Co-designing with Mothers and Neonatal Unit Staff: Use of Technology to Support Mothers of Preterm Infants

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ABSTRACT

There are several digital technologies which have been designed and successfully used to support mothers of preterm infants. However, none have been designed for application in the developing world context. For the existing interventions, none have involved mothers (who are the intended beneficiaries of these technologies) in the design process. This paper reports on a process that involved Neonatal Intensive Care Unit (NICU) staff and mothers in the design of technological interventions that focus on enhancing communication between mothers and staff in the NICU context. We used the co-design approach, focusing on identifying methods that ensure participants fully participate in the design process despite facing co-design dynamics such as power imbalances and conflict. Our results demonstrate the benefits of choosing an approach that focuses on building trust with stakeholders before delving into co-design process and empowering participants thus enabling them to fully participate in a design process. We argue that while working with multiple stakeholders, co-design readiness is dependent on methodological choice, stakeholders' relationship with the researcher and stakeholders' cohesion.

CCS CONCEPTS

• Human-centered computing •Interaction Design •Participatory Design.

KEYWORDS

Premature Infants; NICU; Stress; Communication; Co-design.

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1. INTRODUCTION

Designing healthcare technologies for developing regions has been suggested as a way to effectively engage patients to ensure the interventions are effective at meeting needs identified by users [11]. Traditionally, healthcare practitioners were actively involved in the design phase. Patients and their caregivers were perceived as passive recipients of health services. This top-down approach has led to non-adherence of healthcare systems by many patients [34]. Co-design, an approach that involves all stakeholders throughout the design process, is recommended to achieve dependable, usable, and well-designed technologies in healthcare [39].

In this paper, we present a case of a co-design process of technological interventions aimed at supporting mothers while their preterm infants are hospitalized in the Neonatal Intensive Care Unit (NICU). Mothers of preterm infants are vulnerable to emotional stress due to the uncertainty of their infants' health outcome and they require constant support from NICU staff [21]. In the developed world, a few studies have focused on the design and development of tools to support mothers of preterm infants. These tools are mainly used to provide information such as neonatal information [32], parental education [17,32] and ad hoc communication in the NICU [19]. However, none of these studies involved mothers in the design process. Instead, health practitioners hired software developers who designed the tools based on health practitioners' requirements. Mothers' inputs were considered during the evaluation process only. In addition, these studies do not clearly show the methodologies used during the design process of these interventions.

The aim of this paper is to discuss how technology design processes with and for mothers of preterm infants who are susceptible to stress look like in practice. We present what worked and did not work in the early stages of this co-design process and discuss 1) the favorable practices while working with participants who are vulnerable to stress 2) some of the challenges in uncovering the needs of these user groups 3) the importance of empowering participants through proper methodological choice to produce co-design readiness.

The contribution of this paper is the articulation of effective research methods that support constructive feedback from multiple participants as part of the design process of communication tool in the NICU. We seek to investigate the appropriate methodological approach that can be employed while working with mothers of preterm infants. Furthermore, we seek to understand how we can fully involve mothers from low-income settings in the design process considering the socio-structural factors that affect their use of technology, as well as the specifics of how the demands of motherhood affect the design process.

2. RELATED WORK

Co-design's innovative way of actively involving health practitioners and patients in health interventions, services and programs design has been gaining traction over the last few years [6, 35]. Several health projects have adopted this approach to understand and integrate different users' ideas in the design of health interventions to ensure a better fit between the health systems/applications and users' needs, and also to improve satisfaction of users.

For example, Tuck Voon [23] involved mobile technology experts and rehabilitation practitioners in the design of a cognitive telerehabilitation system. Molapo et al. [31] engaged Community Health Workers (CHWs) in the design process of a mobile multimedia feedback-integrated platform for community health. Wardle et.al [46] engaged mothers in a co-design process of a mobile application meant to motivate breastfeeding mothers to donate their surplus breast milk to the local milk bank. Bird [3] collaborated with users to design medical imaging equipment.

However, co-design is sometimes used as a "buzzword" and it is not clear how all stakeholders are involved in the design process [40]. This approach is more complex when researchers are conducting research with vulnerable populations and in sensitive contexts such as end of life care bereavement support [26], social support for people with mental health issues [41] and social support for children and elderly people [7]. These studies raise new and complex co-design challenges including signs of distress among participants and researchers during collaborative design and digital content creation [26,41], power imbalances and conflict [20], difficulty in participant recruitment [39,45], dilemma in appropriate response to vulnerable participants [47], loss of participants [9] and difficulty in maintaining boundaries around the researcher's role and the setting of the research [26].

