

The Estrellita System

A Health Informatics Tool to Support Caregivers of Preterm Infants

Sen H. Hirano, Karen P. Tang, Karen G. Cheng, Gillian R. Hayes

Donald Bren School of Information and Computer Sciences

University of California, Irvine

{shirano, kptang, gillianrh}@ics.uci.edu, kgcheng@uci.edu

Abstract—Preterm infants have significantly higher rates of functional limitations and are at risk for delays in cognitive, motor, and other skills. In this demo, we describe a health informatics system we developed to support caregivers of preterm infants. In this demo, we present Estrellita, a system to support caregivers of preterm infants. This system is comprised of a mobile application for parents and a web portal for clinicians. Estrellita supports more efficient tracking and communication among stakeholders and balances the sometimes-competing needs of parents, clinicians, and other healthcare professionals.

Keywords—preterm infants, prematurity, health informatics, capture and access, clinicians, pediatric informatics, mobile devices

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 have 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]. Parents are often tasked with adopting a long-term management plan to care for initial medical complications as well as ongoing developmental concerns. Furthermore, during the transition from the hospital to the home, substantial challenges await parents, including the burden and stress of caring for a preterm infant, the additional effort of documenting the infant’s progress, and the confusion and difficulties in communicating with clinicians, friends, and family about their child [4].

Past work in neonatal care has shown that regular monitoring can provide early identification of developmental delay. Early intervention and rehabilitation can minimize the long-term effects of developmental delay [3, 5]. Typically, such monitoring is done by state-funded high-risk infant follow-up (HRIF) programs, through which healthcare professionals see preterm infants approximately every six months. Between appointments, however, clinicians have limited visibility into the health of the infants. Recent advances in smartphones enables mobile devices to be integrated into the caregiver experience at a low cost. Using mobile phone as a health informatics tools can lead to early identification of potential developmental problems in a cost-effective and efficient manner.

We developed Estrellita to augment in-person HRIF visits through sharing of infant health data via mobile devices and an online web portal. Gathering and responding to health data more

quickly can reduce parental stress while increasing feelings of self-efficacy and ultimately improving health outcomes for the child. In this demo, we present Estrellita, a system to support caregivers of preterm infants. The demo will provide opportunities for user to get a better sense of: (1) the persuasive elements used in the mobile application, and (2) the types of web interfaces that clinicians would need in order to understand patient data that has been entered via the mobile application. The lessons learned in the design of our system can help inform other types of pervasive health applications and in particular those that support tracking of infant and parental health data in a clinically meaningful way.

II. SYSTEM DESCRIPTION

Estrellita consists of two parts. The first component is an Android application (Fig. 1). Parents use this application to enter data that is then stored in an internal SQLite database and is continually synchronized with a broker server in near real-time. The broker server is responsible for satisfying both data requests and submissions, and utilizes a MySQL database along with web API calls for Microsoft HealthVault. The second component in Estrellita is a web portal that patients and clinicians can use to view more detailed infant health data (Fig. 2). Clinicians that use the web portal also have extra patient management tools, including the ability to create and delegate custom alerts. The mobile application and the web portal, which will be shown on an HTC Desire Z and a web browser respectively, work together to provide the following key features.

A. Enable Parent-Clinician Communication & Coordination

Reminders and opportunities are included for reflection in order to encourage parents to attend appointments, get support when appointments are missed, and communicate with clinicians during appointments. In addition to showing these charts, professionals are given extra tools so that they can manage and delegate information. Clinicians are given an extra set of features to create rules that can alert them when patients have particularly concerning data, enabling clinicians to intervene earlier.. These rules can also be configured to trigger messages to be sent by a “virtual coach” to offer support for parents and provide messages of encouragement and advice.

B. Support Many Data Types, Require Only a Few

Estrellita focuses on health data that are most salient for clinicians to assess an infant’s health. By limiting the types of data that Estrellita supports, we help prevent parents feel less

