Addressing the Design Challenges for a Clinically-Informed Data Capture Tool Targeted for Caregivers of Premature Infants

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Abstract

Following discharge from the hospital, substantial challenges await parents of preterm infants. In this work, we focused on the development of novel capture and access technologies that enable improved record-keeping by parents and sharing of collected data with healthcare providers. Based on semi-structured interviews with 18 parents and 11 providers, we designed a system, called Estrellita, to support parents in the recording and monitoring of the following indicators: weight, appointments, diapering, bonding activities, baby moods, and parental mental health. An evaluation of the clinical impact of using Estrellita is currently underway.

Introduction

Recent advances in perinatal and neonatal care have resulted in increased survival of low birth weight and critically ill infants[3, 15]. Although infants with prematurity and other birth complications have lower mortality rates, the impact upon future child development is unclear. Not only may long term management of ongoing complications be necessary, but some developmental concerns may take time to emerge[21]. Low birth weight infants are at risk for delays in cognitive, language, motor, and sensory processing skills, as well as other health issues[4, 17]. Previous research also suggests that parental health and well-being can significantly impact on infants' health and well-being.

Following discharge from the hospital, substantial challenges await parents, including the burden and stress of caring for their children, the additional effort of documenting infant progress, and confusion and difficulties in communicating with clinicians, friends and family about their children. Research supports regular developmental monitoring to provide early identification of developmental delay and consequently early intervention as a way to minimize the long-term effects of developmental delay[4, 17, 21]. Advances in computing technology and the popularity of smartphones have made it feasible to conduct remote monitoring that can lead to early identification of problems. In this work, we focused on the development of novel capture and access technologies[1] that enable improved record-keeping in terms of both the burden of collecting records by parents and clinicians, and the reliability and accuracy of collected data. We also developed visualizations to support the understanding of these interventions for both parents and clinicians. In this paper, we describe a formative study of the needs of both parents of and providers to preterm infants and the design of a mobile capture and access system, Estrellita, emerging from our findings. We close with a brief discussion of our current work in evaluating the health and behavioral impacts of this system.

Related Work: Past Intervention Programs and Technological Solutions

Capture and access technologies have been used in research and in commercial products to help parents record data about their infants, after they have been discharged from the hospitals. The majority of these commercial applications (e.g. Trixie Tracker[18], Baby Insights[2]) typically focus on helping parents to track health information like the infants' feeding times, diaper changes, and sleep schedules. However, many of these systems tend to favor an overly flexible design whereby parents can track almost anything. In our work, we have found that this approach can be burdensome and overwhelming for parents, particularly when caring for premature infants.

Kientz *et al.* developed BabySteps[10], a system for monitoring developmental milestones in children with the aim of providing earlier diagnoses for conditions such as autism. They found that parents were willing and able to record information about their children's progress, particularly when sufficiently motivated through the creation of personal artifacts like photo albums. Our work differs from BabySteps in that our system, Estrellita, captures a different set of infant-related health information and is mainly targeted at data capturing via mobile devices. In addition, we are interested in tracking both parental and infant health information, as we intend to show that such record-keeping can potentially lead to better developmental outcomes for premature infants.

Preliminary Work and Research Methods

This work builds on a study of parent use of smartphones during a three-week exercise intervention[9]. Ten caregivers were trained to perform an assisted exercise intervention with their newly discharged preterm infants at home. Half of the participants used a smartphone application, FitBaby, to log their adherence to the intervention and to

communicate concerns with clinicians and the research team. The other half logged their activities using paper-based forms. The research team found that the accuracy and regularity of the records improved in the phone condition. However, the study also raised many concerns. In particular, the phones did not become a part of their daily lives, and both parents and clinicians requested greater visualization and feedback on the data being collected.