It is vital for researchers conducting research in a sensitive context to familiarize themselves with the research context and the participants before commencing the study [26]. In addition, researchers should learn the importance of self-care and avoidance of "compassion fatigue" [16]. To overcome co-design challenges, researchers need to identify appropriate research methods that include vulnerable participants in the design process without affecting their emotional status. However, only a few studies such as [35,49] have reflected in depth on their methodological approaches. Building on this gap, we sought to explore the research techniques that empower participants to take control of the design process to ensure that the final design meets their needs.

3. BACKGROUND

3.1 Sensitive Research and Vulnerable Participants

Sensitive research is defined as that which involves topics that may be threatening to participants [9,15]. These topics are considered so because of the following reasons: they impinge on the interests of those being studied; they cause stigmatization or fear; or they involve studies of issues that are private, stressful or sacred [10,22]. In addition, sensitive research often has potential effects on personal life and sometimes on the personal security of the researcher [6,26]. Conducting research with patients in the health domain is considered sensitive research because it involves interrogation of participants' experiences thus posing substantial threat to those who are involved in it [28].

Vulnerable participants are identified as groups or individuals who are susceptible to or at an increased risk of physiological or psychosocial harm for a myriad of reasons [6,26]. Research participants may be considered vulnerable because of the group they belong to, the nature of the situation they are in, or the research itself [6]. In our studies, participants are considered vulnerable due to the nature of their experiences which expose them to a range of emotions and feelings as they grapple with the care of premature infants.

3.2 Premature Birth

Premature birth is the world's largest killer of infants, causing more than 1 million deaths each year [33]. In South Africa, more than 8 out of 100 babies are born premature (before 37 weeks of pregnancy) and the country is ranked 24 out of 184 countries for the number of newborn deaths due to complications from premature birth [25,36]. Premature birth and infant admission in the NICU are complex and stressful events for most mothers since they are characterized by uncertainty and fear for the infant's possible outcome [1]. Most neonatal facilities at South Africa hospitals are overcrowded and under-staffed thus mothers receive minimal support from the neonatal staff [38]. In addition, mothers from low-income settings are not able to travel often to the NICU due to lack of transportation cost [38]. Others would like to visit the NICU daily and develop a bond with their infants, but they have to juggle between jobs, the care of older children, and other responsibilities for several weeks before their infants are strong enough to go home [42]. This results in the separation of mothers from their infants and they feel they have lost the motherhood role to NICU staff.

3.3 Groote Schuur Hospital Case Study

The ongoing research is being conducted at Groote Schuur Hospital (GSH), a tertiary, government funded, teaching hospital in the city of Cape Town, South Africa [48]. The hospital provides tertiary level neonatal intensive care, obstetric and antenatal services to women with pregnancy complications from the West Metropole of

Cape Town. The 75-bed capacity neonatal unit admits approximately 2000 infants annually, majority of which are preterm infants. Most parents of these infants live in informal housing settlements on the periphery of the city where overcrowding, unemployment, and poverty are rife [42].

The NICU is under-staffed. Doctors and nurses work for long hours to ensure the health of the infants stabilizes. Mothers rely on brief interactions with the NICU staff to understand their infants' health status. Despite the presence of mothers in the NICU, some have little information about their infants' medical conditions. This exacerbates their level of stress and they are in dire need of emotional support from the staff. There is a need for maternal support interventions where educational and emotional aspects are simultaneously covered, to allow mothers to fully participate in the care of the hospitalized infants. We focus on understanding the appropriate methodological approaches that should be adopted when working with multiple stakeholders to design a communication intervention that can enhance communication in the NICU.

4. METHODOLOGY

4.1 Co-design Approach

Throughout this study, we embody the co-design approach [41] attempting at all stages to incorporate and empower mothers and NICU staff to engage in the design of a solution that could be responsive to NICU communication needs. We did not immediately target specific mechanisms or the development of a software artifact because we believed it was premature to posit a solution before we had the opportunity to understand the problem in depth.

There are six phases in this study where each phase is informed by the findings of the previous phase. These phases are 1. Needs assessment and problem identification 2. Idea generation 3. Idea exploration 4. Prototype 5. Deployment 6. Handover and testing. In this paper, we focus on the first two phases and describe the research methods used and the findings of each phase. We involved mothers and NICU staff in both phases to understand the communication challenges and their perception on the use of technological solutions.