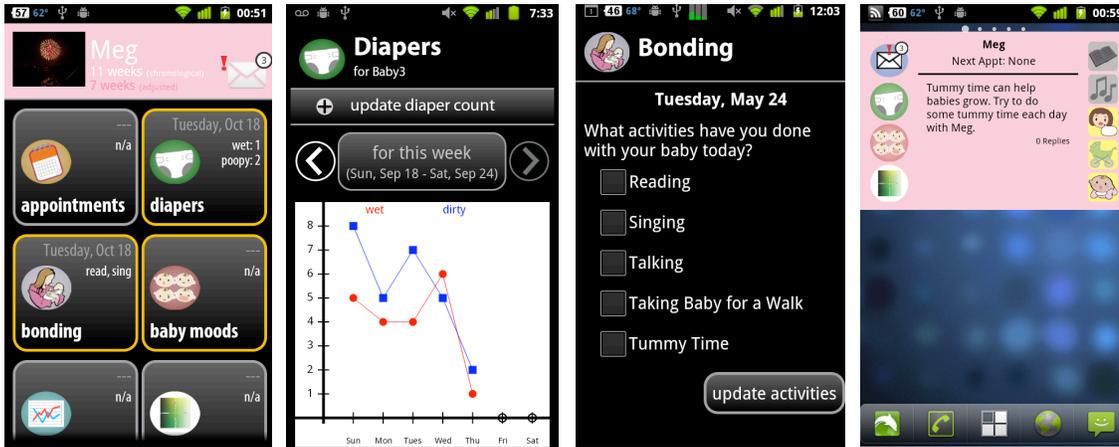


Figure 1. Estrellita screenshots, from left to right: (a) the main screen showing a summary of all of the data captured by the parent, (b) the overview visualization for the diaper counts, (c) the form to record bonding activities, and (d) the Estrellita widget placed on the Android home screen.

overwhelmed by what, when, and how they should be collecting data. The four classes of health data that Estrellita supports are: objective measures of infant health (i.e., weight, diapers, and attendance at appointments), subjective measures of infant health (i.e., fussiness), parental indicators of well-being (i.e., post-partum depression, stress levels, and a subjective mood indicator), and custom information that parents choose to track (e.g., types of medicine an infant takes).

C. Encourage Consistent Data Capturing Routines

Parents are encouraged to track health data in a consistent manner. For health indicators like diaper counts and bonding activities, Estrellita provides daily reminders for parents to input the data. Reminders are provided explicitly (using tactile and audio alerts every evening), ambiently (using a dynamically updated widget placed on the phone's home screen), and subtly (using simple visual cues on the application's launching screen). Just as Estrellita provides cues to encourage routine data capture, it also aims to reduce problematic over-recording and fixation on health data. For example, Estrellita only allows parents to report the infant's weight once a week. If parents try to record the baby's weight more often, the system prevents them from doing so and informs them of the next available date that they can update.

For other types of data capturing (e.g., bonding, parental well-being), Estrellita enforces a more frequent recording routine.

Based on feedback from parents and clinicians, we observed that parents were not at risk for over-reporting bonding and parental data. Thus, Estrellita proactively encourages parents to regularly record these types of data to facilitate more consistent data capture through persuasive features like home screen status elements, regular reminders, and automated messages that provide information and remind parents to relax and bond with their children.

D. Provide Glanceable Reports, Opportunities for Reflection

To help facilitate the communication process between parents and clinicians, Estrellita provides easy-to-read charts that clearly show a historical view of health data that the parent has been tracking for their infant. The graphs can be shown on different time scales and individual data points are clickable so parents can show physicians any notes they may have attached to a previously recorded data point. Estrellita provides historical charts for both maternal and infant health data to give parents an opportunity to reflect on their data. To assist in that reflection, the shortcuts on Estrellita's main menu show the last entered data (Fig. 1a), and before parents can enter new data they are shown a historical graph for that data type (Fig. 1b).

III. ACKNOWLEDGEMENTS

This work is supported by the RWJF Project HealthDesign, NSF grant 0846063, and Google. We thank Monica Tentori and Leslie Liu for their efforts in early stages of this research.

REFERENCES

- [1] J.A. Martin, B.E. Hamilton, S.J. Ventura *et al.*, "Births: Final Data for 2009" *Nat'l Vital Statistics Reports*, vol. 60, no. 1, pp. 1-104, 2011.
- [2] M. Hack, H.G. Taylor, D. Drotar *et al.*, "Chronic Conditions, Functional Limitations, and Special Health Care Needs of School-aged Children Born With Extremely Low-Birth-Weight in the 1990s," *JAMA*, vol. 294, no. 3, pp. 318-325, 2005.
- [3] M.A. Slater, M. Naqvi, L. Andrew *et al.*, "Neurodevelopment of monitored versus nonmonitored very low birth weight infants: the importance of family influences," *J Dev Behav Pediatr*, vol. 8, no. 5, pp. 278-285, 1987.
- [4] L.S. Liu, S.H. Hirano, M. Tentori *et al.*, "Improving communication and social support for caregivers of high-risk infants through mobile technologies," in *CSCW '11*, 2011, pp. 475-484.
- [5] A.P. Winrow, "Growing up: The future for neonatal unit graduates," *Infant*, vol. 8, pp. 234-237, 2007.



Figure 2. A screenshot of the Estrellita web portal, primarily designed for clinicians and other healthcare professionals. This particular page shows details about an infant's diaper count, a graph of past diaper counts, and several system-generated color histograms for problematic diapers.