Designing a Mobile Health Tool for Preterm Infant Wellness

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Abstract—**Preterm infants have significantly higher rates of functional limitations and are at risk for delays in cognitive, motor, and other skills. In this paper, we present the results of a qualitative design study to understand the needs of these families and their professional caregivers. These findings informed the design of Estrellita, a mobile wellness tool to support caregivers of preterm infants. We discuss several features of Estrellita that are designed to encourage flexible and consistent data monitoring. We also discuss our strategy for evaluating Estrellita in a long-term deployment study.**

Keywords-preterm infants, prematurity, health informatics, infant wellness, pediatric informatics, mobile wellness tool

I. INTRODUCTION

More than 12% of all US births each year are preterm, i.e. delivered prior to 37 weeks gestation [1]. Most of these infants have low birth weight (LBW) and significantly higher rates of functional limitations or developmental problems when compared with those with normal birth weight (NBW) [2, 3]. In particular, preterm infants are at risk for delays in cognitive, language, motor, and sensory processing skills [3, 4]. Past work in neonatal care has shown that regular monitoring can provide early identification of developmental delay. In this work, we focused on using mobile technologies to augment existing HRIF programs. Recent advances in smartphones enable these tools to be integrated into the caregiver experience at a low cost. Using these mobile devices as health informatics tools better equips parents to monitor, maintain, and guide them towards health caregiving behaviors.

To this end, we have created Estrellita, a mobile wellness tool to support caregivers of preterm infants. Estrellita addresses the common burdens of monitoring infant healthcare and balances the sometimes-competing needs of parents, clinicians, and other professionals. In this paper, we describe the results of an interview study and extensive design process that led to the development of Estrellita. In particular, we present the diverse challenges that parents and clinicians face when attempting to document, understand, and share infant health data. Efficient and usable data tracking is a critical component of successful wellness applications as data awareness can allow users to make better health decisions. Based on our findings, we outline design implications that are broadly applicable to applications for preterm infant care.

II. BACKGROUND AND RELATED WORK

Despite calls for pediatric-specific health tools [5], little has been published focusing on pediatric informatics, and even less

on the specific needs of preterm infants. In one recent project relating to preterm infants, Gray *et al*. evaluated an Internet-based telemedicine program called Baby CareLink, which allowed parents to remotely check on their infant during his stay in the hospital's Neonatal Intensive Care Unit (NICU) [6]. Although these types of tools are important for inpatient care, they neglect the time after discharge. Motorola is doing work related to transitioning from the NICU to the home [7]; however, the focus of Estrellita is to support in-home care.

Past work has shown that even parents of healthy children struggle with data tracking tasks [8] and that families coping with children with chronic illnesses may struggle even more [9]. Thus, researchers have begun to investigate the design of systems to support physiological [8] and developmental [10] health monitoring in families. This work builds on the existing literature and presents results of a formative study that examines the need to balance tensions among the various stakeholders involved in infant care. The Estrellita mobile tool aims to do that using a holistic approach to wellness tracking that considers *both* maternal and infant health data.

III. METHODS

Our approach to designing an effective mobile health tool includes use of qualitative methods, including interviews and observations, to better understand the data capture and access needs for caregivers of preterm infants. Following these interviews, we conducted a two-phase design process over 18 months to help inform the development of the Estrellita system and, more broadly, for infant wellness applications.

Our team conducted interviews with 29 participants living in Southern California between November 2009 and June 2010. These individuals included 18 caregivers (17 mothers, 1 aunt), who were of medium to low socioeconomic status, and 11 healthcare professionals. For simplicity of reading, we refer to familial caregivers as parents or families in the remainder of this paper. At the time of our study, all parents were caring for at least one LBW infant, who was born 24-28 weeks premature, and had been discharged from the Neonatal Intensive Care Unit (NICU) for at least one month. On average, the infants had stayed in the NICU for 59 days.