To follow up, we conducted a study to uncover the issues most important to both parents and clinicians. Over the course of several months, we conducted semi-structured interviews with 29 participants in Southern California. These individuals included 18 caregivers with primary responsibility for caring for a preterm or high-risk infant (17 mothers and one aunt). Interview questions included concerns about caring for their infants, their strategies for preparing for the birth and discharge from the hospital, quality of communication with various providers, strategies for getting help or finding information when needed, and considerations for the design of technologies to support their needs. Interviews lasted approximately an hour and were audio-recorded and transcribed. We also interviewed 11 providers: pediatricians, nurses, psychologists, social workers, and case managers. Providers were interviewed in groups when possible to support varied discussion. Interview topics included their perceptions of what parents are most concerned about, how to integrate data collection and sharing into the clinical workflow, and any other concerns the professionals had while caring for these infants and their families. Interviews were recorded and transcribed when permitted (n=8), and notes were taken for analysis.

In this paper, we focus on the data collection and visualization aspects of the considerations that emerged from this work. Four researchers analyzed the transcripts looking for data elements that can and should be collected, meeting regularly to discuss and categorize those data elements that should be included in a data-capture system. We also invited two providers to join the design team in developing the final application, and they began to attend the regular meetings and provide input on which data to collect and how.

Estrellita: A Mobile System to Support Recording Infant and Caregiver Data

This research seeks to support parents in two goals: (1) to record, communicate, and understand data collected about their infants on a frequent basis and (2) to improve parent and clinician feelings of efficacy as well as quality of care. In this section, we detail the specific health indicators in need of documentation that emerged from our preliminary work and interview study. We also outline both design recommendations for collecting these data as well as the specific design choices present in our application, Estrellita (Fig 1), to support these needs. Estrellita is a combination of a mobile application for parents and a secure web-based application for providers. The smartphone platform allows for mobility, flexibility, and one-handed operation, while the web-based platform allows for viewing of data at multiple levels of granularity and supporting multiple patients at once. Both designs emphasize reflection over input, with both parents and providers viewing summaries of data before reaching data entry screens. The mobile application also includes persuasive elements to encourage parents in healthy behaviors and activities.

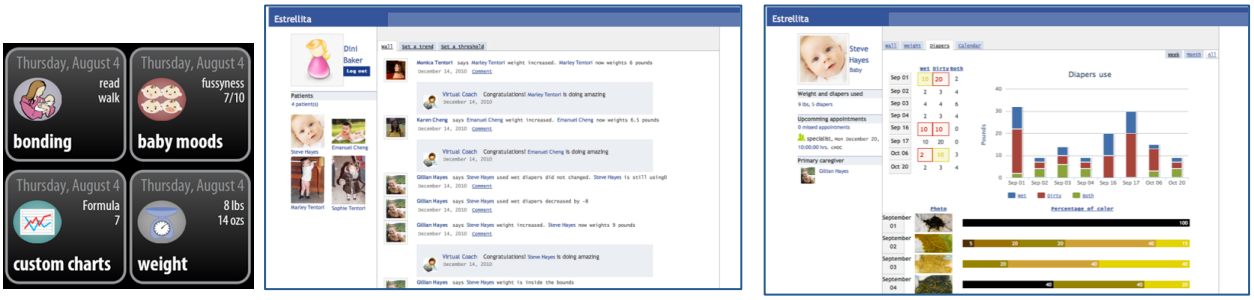

Figure 1. (left) Overview screen for the Estrellita mobile application; **(middle, right)** Estrellita website screenshots

Weight: Healthcare professionals interviewed all indicated that weight has a strong correlation to the baby's health and, in particular, they would be concerned if even a week passed without the baby gaining weight. However, many clinicians also raised concerns about parents dwelling too much on day-to-day weight fluctuations. Thus, systems designed to support collection of weight data for preterm infants must provide guidance around the appropriate frequency of such data collection as well as visualizations that help smooth or hide the kind of daily fluctuations that might cause unnecessary concern. Estrellita prompts parents to record weight data once per week and will not allow more frequent input of this element than that. When parents record these data, they are also required to take a picture of the infant on the scale. Thus, if major fluctuations are seen, a provider can review these images to ensure the

infant was being weighed in a consistent manner and talk parents through any problems in the data collection. Both parents and providers can view simple line graphs showing the weight over time as well as zoom in on specific details, such as time of day of the entry. Any drop in weight will trigger an alert encouraging parents to contact their infant's pediatrician. Registered providers, such as a pediatrician, can also request to receive these alerts.