The research protocol was approved by the University of Cape Town Faculty of Health Science Research Ethics Committee. Each interview or focus group participant signed a consent form before the researchers commenced with the data collection process. Persons present during observation sessions were not required to sign consent forms but were informed by the researchers of the nature of their observation.

At the end of each phase, we transcribed all the data collected including the non-verbal expressions in our final transcripts. We used NVivo to analyze the qualitative data, subjecting it to a three-stage analysis method: data reduction, data display and conclusion drawing [4,37]. Open coding [18] was used to look for recurring concepts in the data.

4.2 Participant Recruitment

In this study, we are engaging with mothers of preterm infants and NICU staff (doctors and nurses) who have worked in the NICU for at least one year. During our preliminary study, we found out that most mothers were unmarried, thus we opted to work with mothers (and not both parents) to ensure inclusion of both married and single mothers. To prevent aggravating the emotional condition of the mothers and ensure health stability of the infants during the design tasks, we chose to involve mothers whose infants had been discharged from the hospital for at least three months. We plan to work with mothers of hospitalized infants in the last two phases of this study.

Much of the initial research entailed observations. We performed observations and made it clear to those being observed that we were carrying out research in the unit. As such, recruitment was not an explicit process. Participants entailed everyone in the parts of the unit under observation, including the mothers' ward, nurses' station, etc. However, participation in interviews and focus groups entailed specific recruitment as listed below:

- Members of the NICU staff were recruited by approaching them through the researchers' contact person at the NICU and during observations.
- Mothers with discharged infants were recruited when they attended their infants' follow-up check-ups which happen every Wednesday at Mowbray hospital[1].

Although we strove for a high response rate in this under-researched field, we balanced it against the need to recruit participants ethically and considerately, particularly given the sensitive nature of this study.

4.3 Phase One: Needs Assessment and Problem Identification

The main objective of this phase was to identify the main barrier to communication between mothers and the NICU staff. We used a user-centered approach [2] to focus on the explicit understanding of participants, tasks, and environments in which they work from. We chose this approach because it agrees with healthcare institutions/organizations such as the National Academy of Medicine (NAM) that advocates for user-centric approach when developing healthcare technologies [43]. To ensure triangulation of data, we used observation and one-on-one interviews data collection methods.

4.3.1 Observation. Observations were conducted in two parts. In the first part, we volunteered to work in one section of the NICU that admits stable infants who are monitored before being discharged. Over a period of 2 months, we visited the section once a week (for 1-3 hours) and helped the nurses to cup feed and clean the infants. Through this, we were able to familiarize ourselves with

[1]A nearby secondary referral maternity hospital where mothers typically go once the baby has been discharged from GSH.

the NICU environment as well as build trust and working relationships with both the staff and mothers.

In the second part, we conducted nine observation sessions in all sections of the NICU. Each observation session lasted approximately 45-60 minutes and was distributed across different time periods (in the morning hours, during the day and at night). This approach was chosen to allow comprehensive data collection and comparison of unit activities at different times of the day. Attention was paid to understanding NICU staff interaction with the mothers and how they carry out their daily roles, the challenges in the NICU and the practices around the use of technology in the unit. Field notes were taken during all sessions to aid the researcher to remember and record the behaviors, activities, events, and other features of the observation.

4.3.2 *One-on-one Interviews.* After conducting observations in the unit for four months, we conducted one-on-one interviews with our participants to clarify some of the information identified during observation sessions. We recruited and interviewed 15 NICU staff (5 doctors and 10 nurses) and 15 mothers. We used open-ended interview questions to allow participants to provide additional information including feelings, attitudes and understanding of the research topic. All the interview sessions were recorded, and the researchers took field notes.

4.3.2.1 Interviews with NICU Staff. Based on the observation findings, we focused on understanding the main challenges that hinder communication between mothers and the NICU staff. We interviewed staff from different sections of the unit to understand communication challenges in various sections and to gather their perceptions on how technology can be used to support communication in the unit.

4.3.2.2 *Interviews with Mothers.* These interviews happened at Mowbray Hospital, where mothers take their infants for screening and development check-ups once they are discharged from GSH. We visited the clinic every Wednesday and recruited mothers who were attending their appointments. Initially, it was challenging to recruit them. We had to involve the doctor in charge of the clinic who met the mothers and explained the main objective of our study. In addition, we volunteered to help the mothers dress the infants after being weighed and played with them as their mothers waited for the doctor's prescription. This allowed us to earn the mothers trust, henceforth enabling us to recruit four to six mothers every week. The hospital offered a private room where we confidentially conducted our interviews.

