generative techniques that allow empathy and mutual benefits among participants. To succeed in this co-design process, we combined qualitative methods that encouraged participants to voice their design ideas (incomplete sentence, empty wireframe, icebreaker exercise) and encouraged reserved participants to prioritize and negotiate their needs(emoji cards and card sorting methods). We argue that to succeed in the co-design process with multiple stakeholders, researchers should incorporate methods and techniques that empower and give participants a chance to share their views in the design process. Our study identified that emoji cards and card sorting methods allowed reserved participants who could not engage in discussions to share their design views. Interaction from these reserved participants or those who could not articulate their ideas due to language barriers would not have been possible in this study if we did not give them an option to voice their design opinions.

Although these are not the only set of methods that should be used in NICU settings, we emphasize that HCI researchers should consider the participation objective and participants' expertise and relationships before settling on the co-design methods and techniques. We recommend that researchers should therefore focus on using research methods supporting participants' empowerment and capacity building.

4.7.2 From Simplicity to Creativity

In the activities and discussions held during the prototyping session, we observed that the participants articulated their design ideas with simplicity. We attributed their uncomplicated design skills to a better understanding of the problem they were solving during the brainstorming session, facilitating them to better interpret and clarify the design goals during the prototyping session. In addition, participants used simple design materials, such as colored sticky notes which they were familiar with to visualize their ideas despite their limited design skills. In iteration, NICU stakeholders adopted the "learning by doing" (Ozkaramanli, Desmet, and Özcan, 2016) concept, where they sketched and modified the mobile interfaces on sticky notes and plain papers before transferring their design ideas to android phone wireframes for evaluation.

In consensus, NICU stakeholders agreed that grouping information categories would make it easier for mothers to locate a specific video of interest. They included all the category icons on one page, thus allowing users to locate subcategories information of each category by clicking the main category. Unlike Medhi *et al.* (2013) finding that low-literate phone users prefer interface design with multiple page lists, our study shows that hierarchical information architectures are appropriate for NICU users. NICU stakeholders suggested that displaying all the information categories on one page would help them quickly locate the one-level deep subcategories after clicking the main category. They mentioned that users could quickly find the specific subcategory information they needed to access with the indicative category name. Each page had a back button that allowed users to navigate the home page with all information categories. In addition, they reduced the functionalities of their prototypes to what they envisioned as necessary. These design decisions reduced mothers' memory load during the cognitive walkthrough process, thus enabling them to easily find information by navigating back and forth in the list of information.

After including all the necessary information and functionalities in their prototypes, participants focused on adding visual aesthetics to their prototypes. Reserved participants used emoji cards to provide their feedback on the prototypes, thus encouraging all participants to explore better ways of representing interface aesthetics. They concluded that the final prototype should only be purple color to simplify the interface appearance. This study unearthed cooperative prototyping aspects that resonate with the four design components: reduction, organization, integration, and prioritizing that Maeda (2006) advocates as the core factors of simplicity in technology information structure design. The reduction was attained by avoiding unnecessary or complicated functionality, organization stemmed from having all the information categories on the same page with indicative titles that enabled mothers to locate information at ease. Integration was achieved by having back-and-forth arrows that would allow users to navigate the different interconnected information pages and prioritizing the information categories structure based on the tendency of access by the end-users. Therefore, we argue that the purpose of cooperative prototyping is to develop a technological artifact that conveys participants' requirements and exposes them to a learning experience to understand various ways that technology can support them in their day-to-day lives.

4.7.3 Navigating Ethics in Sensitive Study

Co-designing with vulnerable participants, such as mothers of premature infants in sensitive settings, involves ethical and methodological challenges (Waycott, Vetere, and Pedell, 2013). In this study, we chose not to involve mothers whose infants were admitted to the NICU to mitigate the emotional harm imposed by the design process. However, in this phase, we had a low participants turnout. Therefore, we chose to bypass this recruitment criterion by including mothers of hospitalized infants whose health condition was stable and awaiting discharge.

Although the scientific and research ethics literature offers little practical guidance to engage participants in an emotionally charged study, we consulted NICU management staff, who advised us to create design activities that would benefit mothers participating in the study. To ensure the care of infants was maintained, nurses at the KMC unit were asked to watch over the infants while mothers participated in the design activity. Prior to the co-design activities, we considered two protocols to support mothers. First, we engaged the NICU staff and requested them to provide psychological support to the mothers who exhibited adverse emotional reactions. Secondly, we kept the design sessions short and flexible to ensure the mothers could resume their infant care role in the unit.

To ensure mothers benefited from the design sessions, we decided to incorporate an interactive exercise that encouraged mothers to share their concerns with the NICU staff. In return, they learned about their infants' health conditions. Thirdly, in line with Balaam *et al.* (2015), we used generative techniques that were partly completed to enhance engagement between mothers and NICU staff. These two protocols mimicked the main objective of the interventions being designed, which was to encourage engagement between NICU staff and mothers.

We identified that mothers ' confidence was boosted during the design process, giving them the courage to consult with NICU staff, whom they initially feared. In addition, this design approach proved beneficial to mothers who accessed counseling services, support and health information about their infants' health conditions and premature infant care in general. Based on our experience, we learned that although it is crucial to consider ethical issues when planning research design, it is important to navigate ethical concerns that emerge during the research to achieve optimal design outcomes. This research approach is in line with Munteanu *et al.* (2015) who advocated an adjustment of ethics protocol to allow researchers to adapt to unexpected research conditions encountered while conducting fieldwork. While this does not undermine the importance of a rigorous ethics review process, we argue that HCI researchers should not view participants as human subjects. Instead, they should collaborate with them to identify the appropriate research approach that enhances mutual benefits to ensure that the research achieves its objectives while protecting participants from harm.

4.7.4 No Perfect Co-design: Scaffolding Co-design Approach

Sanders and Stappers (2008) defined co-design as a process that involves designers/researchers and the users of the product or services throughout the design process. Although Dahl and Svanæs (2020) and Dourish *et al.* (2020) advocate using the same participants throughout the design process, the unavailability of the same participants throughout the design process necessitated interaction with different participants with different and conflicting design ideas throughout the co-design process as reported in Chapters 2,3 and this chapter. Also, in the co-design activities reported in this chapter, we involved NICU stakeholders in the initial content creation and prototype design. Still, it was not feasible to involve them in the translation and verification of medical information. The translation process involved only two NICU staff members and hired translators who were not part of the co-design sessions. Even though it would have been ideal to involve mothers in the content translation and evaluation process, they were unavailable due to lack of funds to travel to the hospital, lack of health expertise, demanding needs of their infant's care and other family roles. Although Puri, Sahay, and Lewis (2009) argues that it is important to extend participation to external stakeholders (in this case, translators) to ensure successful implementation of health technologies, our system deployment findings reported in Chapter 5, show that exclusion of mothers in the translation process has an adverse implication the adoption of the home language application. However, like Chawani, Kaasbøll, and Finken (2014), we identified that the involvement of NICU stakeholders in a low-resourced context is not viable.

Thus, in this work, we coin the *scaffolding co-design approach*: an essential aspect of practising co-design that allows researchers to build co-design activities based on the design ideas raised in previous co-design sessions with different participants to ensure a meaningful co-design process when new participants engage in consecutive design activities. The key success of this co-design approach is that it establishes co-design readiness (Molapo, Densmore, and DeRenzi, 2017) among participants with limited design skills. To achieve a successful scaffolding co-design process with multiple stakeholders with divergent experiences, our study showcases that researchers should employ creative, generative techniques based on the information previously collected to facilitate interaction among multiple stakeholders in a context with a power imbalance and to give new participants a point of reference when they are voicing their design ideas. In addition, researchers should employ quantitative methods such as emoticon cards and card sorting to gauge stakeholders' perceptions of the previously shared ideas. These methods offer reserved participants a voice to critique the raised design ideas, thus fostering collaborative relationships and mutual respect during the creative process. These methodological considerations may be useful to other researchers who want to extend this work in co-designing health technologies with and for multiple stakeholders in under-researched NICU settings in a low-resource context.

4.8 Chapter Summary

Unlike in Chapter 3, this chapter presents NICU stakeholders' collaboration in ideation and the prototyping process for a NICU communication intervention. Based on their NICU experiences, NICU stakeholders engaged in co-designing health information and a prototype of the NICU communication intervention. We used generative techniques, interactive exercises and simple design materials to enable creative interaction between mothers and NICU stakeholders. We later worked with NICU staff to evaluate and translate the co-tailored health information into isiXhosa and Afrikaans to ensure that all mothers could access the health information. Unfortunately, due to the heavy workload in the NICU, we could not work with the staff during the information translation process. As an alternative, we hired postgraduate students to assist us with the translation while the NICU staff evaluated the translated information to ensure its credibility. Findings from our co-design sessions demonstrate that generative design techniques enhance mutual benefits and encourage participation in a power-imbalanced co-design setting. Despite their limited exposure to the design process, NICU stakeholders used their NICU experiences, technology exposure and simple design approaches to relay their design ideas and define the interface and functionality of the final NICU communication intervention that would enable them to access health information. We also highlight the challenges of co-designing in low-resourced NICUs and raises an important design avenue that focuses on understanding a feasible approach to engage all stakeholders throughout the design process. In the next chapter, we discuss the system development, deployment and handover process of the co-designed PMC system.

Chapter 5

Co-deploy: PreemieCare System Development, Deployment and Handover Process

5.1 Introduction

This chapter aims at answering research question four. The chapter discusses the development and the eight months of longitudinal deployment and handover process of the co-designed PreemieCare (PMC) system. We developed an offline PMC system as per NICU stakeholders' requirements and deployed it in the hospital for user interaction. The system disseminated health videos in three languages and via multiple interaction channels to encourage multilingual and bandwidth-constrained users to access health information.

Throughout the deployment period and handover period, we collected system logs. We also observed users as they interacted with the system and conducted interview sessions with 36 PMC users to understand how they interacted with the system and whether the accessed information encouraged them to engage with NICU staff. After analysing the usage data and reflecting on the deployment process, our results demonstrate that the shared information was relevant to mothers and their social circles who collaborated with the NICU staff in infant care. We emphasize that having multiple interaction channels enable users to explore various channel affordances before adopting their preferred channel. Additionally, we provide evidence that designing an interface for multilingual users is more involved than making the interface available in multiple languages. Using this evidence, we offer design mechanisms for digital videos meant to bridge the communication gap in a multilingual community. We will begin by describing the research related to the longitudinal deployment of ICT4D projects.

5.2 Related Work

Studies in ICT for development (ICT4D) have shown that deployment and use of ICT interventions have immense potential in improving social-economic development in a low-resource context. However, most ICT4D projects are unable to achieve their full potential because they are not sustainable. Project sustainability can be considered from different perspectives, such as economic, social, organisational, environmental and also in terms of its longevity(Marais, 2011; Remy *et al.*, 2018). Marais (2011) and Manara (2015) highlight that the sustainability of ICT4D projects is affected by myriad factors, such as design actuality gaps, unavailability of funds, lack of experts to run the project and frequent change in organisational structure.

These sustainability challenges also affect Human-Computer Interaction for Development (HCI4D) initiatives that seek to understand people and computer interaction in developing the deployment challenges previously mentioned result in small HCI4D projects that are unsustainable. For instance, Dell *et al.* (2014) deployed a camera-based mobile health system in Zimbabwe for eight weeks and experienced various infrastructure and economic costs that affected the continuity of the project. Similarly, Densmore (2012) deployed the claim mobile application in Southern Uganda and discovered that the scale-up of the deployed technology was not feasible due to financial and infrastructure challenges. Also, Ssembatya (2014) co-designed a secured system that allowed patients and health care providers to access personal health records on mobile phones. Although the project recorded positive feedback on the system, the project was not extended past the evaluation process, thus limiting valuable insights on such a system's sustainability in a low-resource context. Unlike most HCI projects that are deployed for a short period,Molapo (2017) conducted a longitudinal 17 months deployment where they issued smartphones to Community Health Workers (CHWs) to share and educate the community on health-related topics. Donors fully funded the project and despite co-designing an effective intervention that helped CHWs interact effectively with people, the project's continuity was not guaranteed at the end of the project.

In maternal and child health-related studies, HCI researchers have adopted a human-centred design approach to design digital interventions that capitalise on the high penetration of mobile phones in low-resource settings. However, these researchers have experienced challenges such as slow adoption of digital interventions, financial difficulties, language barriers and poor infrastructure that has affected the scale-up of digital health interventions. For instance, Chakraborty, Gupta, and Seth (2019) deployed Interactive Voice Response (IVR) technology in rural India to support behavioural change in maternal and child nutrition practices. Due to the digital divide in the community, they identified that the system's adoption was slow, thus limiting the impact of the intervention. Ramachandran *et al.* (2010b) designed short videos on mobile phones to persuade pregnant women in rural India to adopt the new health practices and services provided by the government. The videos were also meant to motivate community health workers to improve their performance. They gave health workers mobile phones with cameras and deployed the project for eight weeks. Although the videos improved the health workers self-efficacy as they interacted with pregnant women, the project's continuity was halted when the researchers collected the phones after they completed the project evaluation process. Fiore-Silfvast *et al.* (2013) deployed a one year project where midwives used videos on mobile phones to support patients education during postnatal visits. Although the midwives initially faced technical challenges while operating the mobile phone, the study results indicated that midwives accepted the mobile video as part of the workflow for postnatal care examinations. However, the language barrier and lack of proper infrastructure hindered midwives from performing their roles efficiently. Mukisa, Orwa Ochieng, and Waiganjo (2017) highlight that technical issues and lack of infrastructure can hinder the scalability or adoption of mhealth solutions. Alternatively, they advocate that HCI researchers should pay attention to the usability goals and design for sustainability when designing health interventions by addressing technological factors that may hinder health interventions' usage.

Our work builds on and extends this body of work by highlighting design mechanisms that encourage various maternal and health platforms' usage among multilingual users. We developed the PMC platform based on NICU stakeholders' needs and incorporated numerous communication channels to enable users with and without mobile phones to access health information. Our deployment findings show that by combining video features, functionalities and annotating home language videos will English subtitles, multilingual users could interact with the application by pausing and switching from one language to another to enhance their understanding of the digital health content. We also highlight the importance of co-designing generic health content in the NICU context by showing how mothers' social support interacted with the application even though their voices were not included during the design process. We realised that having multiple interaction channels increased PMC system accessibility, thus encouraging interaction between parents and NICU staff, between mothers and their peers and between mothers and their social circle. We also highlight how having multiple channels enhanced system effectiveness when we transitioned from offline to online PMC platform during the handover phase. Although we encountered several sustainability challenges during the handover phases, we recommend possible approaches to ensure similar health intervention in the NICU context.

5.3 PreemieCare System Development

5.3.1 PreemieCare Android Application (Based on Co-design)

Based on the co-design ideas shared in 4, we developed a hybrid Android application, a blend of native and web solutions developed using HTML, CSS and Javascript in a native browser, such as UIWebView in iOS and WebView in Android. We wrapped the offline Android application using the Cordova platform and Ionic framework. We developed animated health videos in three languages using Microsoft PowerPoint software We hired three voice-over narrators who shared health information in three languages. the recording of this information was conducted in one of the professional studios at the University of Cape Town. Initially, we developed an offline Android application that allowed users to access health information In three languages (isiXhosa, Afrikaans and English). Unfortunately, after embedding the health videos, the application size was too big (214 MB), thus exceeding most mothers' mobile phones' storage capacity, i.e. most mothers' phones are low-end Android phones with limited storage capacity).

Hence, we split the application into three language versions to ensure each application used minimal phone storage. In addition, we enabled video functionalities in each app version to enable us to collect usage data. Finally, the three applications were evaluated on various Android phones to ensure that the video streaming functionality worked well. Figure 5.1 shows a sample transition diagram of the final application.

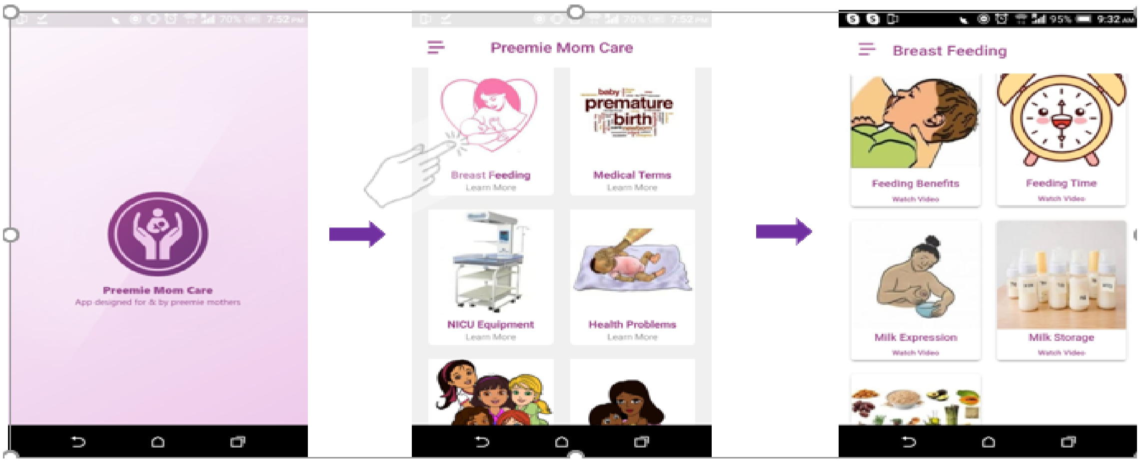


Figure 5.1. System Transition.

5.3.2 PreemieCare App Deployment Infrastructure

Following the successful development of the mobile application based on NICU stakeholders' specifications, we investigated an additional cost-effective strategy for sharing and disseminating health information to mothers with and without Android phones. Initially, we had planned to secure a tablet in a wooden box mounted on the unit's wall so that mothers could pair their phones with the tablet and download their preferred application language version using Bluetooth technology. However, we were informed by the unit management that we could not drill into the unit's wall to mount the box. In addition, they raised security concerns about leaving a tablet unsecured since it could be easily stolen.

As an alternative, we opted to use Raspberry Pi 3B+ (Raspberry PI Foundation, 2019) as a local server to host a web page with links to the three language versions of the application to allow mothers to download their preferred application. We chose to use Raspberry Pi because of its low cost (35 USD), ability to function as a personal computer and its onboard wireless capabilities that allowed users to access information via a wireless network.

Additional Video Streaming and Chat Services

In addition to the PMC mobile application, we set up two additional services, YouPHPtube (YouPHPTube, 2017) and Rocketchat (Rocket.Chat, 2019) as streaming and chatting probes, respectively, to explore their feasibility in the NICU context. The criterion of incorporating the streaming service was to allow mothers with limited phone storage space to either watch or download specific health videos and store them on their phones for future access or sharing with their peers or family members. On the other hand, the chat server was included to encourage mothers to interact with each other and NICU staff. We incorporated this chat server since the co-designed offline mobile application could not incorporate the chatting features that mothers had requested during the brainstorming session. To localize the server, we dubbed the streaming and chat server as *Preemietube* and *Preemiechat*, respectively to match the mobile application name, Preemie Care (PMC) name suggested by the NICU stakeholders during the prototyping session.

Streaming Videos on TVs

To enable mothers without Android phones to access health information related to their infants' health, we decided to stream videos on television. The hospital technicians helped us mount two televisions in the NICU; one in the breastfeeding room and another in the KMC lodging room. We decided to put televisions in these areas because the breastfeeding room was accessible to all mothers caring for infants in the unit and the KMC lodging room was accessible to mothers who were boarding in the unit. We connected the local server to the television using a High-Definition Multimedia Interface (HDMI) cable and used the installed Preemietube server to stream videos on the television.

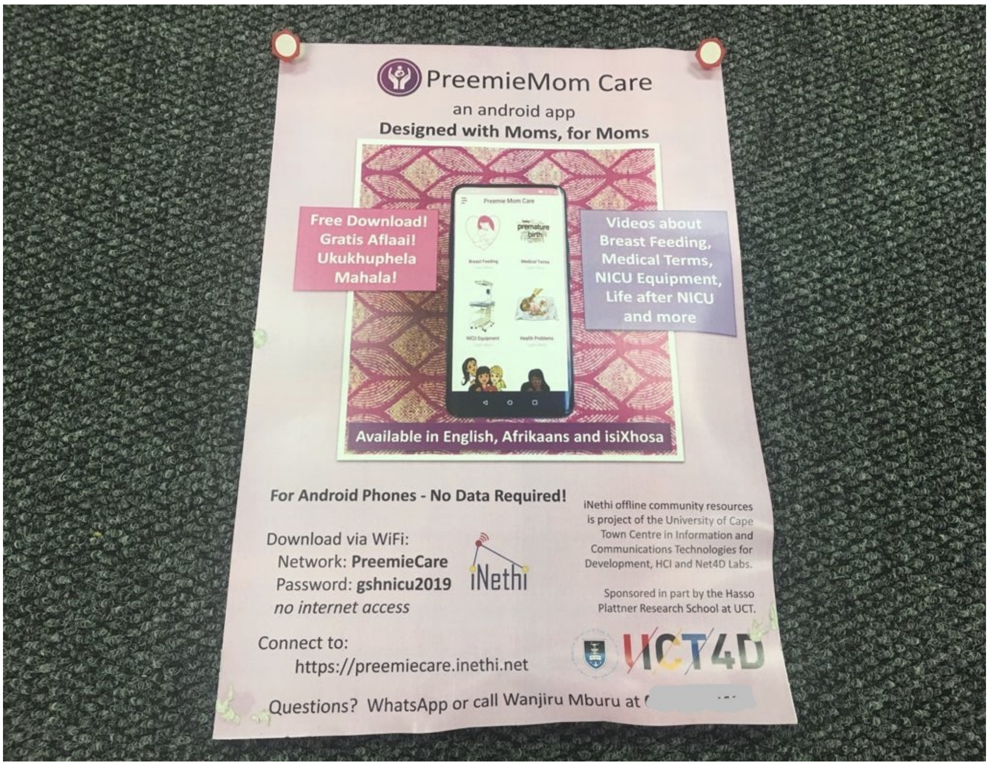
However, while streaming video on television using Preemietube, we realized that the projected videos were buffering. For an alternative way of streaming videos on the television, we installed the VLC media player on the local server. We configured VLC to play the three languages videos on the television at random.

5.4 PMC Platform Deployment

5.4.1 PMC Platform Configuration and Installation

In August 2019, we completed the configuration and testing of the PMC system and it was ready for deployment at GSH NICU. We configured two Raspberry Pi 3B+ as the system's local servers and WiFi access points. Then we installed the video streaming server (PreemieTube) and chat server (PreemieChat) in the local server and hosted the PMC project website, which provided an online consent form, brief description of the project, usage instructions and links to download the Android applications in each of the supported languages. We later uploaded health videos on PreemieTube and created different discussion channels on PreemieChat to enable mothers to access their preferred discussion topics easily.

