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# Designing Multimodal Tools for Parents of Premature Babies

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**Abstract**

The paper describes our efforts in designing and developing a tool for supporting parents of premature babies during their critical time in a Neonatal Intensive Care Unit (NICU). The identification of the needs are described from the parents' perspective, and supporting evidence is presented from the babies' development point of view. The paper presents our research on identifying the lived experience of parents of premature babies through a large scale international study. The findings of the study are detailed to show how they led to the experience design criteria of a multimodal journaling tool. The paper closes with an overview of ongoing research of practical solutions to multimodal interfaces, the implementation of multimodal integration techniques, and a discussion on the generalization of the multimodal journaling tool to the larger context of patient engagement applications.

**Author Keywords**

User-centered design, experience design, multimodal interfaces, parents, healthcare, neonatal care, patient engagement

**ACM Classification Keywords**

H.5.2 [Information Interfaces and Presentation]: User Interfaces, User-centered design

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**Figure 1:** Kangaroo-care given to a premature child by the father. (Permission to use the above picture was received from the child and the father.)

## Introduction

Premature birth of babies affects a significant number of families annually around the globe (see statistics in sidebar). It is a worldwide phenomenon, despite the enormous advances in neonatal medical care in the past decades. Behind the numbers (on the left below) are not only the babies' lives, but also those of their parents and their lived, often traumatic, experience.

Small actions can make huge improvements in the outcome of the care. It is important to involve and encourage the parents in the care of their baby, like providing daily Kangaroo-care (skin-to-skin interaction with the baby) as shown in Figure 1. Parents need support from everyone through their journey in the NICU: from the care team, the provider, the extended family, and even employers and the society at large. Innovative programs, such as in Finland and the U.S.A., have demonstrated improved clinical quality results when parents are more actively engaged in the care of their premature baby [9], [6].

Furthermore, information sharing can help to better cope with the unexpected situation. For instance, Hollywood & Hollywood focused on how fathers experience their baby's stay at a NICU [3] and how information sharing can relieve "parental anxiety." Providing consistent answers from the care team in layman's terms is a desired aspect of information sharing.

Also, the first author's personal experience, as a father of an extreme low-weight premature baby and his lived experience while spending endless hours bedside in two NICUs, is a driving force for this work to develop and implement meaningful technical solutions for parents of premature babies. The use case for NICU parents support represents a technically challenging, motivating, and socially valuable opportunity.

The paper has three parts: first, related works are summarized briefly. Then, the design efforts to identify parents' needs are described. The last part draws conclusions from the findings of the conducted user study, and outlines the next steps in implementing a multimodal journaling tool.

## Relevant Works

Next a brief overview is presented about two of the dedicated efforts to support parents in neonatal care.

### *Information tools for parents*

Information tools help the parents stay on top of their mission to care for their babies. For instance, the information sharing method Palma et al. experimented with, the Daily Patient Update Letter, provided updates and essential information to parents that they could digest at a glance [8]. Also, support for parents after transitioning home from the NICU is crucial. Being suddenly in a non-medical environment with a baby that is only a few months old brings another set of challenges. Lee et al. studied how information technology can support parents with training methods during the transition period from NICU to home [4].

### *Family-Integrated Care*

One major trend is to involve parents in the care is implemented under innovative programs like the *Close Collaboration with Parents Training Program* by the Turku University Hospital in Finland [10], and the *Family-Integrated Care* by the Mount Sinai Hospital, Toronto, Canada [7]. Both the philosophy and the entire organization of these NICUs support the parents' involvement, and most notably, the implementation of family rooms where the parents stay with their babies (see more details on the next page).

The next section describes the design methods to identify needs, problems and opportunities in the parental care of premature babies.

## Prematurity in numbers:

- 15 million premature babies born globally per year,
- 90% of babies are saved in wealthy parts of the world,
- 90% mortality rate in developing countries,
- premature birth rate 18% in some parts of Africa and Asia, in Scandinavia as low as 5-8%,
- the global average is 11%,
- in the U.S. 500,000 premature births per year, or 11% of all the live births.

Source: WHO report [11].

## Family-Integrated Care

**Origin:** In 1979 a new “humane” model of care was implemented by the Tallinn Children’s Hospital in Estonia, allowing and encouraging mothers to stay with their babies 24/7 due to a shortage of nurses. Except for administering medication, examinations and medical care by the nurses, the mothers learned to care for their premature babies.