To allow anonymity of our participants, photo taking was not allowed in these sessions. We focused on understanding the challenges mothers faced during their infants' hospitalization, their communication with NICU staff, how they used technology to access parental and neonatal information and their suggestions on how technology could be used to help them access information. The interview sessions were emotional for both the mothers and researchers and in numerous instances, we had to divert the interview to more general topics. The researchers also offered to play with the infants in between the sessions to give the mothers the time to recollect themselves before resuming the interview. To mitigate the risk of emotional distress, the researchers had contacts of the clinic counselors who would support the mothers in case they were overwhelmed emotionally. At the end of each session, we offered each mother a picture book recommended to enhance brain development of premature infants.

4.4 Phase Two: Ideas Generation

After analyzing the data collected in phase one, we identified unique cultural and socioeconomic factors, that were affecting mother-staff interactions in this context. We focused on brainstorming on these factors to further understand how they influence communication in the NICU. In addition, we engaged stakeholders in an ideation process based on the suggested technologies in phase one. We presented phase one findings to our participants and organized separate focus groups with nurses, doctors and mothers.

Later, we held a joint focus group to ensure all participants agreed to the ideas generated at the end of this phase. We worked with three doctors, five nurses and four mothers. We introduced new participants in this phase (2 nurses and 2 mothers) to allow new ideas as well as to solve the lack of participants challenge which is common in longitudinal studies.

4.4.1 *Doctors' Focus Group.* From the five doctors we interviewed in phase one, we involved three in the focus group session. We presented the findings of the first phase and introduced new themes that were unique in this context. We asked the participants to talk about their experience as caregivers in the NICU and challenges they face while interacting with mothers. There were disagreements during this session especially when doctors discussed approaches of interacting with mothers in the NICU. One doctor had a difficult time letting go of their initially suggested ideas thus complicating negotiating ideas with other participants. We opted to introduce *scenarios* and *brainstorming* research techniques to ensure conflicts were transcended and translated into meaningful design concepts.

We later shared a list of technologies suggested in the first phase and asked doctors to discuss the feasibility of the solutions. Through this process, they narrowed down the suggestions to solutions that are viable in developing world context. We allowed them to take control of this discussion and provided sketching materials to facilitate the ideation process. Role-playing and scenario techniques were used to showcase how technology could be used to share information. In addition, participants used sketching technique to visualize their design ideas. They sketched a workflow indicating the interaction between the staff and the mothers. Throughout this session, the researchers recorded the conversation and took notes to capture the statements made by the participants during the discussion.

4.4.2 *Nurses' Focus Group.* We recruited five nurses of which three had participated in phase one interview sessions. Among the participants, we had a nurse supervisor who had worked in the unit for more than seven years. Unfortunately, the junior nurses were not free to share or criticize one another's ideas. To prevent the supervisor from dominating the discussion and allow other nurses to voice their ideas, we decided to introduce the *brain dumping* [8] and *card sorting* [39] techniques. This approach empowered the

junior nurses and they gained confidence to share their ideas. This led to a constructive discussion that allowed the nurses to agree on the different possible solutions that could be used to enhance communication between mothers and NICU staff.

4.4.3 Mothers' Focus Group. We visited Mowbray hospital and recruited seven mothers who agreed to attend the meeting at GSH. We unsuccessfully organized the meeting twice but on the third chance, only two mothers attended the focus group, prompting us to include two mothers in the meeting via telephone calls. The mothers had limited exposure to technology and we opted to use the scenarios [29] to intrigue their design thinking. This method helped the mothers to collaborate and generate design ideas which they later brainstormed on. They raised the socioeconomic, cultural and technological aspects which influenced the choice of the final solution they suggested. During the session, we had to stop the meeting several times as the mothers received calls from their family members. In addition, one mother who was on phone call dropped the call because her child was crying and she had to feed her. At the end of the session, we compensated mothers by offering lunch and transport funds.

4.4.4 *Joint Focus Group.* This was a brief session that focused on discussing the findings of all the focus groups to ensure that the stakeholders agreed with them. We shared the findings of each group and allowed the stakeholders to discuss the most viable approach to solving the communication challenge between the mothers and the staff. Brainstorming and sketching methods were used to visualize the final possible solution that was collaboratively designed by the stakeholders.