We secured the local server with adhesive glue to the back of the television. Next, to display the videos hosted on the local server, we connected the server to the television using a High-Definition Multimedia Interface (HDMI) cable. Finally, we used a mini Wireless keyboard and mouse combo to interact with the services installed on the local server. Users would connect to the local server WiFi access point using the Service Set Identifier (SSID) and password shared on posters on the unit's notice boards.



PreemieMom Care
an android app
Designed with Moms, for Moms

Free Download!
Gratis Aflaai!
Ukukhuphela Mahala!

Videos about Breast Feeding, Medical Terms, NICU Equipment, Life after NICU and more

Available in English, Afrikaans and isiXhosa

For Android Phones - No Data Required!

Download via WiFi:
Network: **PreemieCare**
Password: **gshnicu2019**
no internet access

iNethi

iNethi offline community resources is project of the University of Cape Town Centre in Information and Communications Technologies for Development, HCI and Net4D Labs.

Sponsored in part by the Hasso Plattner Research School at UCT.

Connect to:
https://preemiecare.inethi.net

UCT4D

Questions? WhatsApp or call Wanjiru Mburu at [redacted]

Figure 5.2. Preemie Care Posters in the NICU.

In our configuration, we ensured that after connecting to the SSID, the user was presented with a captive portal with a consent form explaining the research objectives and the anonymous usage data being collected for research purposes. Upon providing consent, the users were redirected to the PMC home page to access the PreemieTube, PreemieChat and links to download the three PMC language applications. To ensure network coverage in the entire unit, we measured the strength of the WiFi and used two repeaters to extend the WiFi connection. We also installed the TeamViewer [1] application to the local server and used a mobile WiFi dongle to connect the local server to the Internet so that we could access the server remotely. Figure 5.3 provides an overview of the PMC platform.

5.4.2 PMC Platform Activation

The Preemie Care platform was activated in the NICU on 7th August 2019. The deployment was done in two parts. In the first part (from 7 August - 15 September), we visited the unit daily to observe and support mothers and staff as they interacted with the platform. Unfortunately, the local server was only available in the unit when we visited. In the second part (16 September onward), the local server was permanently placed in the unit and we visited the unit twice a week to observe mothers as they interacted with the system and helped them if they needed any support.

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[1] 1A remote access and remote control computer software that allows maintenance of computers and other devices. https://www.teamviewer.com/en/

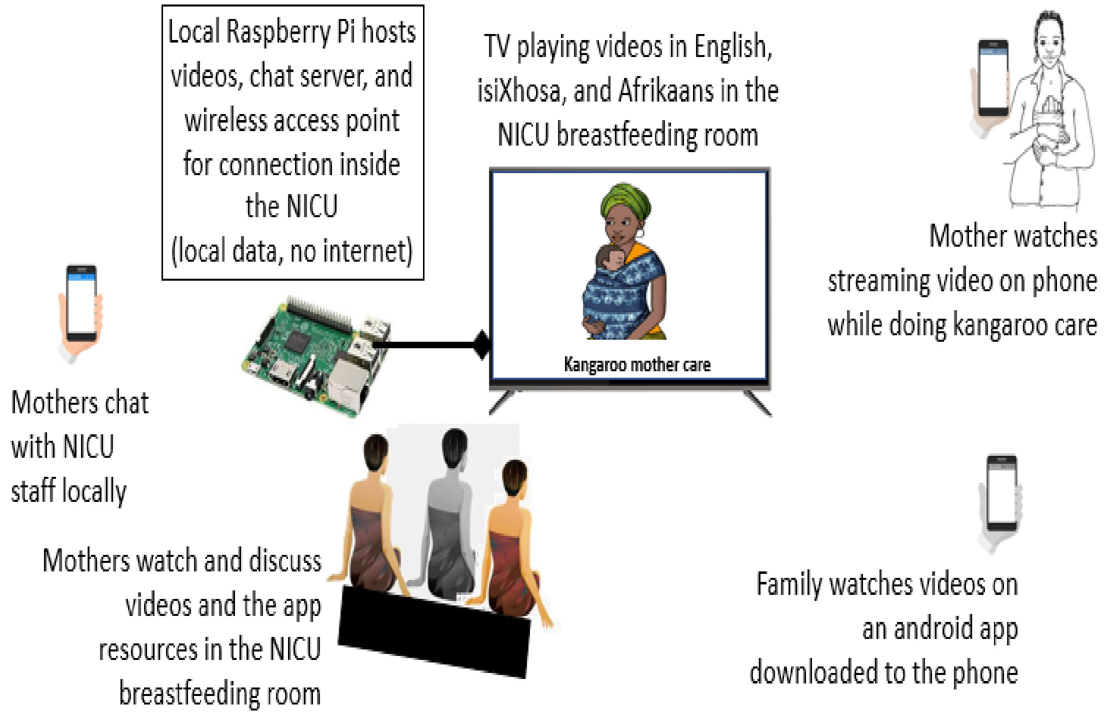

Figure 5.3. Overview of Preemie Care system Deployment Diagram

Mothers used the information shared on the application to discuss challenges related to premature birth and provide peer support for each other. Mothers who did not have enough storage capacity for the Android application used PreemieTube to watch or download specific videos on their phones. We also gave mothers pamphlets— which had similar instructions as the poster, to help them access WiFi connection instructions if they were holding their infants and unable to access the poster on the noticeboard.

We conducted observations in the unit and interacted with parents and NICU staff regularly whenever they needed our support on matters related to the system. Moreover, we conducted one-on-one interviews with 15 mothers, seven fathers and three grandmothers whose infants were currently hospitalized at the NICU. We focused on understanding their user experience, views on the platform and perception of health information shared in three languages. We also conducted semi-structured interviews with three nurses and one doctor who engaged in the co-design activities to get their views on the platform's usefulness. We continued monitoring the system logs to identify the video consumption trend from the multiple channels. In addition, we visited the unit once a week to support users as they interacted with the system. We mainly focused on helping new mothers who needed assistance with the application's installation.

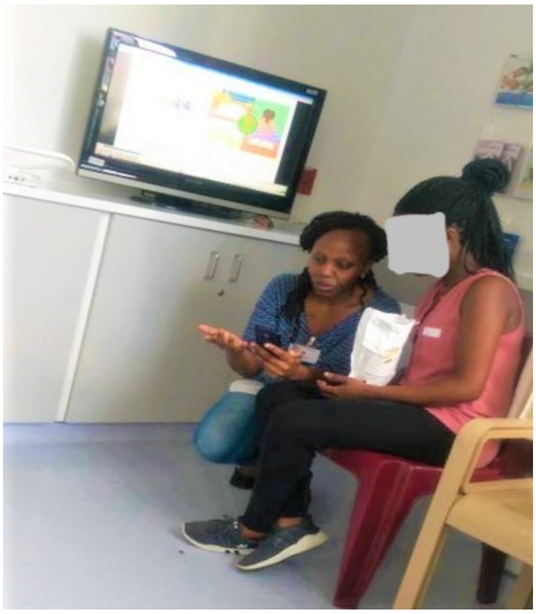

Figure 5.4. Supporting a mother with PMC App Installation.

5.5 System Handover Workshop

In November 2019, we organized a workshop with NICU stakeholders (three doctors, four nurses, one secretary and two mothers) to discuss the system handover process. Before the meeting, our NICU contact person introduced us to a tech-savvy NICU secretary appointed to manage system operations in the unit. We conducted system training with the secretary focusing on guiding her on system operations and troubleshooting. We later handed over all the equipment to her and provided the system user manual and troubleshooting instructions.

During the handover meeting, we presented the system usage trends and highlighted some of the challenges we were facing in the project. We also discussed possible strategies for enhancing the usage of these services, other avenues where the health information could be used, mothers experiences as they used the system and engagement of NICU staff in encouraging parents and their families to use the system.

Based on the suggestions made during the handover workshop, we decided to merge the three language applications and hosted the PMC application on Google Play Store [2]. Considering limited phone storage capacities on users' phones, we compressed the downloadable PMC app to 12 MB to ensure users with limited phone storage space could install the application. In addition, we confirmed the application did not locally store the videos on the phone by hosting the videos on an online server. This design approach enabled users to access the videos when playing videos remotely. Also, we enabled video caching to ensure bandwidth-constrained users did not require internet access when rewatching videos.

Following the successful hosting and testing of the application with various

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[2] Link to PMC app on Google play store: https://play.google.com/store/apps/details?id=com.preemiemomcare&hl=en_ZA&gl=US

Figure 5.5. Discussion with NICU Stakeholders during the Handover workshop.

Android phones, we configured our dashboard to collect and visualize the usage data of the online application. We continued monitoring the system logs from all information channels for four months. In addition, we conducted semi-structured interviews with four parents and two nurses supervisors to evaluate their views on system usability. We also continued visiting the unit whenever the system administrator requested our technical support.

In March 2020, when the COVID-19 crisis became apparent, supporters of the NICU put out a call for sponsorship for internet access for mothers in the unit. This decision was considered especially important for fathers and family members who were no longer permitted to visit due to hospital policy to enable them to interact with their infants remotely. As a result, from April 2020, free internet was made available for anyone inside the NICU. Internet accessibility enabled mothers to access videos through the PMC online application. We also created the PreemieCare YouTube channel and enabled the comment section of all videos to allow mothers to seek or share additional information [3]. This channel allowed users to stream or download specific videos in either of the three languages.

5.6 Data Collection and Analysis

During the eight-month-long research period describe from section 5.3 to 5.5, we collected both qualitative and quantitative data. Regarding the qualitative data,

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[3] Link to PreemieCare YouTube channel: https://www.youtube.com/channel/UCRbYXg_CyzV0d2Ws9ytphtQ/featured

we used the inductive data analysis approach. We subjected the data to a three-stage analysis method: data reduction, data display and conclusion drawing (Bottoman, 2004). during the data reduction stage, we read the raw data in detail and summarise it in summary format. We then established a clear link between the summary findings and the research objectives. Open coding was used to look for recurring themes in the data. Using Nvivo, we could easily identify the relationships between themes and figure out underlying ideas and meanings among them.

As for quantitative data, the PMC system logged users' usage trends. For example, PreemieTube and PreemieChat usage logs indicated the number of users, the time they accessed the information, and any user comments. In addition, we developed a dashboard that provided logs on the users' phone identification number, the timestamp when the application was installed or modified, the app language installed, the specific video watched, video likes, the role of the user (parent, relative, nurse, doctor, researcher and other) and the interaction of the user with the video (whether the video was paused, stopped, replayed and if so if it was it played fully).

The usage logs were collected throughout the eight months. However, we eliminated 58 app installations made in the initial deployment stage because the first application release did not include a consent form. Instead, we received oral consent from users in the NICU and we were not sure whether they were sharing the application with their relatives and friends whose usage data were being collected without their consent. Therefore, to avoid breaching third-party app usage privacy, we excluded their usage data. We halted the installation process during the deployment period and incorporated the online consent form before resuming app installation in the unit.

We had a total of 95 app installations after excluding the apps installed at the inception of deployment. The collected system usage logs were extracted and organized in a Microsoft Spreadsheet for the cleaning process before commencing with the analysis. We defined the type of views as follows: "Complete view" if the video was fully played, "Paused view" if the video was paused at some instance but fully played, "Partial view" if the video was viewed for more than 10% but stopped or paused before the video is fully played and "Incomplete view" if the video was played for less than 10 % of the total length of the video.

We excluded all the incomplete views assuming that the researchers and users played the videos for demonstration purposes after app installation. We also eliminated 1) any redundant video view entries, assuming that the users could not watch the same video more than ten times in less than ten minutes and 2) views from the researcher assuming that the researchers used the application for testing purposes.

After cleaning the data, we carried out descriptive quantitative data analysis of the system's usage logs to answer research question four: What are the usage consumption patterns for Preemie Care system users? This research question mainly focuses on the usage trend of the co-designed intervention, and its sub-questions are outlined below:

1. Did multiple channels increase accessibility of videos to the users?

2. What did the video-watching pattern tell us about video design in the NICU context?
3. How did primary users (mothers) and secondary users (fathers, relatives and friends) engage with the PMC system?
4. What are the video design mechanisms for the multilingual NICU community?
5. What was the user experience on the PMC system and the main cause of actions to enhance its usability?

To triangulate the quantitative data collected from usage logs, we transcribed the qualitative data collected during interview and observation sessions and used NVivo software for thematic analysis. According to Burrell and Toyama (2010), triangulation of different research methods while conducting ICTD research is key to strengthening the reliability of the results. Therefore, our aim of using both qualitative and quantitative methods was to answer the research questions mentioned above. In the next section, we present our findings.

5.7 Results

?? This section shares PMC users' experiences as they interact with the system, users' video watching patterns, and the design mechanisms that supported them while engaging with the videos. We acknowledge that our analysis mainly focuses on PMC mobile application, television and YouTube channel data analysis. The PreemieTube and PreemieChat media had limited access, thus providing limited insights into our data analysis.

5.7.1 RQ1: Multiple Channels Increased Video Accessibility

During the deployment process, we learned that the security of the information access point was a key consideration to take into account. People from different walks of life visit low-income NICUs and it was essential to ensure the security of the communication devices was enhanced. It is for this reason that we decided to use the Raspberry Pi device as our local server. The device offers numerous capabilities that allowed us to include numerous features which will enable users with and without Android phones to access health information in various channels.

Sharing information in multiple interaction channels increased the accessibility of health videos. We analyzed the various PMC information-sharing media and discovered that users utilized the platform differently. The mobile application, television and YouTube channel were the most used media for accessing videos. Although we did not log the view of the television, we observed mothers watching videos as they engaged in discussions of their infants' health conditions on the television mounted in the two NICU rooms. Mothers said that the television encouraged them to interact with and support each other. For instance, one mother whose infant had a brain haemorrhage saw a video describing the brain health conditions and complications that premature infants experience and said, *"Yes, the doctors told me there is a possibility that my baby will never talk or walk...."* -Mother in the breastfeeding room, Observation

This comment triggered a conversation where mothers talked about their NICU experiences whenever they received discouraging infants' health updates. Mothers acknowledged that an infant's health status fluctuates and they had to remain positive during their infants' hospitalization. These interactions encouraged peer support among mothers. Mothers used such opportunities to encourage each other by sharing various instances when they were uncertain of their infants' survival, but they eventually pulled through. During our observations, staff would briefly join mothers in the breastfeeding room and provide answers to some of the information that mothers were struggling to understand. In one instance, we observed a couple watching breastfeeding information on the television. The mother was struggling with milk expression. To offer support, her partner approached a nurse in the room and asked:

"My wife has not enough breast milk, is it okay for us to feed the baby with formula milk?" –Father, Deployment

The nurse encouraged the mother to exclusively breastfeed her child by listing the benefits of breast milk over formula milk. She recommended the couple install the PMC application to access all the information she had shared with them and other breastfeeding information. Unfortunately, the mother did not own a mobile phone and she requested her partner to install the application to access health information related to their infant.

Every Monday, mothers of discharged infants and those transferred to hospitals near their communities visited the hospital for their infants' eye check-up appointments. They sat in the breastfeeding room as they waited for the doctor's consultation. While waiting for their appointment, mothers used the videos they watched on the television to discuss their infants' development and the challenges they faced while at home or with their infants transferred to other hospitals. To further understand the information, a majority of the mothers asked the researcher to help them install the Android application on their phones to share it with family members and other mothers in their respective hospitals.

Generally, we recognised that most mothers used the television to decide whether to install the mobile application on their phones. This resulted in the popularity of the app over other PMC media. There were 95 offline app and 68 online app installations over the eight months, with an average of 74 app interactions per month. Users mentioned they preferred the mobile application because they could easily access the information from any geographical location, unlike the Preemietube and Preemiechat media that required them to be in the unit. Moreover, mothers lodging in the unit mentioned that they preferred the online PMC application because their partners and family members could access health information away from the NICU. In addition, mothers said that the online application made it easy for them to discuss their infants' health conditions with their social circles since they could direct them to the specific health information on the app when they were interacting remotely.

In addition to the app usage logs, our analysis identified seven and five users' interactions with PreemieTube and PreemieChat server, respectively. On PreemieTube, users mostly interacted with breastfeeding and health problem information categories. The users left comments on the videos they viewed to indicate if they liked the video or to seek information clarity. When we asked mothers whether they used the PreemieTube server, they mentioned that they rarely used the server because it involved a lengthy and slow login process that required them to enter login credentials before accessing videos. In addition, those who used PreemieTube mentioned that the videos sometimes buffered and timed out, thus deterring them from using the streaming server.

Concerning the chat server, users mentioned they were not familiar with the chatroom's user interface. They said it was difficult to navigate the various discussion channels of interest. Also, they mentioned that the login process, akin to the streaming server, was cumbersome. One mother who frequently accessed the chat server mentioned that she hoped to use the chatroom to interact with NICU staff and access additional information about her infant. Unfortunately, there was limited response from the staff and that stopped her from using the chatroom. We followed up on the issue with the nurses to investigate why they were not interacting with mothers on the chat server. One nurse said:

> *"I would like to use the platform, but there are unit regulations that limit us from using personal mobile phones in the unit. In addition, there is a staff shortage in the unit and we hardly have spare time to log in to the system."* –Nurse 1, Interview Deployment

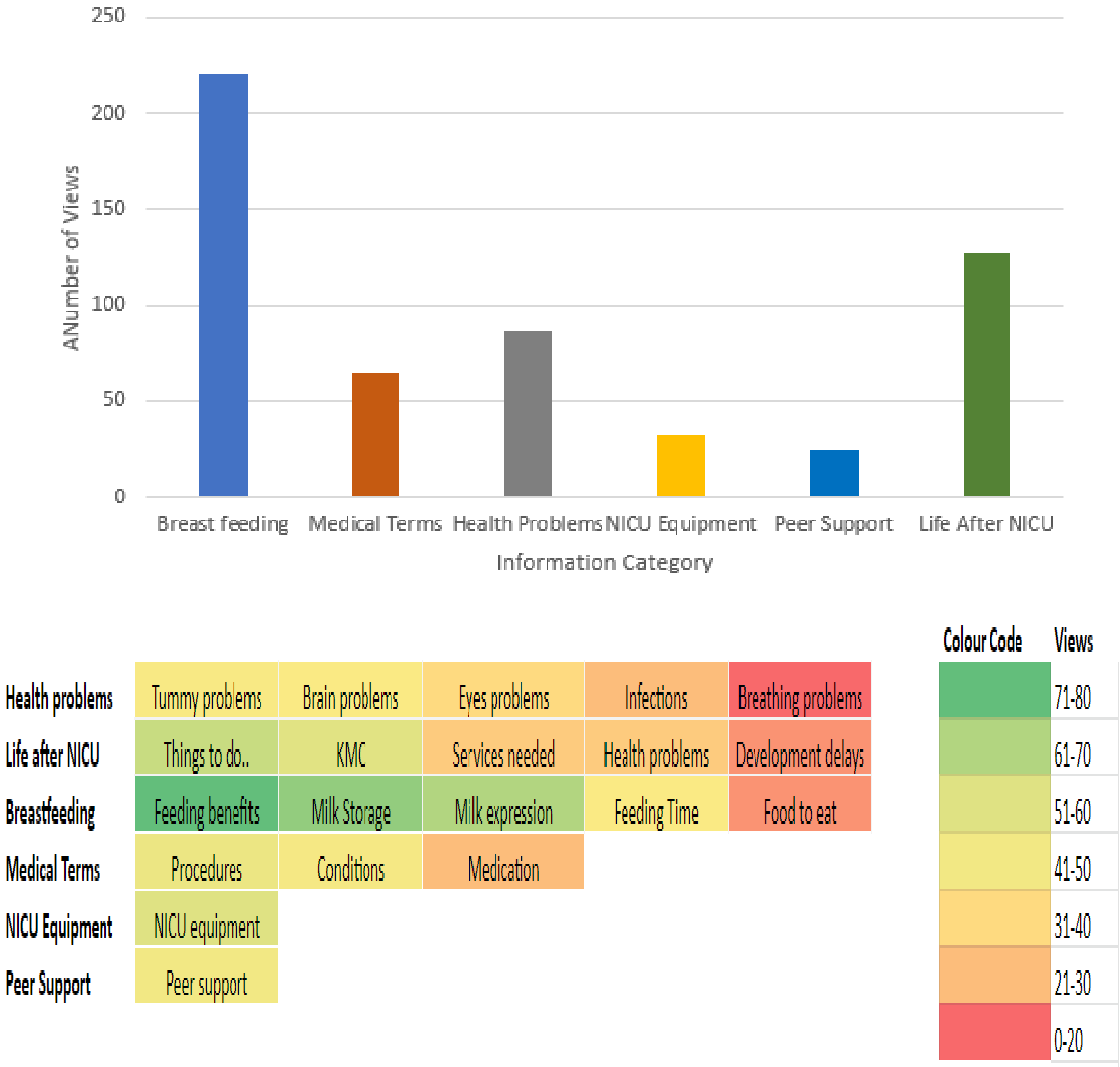
Due to these technical and organisational issues, most users preferred to use the television and PMC mobile application to access health information. We also had six YouTube channel subscribers with over 700 views. However, due to the COVID-19 pandemic, we were unable to get users' feedback on the platform since we could not visit the hospital.

5.7.2 RQ2: Health Video Watching Trends

Video Preferences

When we asked mothers about their interaction with the videos, all of them said they preferred watching videos related to breastfeeding (36% of total views) and babies' lives after hospital discharge (22% of total views). The primary reason for the high usage of breastfeeding videos was because 15 out of 17 (92%) of the interviewed mothers reported having struggled with breast milk production. These mothers said they got immense pressure from the nurse who urged them to hand-express breast milk to ensure the growth and quick recovery of their infants. For this reason, mothers sought support from the platform to identify ways of increasing their milk production. They mainly focused on understanding the benefits of breastfeeding, breast milk expression and proper ways to store expressed milk.

Mothers who sought to understand their infants' feeding schedules, they occasionally accessed the feeding schedule videos (22 views) to learn when they



Health problems	Tummy problems	Brain problems	Eyes problems	Infections	Breathing problems
Life after NICU	Things to do..	KMC	Services needed	Health problems	Development delays
Breastfeeding	Feeding benefits	Milk Storage	Milk expression	Feeding Time	Food to eat
Medical Terms	Procedures	Conditions	Medication		
NICU Equipment	NICU equipment				
Peer Support	Peer support				

Colour Code	Views
🟩	71-80
🟩	61-70
🟨	51-60
🟨	41-50
🟨	31-40
🟧	21-30
🟥	0-20

Figure 5.6. Heat map showing viewership of each video.

needed to store expressed milk in the fridge so that nurses could collect it prior to the scheduled feeding time. Also, there were 21 views of the "Food to eat" video where mothers reported they were looking for healthy meals that they could include in their diet to improve their breast milk production. For instance, we interacted with a mother struggling to express enough breast milk for her twins. She said that based on the instructions provided in the health videos, she stopped eating junk food and included whole grains and vegetables in her meals to improve her milk production. She also brought out a pack of rooibos tea bags from her drawer and placed them on her side desk. She said that the app information recommended rooibos tea to lactating mothers and it was working for her.

