Estrellita: A Mobile Capture and Access Tool for the Support of Preterm Infants and Their Caregivers

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In this article, we describe the design process and principles used in the development of Estrellita, a tool to support parents of preterm infants to track health data. We tested Estrellita in the homes of seven families for 4 months while following seven additional families without Estrellita. The feedback from this trial, including in-depth interviews, surveys, and log analyses, sheds light on how parents can use a mobile data collection tool to enhance their problem-solving processes about their own health and that of their infants, as well as to share with others who support them in this care. In addition to presenting the design of a recording technology for preterm infants and its use in a real-life setting, the results of this research provide a deep understanding of how technology can and should be used to support home care of at-risk patients, in which data capture may be essential.

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1. BACKGROUND AND INTRODUCTION

Novel capture and access technologies can support the parents of infants who are at increased risk for delays in cognitive, language, motor, and sensory processing skills and other long-term health impairments [Campbell et al. 1993; Greenough 2008; Greer 2007; Marlow et al. 2005] due to being born very preterm (between 23 and 32 weeks' gestational age). In this article, we describe the design process and principles used in the development of a tool to support parents of high-risk infants born prematurely to track health data as well as the evaluation and resultant findings from use of the system.

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Using a mixed-method design and evaluation approach, we first established key design principles, which we then validated through the design, development, and ultimate deployment of the Estrellita system. We explored research questions, such as the manner in which families might react to, adopt, and integrate a mobile capture and access tool into their lives as well as how these types of technology might sensitively support data collection practices and caregiving approaches. We tested the use of Estrellita in the homes of seven families for 4 months while following seven additional families without Estrellita as a comparison group. The feedback from this user trial, including in-depth interviews, surveys, and analyses of software logs, sheds light on how parents can use a mobile data collection tool to enhance their problem-solving processes about their own health and that of their infants, as well as to share with others who support them in this care.

A major contribution of this work is the description of the design of a recording technology for preterm infants and its subsequent use in a real-life setting. This design and deployment case study provides a deep understanding of the ways that technology can and should be used to support home care of at-risk patients, in which data capture may be essential.

Deploying a research prototype in sensitive and high-risk settings requires intense cooperation from community members [Hayes 2011]. In our case, clinicians and parents[1] served as members of the team and worked alongside us in the design of both the technology itself and the research study to evaluate feasibility and efficacy. Our research team included a pediatric psychologist who works closely with families of high-risk infants (fifth author) and a nurse who specializes in the care of high-risk infants (sixth author).

These community partners helped shed light on issues related to health disparities for low-income women that leads them to deliver increased numbers of preterm births over their higher-income counterparts [Luo et al. 2006; Morgen et al. 2008; O'Campo et al. 2008]. Although our study did not explicitly target low-income women, the very tendency to deliver increased preterm infants noted in the literature made us particularly interested in ensuring that Estrellita was designed to be usable by them as well as by their higher-income counterparts. Additionally, community partner engagement with us made clear two additional goals beyond supporting the health of the infant: caring for the mother in parallel and supporting the transition from hospital to home.

In addition to the contributions of this solution to the fields of medical informatics and pediatric care, this sensitive domain problem results in an authentic setting in which to push on interesting issues of HCI research. Potentially straightforward and commonly considered issues, such as efficiency, usability, and utility, must be reconsidered in light of multiple stakeholders who may be emotionally and physically fragile. Likewise, parenting and healthcare are two hot-button political and moral concerns, making all design in this space heavily value laden. Simultaneously, we must explore such touchstone issues as surveillance, privacy and control of data, and the empowerment of users to make decisions for and about themselves and those in their charge.