All families were interviewed either in their homes (n=15) or in the hospital where their infant was born (n=3) as individuals (n=16) or in pairs (n=2). Interviews were conducted in English (n=16) or Spanish (n=2), according to the participant's comfort level. During the interview, our primary interest was to understand how parents kept track of the

development and health of their preterm infants. In particular, we asked about the types of information parents recorded, the barriers to and tools used for data capture, and how parents made sense of their records. We also asked about parents' current practices for caring for their infants, their strategies for preparing for their discharge from the hospital, the quality of communication with their infants' healthcare providers, and their strategies for getting help or finding information about how to care for their infant. Interviews lasted 1 hour and were audio-recorded, transcribed, and translated when applicable.

To supplement our family interviews, we also interviewed 11 healthcare professionals either in groups (one group of seven and one pair) or as individuals (n=6). These professionals included nurses, pediatricians, developmental psychologists, and social workers who all specialize in caring for preterm infants. Seven worked at a high-risk infant follow-up (HRIF) program affiliated with a 238-bed regional hospital that houses a 54-bed Level III NICU. The remaining professionals worked at a 422-bed academic medical center that houses a 45-bed Level III NICU. The HRIF program is responsible for state-mandated monitoring of most preterm infants in the surrounding geographic areas. These include any infants admitted to a hospital's NICU, as well as those who are considered high risk, either due to an illness or because they were born prematurely, but were not admitted to the NICU.

When interviewing the clinicians, we focused on their perceptions of parental concerns, how data collected by parents impacted clinical workflow, and any other concerns they had about caring for preterm infants and their families. Group interviews lasted several hours; individual interviews lasted one hour. Interviews were recorded and transcribed when permitted (n=8). In all cases, detailed notes were taken for analysis.

We coded all interview transcripts and field notes using an emergent open coding scheme to identify recurring themes related to how caregivers manage and monitor the health of their preterm infants. Additionally, we used themes from the literature (*e.g.,* parental stress, inadequate feelings of self-efficacy) to confirm recognized challenges in our population. These themes developed iteratively over several months, with the entire research team meeting regularly to discuss the data.

Building on the findings from the first phase of this work, during August 2010 to August 2011, we conducted participatory design sessions. Specifically, we invited four healthcare professionals to join our design team. All four professionals were recruited from the same HRIF program used in our first round of interviews. Three of the professionals had participated in the first phase of our design process, including two case managers and a nurse who manages the HRIF program. The fourth design team member is a psychologist who focuses on pediatric mental health and development.

We conducted ten participatory design sessions of approximately one to two hours each. During these sessions, we conducted several participatory design exercises, including ideation, card-sorting exercises, and low- and high-fidelity prototyping. Design sessions were recorded and transcribed when possible (n=4). In all cases, detailed notes were taken for analysis. Between design sessions, conference calls occurred every two weeks among the entire design team, including both the professionals and the researchers, which enabled continued communication and feedback regarding the design of Estrellita.

IV. PEDIATRIC CAPTURE AND ACCESS CHALLENGES

In our interviews, we found diverse challenges facing parents and clinicians attempting to document and understand, infant health data. In particular, parents described struggling with *when* to collect data, while clinicians reported being more concerned about *what* and *how* parents track infant health.

A. Challenges for Parents Caring for Preterm Infants

The transition from the NICU to home can be stressful for parents, because the level of care required is beyond that of the usual parental role [11]. At the same time, the first year is a critical time for infant growth and development. In our interviews, we asked parents to discuss their caregiving experiences, paying particular attention to tracking of health data. All of the parents in our study confirmed that the transition to in-home care was challenging. Parents also agreed that these challenges had not diminished over time, despite our interviews being an average of 8 months after NICU discharge.

One particular challenge for parents of preterm infants is the difficulties of managing their baby's appointments. Nearly two-thirds of preterm and LBW infants continue to have medical and/or developmental concerns beyond the NICU [12]. As a result, many NICU graduates have significantly more clinic visits than NBW infants [13]. Managing these appointments was overwhelming for the parents in our study, especially since their infants often had to see a variety of different doctors and service organizations.