"My babies are feeding well now. The tea helps me to relax, and my milk production is increasing gradually." –Mother 2, Deployment

Interviews with partners, relatives and friends also indicated that they watched videos related to breastfeeding to identify suitable approaches to support mothers. As a stress-coping strategy, they made an effort to understand the solution to

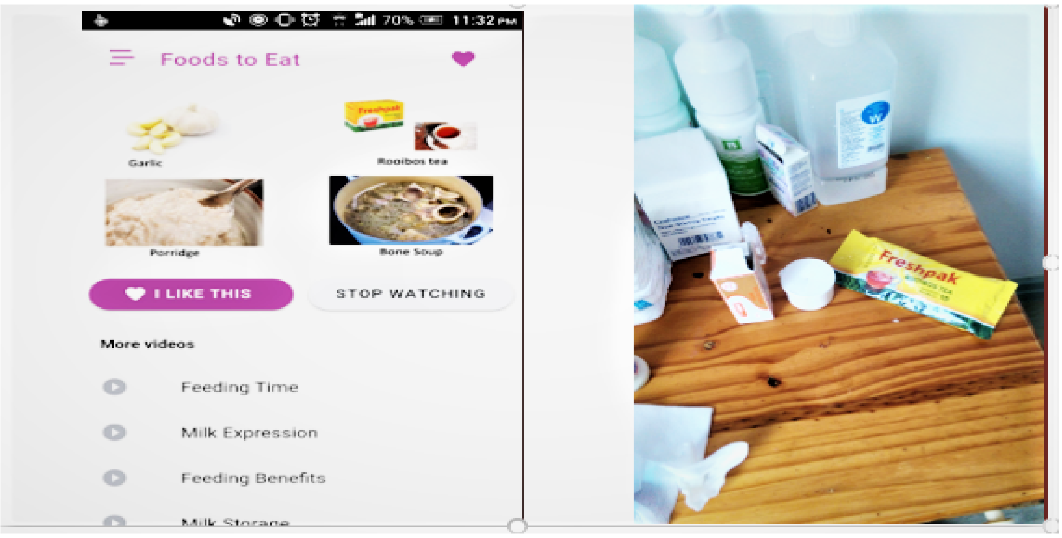


Figure 5.7. A mother shows the app and the packet of tea recommended to help in milk production.

the mothers' problems to establish ways of supporting them. PMC users stated that the basic information shared on the app prompted them to acquire more detail and seek psychological support from the NICU staff. For instance, a partner mentioned:

"I want to understand the information provided so that I can support my wife where I can. If I don't understand it, then I can easily ask the nurses to get accurate information. At least the app information helps me to start the conversation." –Father 1, Deployment

The videos providing information related to infant care after hospital discharge (Life after NICU information category) were also popular among PMC users. Most of the mothers we interacted with were currently nursing their infants admitted at the KMC section. These infants were waiting to be discharged from the hospital. Thus their parents and relatives were curious to learn how to take care of these infants at home. They were keen to understand their role in infant care and the effects of premature birth once their infants were discharged from the hospital. Mothers of infants in the high care unit were also interested in videos that explained infants' development and services needed in case their infants experienced developmental delays. For instance, one mother whose infant had a brain haemorrhage mentioned that the doctors had informed her that her child might have developmental delays. She, therefore, was interested in understanding these conditions to learn the services she needed to seek for her child once she was discharged. Fathers and relatives said they watched the videos to support mothers, especially during the transition from NICU to home. PMC users stated that they could easily relate to the contextualized household information provided on the app, which helped ensure parents and relatives adhere to the rules provided while taking care of the infants at home.

"You know our ladies like going shopping with small babies. It is good that the app information instructs the mother to keep off the shopping centre." –Father 1, Deployment

"People in most households smoke a lot in the house. With this app, you can ask them to smoke from outside since they trust information from the hospital." -Nurse 2, Deployment

Occasionally, mothers watched health and medical terms videos after interacting with doctors during the ward rounds. They said they wanted to understand their infants' health status before interacting with doctors during the ward rounds. Although the videos contained medical jargon, they predominantly relied mostly on the imagery to enquire for more information from the NICU staff.

"I use the medical terms and pictures provided in the app to ask for more information about my baby's health status and if she will have any complication." –Mother 2, Deployment

Similarly, mothers viewed the NICU equipment video when a device was changed during their infant's treatment. For instance, a mother of an infant who had breathing problems stated that whenever the staff changed the mode of ventilation used on her son, she would refer to the video to understand the use of the device. However, she admitted that she did not watch the entire video—which was four minutes long. Instead, she focused on the description of the specific device. Among other mothers, she appreciated the video functionalities that allowed her to skip a particular part of a video by dragging the button or tapping the video section they wished to watch. Mothers also appreciated the pause functionality, saying that it helped them use the video's imagery to understand the shared health information.

Nurses, especially from the supervisory team, were interested in the health and medical terms videos. During our initial interaction with them, they stated that the information shared was easy to understand. In addition, it covered most of the common terminologies used in NICUs. Surprisingly, one supervisor nurse mentioned that they considered the app information as additional teaching resources during their continuing professional education course. She said:

"Nurses can use the app to provide simplified information to mothers when they interact with them. This is relevant, especially for those who use local languages to share medical information. " - Nurse 2, Handover

Overall, NICU stakeholders appreciated the simplicity and accuracy of the information shared and they said they would recommend it to new mothers in the NICU. The graph in Figure 5.8 indicates the information categories preference described by the various PMC users, with breastfeeding videos the most viewed videos followed by Life after NICU videos.

Videos Repetitively Viewed

Figure 5.9 shows the frequency with which users consumed the videos repetitively throughout the eight months study period. We calculated the mean number of repeatedly watched views for each information category per month. During the data analysis, we identified that users first watched all the videos and then rewatched specific videos of interest. This watching trend prompted users

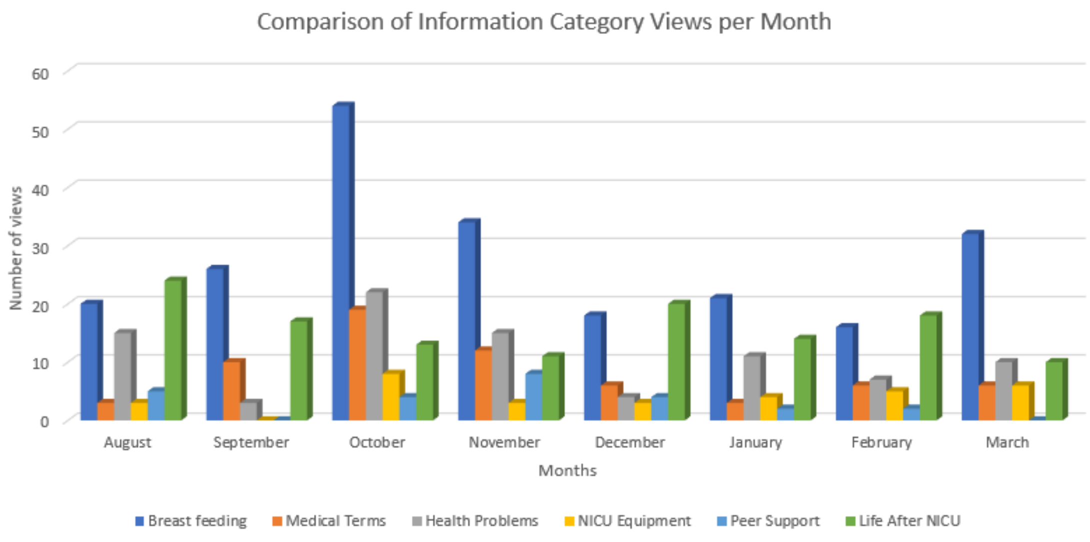
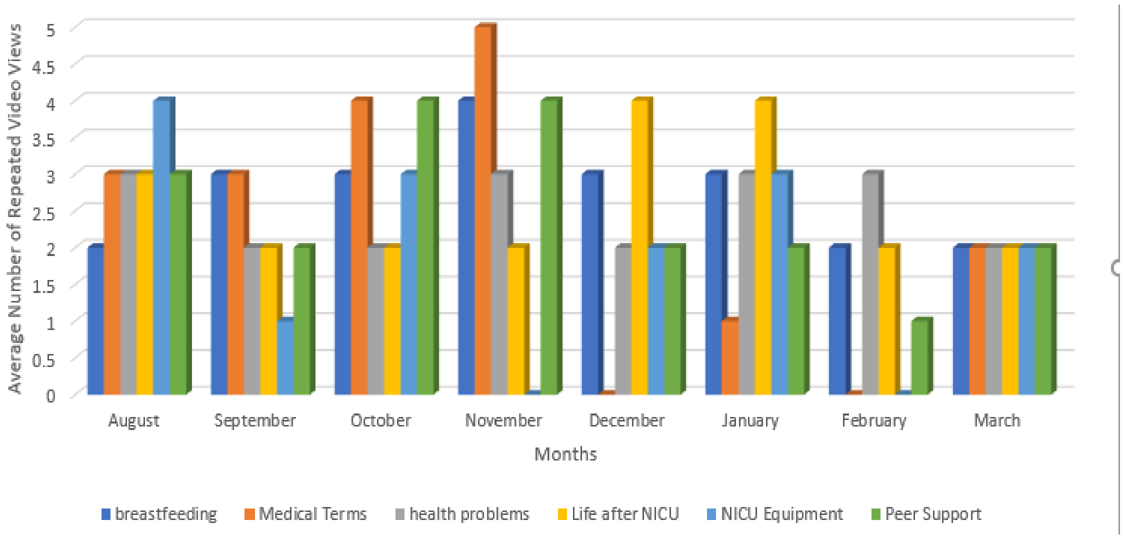


Figure 5.8. Comparison of Information category Views per Month.

to watch other related videos in the same category after rewatching a specific video.



After interacting with users, we discovered various determinants that influenced their video re-consumption trend. Firstly, they mentioned that they rewatched videos related to their infants' current health conditions to enhance their knowledge of the condition. Consequently, this helped them to engage in constructive conversation with the doctors. During their engagement with NICU staff, they learn new terminologies, thus encouraging them to rewatch the videos. For instance, one mother said:

"My child has breathing complications and I have to watch the video every time I interact with the doctors so that I can further understand my child's condition based on the pictures on the video." –Mother 3, Deployment

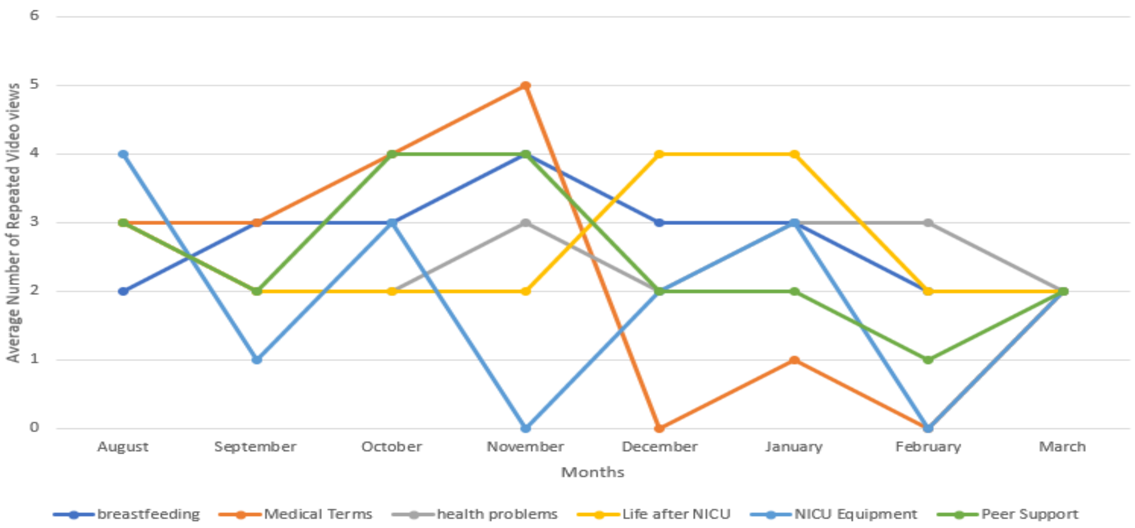


Figure 5.9. Frequency of Information Viewed per Month.

When asked how they interacted with the videos, they said they had to press the play symbol to rewatch the video. They recommended that it would be preferred to have a replay functionality that would allow them to replay the same video without interacting with the video. They said that the replay functionality would allow them to continue listening to the videos, mainly when they cannot operate the phone, especially when holding or feeding their infants. They mentioned that the functionality should either allow them to play a specific video or all videos in a category to enable them to comprehend the shared health information—

"The replay button will enable mothers to listen to the same video or all videos in a category, thus allowing them to gain a deeper understanding of the topic." — Doctor 1, Deployment

Secondly, mothers said they re-watched videos to understand their infants' previous condition. This watching pattern mostly happened when they perused their infants' health report book and identified terms in the videos. The conscious need to comprehend their infants' recovery journey triggered them to revisit the specific video. Gaining this knowledge helped them explain their infants' health conditions to their families and friends who visited the unit. Similarly, they rewatched the videos with their family members when discussing their infants' health conditions, thus helping them compare the severity of the infants' symptoms to the ones provided in the videos. This watching pattern was confirmed by a partner who said:

"My wife and I go through the videos together to understand our child's health progress." –Father 2, Deployment

Lastly, 45% (13)of the interviewees, mostly mothers, said they watched the video repetitively for entertainment purposes. The NICU environment is lonely, and the lack of entertainment facilities urges mothers to watch the videos to keep themselves busy. This was common among lodging mothers who watched the videos at night when they had no one to talk to. They mentioned that this helped them internalise and restore the health information that they had partially forgotten.

Completed vs Partially Watched Videos

Throughout the study period, we had total views of 660 videos. 191 (29 %) of the total video views were watched completely, 152 (23%) were paused but watched completely and 172 (26%) were partially watched (62% paused and 38% stopped and not resumed). The watching trends described in subsection 5.7.2 indicate that users viewed the videos to completion before rewatching them partially. This watching trend helped users to decide which videos were relevant to them.

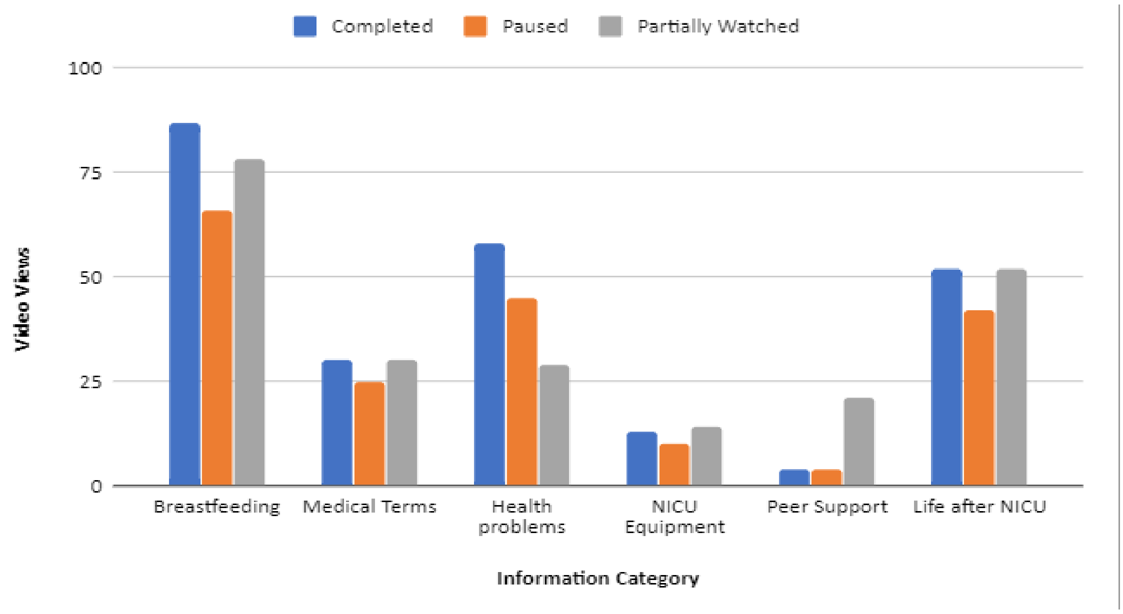


Figure 5.10. Videos watched completely vs those watched partially.

According to Figure 5.10, 36% of Breastfeeding, 24% of Health Problems, 21% of Life after NICU, 12% of Medical Terms, 5% of NICU Equipment and 2% of Peer Support video categories were watched to completion. On the other hand, the partial viewership of Breastfeeding, Life after NICU, Medical Terms, Health Problems, Peer Support and NICU Equipment were 35%, 23%, 13%, 13%, 9% and 6%, respectively. This watching trend indicates that users at least watched the video twice.

During our interview sessions with users, we were curious to learn factors about the influenced video viewership. We identified two factors: 1) the length of the video and 2) the comprehensiveness of information. We learned that short in size and easy to comprehend videos had a high viewership completion rate. According to Figure 5.10 and Table 5.1, the Breastfeeding category had the highest completion rate because most of its videos were short and easy to comprehend. On the other hand, The NICU Equipment and Peer Support videos were lengthy and contained simple explanations of medical jargon. Hence they had a low completion rate. Users watched them partially when they wanted to access specific

Information Category	**Video Length (In minutes)**		
Breastfeeding	**English**	**Afrikaans**	**isiXhosa**
Feeding benefits	0.30	0.39	1.02
Feeding time	0.40	1.01	0.46
Milk expression	0.56	1.20	1.04
Milk storage	0.44	0.40	0.46
Food to eat	1.00	1.17	1.30
Medical Terms			
Procedures	1.25	1.40	1.25
Conditions	1.22	1.37	1.46
Medication	0.25	0.31	0.30
Health Problems			
Brain	0.55	1.01	1.17
Tummy	0.38	0.39	0.43
Breathing	1.27	1.58	2.06
Eyes	0.25	0.36	0.28
Infections	0.56	1.11	1.10
Life After NICU			
KMC	0.54	0.56	0.58
Health problems	2.02	2.33	2.46
Development delays	0.45	0.58	1.06
Services needed	0.4	0.45	0.53
Things to do at home	0.41	0.54	0.59
NICU Equipment	3.4	3.44	4.41
Peer Support	1.43	1.43	1.43

TABLE 5.1

Video length in minutes.

information. This watching pattern explains the relative high pause and stopping actions on these videos.

In interviews, some users, mainly mothers, confirmed that they paused the videos whenever they wanted to acquire specific information from the NICU staff. They also paused when focusing on getting specific information from the imagery on the videos. When asked whether they used the pause and stop video functionalities when interacting with their families back at home, one mother said:

"When my husband asks me how the baby is doing, I show him the video and pause at a certain point on the video to explain our child's condition. This gives him a view of what is happening in the NICU." –Mother 1, Handover

In addition, during our observation sessions in the unit, we identified that mothers in their lodging rooms supported each other by discussing the health problems information related to their infants' condition. For instance, we observed a mother whose infant previously recovered from breathing problems supporting a new mother in the NICU with a sick infant with similar health problems. Although the sick infant was not premature, the experienced mother paused at various part of the videos to show the new mother images of the health condition that affected her infant. She said that with continuous care and treatment, her infant had recovered and was being monitored by the doctors before being discharged from the hospital. Such interactions motivated new mothers to install the application to access information on their own or family members' devices.

Our data analysis indicated that of the 26% partial video views, 62% were paused and 38% were stopped before completion. However, users initiated a new session to view the same video after closing it. This watching pattern confirms our observations during app installation and demonstration sessions. In addition, we identified that 63% of mothers confused the pause and stop functionality to video skipping functionality. They often paused or stopped the video when they wanted to skip to a section of the video to access particular health information. This watching pattern informs the re-design of the video functionalities to support easy access information that is of interest to users.

5.7.3 RQ3: The Role of Different Users in Video utilization

Health literature places emphasis on holistic Family Centred Care (FCC) when caring for premature infants (Rostami *et al.*, 2015; Ramezani *et al.*, 2014; Coats *et al.*, 2018). Indeed this approach to care, where NICU staff, parents, extended family and friends are involved with an infant's, care helps mothers to manage stress and cope with the NICU environment. Based on PMC application usage analysis, we sought the extent to which partners, relatives, and friends provided support to mothers in the NICU. Of the 95 app installations, 55, 14, 4, 8 and 4 were installed by parents, relatives, doctors, nurses and friends, respectively. The rest of the installations were completed by the researchers, whom we are not considering in the analysis of this study's data. Table 5.2 further analyzes the gender distribution of these users.