5. FINDINGS

5.1 Phase One Findings

In the first phase, we identified factors that hinder communication in the NICU, the current technological interventions used to support mothers' and participants' suggestions of how technology could be used to enhance communication in the NICU.

5.1.1 *Insufficient Communication in the NICU.* Through observation and interview sessions, we learned that there is minimal communication between NICU staff and mothers of preterm infants. Most mothers are stressed by the uncertainty of their infants' health condition and they require support from the NICU staff to help them partake in the care and decision making of their hospitalized infants. However, the NICU staff have a heavy workload and they rarely have time to interact with the mothers. Even so, when NICU staff interact with mothers, they use medical terms that mothers are not able to understand. This was confirmed when one mother said:

> I could not understand the medical terms used by the doctors to explain my child's diagnosis.

In addition, mothers are not able to interact with staff due to language barriers. They fear approaching NICU staff in the unit because they are not able to express themselves in English. In such cases, the unit uses interpreters who often provide incomplete information. More so, the hierarchical relations in the NICU hinder the mothers from approaching staff. They trust and hope that the staff; who are the main caregiver, will prioritize infant's health to ensure it stabilizes. As a result, this makes them feel left out in the decision-making process of their infants' care. This situation is worse for mothers who are not able to visit the unit regularly due to financial challenges. For instance, one mother reported:

> I sometimes skipped hospital visits and during this time, I did not know what was happening to my child. This was frustrating.

To ensure that these mothers are updated on their infants' health status, the NICU staff use phone calls and text messages to share information. These calls are predominantly made by nurses who receive infant care instructions from the doctors. However, these communication channels are not effective. This is because they are expensive and mothers are not accessible when they change their phone numbers, which they often do. One nurse said:

> Some mothers change their phone number quite often and we cannot reach them via phone call.

Another nurse said:

> During child admission, we are sometimes given non-existing phone numbers and physical addresses. Sometimes the partner put their phone number as the main contact number and since they are not married we cannot share information with them.

In addition, mothers who call the hospital to follow up on their infants often experience long delays before their calls are transferred from the main hospital switchboard to the NICU extension. There is evidence of communication need in the NICU where mothers are provided with information to help them make prompt decisions about their infants' care. This would help them regain their maternal role in the NICU, thus reduce the stress related to premature birth.

5.1.2 Perceptions and Views towards the Use of Technology in NICU. During the interview sessions, the participants suggested three categories of information that technology could be used to relay. These are 1. Breastfeeding information 2. Infant's health status 3. Inter-section transfer and hospital discharge information. Staff mentioned that during their interaction with mothers, these are the main information they share with mothers. They mentioned that some mothers own mobile phone, but they are not able to afford the high cost of internet and talk time in South Africa. One nurse said:

> Some mothers have phones that can connect to the internet, but they mostly use text messages because they cannot afford the internet or talk time cost.

Most mothers said they experienced lactation challenges and they suggested that sharing information that would help mothers learn how to increase their breast milk production would support many mothers. One mother said:

> First time and teenage mothers struggle to express breastmilk. It would be good if text messages were used to educate them on what to eat to increase their breast milk production.

In addition, mothers said they would like to be informed when their infants are transferred from one section of the unit to another. One mother said:

> It is depressing when you visit the unit and you cannot find your baby where you left him. What comes to mind is that he is dead. I think it would be good if they send a text message every morning to inform mothers where to find their infants. This will stop mothers from panicking.

The table below summarizes the solutions that our participants suggested could possibly be used to relay information.

Table 1: Technologies Suggested by Participants

Information Needed	Technologies Suggested by Participants
Breastfeeding Information	• Digital video to teach mothers about breast milk expression • Reminder text messages • Educative interactive website to access breast milk expression information
Neonatal status Information	• Digital video with details of common medical conditions • Use of text messages to update mothers on infants' progress • Use of free toll number
Hospital transfer and discharge information	• Use text messages to share hospital discharge and transfer information

5.2 Phase Two Findings

In phase two we revisited the findings of phase one and focused on understanding how sociocultural and power hierarchy affected the communication in the NICU. In addition, we used these sessions to allow participants to generate design ideas based on the solutions suggested in the first phase. Through this process, we identified power imbalances, conflict and limited design skills as the main co-design dynamics and we focused on exploring research techniques that could overcome these dynamics. In the next section, we discuss the findings from each focus group.