Appointments: Many preterm infants have frequent and sometimes repeated visits to multiple specialists. The sheer number of appointments can be overwhelming to parents, as well as the onerous task of tracking the different doctors and service organizations. Preterm infants can experience adverse effects from poor appointment attendance rates. Unknown to many parents, there are resources available, under specific circumstances, to aid parents in taking their preterm infants to appointments. For example, high-risk infant follow up programs sometimes have limited funds to help with transportation to appointments. Thus, any system designed to support appointment attendance should not only remind parents about upcoming appointments but also query them prior to the appointment about any barriers to attendance – enabling referral to social service organizations that can help with some of the barriers. In Estrellita, parents can add new appointments (Figure 2), which are then stored in both the Estrellita application and the phone's built in calendar system. Parents can also add notes to the appointments (*e.g.,* questions they want to ask a provider during the appointment). Estrellita queries the parents two days prior to the appointment about their likelihood of attendance and any issues that could be addressed by a case manager who is monitoring system input. Finally, because parents are often the only communication between the infant's healthcare providers, the system should give parents an opportunity to document experiences for easy recall later. The notes field in Estrellita allows parents to record advice or recommendations from the appointment with a provider (Figure 2).

Diapering: Even more than feeding schedules, diapering can be a strong indicator of infant health. In fact, even in healthy babies, soiling a diaper is a prerequisite for leaving the hospital after birth. Healthcare professionals ask parents to track diapers because of its strong correlation with the baby's digestive health. Pediatricians in our study reported that many unnecessary calls they receive from concerned parents center around the contents and frequency of defecation. Thus, any system designed to monitor infant digestive health and to support parents must not only allow parents to record the number of dirty and wet diapers but also to take pictures of any diapers that are of concern (Figure 2). In this way, a physician or nurse can quickly examine the diaper contents and determine whether an additional follow-up call or visit should be made. Likewise, for non-urgent concerns, parents can reference these images during a well-baby visit, specialist appointment, and so on.

Bonding and Developmental Activities: Parents often leave the NICU deeply concerned over the medical fragility of their infants, even when those infants do not have substantial complications beyond their low birth weight. Thus, parents of premature infants can neglect bonding activities in favor of addressing the medical needs of the baby or find it challenging to bond and play with their children in the same way they may have done with full-term children. Daily activities designed to support infant development and parental bonding may have a positive impact on the health and development of these infants as well as the emotional wellbeing of their parents. Thus, any system for this population must encourage activities that can improve parent-infant bonding and reward parents for doing these tasks. Based on the input of the providers in our study, in Estrellita, we encourage parents to conduct five such activities: reading, singing, and talking to their infants, as well as taking them for walks outside and doing "tummy time" with the babies. Each day, parents can log simply whether they did any of these activities, and as they check off these items, the icons representing them turn from black and white to color on the widget on the home screen of their phones. If parents log no activities for a day, then at the end of that day, they are prompted to record data about them. Finally, messages of encouragement are presented periodically on the home screen to praise parents (Fig 2).

Baby Moods: New parents often realize that something is wrong with their baby, but do not know precisely what the problem is or what they should be recording about the incident. In these cases, parents sometimes reference how "fussy" their baby is as an indicator of when there might be important health concerns to pay attention to. Although this symptom is qualitative and subjective, it can still be an important clinical indicator of a pattern that could be problematic. Thus, systems should support a general indicator of infant wellbeing, such as fussyness. Estrellita accomplishes this goal through use of the "fussy-o-meter," a simple 10 point scale visualized as a speedometer. Parents can choose their infants fussiness rating and also add any additional notes to explain what they think might be occurring. Both parents and providers can then view graphs by day (showing average ratings per hour), week (showing days), or month (showing weeks) to attempt to uncover any patterns in the data.