The data indicates that relatives and friends interacted with the PMC application to understand the health care of infants. Mothers said they shared the application with their spouses and family members to equip them with health information related to their infants' health conditions. For instance, one mother who was lodging in the NICU boarding facility said:

"I have been in the hospital for more than a month and my family do not visit me because we live far from Cape Town. Sometimes my husband and parents-in-law do not understand why I am overstaying in the hospital. So, I decided to send my husband

	App Installation		
Users Role	**Total Installation**	**Female**	**Male**
Parents	55	42	13
Relatives	14	7	7
Friends	4	2	2
Doctors	8	2	6
Nurses	7	7	0

TABLE 5.2

PMC App Installation by Different Users.

the application via Whatsapp so that he can learn NICU terms that I often use when explaining my child's condition." –Mother 2, Handover

In another instance, a mother said:

"My child was doing fine, and I informed my mother that we would be discharged in a few days. Unfortunately, the baby developed breathing problems and she was transferred to the high care section. I asked my sister to install the application from Google store so that she could explain the condition to my mother back at home." –Mother 4, Deployment

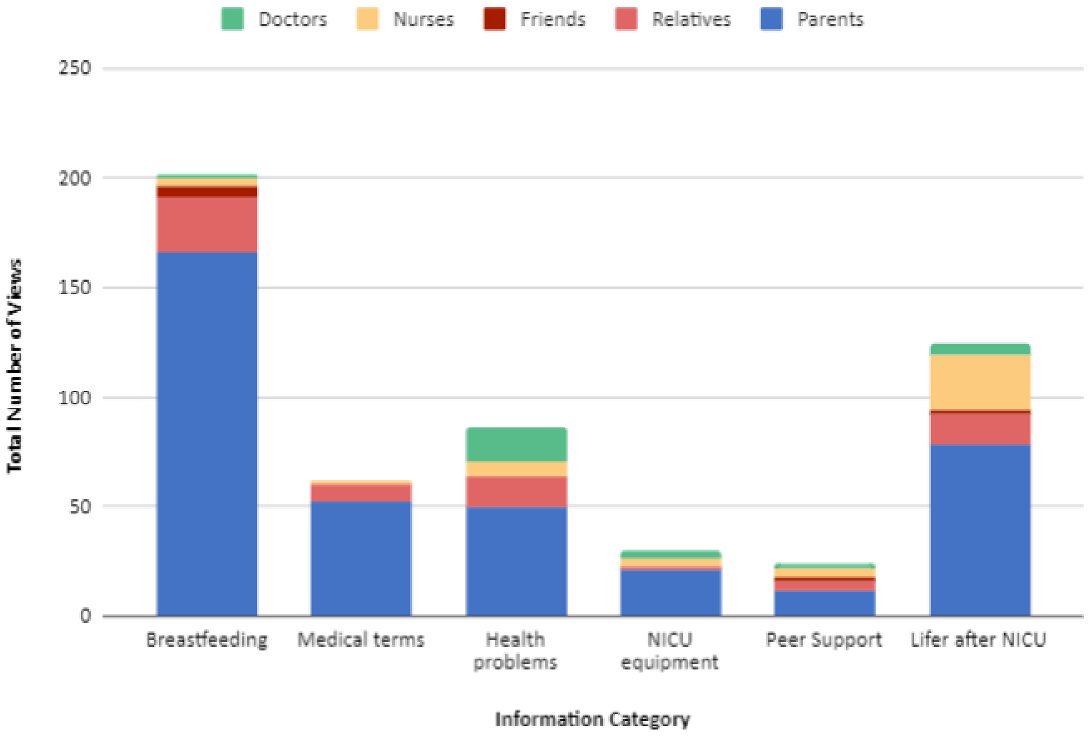


Figure 5.11. Diverse Users' Video Viewership.

The viewership graph represented in Figure 5.11, it indicates that 72% of the videos were consumed by parents (88% female and 12% male). Figure 5.12 shows

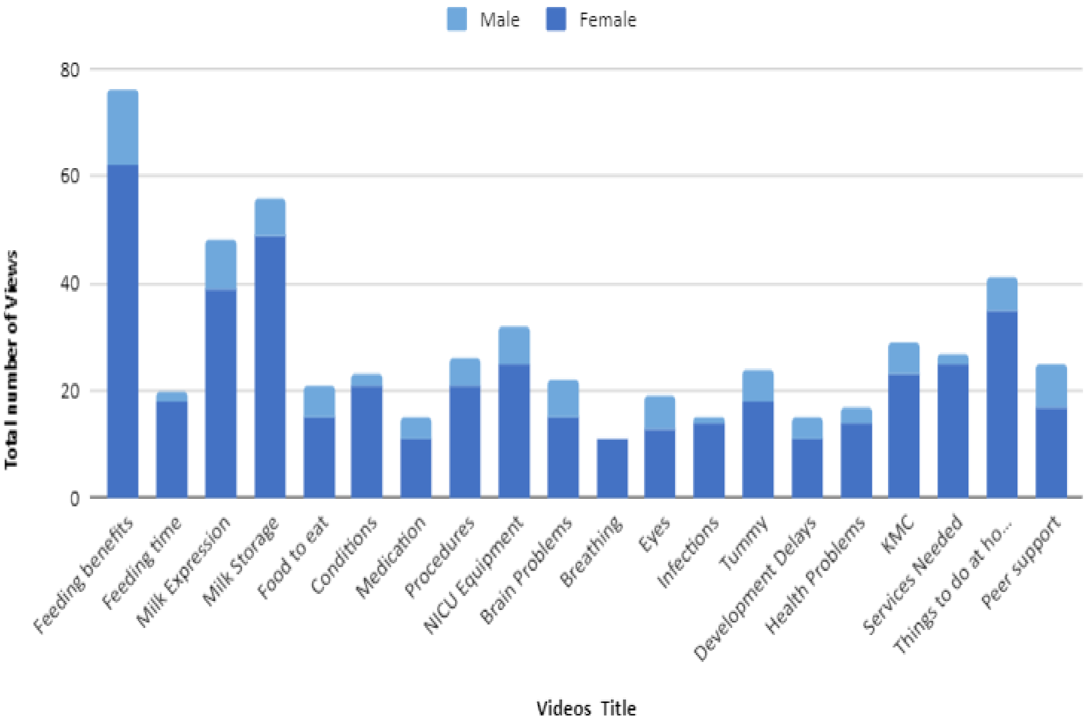


Figure 5.12. Gender distribution in infant care.

that partners and male relatives were mainly interested in breastfeeding information and learning technical terms that related to infants' care and the NICU environment. This watching pattern was confirmed during the interview sessions when two fathers said that they watched the video with technical terms that their wives could not understand so that they could interact with NICU staff to seek information clarification.

"I always ask nurses support because I want to share the hard words with my wife in a way that she can understand." –Father 1, Deployment

"I want to understand the information provided by the app so that I can help my wife where I can. I can easily interact with the nurses as my wife watches the baby." – Father 2, Deployment

We also learned that foreign mothers who could not communicate in English often asked their partners— who visited them in the evening after work, to translate the health information on the app in their respective home languages.

"Her (the wife) English is not good, so I try to explain the information on the app in Chichewa." – Father 3, Deployment

We further examine the role of various PMC users in the care and support of both the mother and hospitalized infant by analysing their app usage. We found a collaborative relationship between different users in the care and support of infants. Parents and relatives focused mainly on accessing breastfeeding, medical terms, health problems and life after NICU health information. During interview interactions, we learned that they primarily accessed these information categories to understand the current condition of the infant so that they could support mothers accordingly.

On the other hand, nurses accessed 8% and 4% health problem and life after NICU information categories respectively, and doctors accessed 17% health problems and 20% life after NICU information, respectively. From the analysis and interaction with doctors, we identified they preferred to explain the information off their head instead of relying on the application. They only used the application when motivating mothers to install the application.

"I have the app on my phone, but I rarely use it when engaging parents. I only open it when sensitizing them to install it." – Doctor 1, Deployment

This finding was discussed during the handover workshop and we agreed that doctors and nurses could install the application to encourage mother and their relatives to utilize the PMC platform. However, nurses informed us that they could not use the application in the unit because the hospital policy prohibits nurses from using their mobile phones while in the unit. They mentioned that they only accessed the app during their break times whenever they wanted to locate information in the app to interact with parents effectively. While supporting mothers in the unit, nurses requested mothers to use their app to share information with them. To engage nurses in supporting the PMC initiative, we agreed that the unit could assign a nurse to visit the breastfeeding room during tea and lunch breaks to support mothers watching videos on television whenever they needed additional information.

In addition, the senior nurse who was in the meeting said that she and other senior nurses had installed the application and were mainly using the videos to support mothers whose infants were awaiting discharge to prepare them for the NICU to home transition. She suggested that junior nurses were best situated in utilizing the PMC application to support new mothers who lacked information about their infants' care. However, during the interview session conducted during the handover period, we realized that nurses did not want the additional duties of sharing medical information with mothers and their families. Instead, they mentioned that doctors were well-endowed with medical information that mothers needed to learn about their infants. To support these claims a senior nurse said:

"We want mothers whose infants have critical illness to avoid interacting with their phone and concentrate on breast milk expression and skin-to-skin care. They should wait for doctors to share information with them." – Nurse, Handover

It was evident that the adoption of technology to support mothers was not fully embraced by all nurses because they felt that it would add more NICU responsibilities, yet their hands were already full. Nonetheless, some senior nurses advocated using PMC digital information as additional educational material for training junior nurses during their continuous professional training workshops. However, the issue of nurses using their phones in the NICU was still a puzzle that needed the hospital Management team's involvement to ensure the safety of the sick infants was maintained.

5.7.4 RQ4: Effects of Having Health Information in Three Different Languages

As Figure 5.13 shows, there were 66 English, 16 Afrikaans and 13 isiXhosa app installations during the eight months study period. During the co-design process, mothers pointed to language barriers as a significant hindrance to NICU health information access. However, we realized that after PMC deployment, most users preferred using the English application to their home language application.

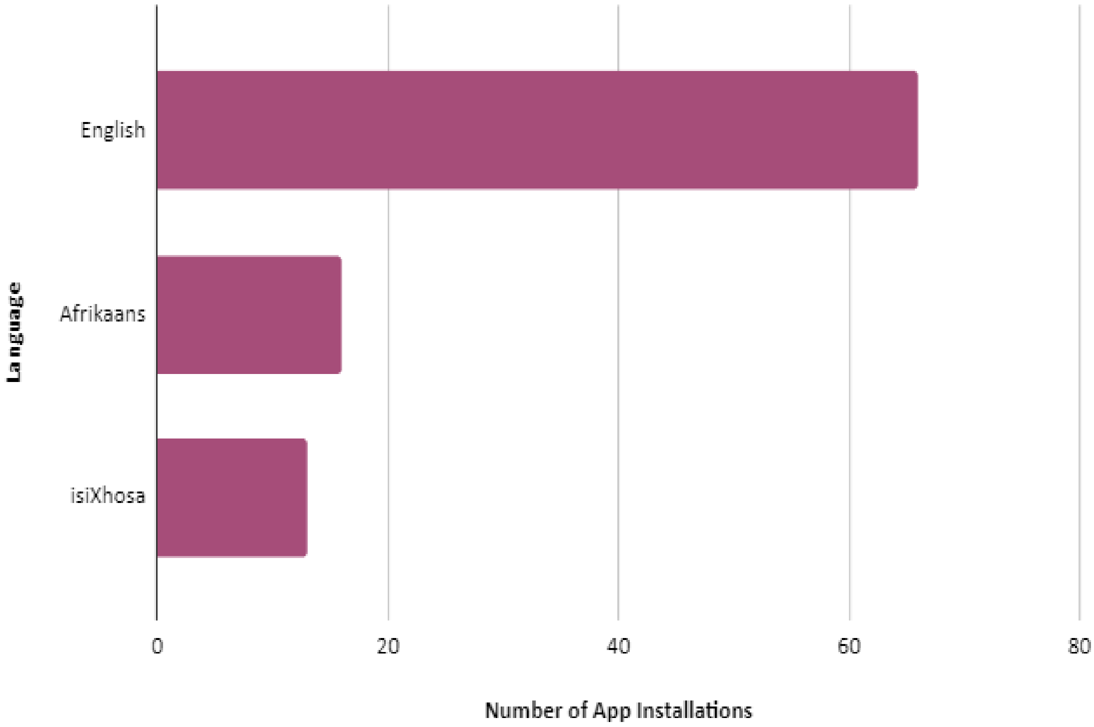


Figure 5.13. PMC app Installation.

This finding was interesting because most mothers we interacted with were not fluent in English and sometimes needed interpretation assistance from their peers. Yet, they insisted that the English version app was easy to understand. Therefore, we sought to identify the language preferred by users to view specific videos from the usage logs.

Figure 5.14 shows that users mainly used the English language to access information categories such as Health Problems, Life after NICU, NICU Equipment and Peer Support, which included information with technical terminologies. We followed up on this finding during interviews sessions and learned that users shied away from using their home language to access health information with NICU jargon. Instead, users mentioned that they first watched the videos on the television to inform their language app choice.

However, this decision-making approach was faced with several challenges, including misinformation. For instance, we identified a Xhosa mother who was watching an English video on the television. She purely relied on the imagery to inform her of the video content. Unfortunately, she misinterpreted the video that explained the causes and effects of meningitis. In the video, an inflamed

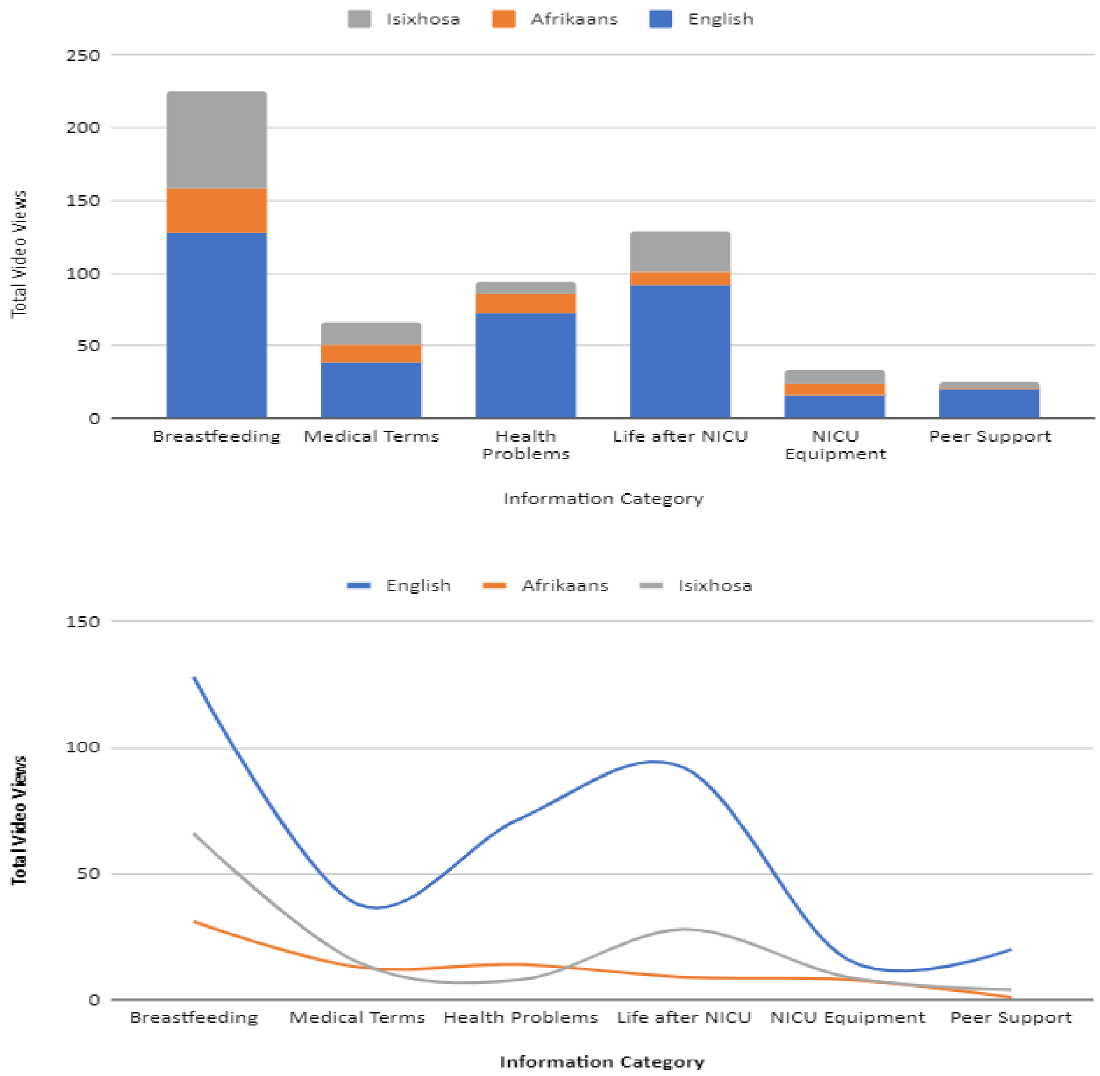
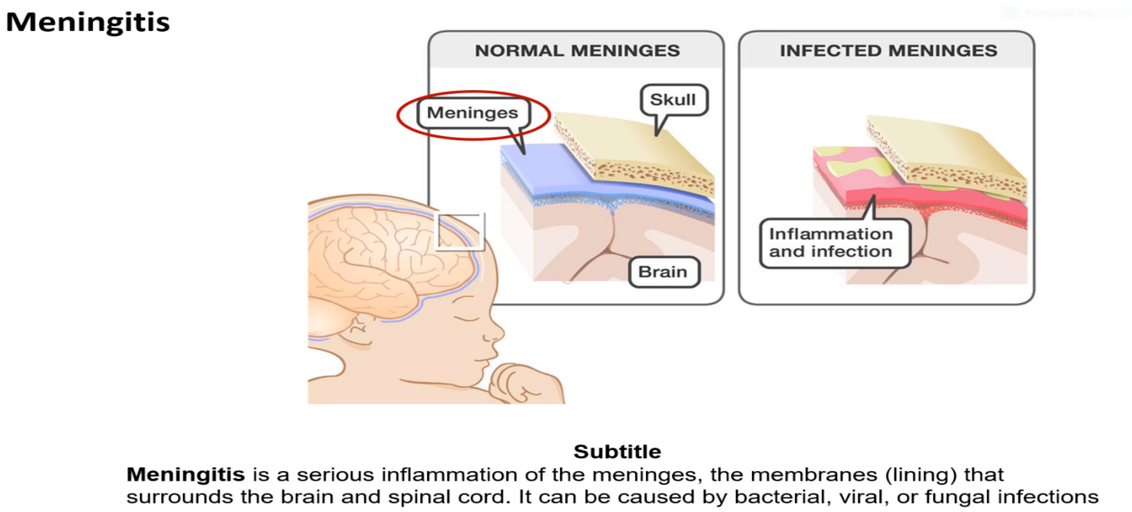


Figure 5.14. Language used to access various health information categories.

meninges was represented by a red spongy layer, as shown in Figure 5.15. The woman interjected and asked:

"So my child can get this infection if I wash his head with a sponge?" – Mother, Observation

To clarify the information, we chose to play the video in isiXhosa to help the woman understand the information. She eventually asked us to install the isiXhosa app version on her phone. However, two mothers who were in the room said they could not follow the explanation in isiXhosa. Instead, they choose to install the English app version. Their feedback revealed that the English app version was easy to understand. They mentioned that in their everyday conversations, they code-switch— a practice of mixing two languages in a conversation, English and their home language when communicating with their peers and family members. Hence, they found it hard to follow videos in their fluent home



Subtitle
Meningitis is a serious inflammation of the meninges, the membranes (lining) that surrounds the brain and spinal cord. It can be caused by bacterial, viral, or fungal infections

Figure 5.15. A screen shot of an image of healthy and inflamed meninges described in a video.

language. They mentioned that only village people or the older generation spoke fluent isiXhosa.

"Fluent isiXhosa language is complicated, that is why I prefer the English version." –Mother 5, Deployment

"Only people in the village and older people speak pure isiXhosa ." –Mother 4, Deployment

Users who installed their home language app version said they used the English subtitles in the video to switch from one language to another. They had to pause the video to read through the English and their home language information.

"....you see, you stop the video and read the subtitle in English and compare it with the IsiXhosa subtitle to understand the information." –Mother 6, Deployment

"I pause the video so that I can read the subtitles. It is easy to understand when you relate the picture and the English and Afrikaans words."—Mother 7, Deployment

We analysed system usage logs to understand whether different user groups had varying language preferences while accessing information. Figure 5.16 shows that most parents used English and isiXhosa to access health information. Doctors and nurses only used the English app version to access information, while relatives (mainly grandparents) and friends preferred using their respective home languages. This language preference resonates with mothers sentiments that the older generation is more conversant with their respective home languages.

Our qualitative and quantitative data suggested that having information in various languages meet various users' needs, thus encouraging family-centred infant care. We further asked users how we could enable users to understand health information in various languages to increase support in the NICU. 30 %

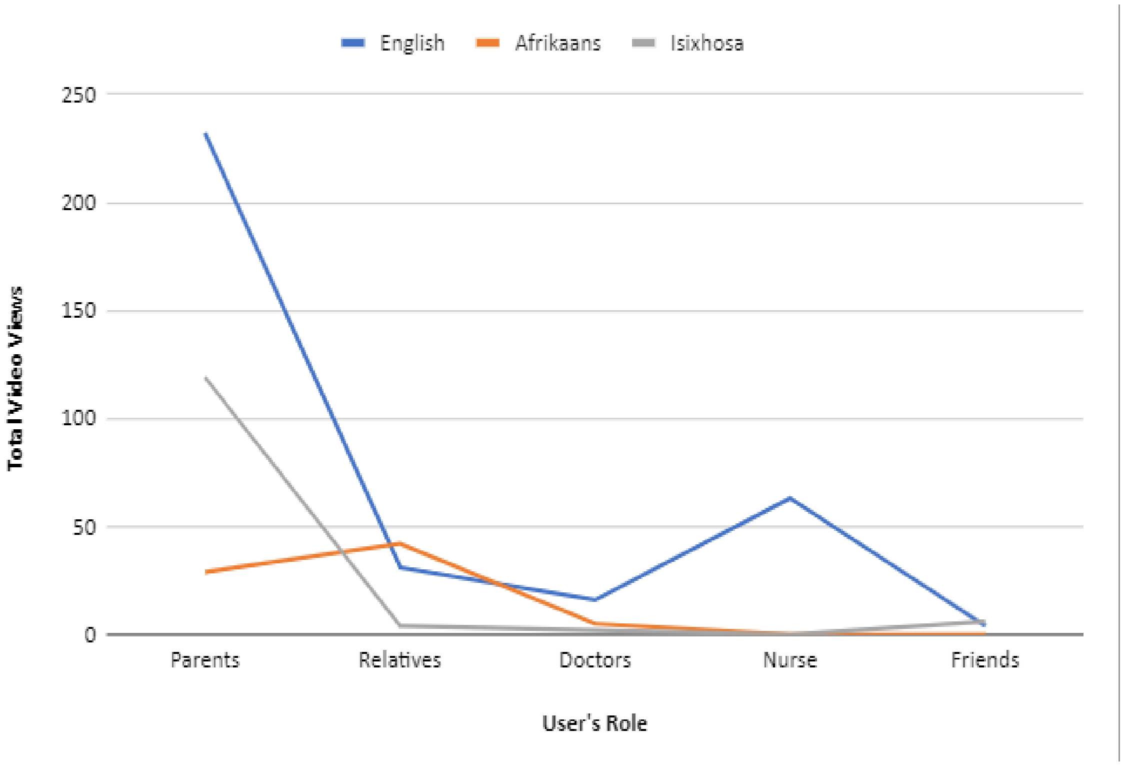


Figure 5.16. Language App version installed by different user groups.

of interviewed mothers suggested that the application could use code-switched language to meet the needs of most PMC users. In addition, 67% of mothers indicated that combining English and their home language app could help them understand the shared information. The merging of the application approach was also supported by NICU staff, who mentioned that it would help mothers interpret English concepts in a language that they fully understood, thus improving their vocabulary, especially while interacting with NICU staff.

