The NICU Design Toolbox: Co-design through Empathic Relationship Building

ABSTRACT

Co-design in practice can be extremely difficult, especially when multiple stakeholders are involved. In this research, we reflect on ways to produce cooperation between low-income mothers, nurses, and doctors, as they work with researchers to co-design an artifact to alleviate communication gaps in a South African Neonatal Intensive Care Unit (NICU). We describe the strategies used to mediate and foster cooperation between these stakeholders; cooperative prototyping techniques can foster collaboration, disentangle participation and enhance participant creativity in spite of power differentials and initial feelings of disconnection. We argue for flexible, responsive design practices that foster readiness to design with other stakeholders.

CCS CONCEPTS

• **Human Centered Computing** → **Interaction Design**; **Systems and tools for interaction design**.

KEYWORDS

NICU, Power dynamic, Cooperative Prototyping, Co-design

1 INTRODUCTION

One of the leading causes of neonatal mortality is premature births, of infants born with a weight of less than 1500 grams [5]. Primary caregivers, often the mother of the infant, are critical stakeholders in reducing premature infant deaths. However, hospital prioritises direct care for the infants, often leaving parents feeling dis-empowered [5]. In addition, since many of the most vulnerable, especially in the context of South Africa, are from low-income settings, parents experience communication barriers with the hospital staff, due to the cost of transport, language barriers and unreliable access to mobile phones [2]. In this work, we employ a co-design approach to engage mothers of premature infants from low-income settings and the neonatal staff in the design process of a possible technological intervention that could mediate communication gaps between these stakeholders. Our findings show that using co-design

in Neonatal Intensive Care Unit (NICU) settings can be challenging due to the hierarchical structures in health institutions. Power inequality inhibits some participants from voicing their health related needs alongside their seniors and researchers. In addition, health information is highly personal and patients/caregivers are uncomfortable sharing their experiences. We identified that the use of mediation techniques during the ideation process enabled participants to negotiate their disparate design ideas thus allowing them to refine technology requirements towards a common goal. In addition, these techniques enhanced mutual learning, mitigating power imbalances and conflicts amongst multiple stakeholders. We emphasize that researchers working in NICU context should consider using empathic design methods to foster relationships and mutual learning amongst multiple stakeholders engaging in a co-design process.

2 METHODOLOGY

We employed co-design approach [4] which allowed for active engagement with the mothers and NICU staff as active research participants throughout the design process. We have six phases in this study namely: 1.Needs assessment and problem identification 2. ideas generation 3. Ideas exploration 4. Prototyping 5. Deployment and 6. Handover. From Nov 2017 - Aug 2018, we worked with mothers whose infants had been discharged from the NICU to develop an understanding of technology uses and needs through interviews and workshops. With our participants, we decided to develop a tool to support the work of nursing staff in sharing needed information with parents, such as medical terms, and breastfeeding instruction [2]. We focus now on the activities of phase four where we engaged six mothers and six NICU staff in brainstorming and prototyping sessions to clarify the design of a specific intervention.

2.1 Brainstorming Session

In this session we focused on clarifying and refining the information categories suggested in phase three [2]. We used the personas, workflows, sketches, and artefacts from previous design iterations to encourage participants' imaginations. We grouped the participants into multi-stakeholder groups (one doctor, one nurse and two mothers in each group) and shared the design materials (pens pencils, eraser and plain papers). We started by encouraging participants to use their experiences to specify the intervention's requirements and identify gaps, [1], then used a sentence completion activity to clarify information requirements. All the design ideas generated during this process were categorised and later ranked according to their priority level using the card sorting method. We formulated six information categories: 1. breastfeeding benefits 2. medical terms 3. health information 4. NICU equipment 5. life after NICU and 6. Peer support. Based on this information, a cooperative prototyping session was organised with the same participants two days later.