5.2.1 *Doctors' Focus Group.* During the doctors' focus group meeting, participants had different ideas as they brainstormed on the possible approach to communicate with mothers in the NICU. One doctor said:

> I sometimes don't understand what is happening to the mothers. My focus is on ensuring that children's health is out of danger.

This resulted in disagreements as two doctors mentioned that their heavy workload does not allow them to interact often with mothers while one doctor insisted that doctors should always focus on supporting mothers to ensure they understand their infants' health status. We did not interrupt the discussion but instead allowed the disagreements to evolve into a cooperative exchange of ideas. To encourage more ideas from the discussion we built scenarios based on phase one findings and asked the participants to provide suggestions of how communication could be improved. Eventually, all participants agreed and said:

> To complement the information we provide, technology can be used to share less sensitive information with mothers.

However, one doctor emphasized:

> We should ensure that the use of telecommunication does not stop mothers from coming to the unit because they are receiving infants' updates at home.

To further understand the possible solution that could be used in the unit, we provided the list of technologies suggested in phase one and asked participants to brainstorm and narrow down the ideas to solutions that could support mothers in low-income context. Doctors said that it was only viable to share breastfeeding information. These statements were made during the discussion:

> The neonatal information changes quite often. Therefore, sending multiple reports to mothers in a day can be traumatizing.

> Sending unit transfer information can be labor intensive. Technology should reduce our work not adding more roles.

> It is only feasible to share breastfeeding information. Having more than that will overwhelm the mothers.

In consensus, the participants agreed that technology could only be used to share breastfeeding information to avoid breaching confidentiality of infants' health data. They used sketching material provided to visualize their ideas in a workflow of possible approaches that staff could use to share breastfeeding information.

Figure 1: Doctors Visualizing their Ideas

To articulate their ideas, two doctors used role-play as the other doctor wrote the emerging ideas on the flipchart. This approach enhanced mutual learning and the development of shared

understandings. Throughout this session, we allowed participants to lead the discussion keeping in mind that they are experts in matters related to NICU.

5.2.2 Nurses' Focus Group. During the nurses' focus group, we noticed that one participant dominated the discussion, and this made it difficult for other participants to voice their opinions. To involve all participants in the ideation process and encourage shy participants to voice their ideas, we chose to use brain-dumping method. This research technique allowed participants to develop their design ideas independently before sharing them with other participants. As a result, they generated numerous ideas which helped them to broadly brainstorm on the appropriate approaches of interacting with mothers in the NICU.

In addition, we shared the list of suggested technologies and asked participants to propose the possible technological intervention that could be used to disseminate information. We used card sorting to help participants make innovative suggestions.

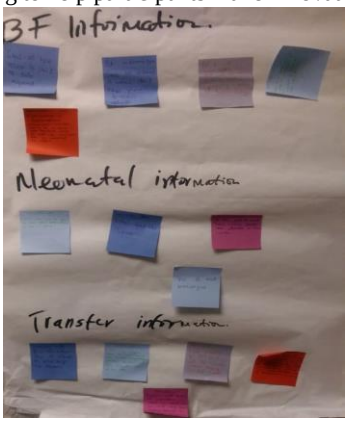

Figure 2: Card Sorting Method

To intrigue their design thinking, we built scenarios and asked nurses to generate their ideas around those scenarios. We evaluated all the suggested ideas by brainstorming on their benefits and limitations. Two nurses said:

> We should put into consideration that most mothers share phones in their household thus we cannot share sensitive information.

Another nurse said:

> We should hold data confidentiality highly especially when sending neonatal information.

Eventually, participants came to a consensus that technology could only be used to share breastfeeding information and common medical conditions that are related to premature birth. Below are some of the comments heard during the discussion:

> We can use video to educate mothers on common health condition so that they understand details written on infants' health report.

> We can use text messages to educate mothers on the importance of breastfeeding. Mother can retrieve the message and read it again.

At the end of this session, we noted that all participants were able to engage in the design process. Shy participants had gained confidence to critique ideas on their peers. The brain-dumping and card-sorting method encouraged group cohesion, allowing participants to negotiate and build on each other's ideas thus allowing them to work towards a common goal.

5.2.3 Mothers' Focus Group. Before commencing the session, mothers asked the researcher to keep the session short because they had to leave and cater to their infants and family needs. During the mothers' focus group, we identified that participants did not want to participate in the discussion because they had limited exposure to technology. We used scenarios to intrigue their design thinking and encourage them to raise design ideas. Mothers were able to relate the scenarios with their experiences in the NICU thus motivating them to suggest possible solutions that could help mothers access information. For instance, one mother said:

> I feared to touch the equipment attached to my infant because I did not know their function. It would be good if videos can be displayed in the hospital to educate mothers on the NICU equipment.