Beyond managing appointments, parents were also often overwhelmed by their transition from the NICU to home. Many parents feel unprepared for their infant's discharge [14], an issue that was echoed in our interviews, in which parents were worried both about immediate care after discharge and over long term development, particularly when compared to other infants who were born full-term. Part of this concern is that many parents are unsure of what is considered 'normal' behaviors for preterm infants. As a result of these uncertainties, parents are often confused by what they should be tracking and end up tracking health data that is not clinically relevant to the infant's professional healthcare providers.

B. Challenges for Clinicians Caring for Preterm Infants

From our interviews, one of the biggest challenges for clinicians was how they could help inform parents about what and how they should be monitoring about their infant's health. However, healthcare professionals often have limited to provide care. During short appointments (typically less than 15 minutes), they must assess the physical health of the infant, answer parent questions, and go over any information that has been shared with them, either through health records systems or by parents bringing data to the appointment. The clinicians we interviewed observed two general types of data reporting behaviors adopted by parents. On one hand, there were parents who were so stressed that it was difficult for them to accurately remember the necessary information from all of their previous appointments. On the other hand, some parents presented the clinicians too much data to examine efficiently and easily.

In addition to the issue of quantity, clinicians also commented on the types of data that the parents were and were not reporting to them. In particular, clinicians raised concerns about certain types of health data that were being overlooked by parents. For example, parental health is strongly linked to infant health. For example, maternal post-partum depression has been shown to adversely affect infant development and may be as high as 40% among mothers of preterm infants [15]. Stress has also been shown to adversely affect infant development. High levels of parental stress have been correlated with maladaptive parent-infant interactions [16]. However, both stress and post-partum depression is traditionally very difficult for parents to monitor.

Another example of health-related data that parents sometimes forget to share with clinicians is infant bonding activities. Bonding with preterm infants in particular can be challenging for parents who may be concerned about the infant's medical fragility. Thus, these activities are often not conducted as often as clinicians would like to be, but the lack of monitoring and tracking this information makes it difficult for clinicians and parents to discuss these types of activities.

V.   ESTRELLITA: A MOBILE HEALTH INFORMATICS TOOL

Drawing from our interview findings, we designed Estrellita to consider the information needs for both families and clinicians. In particular, two prominent themes in Estrellita's design are: 1) monitoring the right kinds of data for preterm infants, and 2) encouraging consistent and longitudinal data monitoring by parents caring for preterm infants.

A. Monitoring a Flexible, But Focused Set of Data Types

As previously mentioned, many preterm infants must juggle an overwhelming number of specialists and pediatric hospital visits. In addition, poor appointment attendance rates are correlated with higher risks of developmental complications in preterm infants [17]. Estrellita provides several features to help with appointment management, including reminders and opportunities for reflection to encourage parents to attend appointments, get support when appointments are missed, and communicate with clinicians during the appointments.

Aside from appointments, Estrellita supports tracking of other data types as well. Because each infant is unique and may require particular information to be collected, infant wellness applications should support a variety of data and information types. But because we have seen that some parents may end up tracking too much information, Estrellita focuses on a limited set of health data, which represents a sampling of what is most important to both parents and healthcare professional. Specifically, Estrellita supports four classes of health data: clinically relevant pediatric health data (such as weight and diapers), parental indicators of wellbeing (such as parental mental health and wellbeing), pragmatic care information (such as appointment attendance), and custom information (such as tracking feedings or medicine dosages).

B. Encouraging Consistent and Longitudinal Data Tracking

Because parents can be inconsistent in tracking data and often record information only when they sense that there might be a problem with their infant's health or just before an appointment, the window of relevant health data may be much wider than the period of actual recording. Thus, Estrellita is designed to encourage parents to track health data regularly and consistently. For health indicators like diaper counts and bonding activities, Estrellita provides daily reminders for parents to input data. Reminders are provided explicitly, ambiently (using a dynamically updated widget placed on the phone's home screen), and subtly.

