Chapter 16

Experiencing the Unexpected:
Human-Centred Design in Neonatal Intensive Care

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ABSTRACT

This chapter discusses a fundamental concern deriving from the need to increase the focus on the social, emotional and intimate aspects in the design of healthcare technologies. The development of such technologies is in fact often afflicted by conflicting perspectives. While technical perspectives demand rational methods, social perspectives ask for non-rationalistic, phenomenology inspired approaches (Jacucci, 2007). The issue is addressed from the standpoint of a particular socio-technical setting, the Neonatal Intensive Care Unit. In particular, the chapter describes the human-centred and participatory design process, from problem analysis to concept generation, prototype development and testing of a new incubator system employing different technologies. All these technologies aim to provide unobtrusive monitoring, improving the baby's comfort as well as parent-child bonding by lowering the emotional barrier created by the current incubator setup. The specificity and the delicateness of the NICU setting offers an opportunity to reflect on how different stakeholders perceive, interpret, and take part in the premature baby's care, and on the role that design can play in envisaging technologies that respect and harmonise different views and needs making the unlucky event of a premature birth a more sustainable experience.

INTRODUCTION

The progress that has been made in treatment of neonatal pathologies has significantly increased the life expectancy of children born prematurely (Costeloe et al., 2000).

However, while premature babies' chances of survival continue to increase, it is still difficult to reduce the sense of discomfort associated with a birth with complications.

In the event of a premature birth, the parents' expectations in relation to their child's birth and early childhood are completely overturned by a new, unforeseen situation. Just as the child is

unprepared to cope with the environment outside the uterus, the parents are unprepared for their role in this situation.

A feeling of inadequacy pervades the parents, who feel unable to deal with the event and take care of their child. They are experiencing an unexpected event in which they seldom receive all the support they need.

The incubator often appears to be an incomprehensible and frightening machine which is intimidating and emotionally overwhelming to parents.

Alarms, wires, tubes and complex displays contribute to increasing the sense of discomfort and make it difficult to appreciate any improvement in the baby's health.

Many different players take part in the care of premature newborns from the moment of delivery. Medical staff members take care of the babies, attempting to fulfill all their needs and dealing with any possible problems or complications.

They may share the same workspace, but they do not share the same work: different actors have their own specific competencies, their own tasks and their own schedule for performing their duties. Parents try to get involved, but they are easily confused due to the stressful situation and their lack of knowledge about what is going on.

Development of technologies for the Neonatal Intensive Care Unit (NICU) therefore requires accurate interpretation of different viewpoints, roles and expectations, so that the necessities of the child, the medical personnel and the family can co-exist in a sustainable way.

THE INCUBATOR: THE TENSION BETWEEN PROTECTION AND BARRIER

The incubator is the main stage in care, as it aims to recreate some of the conditions of the mother's womb, providing the baby with an optimal growing environment with the right amount of heat, humidity and oxygen.

Most medical treatments are administered directly in the incubator to reduce the risk of complications due to outside elements.

The environmental qualities in the incubator are tightly controlled. For example, air temperature may be set to a specific value or automatically adjusted if the temperature of the baby's skin drops and needs to get warmer.

The NICU is a socio-technical system composed of other additional machinery and different stakeholders, including the parents, who have different access to the incubator and different requirements depending on their role.

The working practice of the neonatal team is based on the continuous combination and integration of data generated by different sources.

Various monitors are placed around the incubator and display the heartbeat and rate of breathing, blood pressure and oxygen level in the blood. Other parameters may also be displayed, depending on the baby's condition. For example, diagnostic tools permit data integration across the hospital, showing the baby's x-rays, laboratory results and other information at the bedside that might help clinicians speed up the decision-making process.

Most monitors are equipped with alarms to keep medical staff aware of any changes in the baby's condition; unfortunately, jarring warnings often alarm the parents, who need to figure out what is going on, and disturb the baby.

The infusion pump administers intravenous medications and fluids. Since the premature baby is sensitive to small changes and therefore precise dosing is fundamental, the pumps are fitted with safety features and alarms to control the dosages. This contributes to the machine's frightening appearance.

The ventilator administers oxygen to assist the underdeveloped baby's lungs until they mature to the point where the baby can breathe alone. Use of this machine is one of the causes of the baby's separation from its parents, creating an emotional barrier against holding the baby.

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