After developing the merged application, we realized that 68 users were using the application. However, we could not collect qualitative data from these users due to the COVID-19 pandemic. Therefore, we could not identify whether the application installations were made by users in the South African context or other parts of the world. We had similar challenges when analysing the usage trend for the YouTube videos.

5.7.5 RQ5: PMC User Experience

We addressed research question five by looking at participants' reactions and attitudes towards PMC platform usage. We used observation and interview findings to represent users' first interactions and perspectives towards the PMC platform.

Hesitation in PMC Application Download

We observed several instances where users, especially mothers, were hesitant to download and install the application on their phones. Most users said they did not have mobile data or did not want to use their limited mobile data to download the application. We explained to users that the download process was free and they only needed to connect to the WiFi to download the application. They seemed not to understand the "free download" concept. Instead, they presumed that one needs an Internet connection to download any application on their phone. These are some of the comments we heard during the installation process:

"How is the download possible without internet connection?"– Nurse 3, Deployment

"Where is the application coming from? How can we download directly from the television?"– Mother, Deployment

"Please, can you send me the application via Bluetooth or SHAREit?[4] *It is free."*– Father 2, Deployment

To help users understand the "free download" concept, we showed them the local server hidden behind the television. We also gave them pamphlets with the system instructions to help them understand the download process. Furthermore, we asked them to switch off their mobile data to ensure no data cost was incurred during the installation process.

Nevertheless, many of the participants were still hesitant to download the application. When they downloaded the app, we observed them check their data bundle balance after installation to clarify zero data usage. For instance, one mother checked her download file and said:

"From downloads file, I see I have used 67 KB file after downloading the file. That's a lot of my data"– Mother, Deployment

Two mothers next to her said they did not have any data bundles, yet they managed to install the application. They also told her to check her data bundle balance to confirm their claim. Our observations over time suggested that participants trusted the installation process after receiving recommendations from mothers who were already using the application. Therefore, we used the "word of mouth" approach to reach out to users who were hesitant to download the application. In addition, we placed posters on NICU walls to provide installation instructions to users.

This user support approach encouraged users to help each other during the installation process. Users only requested our assistance when they faced installation challenges such as phone software or storage limitations. The installation process allowed us to help users update their phone software and create more storage capacity by deleting some folders, such as the sent WhatsApp folder that unknowingly used most of their phone storage capacity. Eventually, we were able to install an average of four applications per week.

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[4] SHAREit (https://www.ushareit.com) is a cross-platform set of applications that allow peer-to-peer sharing of files and applications between devices.

Relevance of Information Shared via PMC Platform

Mothers' and their relatives' responses confirmed the relevance of information shared via PMC. During the interviews, they mentioned that the information was useful because it helped them familiarize themselves with the NICU environment and medical procedures and terminologies.

We identified that not only mothers of premature infants were using the application but also mothers of full-term infants. For instance, while walking in the unit, we engaged with a mother who previously had three premature births. She said her fourth delivery was full term, but the infant's weight dropped three days after delivery, thus necessitating the baby's admission to the NICU. She commented:

> *"It feels like I am raising a premature baby once again. I think the app will provide me with relevant information since I am struggling with breastfeeding."* – Mother 5, Deployment

Similar to this mother's predicament, we encountered another mother whose full-term infant had a feeding disorder. The infant was fed via a tube and had several NICU equipment surrounding her. She observed us helping a mother install a PMC application and asked:

> *"Why are you passing me? My child is full term, but I want to learn about the feeding complication from the app. I watched the videos in the breastfeeding room and they are useful."*– Mother, Deployment

We helped the mother install the application and recommended that she use breastfeeding, health and medical terms video information since they were the only relevant information to her case. Three days later, we met the mother and she mentioned that the information was credible. She said the information previously accessed on a reliable website was similar to the app's information. She proclaimed that she preferred the PMC app because it required no internet access and the language used in the application was easy to understand.

Moreover, the nurses and breastfeeding counselors who supported mothers with lactation challenges commended the exhaustive breastfeeding information provided by the application. They enunciated the importance of the platform to breastfeeding mothers in the NICU.

PMC Usage and Areas for Improvement

Overall, the interview feedback suggested that users found PMC easy to use and the information shared was easy to understand. They mentioned that the app logo and color was distinctive and easy to locate among the numerous applications installed on their phones. In terms of usage, they stated that the interfaces were repetitive and did not require memorization while using the app. Users liked the video functionalities that allowed them to play, pause and stop the videos stating that it encouraged them to focus on specific information that they purposed to learn. Also, they appreciated the aspect of the app that gave them the freedom to choose the specific video to watch instead of random auto-play videos like on the television display.

Moreover, they commended the simplicity of the information shared, saying it was easy to understand. The grouping of videos in various categories made it easy for mothers to locate the specific video of interest. However, they mentioned that the medical terms and health terms videos were confusing since they were interlinked. One mother said:

"Some information in health and medical terms have similarities and I have to play the videos back-to-back to understand them in detail." –Mother 2, Deployment

To understand their preference, we asked them whether they wanted the merging of the two categories. They stated that the categories provided discrete information and they preferred having them separate.

"I don't mind having the two categories separated, it is easy to navigate through the application." - Mother 4, Handover

Additionally, users stated that subtitles in the videos allowed them to either listen or read the information. Moreover, it enhanced content comprehension. They easily switched from the subtitles in English to the narration in their home language to understand the information shared.

However, mothers also voiced the shortcomings of the app. They said that the video would start playing from the beginning whenever they resumed playing a stopped video. They requested us to change that functionality to enable them to watch videos from where they stopped. We informed them that instead of using the stop function, they could easily use the pause function whenever they wanted to watch the video in bits. Mothers also asked for more videos in the peer support and breastfeeding categories. In the peer support category, they suggested that mothers discharged from the hospital could testify on their infant health and development to encourage mothers who were still caring for their hospitalized infants. In addition, they wanted recommendations of cheap breast pumps included in the breastfeeding category.

In terms of video sharing, mothers asked whether they could download the video from the app for sharing purposes. They complained that download from the PreemieTube was slow and sometimes the process would time out. In addition, they asked us to include functionality that would allow them to add comments on the specific videos in the app. This comment was heard from a mother during the interview session:

"Instead of only liking the videos, we would like to add comments and emojis just like we do on Facebook." - Mother 2, Deployment

To implement this recommendation, we created a YouTube channel that allowed users added their comments. Unfortunately, we could not get users' feedback on the channel since we could not visit the NICU in the COVID pandemic.

For the merged online application, users said that the availability of videos in all languages helped them switch from videos in their home language to English videos whenever they did not understand the medical terms in their home languages or vice versa.

"...eeh it is easy to move from one language to another. This is good when you want to understand information in two languages" - Mother 4, Handover

"...I like the application because I can watch the videos in any language without stopping....." - Father 4, Handover

5.8 Discussion

The outcomes of PMC deployment and handover phases revealed that the PMC system reduced health literacy disparities between parents and NICU staff, thus encouraging them to interact and cooperate in infant care. The outcomes have also uncovered unanticipated needs for multilingual and bandwidth-constrained NICU users. This revelation opened new design avenues for future researchers who focus on designing digital health videos to bridge communication between multilingual users and health care in a low-resource context.

The discussion in this section is structured into three sections. The first section discusses improved NICU stakeholders' interaction due to parents enhanced knowledge around their infants' healthcare. The second covers analyses of PMC usage trends based on users' feedback and system logs. Lastly, the third section addresses the design implications for NICU communication intervention and possibilities for future work.

5.8.1 Improved Interactions Between NICU Staff and Parents

Our results show that parents gained the confidence to interact with NICU staff after accessing health information on the PMC system. Unlike prior technologies that promoted electronic (Lindberg and Öhrling, 2012; Gray *et al.*, 2000; Hayes *et al.*, 2014; Mahamood and Reiter, 2011) and written (Hesham *et al.*, 2016; Vijver and Evans, 2015) Parents-NICU staff communication, the PMC system focused on bridging the NICU communication gap by improving mothers' health literacy to empower them to engage in face-to-face conversation with NICU staff. Despite including a chat service in our system, we realized that mothers underused the chat services and preferred using the television and PMC app to access information. We learned that these channels encouraged mothers interactions with their social networks, peers and NICU staff. In addition, to articulate their infants' health concerns, PMC users re-consumed videos to improve their medical vocabulary, thus giving them the courage to communicate with NICU staff. This watching trend reveals the importance of having multiple access channels in the NICU context to enable users to access and discuss health information with their peers and NICU staff.

We learned that similar to persuasive health videos, videos meant to bridge the communication gap should incorporate behavioural change messages and imageries that motivate NICU parents to seek further support from NICU staff (Cameron and Chan, 2008; Katule, Densmore, and Rivett, 2018). However, unlike persuasive health videos features such as reminders, praises, prizes, suggestions etc., that encourage user engagement (Senette *et al.*, 2018; Ramachandran *et al.*, 2010a), communication bridging videos should be flexible and not suggestive to allow users access their preferred videos. The video access flexibility can be encouraged by creating short videos with a brief description of health information and familiar graphics related to infants' care to prompt the user to seek more information from NICU staff. In addition, to enhance the medical vocabulary of multilingual parents, video designers should annotate the video with two languages—preferably parents' home language and a common national language, to encourage code-switching from one language to another. This design mechanism empowers parents to code-switch between languages—as It is common in their everyday conversation while engaging with NICU staff or their peers.

Although there was minimal PMC usage among NICU staff, they appreciated that parents showed interest in understanding their infants' health journey. They said collaboration with parents in infant care ensured that parents gradually became independent and took full responsibilities for their infants' health before they are discharged. In addition, parents- NICU staff interaction had a positive outcome on the psychological status of parents. For instance, a mother who had lactating challenges said she felt a great sense of competence in caring for her twins after changing her diet, as recommended in the PMC videos. Furthermore, she mentioned that the availability of information and interaction with nurses relieved maternal stress, thus boosting her breast milk production. This feedback highlights that mothers empowerment in NICU is integral for positive outcome of infants' health.

Although empowering patients and caregivers through technology is an increasing concern in the HCI community, we realized that empowering mothers in the NICU context is multifaceted, requiring mothers to improve their interpersonal, interactional and personal capacity. In line with (Toyama, 2011) theory of technology amplification, this study evidence that mothers empowerment to interact with NICU staff was not only attributed to technology but also other attributes such as the willingness of mothers to learn, NICU staff responsiveness toward mothers' requests and support from peers and family members. Therefore we argue that researchers working towards using technology to empower NICU parents should analyse the health environment to identify external attributes that can enhance parents care and focus on using the adopted technology to enhance them.

5.8.2 Analyses of Video Consumption Trends

PMC System User Diversity

We designed PMC system to support mothers of preterm infants who were the primary carer in the NICU. Although we did not understand the fathers and relatives' design needs, our data analysis indicated a diverse usage from mothers and their social circle. Similar to Kumar and Anderson (2015), we identified that mothers' social circles interacted with the system to understand infants' health status and also to learn how to support mothers who were caring for infants in the NICU. For mothers who could not understand health information either due to information technicalities or language barriers, their partners used the PMC application on their behalf and interpreted the information to them. In other instances, the partners also acted as mediators between mothers and NICU staff. They interacted with NICU staff to seek help and clarify certain health information that they could not understand. However, mothers whose families could not visit the NICU due to long-distance or lack of travel funds shared the offline PMC application via WhatsApp. Alternatively, mothers requested that their social circle to install the PMC app available on the Google Play store to share and discuss infants' health information with them.

Similar to the work of Kim, Garfield, and Lee (2015) and Gibson and Hanson (2013) work, we identified that the collaborative use of technology encouraged each NICU parent to take up a different role in ensuring that they educated and supported each other during their infants' hospitalization. Despite seldom NICU visits by infants' fathers, they used information shared on the PMC platform to update themselves on their infants' health progress and learn ways to support mothers, thus creating synergy in caring for their infants. In cases where partners were not available, relatives, especially the maternal grandparents, played a distinctive role in supporting mothers by providing relevant encouragement based on the information shared on the PMC application.

When designing health videos to bridge communication gaps, we learned that it was important to develop videos with general health information to ensure mothers and their social circles could utilise them. In line with Peyton and Wisniewski (2019) recommendations, the PMC user interface did not focus on color and graphics that were specific to mothers. Instead, the application used purple color and graphics that mainly focused on premature infants' care in the NICU, thus encouraging diverse usage. These videos design features enabled users to learn about their infants' care and ways relatives could support mothers.

These results point to the importance of embracing Family Centred Care (FCC) in the NICU. Although Al-Motlaq and Shields (2017) and Makworo, Bwibo, and Omoni (2016) indicate that FCC is not applicable in low-income setting NICUs due to socio-economics and cultural influences, our findings are evidence that with a reliable information source, mothers and their social network can collaborate and interact with NICU staff in infant care. Consequently, this relieves mothers' stress levels and increases their self-esteem, thus enabling them to fully engage in their infants' health care. Even though little work has been done in understanding how technologies can enhance FCC in NICU, this study initiates and contributes an understanding of how technology intervention can be designed to improve the usage of different user groups participating in infant care.

This design revelation shows the potential of collaborative co-design in the NICU context. Although mothers' social circles were not part of the design team, the collaboration of NICU staff, with lengthy NICU experience, and mothers translated their unique NICU experiences to creative ideas that addressed the needs of both primary and secondary users. This finding contributes to a better understanding of processes needed to effectively engage NICU participants in a productive co-design process considering the disparate role and knowledge in infant care. Therefore, we argue that researchers should focus on features and information that encourage collaboration and social support to ensure that mothers' relatives and friends can access information and support mothers accordingly.

Factors Affecting Video Viewership Completion Rate

Our results show that the viewership completion rate was affected by the length and comprehensibility of information in a video. Unlike in Molapo (2017) study, where the length of the video did not affect viewership, our results show that users were hesitant to view long videos and those that included an explanation of medical terminologies. Instead, users chose to watch videos partially and use imagery to help them gather specific information from the videos. We learned that NICU parents have limited time to watch lengthy videos because they are busy holding or feeding their infants. They often skip the video to access and learn specific medical information to enable them to seek further information from the NICU staff. This viewership pattern was important to encourage PMC users to interact with NICU staff. Thus, we emphasise that videos meant to bridge communication gaps should be short and easy to understand to enable users to access and interact with the information that holds their interest. In addition, these videos should incorporate familiar imageries and video functionalities such as skip, stop and pause to enable flexible interaction with the video.

5.8.3 Benefits of Multiple Interaction Channels

We provided six information-sharing channels in parallel to enable users to choose their preferred information access media. Feedback obtained during the interview sessions revealed that users adopted a specific channel based on their various affordances. For example, the television enabled users with and without a smartphone to access health information. We learned that users mainly used the television to decide whether to install the mobile application and their preferred language to access information. Also, this channel allowed users, especially mothers to gather in the breastfeeding room and engage in discussions related to their infants' health.

On the other end, the PMC mobile app uptake was influenced by its accessibility in any geographical location and the fact that it allowed users to access content in private. It is for this reason that some mothers chose to use free file-sharing software to share the PMC apk. file with their partners and relatives to allow them access to health information while away from the NICU. To support users who were not in the NICU, we uploaded the online PMC mobile application on Google Play Store to enable installation from any geographical location. However, the television and PMC mobile application did not have the feedback functionality that Preemietube and Preemiechat supported. Although these two channels were only accessible in the NICU, they enabled users with limited phone storage capacity to interact with the videos of their choice and share their feedback or enquiries on the platform. We extended this video functionality by creating an online Youtube channel to allow users to interact with the videos within and outside the NICU. However, we were unable to interact with users to gauge their feedback on the channel.

Based on our findings, having multiple channels was beneficial because it encouraged users to adopt the channel that met their technical needs. As a result, this increased video accessibility allowing users to engage with the system as they wished. Even though participants did not request extra access channels (

TV, PreemieChat and PreemieTube) that we included in the system, they adapted and appreciated the services. We learned that understanding mothers and their socio-economic status were integral in designing a flexible multi-channel platform that catered to NICU users' needs based on their varying devices' capacities. In addition, the PMC channels provided information redundancy, enabling users to access health information with or without their phones. Moreover, when the Internet was deployed at the NICU, the PMC system proved resilient and extendable since we could easily upload the videos to the online system, allowing users who could not visit the NICU due to the COVID-19 pandemic to continue interacting with the videos.

Similar to Densmore *et al.* (2013) and Derenzi *et al.* (2016), we reiterate that multiple channels should reinforce and complement each other based on their different affordances. The affordance of various PMC information sharing channels enhanced system adoption, resulting in increased parent interactions with NICU staff and involvement in their infants care. We also learned that system disseminating health videos should be resilient to change of infrastructure to allow continuity of use. Researchers should ensure the channels share consistent information to provide a similar user experience to let users interact with various channels before adopting the channel that suits their device capacities and engagement needs. Therefore, we argue that it is essential for NICU researchers to understand the needs of NICU users to ensure the final solution does not discriminate users' information access based on technology limitations common in low-income settings.

5.8.4 Design Implications

Designing for Multilingual Users

We expected that users who were not proficient in English would access health information in their home language. Despite involving health personnel and professional translators in health information translation, our results show the inefficiency of information translation in the health sector. We learned that users do not use pure home language while interacting with their peers and relatives. Thus, it was challenging for them to understand health information shared in their home languages. In addition, users mentioned that they could not understand medical terminologies in their home language because no equivalent terms represent the NICU's medical terminologies. Consequently, like (Karusala *et al.*, 2018), 60% of interviewed PMC users said they preferred accessing health information in English to their home language despite not being proficient in English. With the help of imageries, they said they could identify medical terms that doctors shared with them during the ward rounds since English was the official language used in the unit.

Users who used their home language app said they code-switched from their home language video narration to English subtitles to comprehend information. With the help of familiar NICU imageries, users utilised the stop and pause video functionalities to read the subtitles and use the visual cues in the video to understand the information shared. This explains the high rate of repetitive and partial video views discussed in section 5.7.2. Using two languages while accessing health information improved their medical vocabulary, thus enabling them to interact with NICU staff. In addition, senior nurses recommended these video features saying that nurses who interact with mothers in their home language could code-switch from one language to another while discussing health information. This code-switching pattern was apparent when we merged the three applications into one application. Users appreciated the fact that they could switch from one language app to another.

In health literature, Staczek (1983), Singo (2014), Vickers, Goble, and Deckert (2015), and Menz (2016) highlight the importance of code-switching in health-related communication. They indicated that code-switching during doctor-patient communication increases patient involvement and adherence to health care. Despite the clear implication of code-switching in improving doctor-patient communication, to the best of our knowledge, no study focuses on understanding code-switching in digital technologies that disseminate health information. Instead, studies such as Turner *et al.* (2012) and Nhampossa (2005) recommend the use of crowdsourcing methods and online translation, respectively, to support health information translation from one language to another. However, our results show that health information translation is not sufficient. Instead, multilingual users prefer code-switching between multiple languages to comprehend health information. We learned that designing interfaces for multilingual users is more than making the interface available in various languages. In addition to translating health information to simple languages that users could understand, we realised that annotating home language video in the English language, incorporating stop and pause video functionalities and including familiar imageries supported code-switching, thus improving users' medical vocabulary during their interactions with NICU staff. This usage pattern explains why users suggested merging the three language apps to enable them to watch the full video in their home language before switching to the English video. Although we were unable to evaluate the watching trend of the merged PMC app, the few users we interviewed suggested that the app enabled them to watch specific videos in their preferred language, thus enabling them to share or discuss their infants' health conditions with NICU staff, partners and relatives. Therefore, we emphasise that it is important to annotate the videos with a different language from the narrative language and incorporate familiar NICU imageries and video functionalities to enable users to read, listen and use the visual cues to enhance their bilingual competence while communicating health information.

Designing Beyond the Primary User

Our study's key important lesson is that designing beyond the target user is important in enhancing Family Centred Care in the NICU. We realised that despite not including mothers' social networks in the design process, the collaborative co-design between mothers and NICU staff resulted in health information relevant to both NICU staff, mothers and their social circle. An essential part of co-designing health information pertinent to mothers' social networks was our in-depth study and understanding of the NICU information sharing protocol to mothers' and their social structures. Earlier in the study, as reported in Chapters 3 and 4, we learned that the unit encouraged visits and general information sharing with infants' families either by word of mouth or using the available communication channels. However, sensitive information and infants' health status were only shared in person with the parents. To mimic this experience, the PMC application only provided generic health information, which helped users understand the NICU environment and terminologies. To achieve this study objective, which was to encourage communication between NICU staff and mothers, parents who needed further consultation used the PMC information as a basis for engaging the NICU staff.

Although this study does not refute Peyton and Wisniewski (2019) recommendation on the importance of including mother's social supporters (especially fathers) in the design space of applications that support motherhood experiences, we emphasize that the co-design process for motherhood tools should not only focus on the involvement of a mother's social circle in the design process of the artefact. Instead, researchers should also consider the social-cultural nuances in the design space context and how the design process can positively influence them. In our case study, mothers were the main caregivers in the NICU. Most mothers did not have partners and for those who were married, their partners worked throughout the day. Thus, most of the time, they were unavailable in the NICU. Putting these factors into consideration, we co-designed the PMC application with only mothers and NICU staff, focusing on mirroring the NICU communication protocol. Our design process focused on ensuring that the PMC application was an assistive media that mothers who were the primary users, could understand their infants' health conditions and engage with the NICU staff. In addition to supporting mothers, our results ascertain that the application was also relevant to the secondary users. They used the intervention to enable them to partake in infant care as well as support mothers. Considering the need to adhere to institutional and local norms, we identified that engaging NICU staff and mothers were pivotal in unveiled design ideas that met the needs of the secondary users.

Our results indicated that the increased involvement of fathers and other supportive caregivers played a role in improving family centered care in the NICU. This involvement supports the South African government's initiatives that target men's inclusion in improving outcomes for women and child care (Sonke Gender Justice and Human Sciences Research Council, 2018). It is also in line with the NICU objective of establishing family centred infant care. Hence, our co-design process reveals the importance of understanding infants' primary carer needs and NICU communication protocol to enable maternal and child health intervention design for collective use. Although Makworo, Bwibo, and Omoni (2016), Shirazi *et al.* (2015) and Al-Motlaq and Shields (2017) highlight the obstacles of implementing family centred care in NICU, this study plays a significant role in showcasing the feasibility of using technology in engaging family members in collective infant care. Lessons from our study indicate that digital intervention encourages family members that are within and outside the NICU to explore and discuss infant health information, thus giving them the confidence to engage with the NICU staff. Since this study is among the initial HCI work that reflects the possibilities of using technology to promote FCC, further HCI studies are required to understand design features that can enhance family satisfaction.