Parental Mental Health: Post-partum depression can impact infant development[8] and may be as high as 40% among mothers of premature infants[20]. In addition, high levels of parental stress are correlated with maladaptive parent-infant interactions[13, 14], lowered cognitive resilience of infants[19], and increased stress among children as they grow[7].

Thus, systems should support collection of validated clinical information on stress and post-partum depression. In the case of Estrellita, parents are encouraged to take short surveys on their devices once per month to assess their perceived stress[5] and post-partum depression[6]. Problematic scores are flagged on the provider's interface to allow case managers to make referrals for parental mental health care. Although these scales are useful for clinicians to assess risk for severe problems, they are less useful as tools for parents to reflect on their own patterns. Thus, systems should also incorporate some way to encourage parents, in particular mothers at risk for post-partum depression, to reflect on their own stress, anxiety, and depression levels. In Estrellita, the Mood Map[12] provides an opportunity for parents to record and reflect on their own moods. The tool is a visual representation of the circumplex model of emotions, which plots most major emotions on two dimensions of high/low arousal and positive/ negative affect[16]. Preliminary work with this tool has shown utility in helping people to reflect on their own emotions and take steps to improve their emotional state. Additionally, messages of support and education around stress and depression are delivered periodically via the Estrellita application and, similar to the bonding activities, displayed on both the home screen widget and in the parent inbox.