2.2 Prototyping Session

In this session, we focused on exploring better ways of representing the information suggested during brainstorming session in a simple format that mothers could easily access and understand. We asked the 12 participants to break out into three new multi-stakeholder groups. We asked them to collaborate in the sketching of the application interface and screen transitions, using materials we provided. At the end of the session, all groups presented their low fidelity prototypes. We used cognitive walkthrough and asked mothers to evaluate the usability of the interfaces using emoticon stickers, and inviting them to explain their feelings towards the proposed low fidelity prototypes.

3 FINDINGS

Based on our findings, we identified that series of incomplete sentences and emoticons acted as a mediating technique which encouraged mutual learning amongst the participants. During the prototyping session the use of emoticon encouraged the participants to voice their ideas and critic the features that they did not approve. This prompted constructive discussion towards a common goal. It also encouraged creativity where participants improved on suggested prototypes to incorporate all participants views. The results reported in this paper were derived from analysing the qualitative data using thematic analysis [3]. We transcribed the three hours recording together with field notes and later used NVivo software for coding. Two themes resulted based on clustering of different codes. These are: 1. overcoming hierarchical relationship 2.Empowerment Through Co-design.

3.1 Overcoming Hierarchical Relationships

Doctors, nurses and mothers had disparate NICU experiences which hindered collaboration and created tension within the groups. Initially, the doctors dominated the session, inhibiting the nurse and mothers from participating. However, working relationships among group members was gradually cultivated as they engaged in content formation. Sharing of NICU experiences encouraged engagement, motivating participants to open up and consequently leading a constructive empathic ideation. This active participation of participants enabled them to tailor the information to their specific cultural needs and contexts. In addition it encouraged mutual learning concept among staff and mothers prompting them to work towards a common goal.

3.2 Empowerment Through Co-design

The NICU experience sharing approach helped participants to articulate their needs. This was enhanced by using generative techniques such as series of questions in the brainstorming session and collaborative sketching, card sorting and emoticon in the prototyping session. At the end of the brainstorming session mothers mentioned that they felt privileged to engage with NICU staff who they deem superior in NICU infant care. This interactions boosted their self esteem and three of them mentioned that they would like this kind of sessions to happen often. Staff-mother relationship built during the process were helpful, especially to the mothers who mentioned that they had gained knowledge which would help them as they partake in infant care. In prototyping sessions, participants were

able to unleash their creativity and visualize content representation and transition. Mothers who previously feared the NICU staff gained courage to criticise staff design ideas. In one group, where they had chunk of information, a mother opposed the decision and said " It is hard to scroll through chunk of information while holding a baby in the unit" The group members discussed better ways of sharing information and in unison, they agreed that video format was viable. Overall, we can claim that empowerment was achieved through: self-determination during design sessions, building of mother-NICU staff relationship and the ability of participants to discuss their emotional NICU experiences.

4 DISCUSSION AND FUTURE WORK

Our findings highlight subtle but important nuances of conducting co-design in NICU settings. Instead of using only the conventional co-design methods (brainstorming, card sorting and sketching), we argue that it is important to explore a set of co-design generative techniques to foster appropriation and encourage collaboration among multiple stakeholders with disparate NICU experiences. Participants' NICU experiences should be central to the design process to encourage an empathic design approach. This is key to tailoring content and functionalities to specific cultural needs and contexts.

Starting with the prototypes generated in this phase, we have done further development on making a concrete artefact. A heuristic evaluation was conducted one week later with a neonatologist at the hospital (a co-author). He suggested that content be relayed in simple language without losing the medical meaning. The artefact content was further verified by a nurse and doctor to simplify all medical jargon, and has been translated to isiXhosa and Afrikaans, as requested by our co-designers.

In ongoing work, we will evaluate the usability and impact of the co-designed artefact as NICU parents and staff interact with it. Once the initial evaluation is complete, we will work closely with hospital staff to help them take over content development, maintenance and operation of the intervention.

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