We used brainstorming method to evaluate the solution suggested in phase one. They agreed that technology could be used to share breastfeeding and unit transfer information. They said that first time mothers face numerous lactating challenges and it would be good to use videos to educate them on breastmilk expression. In addition, they mentioned that unit transfer information should be shared with mothers to help them locate their infants when they visit the unit. One mother said:

> It is stressful when you cannot locate your infant in the unit. They should have a screen in the unit showing the section where your infant is admitted.

5.2.4 *Joint Focus Group.* The group cohesion during this session was high and participants were confident to voice their opinion. We shared the design suggestions of the three groups and asked participants to jointly brainstorm and agree on the most feasible solution. They agreed on sharing breastfeeding information and common medical terms used in the NICU. They agreed that neonatal and infant transfer information was confidential and technology such as mobile phones could not be used to disseminate this information. In addition, the mothers mentioned that neonatal and transfer information would make them anxious, especially if they are not in the unit. For instance, one mother said:

> I would not like to receive my child's health condition via text message, it is traumatizing.

To ensure that mothers understand the common medical terms used in the NICU, stakeholders agreed that educational videos can be produced and displayed in the NICU to afford mothers the opportunity to learn about premature birth and complications related to it. In relation to breastfeeding information, the

stakeholder mentioned that technology should focus on supporting mothers who are not able to visit the unit regularly. They agreed that technology could be used to complement the MOM Project[2] to encourage mothers to express breast milk. To visualize their ideas, they sketched the workflow below:

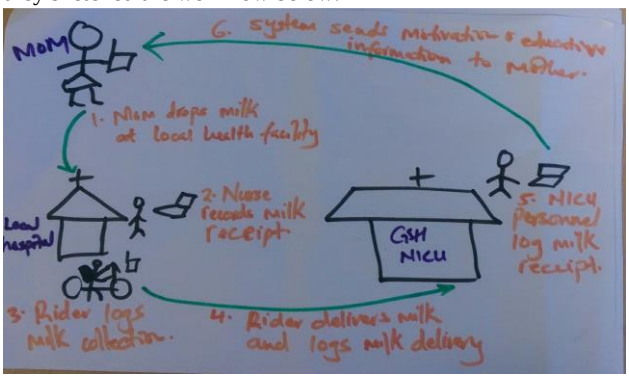

Figure 3: Workflow Suggested During the Joint Focus Group

6. DISCUSSION

6.1 Importance of Staff-Mother Communication in the NICU

In this research, we involved staff and mothers from low-income settings to explore how technology could be used to enhance communication in the NICU. In the first phase, we identified that mothers need continuous support from the NICU staff but due to staff heavy workload their needs are not met.

This makes them feel neglected in the care of their infants thus developing negative feeling towards the staff. This finding is in line with previous studies that demonstrated how lack of emotionally supportive communication aggravate the stress levels of mothers [12,13]. We discovered that mothers' stress levels are aggravated when they are not able to visit the unit regularly due to socioeconomic factors. These mothers rely heavily on staff to update them on the health status of their infants. However, our findings show that the existing communication channels at GSH NICU are not effective thus increasing mothers' anxiety [14]. Looking at the participants' feedback, it is evident that there is a need for effective communication in the NICU where mothers feel involved in the care of their infants. Participants recommended that with the high penetration of mobile phones in South Africa, the technology could be used to disseminate information and keep mothers updated on their infants' health status [13].

6.2 Methods Matter

In this study, we identified the significance of using the appropriate methods to engage participants in co-design process. Throughout the study, we focused on identifying methods that empowered and fully involved participants in the design process. Greg [44] emphasize that designing with vulnerable participants is practically, methodologically and ethically challenging and researchers should focus on identifying methods that enhance participants collaboration to ensure they achieve a common goal. This being an under-researched topic that involves mothers who are susceptible to distress, we aspired to change the "top-down" design approach and empower participants to take control of the design process and ensure the final design incorporates all their needs.

Our methodological choice uncovered co-design dynamics of working with multi-stakeholders. We overcame these challenges by using methods that enhance group cohesion. In the next section, we highlight the impact of our methodological choices.