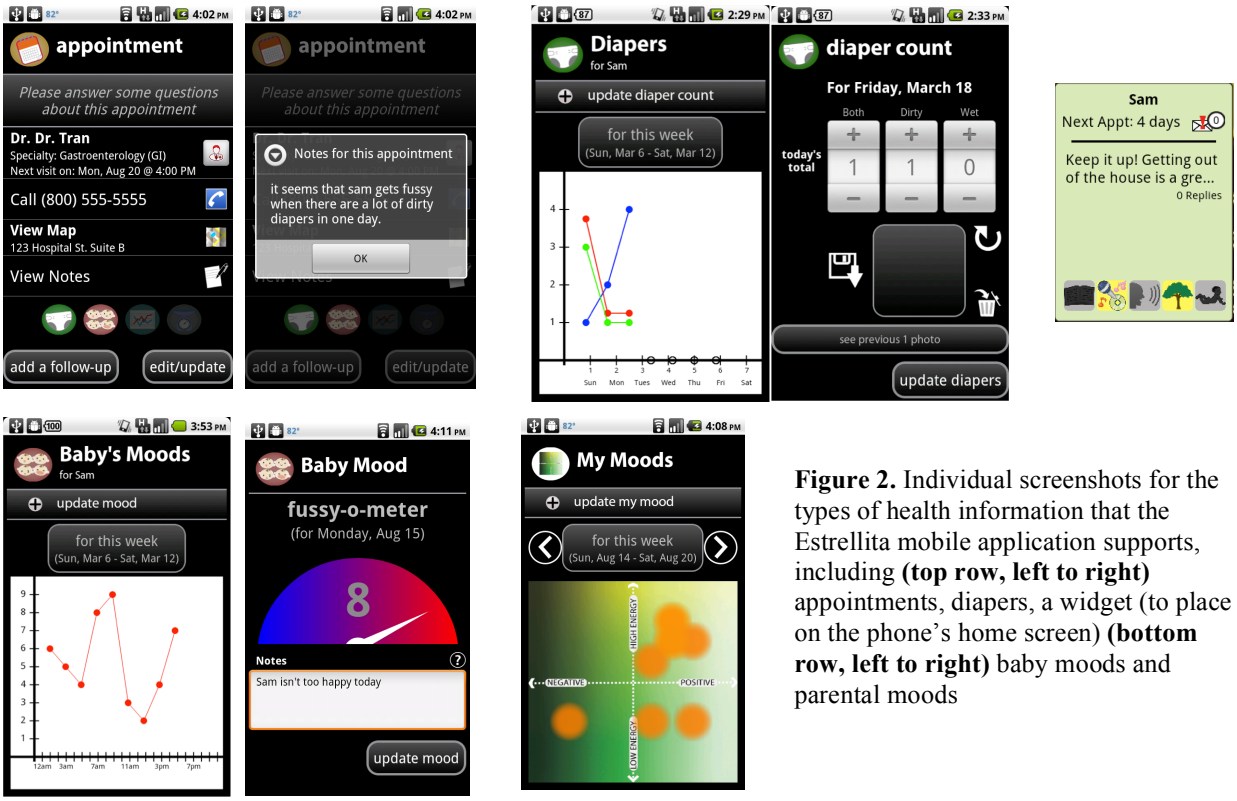

Figure 2. Individual screenshots for the types of health information that the Estrellita mobile application supports, including **(top row, left to right)** appointments, diapers, a widget (to place on the phone's home screen) **(bottom row, left to right)** baby moods and parental moods

Conclusions and Future Work: Evaluating Estrellita

We are currently conducting a randomized control trial to evaluate the feasibility and impact of using Estrellita in the home and in the clinical setting. Half of the parents will receive a smartphone plus Estrellita; the other half of the parents will receive standard care, that is, no phone and no software. We will use open-ended and structured interviews and clinical evaluations to assess parent activation (motivation and self-efficacy to advocate for the children's health), bonding with children, and infants' developmental indicators. Interviews will occur two, four, and six months after discharge from the Neonatal Intensive Care Unit. We expect that parents who use the Estrellita application will report higher activation and bonding with children than parents who receive standard care. We also expect small improvements in the developmental indicators among infants whose parents used Estrellita. We will also examine the provider workflow surrounding the use of Estrellita data. When all of the indicators are "normal," no action is required. When problems can be detected, however, providers will take action based on these data as described throughout the previous section. This study will reveal valuable information about the benefits and challenges of using mobile technology to support parents of preterm infants, enhance parent-healthcare provider relationships, and ultimately improve preterm infants' medical and developmental outcomes.

Chronic conditions in childhood raise unique concerns over the lifetime. Premature infancy, while a challenge and burden in itself, also correlates to many chronic pediatric illnesses and developmental disabilities, warranting additional monitoring and care. However, current practices and tools do not well support the stressed and anxious parents of preterm infants nor their large and dynamic network of providers. Additionally, collection of data with currently available tools does not afford examination on both a personal, short-term level as well as long-term and population-based analysis. As clinics are increasingly not the primary site of care for these and other pediatric patients, home-appropriate record-keeping and support tools must be developed. Based on preliminary work with a different mobile tool and an interview study over several months, we have developed Estrellita, a combination mobile and web-based application to support premature infants and their caregivers. We are currently evaluating the impact of this system. In the future, we hope to expand on this work through both a larger trial and a longitudinal study to examine the potential for impacts on these children as they grow and develop over years or even decades.