### Benefits:

- improvement in weight gain,
- reduction in infections,
- reduction in the length of NICU stay,
- reduction in nurse workload,
- may reduce parental stress due to better opportunity in developing confidence,
- biological ties between the mother and the infant are preserved; no physical, psychological, emotional separation.

Source: Levin’s Estonian Baby-Friendly NICU [5]

## Designing for Parents

Before starting to create any new information support framework, it is of paramount importance to study the real needs of all actors in the domain of neonatal care. The design phase of the work must address not only the full understanding of the parents of premature babies, but also that of the care team, doctors, and the (extended) family.

The design phase covered four areas, each applying a user-centered approach to discover various aspects of parents’ needs. The first two areas focused on the identification of the lived experience of parents. The third area addressed the care team’s view, their efforts interacting with the parents, as well as the perceived needs of the parents. The fourth area was a step-by-step analysis of activities parents carry out in a NICU.

### *On-line questionnaire*

To implement an international study and to gain access to a wider audience, social networking groups and non-profit organizations were contacted to reach out to parents of premature babies globally. The on-line questionnaire was voluntary and all responses were handled anonymously so no mother and father of the same baby could be identified and connected based on their responses. The participants were not compensated for their contribution.

The primary purpose of the study was to identify the lived experience of the parents while their baby was at a NICU. We defined the term *lived experience* as a combination of several factors, including how they coped with the situation, at what level they were engaged in their baby’s care on a daily basis, what tools they used or would have liked to use to be more supported, how they communicated with the care team (how frequently and in what format), and what type of information they received or would have liked to receive.

### *In-situ observations of parents-doctors interaction*

The goal was to discover how parents and doctors communicate and share information about the babies’ development. The observations took place during the doctors’ daily rounds in a leading Scandinavian university hospital’s NICU, where parents and their babies share individual family rooms. In addition, parents, doctors and nurses were interviewed.

### *In-depth interviews with leading neonatologists*

Three leading practitioners kindly agreed to share their experiences. The interview questions focused on the communication with parents, the tools and methods used and/or experimented with in the past to support parents and motivate them for more intensive parental engagement.

### *Personal experience analysis*

This step focused on the first author’s experience as a father of an extreme low-weight premature baby. His experience spread over nearly five months of staying in 3 NICUs, endless hours bedside, and implicitly having the opportunity to observe not only the work of care teams, doctors and social workers, but also what a family goes through while a child is in a NICU. Needs analysis and experience mapping from the parents’ perspective were applied.

## Analysis of Results

A combined summary of the findings from the four design phases is given next. The results are grouped according to the user study topics (see on the side of the next page).

*General* – Parents were very open in sharing their NICU experiences through the on-line questionnaire, as well as during the observation and interview phases. While the goal was to carry out a qualitative evaluation, the relatively large number of responses (Table 1) provided the possibility for a more quantitative evaluation of the data.

	Parents	%
U.S.A.	133	45
Finland	46	15
Hungary	40	13
Norway	19	6
Ireland	18	6
Australia	10	3

**Table 1:** The top 6 countries of the respondent parents, representing ca. 90% of the 298 participants.

#### User Study Aspects

*General:* country, mother or father answering, level of prematurity (gestational age and weight in ranges, e.g. 25-30 weeks, 1-2 lb).

*Communication:* type and frequency of interaction with the care team and beyond.

*Information access:* dealing with the amount and type of information, metrics.

*Coping:* managing emotionally, mentally, physically.

*Engagement:* extent being involved in the daily care.

*Tools:* methods used to follow the baby's development,

*Experience:* initial reaction with three adjectives, reaction when left NICU for home.

*Communication and sharing* – The main form of communication was face-to-face interaction with the care team during visits. Results were similar across geographies. The only significant difference found among the top three countries was the less frequent visits by Hungarian vs. U.S. parents (87.88% vs. 98.37%, with  $\alpha = 0.01$ ,  $p = 0.0027$ ). As for communication outside the NICU, parents extensively used social media to share their experience with their families.

*Information access* – In retrospect, parents would have appreciated easier access to essential information to better understand the “big picture,” such as accessing basic metrics about the progress of their baby. Some expressed their frustration that from different members of the care team they received slightly different updates.