5.8.5 Improved Adoption of NICU Communication system

PMC is an offline system that disseminates health videos with no cost implications. For the online PMC channel, the system is designed in a way that utilizes limited data costs. During the co-design process, we identified that most mothers owned low-end smartphones. However, most of them said they could not afford Internet costs and only relied on zero-rated applications such as Facebook. After this realization, we designed an offline PMC architecture that enabled users to utilize their mobile phones to access health information. This design consideration eliminated the need to buy new phones for the project, which was not sustainable since infants' admissions and discharges were rampant. With this approach, users could continue using the application even after they were discharged from the hospital. To ensure that the developed application was compatible with the varying functionalities of users' phones, we chose to develop a hybrid application. In addition, we included multiple access channels on the system to enable users with and without smartphones to access the health videos. All the channels provided information redundancy, thus allowing users to switch from one channel to another before settling on their preferred access point.

We learned that engaging all NICU stakeholders in the design and utilization of the application was vital in establishing project ownership and sustainability. Users, especially parents, often rely on NICU staff to access their infants' health information. Therefore, users tended to adopt the PMC platform when staff recommended or utilized the videos to share information related to infant care. The qualitative data acquired from users revealed that nurses utilized the information shared via the television because they could not use their phones in the unit. On the other hand, doctors did not utilize the application, but they often recommended the PMC platform to all the mothers they interacted with. Despite the NICU restriction on phone usage, we identified that having a public display channel allowed nurses to support users in the unit. This realization justifies the importance of multiple information sharing channels in enhancing the sustainability of digital health intervention. Nevertheless, during the system handover meeting, we further discussed organisational measures that needed to be taken for PMC platform utilization among staff. Fostering NICU staff-parents partnership was a crucial measure in achieving this objective. The staff acknowledged that the system supported their information-sharing responsibilities in the unit, which was previously hampered by staff shortages and poor staff-mothers relationships. The PMC platform acted as an interaction enabler, enabling staff to understand challenges that parents faced and the information they required to fully engage in infant care.

To enhance staff-mother interactions, the NICU management identified the platform's potential and further expanded the accessibility of the system by providing an Internet connection to enable access to the videos posted on the PreemieCare YouTube channel that we established. This approach combated the technical challenges that Preemietube faced, thus ensuring infant care continuum.

This shows the importance of management engagement in promoting health system sustainability. Overall, we consider the PMC system to be a low cost and sustainable system that is effective for health information dissemination in a low-income context. The platform promotes a smarter and wider use of these multiple communication channels to stimulate staff-parent interaction and parents' engagement in their infants' health care and decision-making.

5.9 Chapter Summary

In this chapter, we discussed the PMC system development and the eight months longitudinal deployment and handover process of the co-designed PreemieCare (PMC) system. The system was developed with multiple access channels to enable users with and without smartphones to access health information. We deployed the PMC system at Groote Schuur Hospital NICU on 7 August 2019 and during the study, we focused on learning the system usage, impact and areas of improvement. Using both qualitative (observation and interviews) and quantitative (system log analysis) data collection methods, our results demonstrated that the PMC system promoted parents-NICU staff communication. Having multiple interaction channels increased system accessibility, thus encouraging users to adopt the channel that met their technological capabilities. Although the system disseminated health information in multiple languages, we realised that the translation of health information in multiple languages does not overcome the language barrier in the health services context. Instead, PMC users code-switched between their home language and English health information to enhance their health information comprehension. Therefore, we recommend that health intervention designers incorporate familiar imageries, stop and pause video functionalities, and annotate health videos in a different language than the narrative language to improve user-video interaction and health information comprehension. These health video functionalities encouraged diverse users to interact differently with the system, thus encouraging family-centred care of infants. Lessons learned from the PMC deployment provide insightful design mechanisms for bridging communication gaps in the health context. In addition, it presents potential avenues for using digital technologies to implement family centred patient care, though we advocate further studies to substantiate technology efficacy.

Chapter 6

Researcher's Reflection

6.1 Researcher Reflexivity

When I[1] began this research in 2017, I purposed to engage Neonatal Intensive Care Unit (NICU) staff and mothers of premature infants in a participatory design process of a possible NICU communication intervention that would enhance mothers-staff communication. The NICU environment is a sensitive and stressful environment that is emotionally charged due to the nature of working with premature infants whose lives are at stake. The NICU environment lends itself to being emotionally charged with mothers stressed about their infants' health and staff striving to ensure the health of the infants improves. As a researcher, the NICU was an unfamiliar environment and I was aware that unveiling some of the idiosyncrasies of participants and neonatal unit circumstances would not be linear.

At the onset of this research, I held a meeting with my supervisors and agreed that a co-design design approach would be suitable. We opted for this design approach since I did not have prior knowledge of the NICU environment and suggesting any NICU digital solution to mothers would be detrimental. Instead, I chose to capitalize on NICU stakeholders' experience to understand NICU communication challenges and explore feasible NICU solutions that would meet their needs. To familiarize myself with this environment, I opted to work as a volunteer in the neonatal unit. During my volunteering sessions, I undertook various day-to-day NICU activities such as helping the nurses to cup feed and clean the infants, helping mothers fetch infants' clothes from the unit's store and labelling expressed breast milk from the fridge. Working in the unit at the initial stage of this study allowed me to observe and understand the NICU workflow, the interaction between staff and mothers and the communication gaps in the unit. In addition, I was able to learn the different cultural backgrounds of both the parents and NICU staff and their effect on NICU communication. My interaction with NICU stakeholders helped me create rapport and build trust with them, which is recommendable in co-design to encourage participation in the design process. Ethically, this relationship-building strategy is acceptable because it encourages mutual benefit where the researcher seeks partnership and generates benefit (by giving back to the community) for the participants.

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[1] In this chapter, I will use the first-person point of view to represent my (the author of this thesis) personal experience, opinions or decisions made without involving other researchers.

In preparation for the co-design process, I chose to use methods of inquiry that would enhance empathy, empower participants, especially mothers and encourage a working relationship between mothers and NICU staff. Despite being aware of the possibility of methodological pitfalls, I still made some wrong choices in methods during the second phase of this study. Having separate discussion groups with stakeholders created social distance between NICU stakeholders, thus inhibiting mothers from sharing their design ideas (detailed discussion in Chapter 3). To bypass these pitfalls, I paired and localized methods (as reported in Chapters 3 and 4) to help stakeholders unlock their design skills and empowered them to use their knowledge and experience to define the design process. My role as an HCI researcher was to support and harness participants' design skills and expertise to raise creative, critical input and translate them into technical requirements. In addition, I focused on facilitating the co-creation process to bridge the relational gap between the NICU staff and mothers instead of getting too bogged down in guiding and making decisions for them in the design process. Therefore, my goal as a facilitator was to use my knowledge to make effective decisions to respond to emerging events and decisions that arose from the design process. These on-the-spot decisions mainly focused on building NICU stakeholders' capacity to enable them to innovate for themselves. They also informed the design methods in subsequent co-design sessions to encourage participation and interaction between NICU staff and mothers.

6.2 Identity and Self-Positioning Within the Research

In this section, I discuss my methodological choices with respect to my positioning in this research. My research focused on exploring the appropriate methods to fully engage both parents and NICU staff in the co-design process to ensure they create a feasible NICU communication tool. Therefore in this thesis, I used the Interpretive Phenomenological Approach (IPA)— a qualitative method that focuses on seeking out the meanings of individual experiences and how these meanings influence the choices made in a research (Peat, Rodriguez, and Smith, 2019; Smith and Osborn, 2007). IPA was developed initially as a method to undertake experiential research in psychology. However, it has gradually gained recognition in other fields to explain the researcher's understanding and interpretation of research topics through a process of in-depth reflective inquiry (Smith, 1996).

I chose to use this approach because it supports the process of examining topics that are complex and emotionally laden, such as the NICU communication context. In addition, IPA helped me to enhance my perception and understanding of the NICU context. I will provide my insights as I explored multiple realities through a reflexive process to interpret my experiences during the design process. This in-depth description will help the reader understand how my methodological choices influenced participants' engagement in the design process. Regarding this, I choose to write this document in the first person singular. However, occasionally I will use 'we' to acknowledge instances where co-designers and my PhD instructors contributed to this study.

6.2.1 Researcher with Prior Maternal Health Design Skills

Before this study, I worked as a project manager where I partnered with clients in five African countries (Ghana, Tanzania, Uganda and Kenya) to design and implement maternal and child health interventions that disseminated health information to mothers in hard-to-reach regions. Despite having experience of working with mothers in a developing world context, I had no prior experience with mothers of premature infants and the neonatal unit environment in general. In addition, as a woman of childbearing age, my initial NICU visits were emotionally disturbing as well as intriguing. This situation compelled me to immerse myself in this research and use my previous design and computer science skills to explore possible solutions that could improve mothers' stressful experiences in the NICU.

In my career practice, I used rapid ethnography (due to project timeline limitations) to understand end-users. However, in this study, I had to conduct a longitudinal study to understand the NICU ecosystem in this particular case. Moreover, since I involved participants in their social setting, I needed to take a reflective approach to think about the methodology and methods selection and their effect on participants engaged in the design process. Therefore, I opted to use the co-design approach, which is a Human-Computer Interaction (HCI) method that is advocated, especially when developing new solutions for marginalized and vulnerable people in developing countries by Sharma *et al.*, 2008. This approach shares the view that every participant is an expert in how they live, their lives and design ideas arise in collaboration with participants from diverse backgrounds (Sanoff, 2010). In our opinion, this was the appropriate methodological approach because it would help us understand NICU experiences from a different perspective and focus on empowering participants by allowing them to partake and lead in the design process.

As a volunteer in the NICU, my position helped me understand the NICU workflow and the communication challenges that mothers and staff encountered. However, when I started volunteering at the unit, some nurses and mothers were suspicious of my role. Nurses did not want to interact with me, while mothers were afraid of me because they thought I was a doctor. Nevertheless, I helped them care for the infants, allowing them to provide instructions on feeding and changing infants. In addition, these services helped me build rapport with NICU stakeholders who voluntarily shared the various challenges they faced in the unit and their aspirations for how the NICU workflow should be. For instance, nurses wished that mothers would visit their infants more often to take up the infants' feeding and cleaning duties which took up a lot of their time.

On the other hand, mothers wished the NICU staff would interact with them quite often and support them to learn to express breast milk and cup-feed their infants. My support and frequent interactions with NICU stakeholders motivated them to embrace my research objective, which focused on using digital technology to alleviate NICU communication challenges. In addition, these interactions eased my recruitment process because most NICU staff were aware of my research objective; thus, they were willing to engage in the design process, hoping that the overall outcome would support and improve NICU communication.

Thus, I learned that although I had prior experiences working with mothers, I needed to forgo the previous research practices and adopt a new design approach that considered the sensitive NICU setting. This design approach became apparent as I continued engaging the NICU stakeholders. Thus, researchers working in sensitive settings should have a list of methods, which we refer to as a basket of methods, to ensure they achieve their design objectives.

6.2.2 Researcher in a Hierarchical NICU Setting

As a female researcher, it was easy for me to interact with participants—most of them being women, throughout the study. However, some participants did not understand my role as a computer scientist in the medical field during the observation sessions. Initially, nurses in other unit sections (other than the one I was allocated as a volunteer) assumed I was spying on their work. Despite being introduced as a researcher by the head nurse they reported to, they keenly conducted their day-to-day role as they observed my reaction to their actions. This affected my data collection process. I had to inform them that I was not there to report on them but to collaborate with them to identify common NICU communication challenges and possible solutions. In addition, some nurses speculated that the unit was planning to introduce new technologies in the unit. As such, they expressed interesting requirements for interventions that would automate and replace the practice of handwriting medical reports. I did not dispute their desires but instead reiterated that we focused on supporting their interactions with the parents.

On the other hand, mothers thought I was a medic and they often approached me to help them interpret medical information written in infants' report books. Although I had knowledge and skills in maternal and child health care after enrolling in an online course prior to my fieldwork, I was still not in a position to share the information since it would have been inappropriate to offer advice given their perceptions versus my actual training. Instead, I acted as a mediator between parents and NICU staff. I would relay the information to the NICU staff who supported parents. However, the mediator role did not sit well with mothers when NICU staff forgot to call or share information with them. For instance, some mothers I interacted with during the interview sessions frequently called me early in the morning and late at night with medical questions, for which I needed to seek feedback from the doctors. I felt obliged to visit the unit to remind the staff to call the mothers who needed information to support their discharged infants. These experiences gave me additional insight into the specific information required by mothers of premature infants. In addition, I familiarised myself with the NICU workflow, helping me understand the communication gaps between staff and mothers.

6.2.3 Black Non-South African Researcher in a South African Institution

Although I got hold of the NICU workflow, I would have been better positioned if I had knowledge of South African culture and languages. As a black non-South

African researcher, I faced challenges when interacting with mothers who were not fluent in English. Mothers used their home languages to interact with me. Since I am not conversant with any of the official languages in South Africa, except English, I responded to them in English to inform them that I did not understand their home language. This language barrier made mothers disengage from our interactions. To build a rapport with them, I linked them with NICU staff, who provided them with the information or support they needed. Although this was helpful during the observation sessions, I could not use the same approach during interview sessions. Instead, I chose to exclude this category of mothers. I believe they would have provided additional insights into the NICU language barrier issues. In the subsequent discussion group, I hired an interpreter to ensure all mothers were included in the design process despite their proficiency in English. I relied on interpreters' and nurses' explanations to understand mothers' design ideas and cultural practices.

Being a non-South African also influenced the research when I visited mothers at home. Mothers did not want to invite me to their homes due to security issues. I learned that families in the community became a target of community gangs whenever a stranger visited them. Being a foreigner made the situation worse because they often related foreigners to swindlers. To protect themselves, mothers suggested we meet in public hospitals, police stations or shopping centres. To build trust and enhance engagement, I chose to accept their preferred meeting points and allowed them to interrogate me before commencing with our interview. With time, I learned that parents felt appreciated when I attempted to engage with them in their home language. During the deployment phase, I learned how to greet mothers in their home language, which helped me interact with them. In cases where mothers could not interact in English, I got interpretation support from other mothers, partners, and nurses. Therefore, I emphasize that researchers conducting studies in foreign contexts should focus on learning their participants' cultural practices even if it means learning their greetings before embarking on the research.

6.3 Co-design in NICU Contexts

Co-design is recognized as a methodology that supports inclusive problem solving and solutions finding (Jones *et al.*, 2008). However, despite the numerous benefits we identified while co-designing NICU communication intervention, I realized that this design approach is complex among multiple stakeholders in a hierarchical infant care structure. This section will discuss my experience working with multiple stakeholders in the NICU context, expounding on the challenges I faced and the measures I took to overcome them. I start by discussing my experience of working with multiple stakeholders.

6.3.1 Working with Multiple Stakeholders

Working with NICU staff and mothers increases diversification through the broadness of information, knowledge and suggestions for possible solutions. During the interview sessions, I realized that mothers feared the NICU staff. To improve participation during the initial focus group sessions, I decided to hold separate sessions with mothers, nurses and doctors to avoid power imbalances. Nevertheless, I still experienced co-design dynamics, such as power dynamics, conflicts and group thinking in nurses, doctors, and mothers' sessions, respectively. These dynamics hindered collaboration and as a researcher, I felt I had no enough NICU experience to navigate the discussions. Instead, as a facilitator, I made immediate methodological alterations based on the group discussion dynamics. For instance, to avoid conflict during doctors' engagement, I identified the main scenarios they disagreed upon and created scenarios based on the examples they shared before asking them to role-play and provide the optimal design ideas that could improve the NICU communication challenges. This exercise was beneficial in helping doctors to engage in constructive discussion, thus enabling them to realign their design ideas. I realized that it was important for a facilitator to have a list of methods; which I refer to as a "**basket of methods**"; when working with multiple stakeholders to enable them to make on-the-spot modifications of the design methods based on the immediate challenges they are experiencing during the design process.

Another struggle I had while working with multiple stakeholders was centred around incorporating their disparate needs in the study and producing an intervention that appeals to NICU staff and mothers. During the separate focus groups, each group wanted the study to focus on specific communication needs that would relieve their role in infant care. For instance, doctors and nurses wanted a tool that would relieve them from handwriting medical reports. In addition, nurses wanted an automated intervention that would remind mothers to visit their admitted infants so that they could be relieved from the infant feeding and cleaning duties. On the other hand, mothers wanted an intervention that would provide up-to-date information on their infants' health and information on caring for their sick infants while in the NICU and after they are discharged from the hospital. Although these numerous design ideas made me aware of the challenges that each group faced in the NICU, the study could not meet each group's needs and requirements. Therefore, although I did not dismiss their design ideas, I decided to have a joint focus group with multiple stakeholders to encourage them to negotiate their disparate requirements. During the session, I acknowledged the design ideas shared by the different groups and used card sorting and sketching methods to allow participants to realign their design ideas with the main objective of this study: to improve NICU communication between staff and mothers. My methodological choices drew from the literature on maternal and child healthcare, human-computer interaction for Development (HCI4D), psychology and Information Communication and Technology for Development (ICT4D). Although my experience and knowledge in health and psychology are limited, I occasionally use the basic knowledge gained through the online courses that I pursued to identify potential problems prevalent with various methods in these fields.

I would like to acknowledge that my methodological considerations from these multidisciplinary fields made my solution exploration approach more of a "trial and error" approach. This approach, although challenging, helped me learn that methodological solutions in such sensitive interdisciplinary studies are not achieved instantly as one would expect. Instead, it takes time and effort to understand the environment and the people to ensure that the participatory method empowers the stakeholders to articulate their needs to meet with the researchers/designers jointly.

6.3.2 Handling Conflict in Co-design

There were several instances when conflicts and disagreements arose during the co-design process. This depicted the hierarchical working relationship in the unit. As a researcher, this created an awkward design environment since I did not have the expertise and NICU experiences of the scenarios being discussed by participants. Hence, I opted not to interject the discussion, but instead, I decided to transform the conflicting topics/scenarios into problems to explore viable approaches to solving them. For instance, during the doctors' focus group, participants had different approaches to solving mother-staff NICU communication leading to disagreement and conflict. To avoid the disagreement from escalating, I created scenarios based on the participants' information and asked them to role-play the scenario by asking the opposing participants to role-play as the proposing team. Although this action enabled participants to negotiate their ideas and engage in a constructive argument, I would like to acknowledge that I was unsure of the outcome since I was dealing with NICU experts who had vast knowledge of NICU communication challenges. I did not have any guidelines on handling the conflict, yet I felt that not taking action would limit progress in the co-design process.

Hence, in agreement with Rogers and Mardsen (2013) who emphasis that HCI researchers should focus on facilitating the design process and refrain from helping participants in the design process, I chose to remain a researcher and put my effort into exploring appropriate methods to encourage collaboration and enable participants to reach a consensus. In my view, the co-design conflict I experienced helped me to understand the different perspectives of participants, which enabled me to see design ideas through their lens and learn why they were pushing back on other participants' ideas. Therefore, HCI researchers should view disagreements and conflict as an avenue to gather more design ideas for the solution or intervention they are co-designing.

However, before embarking on co-design in such a sensitive context, researchers need preparation to navigate conflict to a constructive discussion. I appreciate gaining knowledge from reading health ethics reports such as the Belmont report (The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 2014) and pursuing an online course that provided a guideline for researching with participants in the health field. Despite learning how to engage participants in the health field, I felt that it would have been essential to receive facilitation training before embarking on this study to manage the NICU context's institutional hierarchy. Based on my experience, I recommend that researchers conducting studies in such sensitive contexts should receive facilitation training beforehand to avoid feeling inferior or unsure of their methodological actions. This training should focus on handling participants' differences and devising alternative dispute resolution methods to reduce conflict.

6.3.3 Considering Self-care in Emotion in Research

In the initial stages of this research, I was emotionally disturbed as I conducted observations and interviews in the NICU. The sight of sick infants in the incubator and stressed mothers took an emotional toll on me. During my interaction with NICU stakeholders, they shared their life experiences that described the stressful infant care journey, the uncertainty of infants' health, the stigmatization of premature birth by community and family members and even the deaths of infants or mothers. The narration of these experiences affected the participant and me, especially when the interviewee cried. For instance, one disturbing story was that of a woman who told me about the ordeal of her sister-in-law, who died in the delivery process. The interviewee said she immediately became the primary carer of the sick child who spent two months at the NICU since she was in a critical health condition. Such stories were heartbreaking and I chose to discontinue the interview and divert the discussion to general topics to ensure the participants were emotionally stable before resuming the interview if participants were willing to continue sharing their infant care journey. During this break, I chose to play with the discharged healthy infants as we chatted with the mothers or when the mother requested me to keep an eye on their infants as they interacted with the nurses who were dispensing medication. These interjections positively changed some mothers' moods, especially when they watched their children enjoy playing around with me. However, I had to terminate the interview for some mothers and refer them to the nurses who were assigned to offer counseling support to mothers.

These emotional scenarios helped me to learn the importance of arranging for counseling services prior to embarking on sensitive research. In my case, the online course I pursued and ethics documents provided a base that helped me to handle emotional participants during the data collection process. I also learned that methods influence how participants react to emotions. Although researchers might be tempted to avoid joint focus groups with patients or caregivers and health practitioners to avoid power imbalances, my experience with NICU stakeholders shows that it was beneficial to have a joint focus group because mothers could easily get emotional support from the NICU staff. I learned that when planning a co-design activity, it was important to consider participation methods that matched the study's objective. For instance, during the joint focus group, I used generative methods that encouraged NICU staff-mother interaction, which is the study's main objective. These interactions were enabled by convening a few members in each group to allow each member to air their design views and aspirations. Mothers mentioned that the information they received from NICU staff relieved them of stress since they had a better understanding of their infants' health status.

Despite being empathetic with the participants, I did not consider my emotional safety and well-being as I conducted the study. Instead, I upheld a naïve view of what such sensitive research studies and participants' collaborations require in terms of time and resources. As a result, planning and adhering to the approved research ethics was challenging and I had to navigate the ethics as I focused on the safety of the participants to achieve the research objectives.

In some instances, participants could ask about my personal life, which I shared with them to develop a working relationship with them. Naturally, I am an introvert and these scenarios made me feel uneasy. However, I felt like It was necessary to put myself on a level playing field with the participants. In retrospect, I had not assessed the harm these emotional situations would have on me when I was developing the submitted ethics protocol to the Institution Ethics Board (IRB). The protocol only explained the measures I would take to manage any possible risk and harm that participants would be exposed to during the study. I did not envision any emotional effect on myself since I thought I could handle the emotional situation appropriately. Unfortunately, the emotional impact influenced my data collection process, the interpretation of the participant's responses and also my personal life after the study. For instance, during the interview sessions, I tried to avoid questions that would trigger an emotional situation in consecutive sessions. Every time, I found myself stopping the interview session because the participants were emotional.