References

1. Abowd, G.D., and Mynatt, E.D. (2000). Charting Past, Present, and Future Research in Ubiquitous Computing. *ACM Trans. Comput.-Hum. Interact.,* 7(1): 29-59.
2. Babble Soft. Baby Insights. Retrieved August 15, 2011, from http://www.babblesoft.com/managerwebmobile.php
3. Callanan, C., Doyle, L., Rickards, A., Kelly, E., Ford, G., and Davis, N. (2001). Children Followed with Difficulty: How Do They Differ? *Journal of Pediatric Child Health,* 37: 152-156.
4. Campbell, M.K., Halinda, E., Carlyle, M.J., Fox, A.M., Turner, L.A., and Chance, G.W. (1993). Factors Predictive of Follow-up Clinic Attendance and Developmental Outcome in a Regional Cohort of Very Low Birth Weight Infants. *Am. J. Epidemiol,* 138(9): 704-713.
5. Cohen, S., Kamarck, T., and Mermelstein, R. (1983). A Global Measure of Perceived Stress. *Journal of health and social behavior* 24(4): 385-396.
6. Cox, J.L., Holden, J.M., and Sagovsky, R. (1987). Detection of Postnatal Depression. Development of the 10-Item Edinburgh Postnatal Depression Scale. *British Journal of Psychiatry,* 150: 782-786.
7. Essex, M.J., Klein, M.H., Cho, E., and Kalin, N.H. (2002). Maternal Stress Beginning in Infancy May Sensitize Children to Later Stress Exposure: Effects on Cortisol and Behavior. *Biological Psychiatry,* 52(8): 776-784.
8. Grace, S.L., Evindar, A., and Stewart, D.E. (2003). The Effect of Postpartum Depression on Child Cognitive Development and Behavior: A Review and Critical Analysis of the Literature. *Archives of Women's Mental Health,* 6(4): 263-274.
9. Hayes, G.R., Patterson, D.J., Singh, M., Gravem, D., Rich, J., and Cooper, D. (2011). Supporting the Transition from Hospital to Home for Premature Infants Using
10. Integrated Mobile Computing and Sensor Support. *Personal and Ubiquitous Computing,* In press.
11. Kientz, J.A., Arriaga, R.I., Chetty, M., Hayes, G.R., Richardson, J., Patel, S.N., et al. (2007). Grow and Know: Understanding Record-Keeping Needs for Tracking the Development of Young Children. In *SIGCHI conference on Human factors in computing systems (CHI '07)*, ACM, 1351-1360.
12. Liu, L.S., Hirano, S.H., Tentori, M., Cheng, K.G., George, S., Park, S.Y., et al. (2011). Improving Communication and Social Support for Caregivers of High-Risk Infants through Mobile Technologies. In *ACM Conference on Computer supported cooperative work (CSCW '11)*, ACM, 475-484.
13. Morris, M.E., Kathawala, Q., Leen, T.K., Gorenstein, E.E., Guilak, F., Labhard, M., et al. (2010). Mobile Therapy: Case Study Evaluations of a Cell Phone Application for Emotional Self-Awareness. *Journal of Medical Internet Research,* 12(2).
14. Muller-Nix, C., Forcada-Guex, M., Pierrehumbert, B., Jaunin, L., Borghini, A., and Ansermet, F. (2004). Prematurity, Maternal Stress and Mother-Child Interactions. *Early Human Development,* 79(2): 145-158.
15. Pianta, R., and Egeland, B. (1990). Life Stress and Parenting Outcomes in a Disadvantaged Sample: Results of the Mother-Child Interaction Project. *Journal of Clinical Child & Adolescent Psychology,* 19(4): 329-336.
16. Roberts, G., Howard, K., Spittle, A., Brown, N., Anderson, P., and Doyle, L. (2008). Rates of Early Intervention Services in Very Preterm Children with Developmental Disabilities at Age 2 Years. *Journal of Pediatric Child Health* 44: 276-280.
17. Russell, J. (1980). A Circumplex Model of Affect. *Journal of Personality and Social Psychology,* 39(6): 1161-1178.
18. Slater, M.A., Naqvi, M., Andrew, L., and Haynes, K. (1987). Neurodevelopment of Monitored Versus Nonmonitored Very Low Birth Weight Infants: The Importance of Family Influences. *J Dev Behav Pediatr,* 8(5): 278-285.
19. Trixie Tracker. Baby Tracker for Iphone, Android and Web. Retrieved August 15, 2011, from http://www.trixietracker.com/
20. Tu, M., Grunau, R., Petrie-Thomas, J., Haley, D., Weinberg, J., and Whitfield, M. (2007). Maternal Stress and Behavior Modulate Relationships between Neonatal Stress, Attention, and Basal Cortisol at 8 Months in Preterm Infants. *Developmental Psychobiology,* 49(2): 150-164.
21. Vigod, S., Villegas, L., Dennis, C.L., and Ross, L. (2010). Prevalence and Risk Factors for Postpartum Depression among Women with Preterm and Low-Birth-Weight Infants: A Systematic Review. *BJOG: An International Journal of Obstetrics & Gynaecology,* 117(5).
22. Winrow, A.P. (2007). Growing Up: The Future for Neonatal Unit Graduates. *Infant,* 8: 234-237.