In the remainder of this article, we first describe the research that is most closely related to our work, including both pediatric informatics tools and mobile health tools for supporting healthy behaviors. We then describe the Estrellita design process and outcomes of that process, namely, the prototype Estrellita system. Following this description, we lay out the methods by which we evaluated Estrellita and the outcomes

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[1] In the vast majority of cases in this work and other pediatric technologies we have studied, mothers are the primary caregivers and users of this technology. We did, however, include fathers as well as other family members who act as parents when possible. Thus, we use the term "parents" throughout this article for ease of reading.

of that evaluation, concluding with reflection on the ways in which mobile tools can support not only the high-risk infant population and their caregivers but also others experiencing or at risk for chronic illness. This article contributes to the discussion around interactive technologies for health by examining the design, development, and deployment process end to end for a novel health informatics tool. Additionally, the context of this work raises particular concerns for design, including the ways in which tools can be designed with multiple caregivers and "patients" in mind as well as the ways in which issues such as flexibility and customization, patient empowerment, and the potential for risk and reward in system use come into play for tools in these sensitive domains.

2. RELATED WORK

The related work in mobile and ubiquitous computing tools to support health is vast and varied. This work particularly builds on the concept of pediatric informatics tools—particularly in consideration for how they might differ from other health technologies—and mobile health tools. We describe those research efforts most related to our own work in the next sections and draw from these and other publications throughout this article.

2.1. Pediatric Informatics Tools

Children possess unique physiology, come from a wide range of backgrounds, and experience diseases that are largely unique to their age range [Shiffman et al. 2001]. These factors make them particularly complex patients, with complex health information needs. Yet despite calls for pediatric-specific health tools [Shiffman et al. 2001], few studies have been published focusing on pediatric informatics (examples include Fiks et al. [2007], Johnson et al. [2005], Kientz et al. [2007], and Slagle et al. [2010]), and even less on the specific needs of preterm infants. In one project focusing on preterm infants, Gray et al. [2011] 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). 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 [Lee et al. 2011]; 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 [Jeong et al. 2008] and that families coping with children with chronic illnesses may struggle even more [Gallo et al. 1991]. Findings indicate that families who are educated about a condition and involved with the management of it can better cope [Deaves 1993; Whyte 1992]. Thus, researchers have begun to investigate the design of systems to support physiological [Jeong et al. 2008] and developmental [Kientz et al. 2007] health documentation in families. Using capture and access technologies [Abowd and Mynatt 2000], data can be automatically, semiautomatically, or manually recorded and made available for later review. Through the deployment of one such system, BabySteps, Kientz et al. [2007] found that parents were willing and able to record information about their children's progress. However, they required additional motivation to do so in the form of personal artifacts, such as creating photo albums.

Several commercial products exist to help parents record data about their infants. The majority of these commercial applications (e.g., Baby Connect,[2] Trixie Tracker,[3] and WhatToExpect.Com Baby Tracker[4]) support parents to track health information such as an infant's feeding times, diaper changes, and sleep schedules. However, these systems tend to favor an overly flexible design through which parents can track almost

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[2] http://www.baby-connect.com.

[3] http://www.trixietracker.com.

[4] http://www.whattoexpect.com/mobile/photo-gallery/baby-tracker-app-for-iphone.aspx#.

anything, including but not limited to nursing (which side, for how long, whether or not there was spit up), pumping, bottle feeds (how many ounces, whether served warm or cold, whether or not there was spit up), diapering, activities, milestones reached, solid foods offered and either consumed or refused, medicines, sleeping (including sleep location, duration, and other conditions), and so on. In our early interviews, we discovered that some parents found this approach burdensome and overwhelming, particularly when caring for preterm infants. Thus, in the design of Estrellita, as described later, we focused on a constrained set of indicators that are both clinically relevant and interesting to parents.

In summary, related research in pediatric informatics demonstrates that information tools are needed for this population. However, the information needs of parents, clinicians, and other caregivers of children are unique, as are the constraints to addressing those information needs. Additionally, the ways in which design is (or should be) influenced by the link between parental health and child health is underexplored.