Confirming preliminary expectations, more than half of the parents (53%) had difficulty dealing with *the amount of the information* received daily. Comprehending the *new type of information*, learning an entirely new vocabulary, and understanding the situation in simple terms proved to be challenging for even more: 61% required some or lots of effort to deal with the information. As a mother expressed her situation: “*I was terrified and confused about all the new terminology I was hearing. I also felt empty inside.*”

*Coping* – The unexpected situation was hard for many. The majority (nearly 80%) tried to be involved in the care as much as possible. However, 60% admitted they “*just went on day by day,*” and 25% had to reach out for extra support.

*Engagement* – Parents' involvement in the care was not equally possible for everyone. One mother lamented, having experiences in two NICUs in two cities, that the second hospital did not support parental engagement as much as the first, causing her conflicts and extra emotional distress. 78% of parents were involved in the care very intensively, while nearly 11% of the parents either were not able to participate or it was not possible for some reason.

Interestingly, when the interaction between doctors on their daily rounds and parents caring for their babies 24/7 in a family room was observed, 80% of the time the parents talked, giving their summaries to the doctors and nurses. In the remaining 20% of time the doctors only described the next examinations and steps in the care.

*Tools* – About half of the parents used some kind of method to log the daily progress, the ups and downs, the metrics, the examinations/medications their baby received. For many it was part of coping and survival during the challenging time. Some started blogging, used social networking, or made notes with mobile phones, took pictures of charts, etc. A small number of parents took only “mental notes” but still were able to follow their baby's progress. However, 20% did not track progress at all.

When asked what kind of tool would be most helpful, responses emphasized communication and seamless access to information, knowledge sources, and easy to follow explanations. The most important aspects desired were:

- better communication with the care team (60%),
- real time flow of information (52%),
- better way to understand the baby's development, the most important metrics, and the “big picture” (51%).

Nearly half of the parents wished for some form of diary. Their only concern was that such a tool might take time away from the care: the user interaction, especially in a NICU environment, should be effortless and seamless.

*Experience* – The parents' overall experience changes during the time spent in a NICU. It is a journey. The initial experiences are uniformly those of shock, confusion and being overwhelmed – emotionally, mentally, and even physically. However, when the time comes for transitioning home, the parents are more confident, optimistic and relieved, albeit nervous about caring for their babies on their own. This emotional journey is depicted in Figure 2.



**Figure 2:** Parents' emotional experience: when getting to the NICU (above), when transitioning home (below).

## Design and Implementation Implications

The following design criteria have been established:

1. Information presentation, e.g. metrics, must be rendered by visual storytelling principles *at-a-glance*: visualizing longer temporal understanding (“the big picture”) and instant values (the real-time aspect).
2. The input mechanism must be *non-intrusive and adaptable* both within and outside the NICU.
3. *Contextual access* to the right type/amount of knowledge is a must. Becoming knowledgeable is reassuring.
4. Communication with the care team and peers, as well as *experience sharing* with family and beyond must be real-time, implemented by seamless interaction paradigms.

Following these findings, a *multimodal journaling* tool has been identified as the scope of implementation, with advanced input mechanisms and storytelling-based visual output rendering, using the following enabling technologies:

### Multimodal Integration

The technical implementation of multimodal user interfaces often views speech as the primary input, and additional modalities (gesture, touch, gaze) as add-ons. Earlier work on contextual multimodal integration argued that from a semantic interpretation point of view all input channels, context and sensor inputs, are to be handled equally. We found that context improves the integrator performance [1].

### Experience Sharing

A practical use of multimodal inputs along with sensor and contextual information was implemented in an experience sharing demonstration application [2]. The goal was to translate experiences via a multisensory acquisition process into an immersive visual summary.

The longer term plan is that the multimodal journaling tool will build on the above technologies, provide ease-of-use, and deliver a meaningful experience for many. Furthermore, beyond the neonatal care, it will extend towards a general patient engagement platform.

## Conclusion

We presented the findings of a user-centered design process to provide support for parents of premature babies during their critical time in a NICU. The paper described the design implications, leading to a multimodal journaling tool with advanced multimodal capabilities to keep track of and communicate the babies' development with ease. Finally, ongoing research on practical solutions to multimodal interfaces and integration techniques were presented, and the generalization of multimodal journaling to the larger context of patient engagement applications was discussed.

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