This influenced the quality of the data I collected. I assume the quality of data I collected would have been different if I did not avoid asking emotional questions. This, however, does not mean that the quality of data I collected was less valid, but it might have been different. Also, when I became pregnant after finalizing the data collection process, the sad stories of mothers who gave birth prematurely engulfed me. Throughout the pregnancy, I was afraid of losing my child or giving birth prematurely.

Therefore, while it is important to empathize with participants, researchers conducting studies in a sensitive setting should consider organizing support at the onset of the research to ensure that they receive psychological support whenever they encounter emotional situations. In addition, they should avoid having more than two interview sessions in a day to allow enough time for them to recover from the emotional interactions. These considerations should be given thought at the inception of the research to allow researchers to provide practical suggestions while seeking ethical approval from the IRB. Researchers should ensure that the ethics application protects both the participants and themselves.

6.3.4 Navigating Research Ethics

At the onset of this study, I developed and submitted an ethics protocol to the IRB responsible for ensuring that my research followed sound ethical principles. The protocol provided detailed information on the recruitment criteria, the research methods, the measures taken to protect the participants, research consent and storage of the collected data. While conducting the study, I encountered numerous hurdles that I had not envisaged. For instance, I planned to work with mothers of infants discharged from the hospital to ensure that they were emotionally stable to engage in the study.

However, I realized that recruiting this category of mothers was challenging due to various reasons, such as lack of transport money and family commitments. Thus, due to low participant turnout during the brainstorming and prototyping sessions, I chose to include mothers of hospitalized infants who were healthy and awaiting discharge. Although this was not in line with our approved ethics protocol, I had to adjust my recruitment procedure and ensure that the co-design process did not harm the participants. I sought advice from NICU staff, who advised me to interact with mothers who had been in the unit for an extended period and were awaiting their infants' hospital discharge. They mentioned that this category of mothers had vast NICU experience. In addition, they mentioned that the session would be advantageous to them since they would learn about their infants' health and appropriate ways of caring for them once they transitioned from the hospital to their homes. I was dealing with mothers with low literacy mothers and it was difficult to ensure that they understood the consequences of their participation before providing informed and voluntary consent.

This experience made me realize that the realities of researching in a novel context such as the NICU differed from the stipulated ethics protocol. Thus, as a researcher, one needs to adapt to emerging ethical challenges. Similar to Munteanu *et al.* (2015), I argue that it is essential for the researcher to have a flexible research design that would allow them to make adjustments to the research protocol to navigate the unanticipated ethical challenges in the field. This decision should not be made solely by the researcher. Instead, researchers should have a continuous conversation with the participants and ethics review board to ensure they are aware of the adjustment made during the research.

6.3.5 Project Sustainability

Although many health systems deployed in low-resourced contexts have shown potential in disseminating health information, a significant number of them have failed because the deployment team did not plan for sustainability (Mukisa, Orwa Ochieng, and Waiganjo, 2017). In this study, we planned for the sustainability of the NICU communication system from the onset of this project. We planned with the NICU management team to take over the operation and management of the co-design system after the deployment phase. Three months after deploying the PMC system, I organized a workshop with NICU stakeholders to discuss the system handover process. The NICU administration was assigned the role of managing the system's operation. We agreed that I would cooperate with them for three months to provide technical support.

Unfortunately, during this period, the Covid-19 pandemic emerged in South Africa and all researchers were prohibited from conducting research on-site. GSH was out of bounds and it is for this reason, I was unable to finish conducting exit interviews and observations in the NICU. Also, I could not address the technical issues that the NICU administration was facing, thus limiting the services users could access. We responded to these sustainability challenges by extending the PMC system to an online platform when the NICU installed the unit. This deployment approach enabled users to continue accessing health information. Although I could still collect the system logs on the PMC dashboard, it was challenging to evaluate system performance or justify whether the system usage logs were from participants within the NICU or from elsewhere in the world. For this reason, I was unable to report the data collected during the handover phase. In my view, there is no other way we could ascertain the sustainability of the PMC system despite planning for it at the onset of the project.

Chapter 7

Summary, Conclusion and Future Work

7.1 Introduction

The work reported in this thesis built upon the growing proportion of HCI researches that focus on exploring the appropriate methodological approaches of engaging vulnerable participants in a participatory design process and the design mechanisms for a possible NICU communication intervention in low-income setting. There is increasing recognition that conducting qualitative research with vulnerable participants in sensitive settings, like the health sector, poses many challenges for participants and the researchers. Furthermore, there are methodological gaps in HCI literature on how to engage multiple stakeholders with disparate design ideas in collaborative design space to ensure the designed technologies are empowering and not putting participants or users at risk of negative effects. In the NICU context, researchers have mainly focused on engaging health personnel in the design of NICU digital intervention, thus neglecting the voices of parents, who are the primary caregivers to the admitted infants, due to their vulnerability. Research is such environment should be undertaken sensitively, or else, the design process may expose and exacerbate participants' vulnerability or negatively affect the researchers. Beyond the advancement of technologies designed in increasingly sensitive settings, there are limited studies that highlight the communication barriers within the NICU setting and approaches of using technologies to enhance holistic health care where both health personnel and families of the patients are involved in the care of the hospitalized infant. Additionally, language localization is a complex topic in HCI research. There are gaps in designing multilingual systems to enable code-switching for users who use different dialects or mixed languages in their conversation. To the best of our knowledge, no HCI study focusing on designing user interfaces for health technologies that have provided user interface design features that enable code-switching while accessing health information.

In this research, we worked in a sensitive NICU context to understand barriers to communication between NICU staff and mothers. During the co-design process, we engaged NICU stakeholders with disparate knowledge, skills and experience in infant care to understand the NICU communication gaps and possible interventions that could improve mother-staff communication in the NICU. This study being the first of this kind research in a low-resource NICU context, we used the reflection-on-action co-design cycle (Yoo, Huldtgren, and Woelfer, 2013) to identify the appropriate co-design techniques and methods that fostered collaboration and cooperation between disparate stakeholders in a sensitive and power unequal NICU setting. We co-tailored health information through mutual learning and emphathetic interaction with NICU stakeholders and co-designed a prototype of a mobile application referred to as Preemie Care (PMC).

PMC aimed at mitigating NICU communication barriers and encouraging holistic infant care by enabling mothers to access health information related to infant care and encourage them to interact with NICU staff and partake in their infants' care and decision-making processes. To bridge the language barrier, NICU stakeholders suggested that the PMC application should disseminate health information in three common languages widely used in Cape Town to enable multilingual users to access the information. We involved health care workers, postgraduate students and professional translators in the translation process to ensure the information shared was accurate and easy to understand. As a result, we developed an educational resource; accessible in multiple languages and through various channels to empowered parents to interact with NICU staff as they take care of the preterm infants in the NICU.

We deployed the PMC system in the NICU for eight months and discovered that availability of health information empowered mothers and their social circle to interact with NICU staff in the NICU, thus enabling holistic infant care. Interestingly, we learned that PMC users preferred accessing health information in English other than their home language. PMC users who were not conversant with the English language installed their home language application and code-switched between the English subtitles and narration in their home language to enhance understanding of medical terms. The multi-modal pattern of video consumption generated valuable insights into the affordances that enhanced health information access among urban users in multilingual contexts.

In the next section, we revisit this study's research questions and discuss how we addressed them. We will also discuss the contribution of this study to HCI literature and conclude by highlighting the limitation of this study and possible work that HCI researchers could explore in future studies.

7.2 Discussion of Research Questions

The main aim of this research was to explore how we could effectively involve low-income mothers of premature infants and NICU staff in a collaborative design process of a possible NICU communication intervention. Previous studies conducted in other sensitive settings reveal existing methodological and ethical gaps that create uncomfortable engagement between researchers and participants, thus hindering an effective collaborative co-design process (Waycott *et al.*, 2012; Munteanu *et al.*, 2015). Furthermore, due to these challenges, researchers are usually not certain of the appropriate strategies to enhance participants' collaboration in the design process, especially when engaging multiple stakeholders. This is attributed to the disparate design ideas shared by multiple stakeholders that often introduce group dynamics in the co-design process (Ho, Owusu, and Aoki, 2009). Ordinarily, these dynamics are disruptive and if not well manage, they wear off participants' creativity, hindering them from achieving the design goal. Also, while most researchers aim to co-design new technologies that support vulnerable users, sometimes these technologies do not fully meet users' needs, resulting in unforeseen adverse effects. The aforementioned co-design challenges formed the basis of our study and through our study we identified lessons that addressed these challenges.

At the onset of the study, we decided not to suggest any intervention to the NICU stakeholders. Instead, over 32 months, we engaged the stakeholders in an iterative co-design process to identify the NICU communication challenges and design requirements for a possible NICU communication intervention that would combat the identified communication challenges. The overarching research question guiding this study was: What is the best approach to engage low-income mothers of premature infants in a productive co-design process for a NICU communication intervention that would encourage their interactions with NICU staff to achieve holistic infant care? The following specific research sub-questions were developed to answer the main question:

RQ1. What are the current communication interventions being used in the NICU?

  1.1. Do these interventions support staff-mother interaction?
  1.2. What challenges hinder existing communication interventions from achieving their roles in the NICU?

RQ2. What are the appropriate strategies for engaging multiple NICU stakeholders in a productive co-design process?

RQ3. What intervention or improvement to the current NICU communication mode can be employed to support staff-mother interaction?

  3.1. Which design considerations should be taken to ensure the designed intervention meets users' needs?
  3.2. What features should be reinforced in the designed intervention to support family-centred infant care?

After engaging NICU stakeholders in an iterative co-design process, we decided to develop Preemie Care system which was deployed in the NICU. During the deployment phase, we develop the fourth research question that focuses on understanding the system's usage pattern and user experience.

RQ4. What are the usage consumption patterns for Preemie Care system users?

  4.1. Did the multiple channels increase the accessibility of videos to the users?
  4.2. What did the video watching pattern tell us about video design for the NICU context?
  4.3. How did primary users (mothers) and secondary users (fathers, relatives and friends) engage with the PMC system?

4.4. What are the video design mechanisms for the multilingual NICU community?

4.5. What was the user experience on the PMC system and the main cause of actions to enhance its usability?

We addressed these research questions by analyzing the qualitative and quantitative data collected throughout the design process. These data include the NICU environment observation data, qualitative data collected during the exploratory co-design process and deployment phase and the recorded usage logs for the PMC system.

7.2.1 RQ1: Analysis of Current Communication Intervention Used in the NICU

The first phase of this study (needs assessment and problem identification), reported in Chapter 3, focused on understanding the NICU environment and how technology interventions were used to support staff-mothers communication. We investigated the communication patterns in the NICU environment, communication challenges that NICU stakeholders face and their opinion on how technology could leverage staff-mothers interactions. The qualitative data gathered in this phase revealed the structural, relational and trust gaps that hindered mother-NICU staff interaction. These communication gaps eliminate infants' parents from participating in the care and decision-making process of their infants' health. To support mothers in the infant care process, the NICU sometimes use text messages and phone calls to share information with mothers. However, these communication modes are ineffective for the following reasons.

1. They are expensive and the hospital incurs huge phone call costs since most mothers are unable to visit the hospital regularly. In addition, mothers who call the unit incur hefty calling costs because they are always put on hold while the operator at the main hospital switchboard transfers their calls to the NICU.

2. Mothers often change their phone numbers or switch off their phones thus, they are unreachable.

3. Some mothers share phones in their household thus jeopardizing the confidentiality of infants' health information when other members of the family access the information. Also, sometimes the shared information does not reach the mother who is the primary caregiver of the hospitalized infant.

Overall, we established that mothers lack the required information needed to support them in the care of their infants, thus exacerbating their stress levels. To alleviate NICU-related stress, mothers reiterated the need for frequent information that would help them partake in their infants' care and decision-making process. When asked how best they would like to access health information, both staff and mothers suggested that cost-effective technologies could be employed to prevent mothers from incurring costs while interacting with NICU staff.

7.2.2 RQ2: Appropriate Strategies for Engaging NICU Multiple NICU Stakeholders in Productive Co-design Process

The findings reported in 3 indicate that co-designing with NICU stakeholders is challenging due to the emotional situation which revolves around the care of premature infants, the unavailability of participants and the power hierarchy between NICU staff and mothers. We learned that it takes time for stakeholders with disparate skills and knowledge to participate in a creative co-design process. Reflection on the series of co-design activities we conducted shows that researchers engaging multiple stakeholders with disparate knowledge in a co-design process should refrain from having separate homogeneous group discussions before merging them into a joint discussion group. we learned that having separate discussion groups created social distance between different stakeholder groups thus hindering productive engagement.

Instead, we learned that researchers working with multiple stakeholders in a sensitive context should mediate the co-design process by employing generative techniques that encourage equal participation, interaction and mutual learning between the stakeholders. NICU staff and mothers. This collaborative co-design process can be achieved when the researchers structure the design session in a way that makes participants believe their thoughts and ideas matter in the design process. Although we cannot recommend specific research techniques, we argue that to achieve collaboration, HCI researchers should consider participation objectives, participants' expertise and participants' relationships (should allow for participants' mutual benefits) before adopting co-design methods and techniques. Another consideration while working with participants in a power imbalance context is the use of negotiating techniques (such as emoticon cards and card sorting) that allow participants to share their views even without talking. We highlight that this process of arriving at the appropriate design approach may take time. Hence, we recommend that researchers working in unfamiliar contexts should consider having a list of design methods and techniques, which we refer to as a basket of methods, to allow them to explore the effectiveness of other methods once they identify that a method does not encourage participant's engagement and collaboration.

7.2.3 RQ3: Intervention Co-designed to Support NICU Staff-mother Interaction

in 3, we identified that the existing NICU communication interventions were not efficient because they did not consider the cost of sharing information, infant's health confidentiality and parents' technological capabilities. Therefore, throughout the co-design process, NICU stakeholders suggested various design ideas for possible NICU communication interventions that would support NICU stakeholders' interactions. Firstly, we learned that NICU stakeholders were concerned about the confidentiality of infants' health information. They argued that the final intervention should not share infants' health information to avoid breaching the privacy of patients' data (RQ3.1). Instead, they suggested that the communication intervention could share general information related to premature infants' health care to equip mothers with information that would empower them to interact with the NICU staff. They suggested that the shared information should cover regular information that parents enquire about from the staff to ensure that parents are well-equipped with information that would enable them to engage in a conversation with the NICU staff.

Secondly, NICU stakeholders were concerned with the cost required to access health information. They reiterated that the NICU communication intervention should not incur mothers any cost to avoid over-stretching their infant care budget (RQ3.1). Thus, they suggested that the intervention should be offline and accessible through mobile phones, which was their main device in the households of parents in low-resource contexts. In addition, mothers emphasized that the communication intervention should consider the technological capabilities of their information accessing devices, such as phone operating system processor, screen size and storage capacity, of their phone to ensure that the low-end phones that mothers owned could access the application efficiently.

Thirdly, unlike mothers in Wardle *et al.* (2018) study, who did not like accessing information in video format to avoid interrupting infants with flashing displays and loud voices, in 4, we identified that NICU mothers preferred accessing health information in video format rather than scrolling through a chunk of words (RQ3.1). They highlighted that while in the NICU, they are often holding their infants against their chests. Thus, it would be difficult to scroll down a chunk of words on their phones' small screens. To enable easy access to information, we learned that mothers preferred having 1) all information categories displayed on the first page to enable them to locate specific information of their interest. Also, to support users with low literacy, mothers highlighted that the intervention should have reduced functionalities and visual aesthetics to enable them to easily navigate through the shared information. Furthermore, they agreed to use indicative information category titles to reduce users' memory load while searching for specific information.

Lastly, in addition to these app features, NICU stakeholders suggested the importance of disseminating health information in parents' local languages to mitigate the language barriers. However, it is important for researchers to learn that health information translation is a challenging process since some medical terms have no equivalent terms in parents' home languages. Thus researchers need to understand the communication pattern among users so that they can translate health information into a language that users can easily understand. Therefore we emphasize that the involvement of users during the health information translation process is essential to ensure they understand it.

7.2.4 RQ4: Consumption Patterns of PMC Users

After co-designing the proposed communication intervention with NICU stakeholders, we developed Preemie Care, an offline hybrid Android application, to ensure it was compatible will all Android phones (reported in 5). In addition, we incorporated three additional parallel access channels (television, video streaming server, (Preemietube) and chat server (Preemiechat)) to support users with and without smartphones.

However, we learned that Preemietube and Preemiechat services were rarely used because they required the users to log on with their user names and passwords. Users mentioned this process was cumbersome, given the slow network connection of the local server. In addition, they mentioned that they rarely received feedback from healthcare providers whenever they posted their queries. We realized that although NICU staff were willing to support parents, they were hesitant to use the system as part of their daily tasks because they had limited time in their daily schedule to engage in PMC offline conversation. Instead, they suggested that specific health personnel be assigned weekly monitoring roles to respond to questions posted on the system. We realized that the staff were shying away from additional roles in the unit. Thus, this study highlights that consideration should be made for low-income NICUs to ensure communication technology enhances direct staff-mothers interactions instead of technological interactions. However, this does not dismiss the need for online channels in NICU settings. Online interaction channels could primarily be used to encourage peer support. On the other hand, NICU staff can monitor conversations weekly to gauge mothers' understanding of the NICU environment and medical terms. This can prompt staff to determine areas where they need to enhance their support as they interact with mothers and other family members.

The second factor that requires consideration when designing the NICU communication tool is the language used to disseminate information (RQ3.2). We learned that users could not comprehend information relayed in their home language. Instead, they preferred accessing information in English even though they were not conversant in the language. Users mentioned that information shared in their home language was not easy to understand since they do not use fluent vocabulary in their ordinary conversations. We learned that we needed to understand the communication customs of the multilingual community to identify the best way of customizing information. Despite working closely with the health care worker to ensure the tailored information was sound and simple to understand, users mentioned that they preferred accessing information in a code-switched manner that replicated their normal conversations with friends and family. To mimic the code-switching conversation style while accessing information, we realized that users who installed their home language application accessed the information by switching between the English subtitles and images on the videos to help them understand the information relayed in their home language. This usage trait shows the importance of including English subtitles in users' home language videos. Evidence shows that the availability of subtitles in videos gave users a chance to utilize two languages and images to improve their understanding of health information (RQ4.4). Further discussions with users revealed that they would prefer having an application that merged English and their home language application to allow them to switch from one language to another when accessing health information (RQ4.5). In addition, NICU stakeholders suggested that health information could be presented in a mixed language format instead of pure home language (RQ4.5). However, to the best of our knowledge, no work has been conducted in the HCI community to investigate the design of bilingual information systems in the health domain.

Therefore, this study contributes to the HCI knowledge by presenting design considerations for health technologies meant to be used by a multilingual community. There is a paucity of HCI studies that focus on the technology design for multilingual interaction in low-income settings. Most researchers have focused on the design of web services that support the language switch in online searching (Wang and Komlodi, 2018; Mukhopadhyay, 2006). We demonstrate that disseminating health information in multiple languages is not the ultimate solution to curb language barrier issues among low-income users in a hospital setting. Instead, this work provides empirical evidence that indicates the importance of annotating health videos and designing health technologies with video functionalities that encourage code-switching habits while accessing information. We show that the availability of English subtitles in home language videos encouraged code-switching, especially when users sought medical terminology translation. The portrayed code-switching habit supported mothers' interaction with NICU staff since they could switch between two languages during consultation.

This evidence supports health literature that indicates the effectiveness of code-switching in doctor-patient communication (Singo, 2014; Tembrás, 2016; Wood, 2018). However, the application of code-switching in health technologies has not been exploited, despite its real benefits in medical interaction. Code-switching using video functionalities supports users' understanding of health information, thus giving users the liberty to self-express their understanding of medical terms in their cultural context. To further exploit this phenomenon, we incorporated users' recommendations and merged the three applications to allow users to switch from one language to another. Thus, enhancing health videos with features that support code-switching positively impacts users' understanding of medical terms and effective user-staff interaction in the NICU context. However, further research is warranted to explore this phenomenon and the potential influence of localization of medical interaction in the health arena.

The third factor to consider while designing with and for low-income mothers of premature infants is the sustainability of the deployed intervention (RQ4.5). During the co-design process, participants reiterated the need for a cost-effective intervention that would not involve additional costs to mothers' overstretched budgets. We developed the PMC system with multiple interaction modalities to enable users with and without smartphones to access health information in their preferred languages, thus establishing equity consumption of resources. Feedback obtained from users during the system evaluation process revealed the advantage of the different channels and how users explored them (RQ4.1). For example, users mainly used the television to decide the preferred app language version and engage in a peer support interaction. Preemietube was used by users with limited phone storage capacity to access or download specific information. Preemiechat supported feedback mechanism between peers and NICU staff. The PMC mobile application, which was widely used, allowed users to access information from any geographical region. Furthermore, nurses mentioned that they could use it as a resource for their continuing professional development course. The various affordances of these channels provided redundancy, enabling users to access information in the channel that meets their needs.

The versatility of the system supported the adoption and diverse usage of the intervention. Although we designed the PMC system to help mothers who were the primary caregivers of hospitalized infants, our usage analysis shows diverse usage from varying users (RQ4.3). Mothers mainly used the system to gather information about their infants' condition. In other instances, they used the system to engage in peer-to-peer interaction or for entertainment purposes when they were lonely in the lodging room. Family members, mostly partners and grandparents were actively involved in seeking information related to the infants' health progress. Fathers acted as the intermediate between staff and mothers who were facing language barriers. We attribute the various usage trends to the general information shared through the application and the possibility of accessing this information using multiple interaction channels.

Although relatives and friends were not involved in the design process of the application, they confirmed that the system layout was easy to master and interact with as they accessed information. In addition, the information was relevant in helping them understand the infants' health conditions and the required care even users who were away from the NICU. Unlike in other studies (Gray *et al.*, 2000; Lindberg, 2009; Gund *et al.*, 2013), where technology was used to enhance only nurses-parent communication, in this study, we saw the involvement of doctors, nurses, parents, friends and grandparents in the care of the hospitalized infants. The system empowered parents to interact with the NICU staff, encouraged families to support mothers in infant care and promoted peer-support in the NICU. These are the core dimensions of care that enhance integrated family care (RQ3.2). Our results show the system developed a partnership between the parents, their relatives and health care professionals in the care of the infant. Although the language barrier and minimal presence in the NICU still impeded parents from engaging fully in the decision-making of their infants' health care, parents had a better understanding of the procedures conducted on their infants and their roles in ensuring infants' health improved. We affirm that the team-based infant care approach alleviated parents' stress levels, which is a key factor in improving infants' health. Despite the paucity of studies investigating the potential of communication technology in enhancing family-centred care in a low-income NICU context, this study spearheads the understanding of how technology can be used to engage NICU staff and family members in the care of hospitalized infants. For future work, we suggest adopting a participatory action research approach to include a broader range of NICU stakeholders in the design process and usage of designed technology to provide evidence of the efficacy of the technological intervention in promoting family-centred care.