Just as Estrellita provides cues to encourage routine data capture, it also aims to reduce problematic over-recording and fixation on health data. Thus, for data elements likely to raise false alarms, such as infant weight and some measures of parental mental health, Estrellita only allows parents to enter data weekly or monthly. This rate of data capture is sufficient to inform clinicians of important trends over time (i.e., weight gains/loss), without unnecessarily overwhelming the parent with natural day-to-day fluctuations.

These reminders work together to encourage a "healthy" monitoring routine for parents that balances the need to record important health information with the need to limit the potential for parents to become overly concerned with tracking too much data, or tracking the data too frequently.

VI.   EVALUATION PLAN FOR ESTRELLITA

In this paper, we described our two-part design process including both interviews and participatory design exercises. The findings from our design process resulted in actionable design guidelines that, in turn, formed the basis for the design of Estrellita, a mobile health informatics tool for preterm infants and their caregivers. Our next step, which is currently underway, is to evaluate Estrellita in use.

In this deployment study, we are working to compare outcomes for infants and their mothers after four months of system use with outcomes for those receiving standard care. We recruited eligible parents and infants prior to or shortly after their discharge from the NICU. Inclusion criteria require the infants to be born between 23 and 32 weeks gestational age, singleton or twin babies, and from English-speaking families. After consenting the parents, we randomly assigned the participants to one of two conditions. Our study follows a two-group between-subjects design, comparing parents and babies who receive standard care (i.e., the control group) with parents and babies who receive standard care plus the Estrellita mobile health too (i.e., the intervention group). For our purposes, we define "standard care" as including a referral to regional HRIF program, which includes an appointment for an assessment at six months adjusted age, a phone reminder to attend the follow-up appointment, and an evaluation of the infant's cognitive, language, and motor development.

Parents in the intervention group were given a mobile phone with the Estrellita application pre-installed on the phone at around two months adjusted age. We chose this timing based on advice of the regional healthcare partners on our design team who noted that the first months are often very stressful for parents. As our study involves experimental technology, we did not want to unduly overtax our participants and, thus, decided to wait until to introduce Estrellita two months into the parent's care for their preterm infant.

At the end of the study, we are conducting surveys and semi-structured interviews to unpack the kinds of caregiving burdens that are experienced by parents of preterm infants. Our intention is to assess Estrellita according to several dimensions. In particular, we are interested in determining whether and how using a mobile wellness tool can lead to:

- Better infant health and wellbeing, as assessed both by the Bayley Scales of Infant and Toddler Development and through our semi-structured interviews with parents.

- Reduced stress and increased confidence, as measured by the Parenting Stress Index (PSI) at the end of the study and the Perceived Stress Scale monthly.

- Increased parental engagement and involvement, as measured by a revised form of the Patient Activation Measure, designed for parents of preterm infants.

- A positive correlation between parental wellbeing and parental participation in bonding with their infant, measured through our interviews with parents.

In addition, because we are using a repeated measures design over multiple months, we are also interested in evaluating the feasibility of using a mobile tool to track infant wellness over extended periods. Thus, we will probe parents for their assessment of using Estrellita and determine what, if any, are the technical challenges of using a mobile health tool for multiple months and how parents integrated data monitoring into their caregiving routines. We will also evaluate how the mobile tool can help bridge wellness information tracking concerns between parents and clinicians by also conducting semi-structured with healthcare professionals who will interact with the Estrellita data.

VII. CONCLUSION

In this paper, we have presented the results of a qualitative design study to understand the needs of families and their professional caregivers. These results reveal diverse challenges facing parents and clinicians attempting to document, understand, and share infant health data that must be balanced in any pervasive health solution. In particular, parents described struggling with when to collect data, while clinicians reported being more concerned about what and how parents track infant health. Based on these results, we present design implications for applications that cater to infant wellbeing and describe how we addressed those concerns into the design of Estrellita, a mobile health tool to support caregivers of preterm infant. Our hope is that Estrellita can serve as an effective wellness intervention tool that can help monitor, maintain, and guide parents in how to care for preterm infants, who often have many more challenging health needs when compared to full-term infants. We plan to study further probe these design goals in a longitudinal study that is currently underway.

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