2.2. Mobile Health Tools for Supporting Healthy Behavior

Beyond tools designed to support pediatric health, this project builds on the concept that mobile and ubiquitous computing can support a variety of healthy behaviors, particularly through collection of and reflection on data. These ideas have recently gained popularity as part of the growing quantified self [Swan 2009; Wolf et al. 2010] and personal informatics [Li et al. 2011] movements. Additionally, Klasnja and Pratt [2012] provide an in-depth overview of the space of mobile health tools.

Many mobile health research projects focus on helping people achieve healthy behaviors like becoming more physically active [Munson and Consolvo 2012], drinking water [Chiu et al. 2009], and sleeping well [Bauer et al. 2012]. The stage-based personal informatics (PI) model [Li et al. 2010] described the use of these tools as part of cycles of *collection-reflection-action*. For example, in Houston [Consolvo et al. 2006], the user reports step count (collection) on a nearly daily basis, and the act of looking at the leaderboard (reflection) and the subsequent decision to take more steps (action) can occur multiple times per day. These cycles look slightly different in other types of applications. In Baby Steps [Kientz et al. 2009], parents record specific developmental milestones as they occur (collection) and then review progress (reflection) prior to “well child” appointments as a way to have more evidence-driven discussions (action) about any potential health concerns for the child.

Understanding how to design technologies to influence behaviors meant to improve health outcomes in the “user” is a relatively well-trod area in HCI. However, influencing this individual to understand data about and make healthful choices for someone else is less explored. Of course, there are some corollaries to work focused on eldercare or other caregiving settings, but the unique relationship of children, who will one day grow to be adults and who are arguably increasing in independence and agency daily, leaves open interesting design and research questions. For example, these tools have tended to assume the data subject is the data collector or has actively relinquished rights and responsibilities to the data collector. In the case of children, however, the reverse is true. Someone collects data about them and one day they will gain the rights and responsibilities of these data. This work begins to probe at these issues, but infants are only a small subset of the children whose health may depend on the behaviors of their parents and their engagement with these technologies.

3. ESTRELLITA DESIGN

This work included substantial formative and cooperative design work as well as evaluation. Throughout this effort, we worked closely as a cross-disciplinary team of designers, researchers, and clinicians to include a variety of perspectives. In this section, we describe the design activities, in part described elsewhere [Tang et al. 2012], that build on our prior work [Liu et al. 2011; Hayes et al. 2011b], as well as the evaluation efforts reported here for the first time.

3.1. Iterative Cooperative Design

Previously, we explored the ways in which mobile and social technologies might be used to support caregivers of premature infants [Liu et al. 2011; Hayes et al. 2011b]. In that work, our research team conducted interviews with 29 participants living in Southern California including 18 caregivers (17 mothers, one aunt), who were of medium to low socioeconomic status, and 11 healthcare professionals. At the time of our study, all participants were caring for at least one preterm infant. Infants were eligible for the study if they were born between 23 and 34 weeks' gestational age and had been discharged from the NICU for at least 1 month (mean = 59 days).

Building on the results from this interview-based study, we identified the primary goals of collecting and sharing data related to the health and well-being of both the mother and the infant. This work's broad focus necessitated further formative explorations to develop the design principles used in the creation of Estrellita. Thus, we invited healthcare professionals to join our research team. These team members worked closely with us as part of a participatory design effort over the course of approximately a year. In an ideal situation, we would have included parents as well as clinicians in the design activities for a system that would have both as users. However, the burden of caring for a preterm infant precluded participation at this level by any of the interview participants. One clinical participant, however, was also a mother of a preterm infant several years prior to this work. During this time, we conducted 10 design sessions of 1 to 2 hours each with the clinical partners who had joined the design team. We additionally scheduled hour-long conference calls to discuss the research project every 2 weeks regardless of whether design sessions were taking place during that time period or not. Paper prototypes, both high and low fidelity, were useful in iterating quickly on the designs within the team as well as rapid iteration on Android prototype designs. Domain experts on the design team often sketched out new ideas on paper from scratch or provided feedback on the designs we produced.