7.3 Limitations of the Study

This research focused on exploring a suitable approach of engaging low-income mothers of premature infants and NICU staff in a co-design process of a cost-effective NICU communication intervention that could provide supportive health information to mothers. Due to limited prior research that focused on working in a low-income NICU setting, we used a single-case study to capture the nuances of low-income NICU environments and the needs of NICU stakeholders. We used an exploratory research design and provided an in-depth description of the qualitative methods used in our experiences and findings. Although we cannot generalize the outcome of this study, the practical insights and valuable knowledge acquired while working with this particular target group may be applicable in future research of this kind or research that involve vulnerable participants within the health care context.

The second limitation is linked to the usage of PMC applications in the NICU. We hoped the intervention could be used in all unit sections. However, we excluded the ICU section during the deployment phase to avoid causing any emotional harm to new mothers. Although these mothers lacked the required information to care for their infants, we did not have a chance to incorporate them into the study. The nurses suggested that this target group be left out of the study to bond with their infants. As such, we only worked with mothers who had been in the NICU for an extended period. Nevertheless, they actively engaged in using the system and confirmed that they benefited from the acquired information. A future study could be conducted with new mothers to evaluate the efficacy of the system.

Finally, this research did not evaluate the long-term communication and health outcome impact of the use of the intervention. We could not get hold of all users who interacted with the system after they left the NICU. We also did not get time to interact with users who interacted with the system outside of the NICU. This study was a starting point and we wanted to focus mostly on parents who were available in the NICU. However, when the parents moved from the NICU setting, the dynamics changed since they were no longer interacting with NICU staff and their infants health was out of danger. Assuming there was no COVID pandemic, we would have interacted with a larger sample of users to provide more details on the intervention's efficacy and challenges. Such a study is possible and it is part of future work. However, through the study, we realized that the lessons were still applicable to users who were not available in the NICU

7.4 Direction for Future Work

7.4.1 Extension of PMC System Configuration

The PMC system deployment proves that technology could be used to address the communication barrier in low-income NICUs. The system configuration could be upgraded to achieve its full potential. Possible system extensions could include the use of Raspberry Pi 4 Model B that has a higher processing and memory capacity than the existing Raspberry Pi 3B+, the configuration of Lightweight Directory Access Protocol (LDAP) authentication to allow single sign-on Preemietube and Preemiechat and enhancement of feedback mechanism on the chat service. Furthermore, the system installation could be extended to other unit sections to allow all mothers in the NICU to have access to the services. With such additions, the system could overcome the connection challenges we previously experienced, thus allowing users to explore the potential of all the services provided by the system.

7.4.2 Inclusion of Partner and Relative in the Co-design Process

Upon realising the PMC system's potential role in enhancing family-centred care, future co-design processes should involve infants' fathers and relatives. It will be essential to understand their needs as carers and how information that concerns them is incorporated into the system. Such participation will help the mother's social supporters understand their roles in the care of the infant and the mother.

7.4.3 Automation of Language Translation

In this study, we learned that translating health information from one language to another is not efficient. Users prefer to have information in a code-switched language that they use in their daily conversations. This presents an opportunity to explore how a machine learning algorithm can be trained to translate information accurately. Building on Turner *et al.* (2012) , the crowd-sourcing method could potentially be used to gather rapid and relevant feedback on the NICU health information translation process. This process could commence by involving NICU stakeholders in a co-design process to discuss the appropriate way of localizing health information. The generated information could be evaluated to study the adoption of home language applications.

7.5 Conclusion

In this chapter, we recap the objective of this study which focused on understanding strategies of co-designing with vulnerable participants and barriers to communication between NICU staff and mothers. We engaged NICU stakeholders in the iterative co-design process of an intervention that could encourage mother and NICU staff to communicate often during the hospitalization of premature infants. We developed four sub-questions that helped us answer the over-arching question that was guiding this study. We explored various co-design methods while interacting with NICU stakeholders and unearthed three gaps: relation and trust, structural and hidden gaps that hindered effective communication among NICU stakeholders. Using creative methods to mediate the co-design process and capitalizing on NICU stakeholders lived experience, we co-designed the Preemie Care intervention. The intervention focused on sharing health information with caregivers to equip them with the knowledge that helped them interact with NICU staff. We deployed the PMC system at the NICU for eight months. PMC usage trend helped us understand the design considerations for multilingual users in the health context. We identified that information translation to different languages does not curb the language barrier. Instead, we as HCI researchers, learned we should annotate health videos with a different language than the narrative language and incorporate video features that encourage users to utilize two languages to access health information. We also provide the implementation challenges that affect the sustainability of the health system. These results provide useful knowledge that can guide future research and practice while co-designing digital health interventions.

This study advances the methodological knowledge of co-designing digital intervention in a sensitive context by analyzing the effective methods and ethical measures that future researchers should consider when researching the under-researched NICU context. Additionally, our results provide design consideration for a communication intervention that focuses on bridging communication gaps in the health context. We hope this study inspires future researchers who will focus on research in the NICU context.

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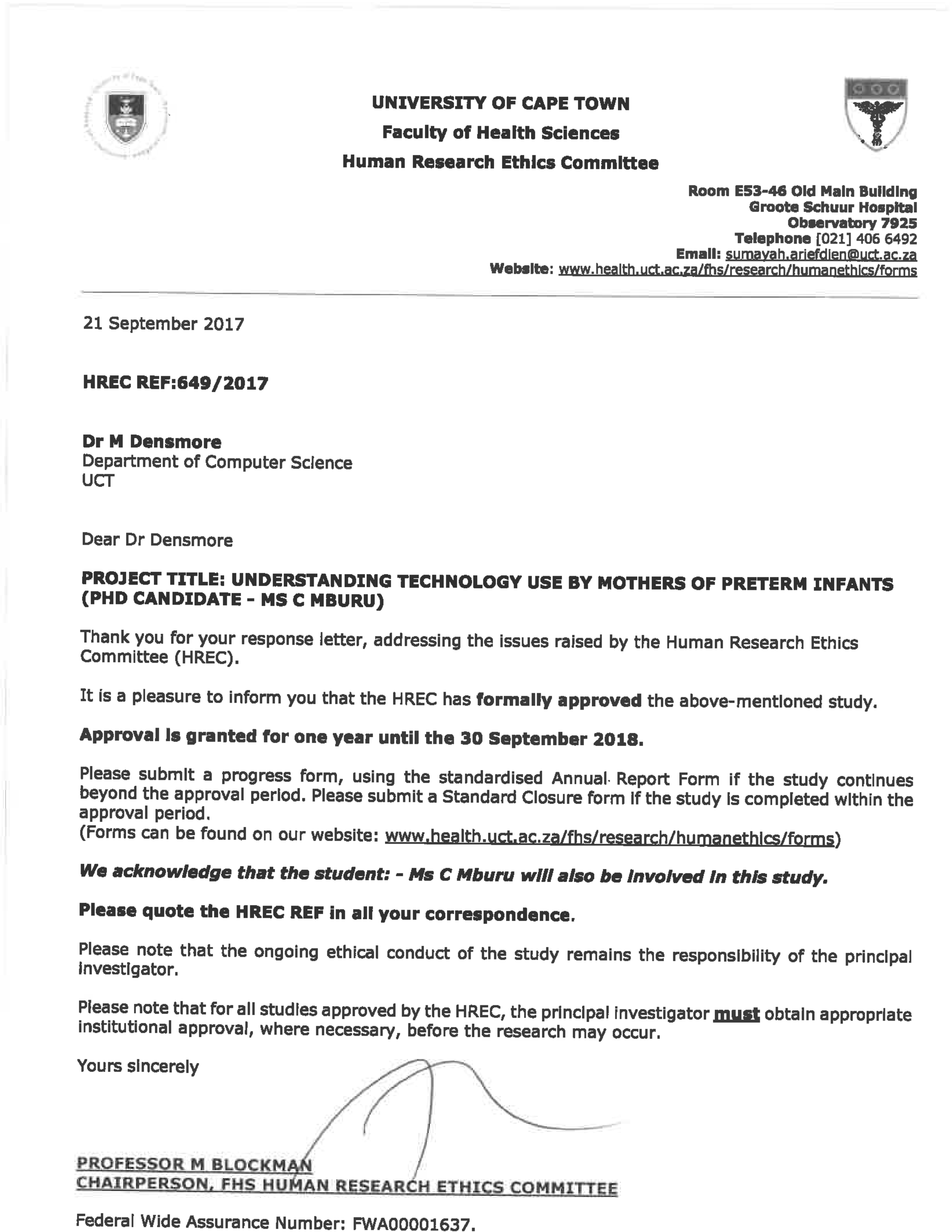
Appendix A

Ethics Approval – Faculty of Health Sciences



UNIVERSITY OF CAPE TOWN
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21 September 2017

HREC REF:649/2017

Dr M Densmore
Department of Computer Science
UCT

Dear Dr Densmore

PROJECT TITLE: UNDERSTANDING TECHNOLOGY USE BY MOTHERS OF PRETERM INFANTS (PHD CANDIDATE - MS C MBURU)

Thank you for your response letter, addressing the issues raised by the Human Research Ethics Committee (HREC).

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year until the 30 September 2018.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

We acknowledge that the student: - Ms C Mburu will also be involved in this study.

Please quote the HREC REF in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necessary, before the research may occur.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE

Federal Wide Assurance Number: FWA00001637.

Appendix B

Interview Questions

Interview Guide

These questions are intended to provide a guide for what topics we intend to discuss during the interviews. However, while we will endeavor to steer the conversation to cover all the questions listed here; we will not necessarily explicitly ask the questions.

Clinicians, Nurses and other NICU staff

1. Tell me about a typical day in your work?
2. How many women do you interact with daily?
3. What kinds of interactions do you have with the mothers of the babies in the NICU?
4. What are your three biggest concerns for these mothers and their babies?
    a. What works well for the moms?
    b. What are some of the struggles they face, or you face in addressing your concerns?
    c. How do you handle/solve these issues?
5. How do you interact with other staff in the unit to support the mothers?
6. How do you help the mothers adapt to the NICU environment?
7. How do you see phones and other information technologies used to help keep in touch with mothers?
8. Currently do you use information technologies to interact with the mothers?
    a. If there is a Tool/system used, are you able to show us how it works?
    b. What are the challenges you face while using this intervention?

    c. What do you believe will help address this problem?
    d. What else do think can help address this problem?

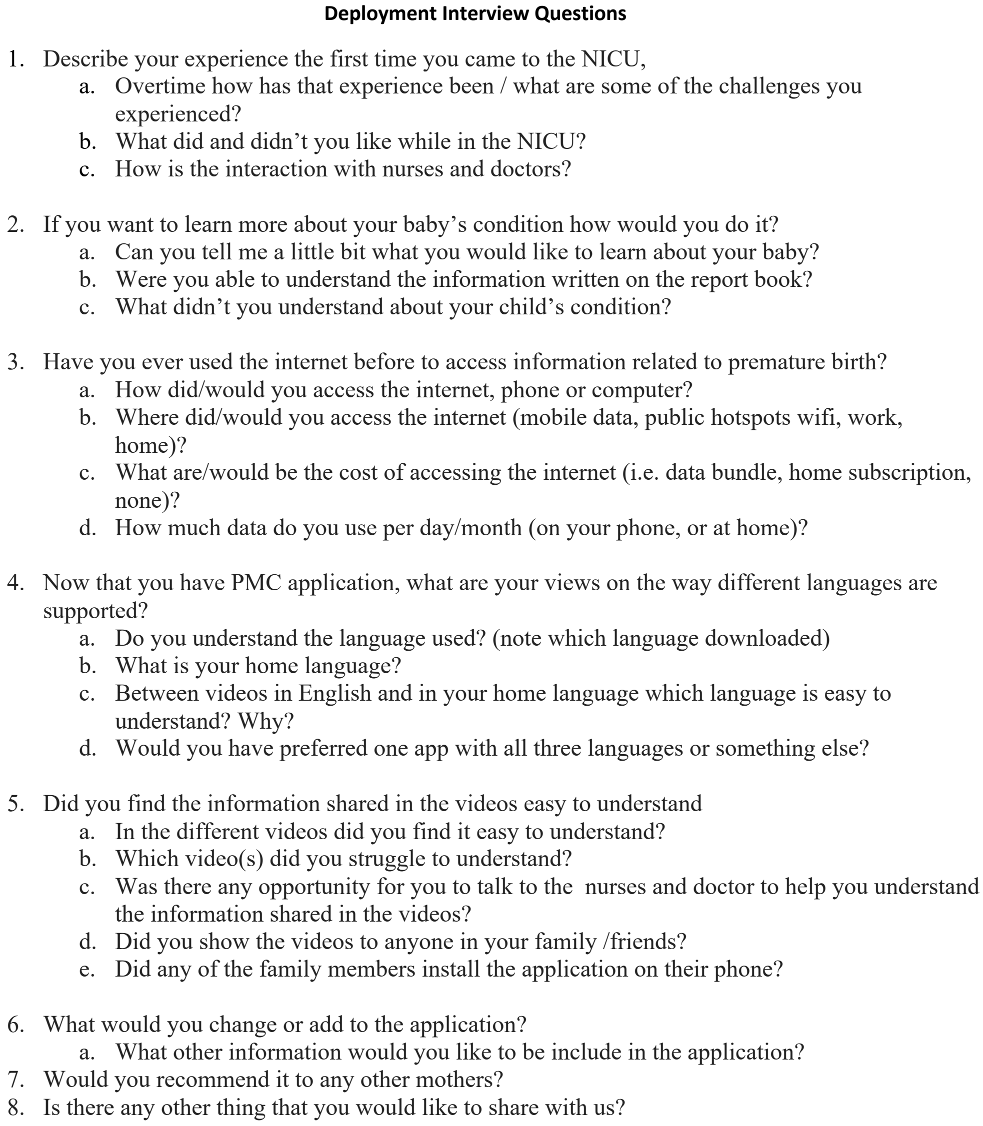
9. How do you feel about the use of phones and other information technologies? How should they be used if at all?

Mothers

1. Tell me about your baby.
2. What was it like for you when the baby was in the NICU?
    a. How long was the baby hospitalized at the NICU?
        i. How was your chat with other mothers with babies at the NICU?
        ii. Did talking with them help you understand how to take care of your infant?
    b. How long did you stay with the baby at the hospital?

Appendix C

Deployment Interview Questions



Deployment Interview Questions

1. Describe your experience the first time you came to the NICU,
    a. Overtime how has that experience been / what are some of the challenges you experienced?
    b. What did and didn't you like while in the NICU?
    c. How is the interaction with nurses and doctors?

2. If you want to learn more about your baby's condition how would you do it?
    a. Can you tell me a little bit what you would like to learn about your baby?
    b. Were you able to understand the information written on the report book?
    c. What didn't you understand about your child's condition?

3. Have you ever used the internet before to access information related to premature birth?
    a. How did/would you access the internet, phone or computer?
    b. Where did/would you access the internet (mobile data, public hotspots wifi, work, home)?
    c. What are/would be the cost of accessing the internet (i.e. data bundle, home subscription, none)?
    d. How much data do you use per day/month (on your phone, or at home)?

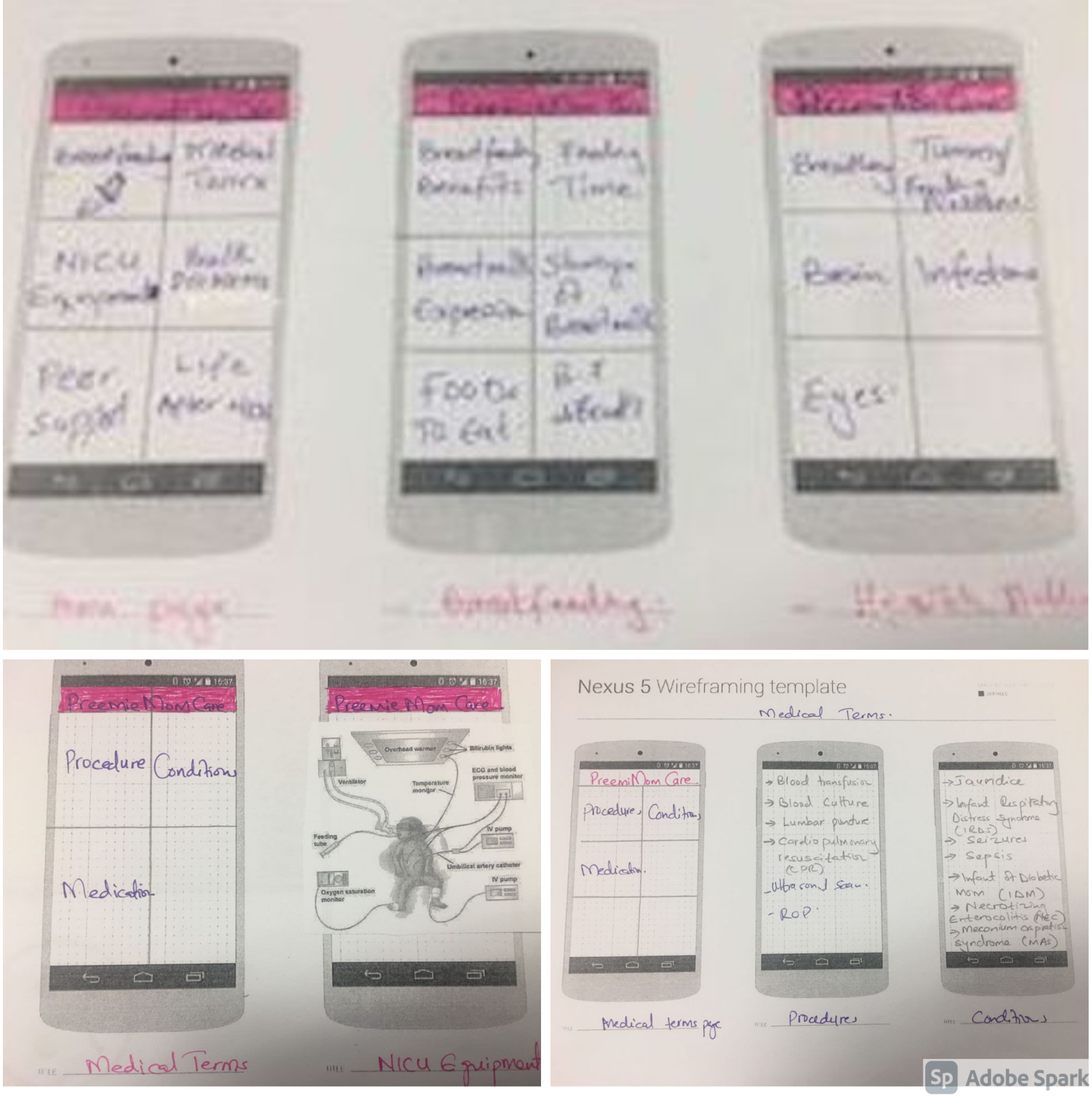
4. Now that you have PMC application, what are your views on the way different languages are supported?
    a. Do you understand the language used? (note which language downloaded)
    b. What is your home language?
    c. Between videos in English and in your home language which language is easy to understand? Why?
    d. Would you have preferred one app with all three languages or something else?

5. Did you find the information shared in the videos easy to understand
    a. In the different videos did you find it easy to understand?
    b. Which video(s) did you struggle to understand?
    c. Was there any opportunity for you to talk to the nurses and doctor to help you understand the information shared in the videos?
    d. Did you show the videos to anyone in your family /friends?
    e. Did any of the family members install the application on their phone?

6. What would you change or add to the application?
    a. What other information would you like to be include in the application?
7. Would you recommend it to any other mothers?
8. Is there any other thing that you would like to share with us?

Appendix D

Paper Prototypes



Appendix E

Certificate of Editing

Certificate of Editing

This is to certify that the dissertation

Co-designing a Digital Intervention to Bridge Communication Gaps Between Health Personnel and Parents of Preterm Infants

by

Wanjiru Mburu

has been proofread and edited for English language usage.

Date: 13 September 2021

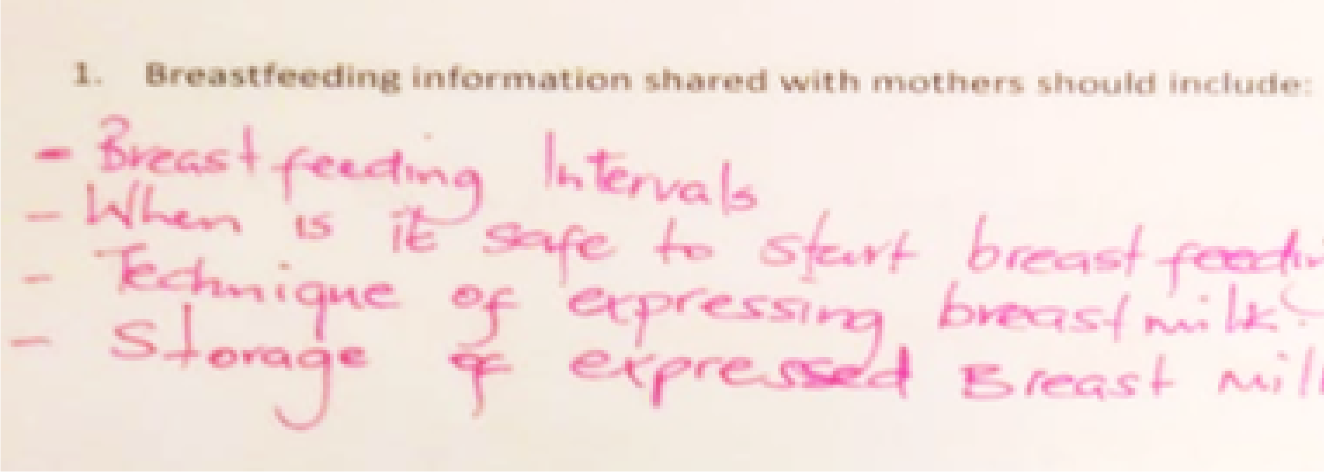
LHugo

Lianne Hugo

Language Practitioner
B.A. (HMS)
PGCE

Appendix F

Unanswered Questions



1. Breastfeeding information shared with mothers should include:

- Breast feeding Intervals
- When is it safe to start breast feedi
- Technique of expressing breastmilk
- Storage of expressed Breast mil