6.2.1 *Building Trust and Relationship for Co-design.* In the first part of observations, we opted to volunteer at the NICU to familiarize ourselves with the environment as well as to build a working relationship with both mothers and staff. Hussain et al. [24] underscore the importance of understanding participants environment before involving them in design process. This approach motivates participants to willingly take part in the study. This resonates with our experience. We identified that stakeholders were willing to participate in the study because we had already created a rapport with them. We therefore argue that researchers should set aside enough time to understand their participants' environment especially when conducting research in sensitive and under-researched topics and use this understanding when engaging with participants.

6.2.2 Engagement Catalyzer Methods. In the first phase of this study, we identified that hierarchical relationship was a hindrance to effective communication in the NICU. According to Foucault [5], power imbalances in medical environments exist because health practitioners possess medical knowledge required to diagnose and the patient/caregiver is allowed to share this knowledge only when invited to do so. To avoid power imbalances in the second phase we opted to have separate focus groups with stakeholders. However, even within the different groups, we identified co-design dynamics such as power imbalance, conflict and limited design skills. These dynamics had an impact on the dialectic process of developing design ideas in the co-design process. To overcome this, Mechelen et.al. [27] argues that researchers should identify methods that allow engagement of all participants to achieve optimum design outcomes.

During the doctors' session, we witnessed participants disagreeing over different ideas. To enhance group cohesion, we used scenarios and role-playing that allowed the doctors to fit into the mothers' world and understand their need for communication. In addition, this technique helped doctors to collaborate in creating new ideas of better ways of interacting with mothers in the NICU. To visualize their ideas and work towards a common goal they sketched the suggested workflow and negotiated on the features that should be included in the proposed solution.

In addition, our findings show that brain-dumping and card sorting are effective techniques that encourage divergent thinking

[2] A project that motivates mothers to express and deliver their breastmilk to local health care facility which is later collected by scooter drivers and delivered to GSH NICU kitchen

thus overcoming power inequality. Furthermore, these methods empower participants with limited design skills by allowing them to share their ideas and elaborate the reason behind them. As a result, this creates a design space where participants have greater control in the design process and they can confidently express their own needs in their own abilities. Our experiences and those of other researchers [3] [24] show that when empowered participants take ownership of the project and are geared towards designing a solution that fits in their lives.

6.2.3 *Methods that Consider Mothers as Co-designers.* We learned that when working with mothers with young children it is important to have flexible design sessions that allow mothers to attend to their children unpredictable demands. This resonates with the findings of Balaam et al. [2] and Wardle et al. [46] which demonstrate the importance of developing design methods that are easily paused and re-started when working with mothers with young children to accommodate the numerous needs of their young children. We also identified the importance of keeping mothers' interview sessions flexible to ensure that mothers who were emotionally disturbed had a chance to recollect themselves and continue with the discussion.

6.3 Co-Design Readiness Through Empowerment

Co-design readiness is defined as a state where participants who are unfamiliar with technology gain confidence and can voice their ideas and opinion to shape a solution that might meet their needs [30]. In the two phases of this study, we observed participants with limited exposure to technology gain courage and share their opinions. In the first phase, stakeholders had numerous ideas of how communication could be enhanced in the NICU. They narrowed down the design ideas in their separate sessions and the findings show that they prioritized to share breastfeeding and parental education information. In the joint focus group, we identified that participants had gained confidence and focused on shaping a solution that would help the NICU staff ease their role in the NICU as well as effectively educate mothers to help them understand the condition of their infants. We argue that our approach of having separate sessions and pairing up methods empowered stakeholders to generate numerous design ideas despite the group dynamics. This eventually helped them to jointly brainstorm and merge their ideas to ensure that the output of the ideation process meets both the staff and mothers' needs.

7. CONCLUSION AND FUTURE WORK

The birth of premature infants and hospitalization in NICU are stressful events for mothers. Communication between mothers and NICU staff can help reduce the emotional burden. In response to this need, we have initiated the process of designing a communication tool that will enhance communication between NICU staff and mothers in low-income context. In so doing, we have identified the common challenges while designing with the multiple stakeholders and provided the methodological recommendations that support constructive co-design in sensitive studies. We demonstrate that when participants are empowered they can design technologies that are relevant to their needs.

In the next phases of this study, we will focus on involving our participants in developing the low and high-fidelity prototype of the suggested solutions from the second phase. The suggested interventions will be developed based on stakeholders identified requirements. We will deploy them at the NICU where we will evaluate and identify whether they will improve the communication challenge in the unit. The final functioning prototype will be handed over to the unit as the researcher continues to monitor the usage of the tool.

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