3.2. Deployment with Healthy Infants

Although it would have been ideal to include parents fully on our design team as well, in practice, we found that the time commitment was prohibitive for parental involvement. We did, however, have three sets of parents of healthy newborn infants conduct pilot tests of Estrellita for 1 week at a time to provide feedback in parallel with our design activities. Parents were trained for 1 to 2 hours in a home visit at the beginning of the week during which they were also provided the phone, scale, and software, all to be used together to log infant and maternal data. They were monitored throughout the week by the clinical and research teams as though in a full-scale evaluation and received messaging both automatically from the "virtual coach" and manually from clinical staff. At the end of the week, every pilot participant was interviewed by a researcher in the home, and the phone and scale were retrieved. Interviews were semistructured in nature but focused largely on the parents' experiences with recording data and using the application and the hardware, and their responses to the suggestions being made by the application. Interviews were recorded and transcribed, with these data analyzed alongside the design activities and formative empirical data. In particular, we made use of their feedback to conduct usability walkthroughs of our system, imagining the usage described and observed by these parents as we did. Additionally, as parents uncovered challenges with the devices or errors were logged through use, we adapted the design and implementation of Estrellita.

4. ESTRELLITA: DESIGN AND DEVELOPMENT

Using the results from our mixed method formative evaluations [Liu et al. 2011; Hayes et al. 2011b; Tang et al. 2012] and participatory design work, we developed key design principles specific to the creation of a system to support the care of preterm infants at home. In this section, we distill those principles to three main points and describe the ways in which our solution addresses them.

4.1. Support Flexibility and Clinical Adherence in Data Collection

Clinicians often report being concerned that parents do not know what health information they should be tracking, and as a result, they record the "wrong" health data, "too much" health data, or simply none at all [Hayes et al. 2011b; Kientz et al. 2009; Lee et al. 2011; Liu et al. 2011]. At the same time, parents struggle to record data when they do not see the benefit of doing so, not unlike other groupware situations [Grudin 1994]. To alleviate this tension, Estrellita seeks a compromise for families and clinicians by requiring parents to record only a handful of indicators that are most clinically important and allowing them to record other information and track their data on a fairly flexible schedule, supported by reminders. Certainly, the use of automatically collected data would be a solution to the challenges of parents recording data accurately and consistently [Hayes et al. 2011b]. However, at the time of this work, such approaches were not yet feasible to implement safely and reliably in the homes of families with young children and medically fragile infants. Instead, Estrellita supports four classes of health data: clinically relevant pediatric health data, parental indicators of well-being, pragmatic care information, and custom information.

Specifically, Estrellita enables tracking of two clinically relevant health indicators for infants—weight and diapers—due to the increased concern over slow weight gain and gastrointestinal infections with this population [Blackburm 1995; Neu 2007]. Estrellita bridges the gap between parental interest in food intake and clinical interest in output by allowing parents to set up custom feeding records if they choose, but focusing on encouraging them to record the kinds of information that will be requested at a clinical visit.

> I might have wanted to track . . . how many ounces they ate. I mean, I don't personally want to know just because he eats too much as it is, no I'm just kidding (laughing) but I could see . . . I guess that's kind of the purpose of the weight though, in a way. Obviously if they're eating, they're going to gain weight.
> – Healthy Baby Pilot Participant J

Beyond helping parents to understand weight as a more important clinical indicator than food intake, Estrellita also helps parents to understand how weight should be interpreted. For example, parents are only allowed by the system to enter weight weekly and are encouraged by the system not to monitor it more closely. It is normal for an infant's weight to vary day to day, and overemphasis on weight can cause unnecessary stress to parents. Attempts to enter weight information more frequently or the detection of major weight fluctuations would trigger educational messages designed to help parents determine if and when to intervene or contact a healthcare professional.

Similarly, the constellation of mechanisms for collecting parental mental health data represents a compromise and blending of clinical and parental interests. Estrellita enables monitoring of three indicators of parental mental health and well-being: postpartum depression (using the Edinburgh Postnatal Depression Scale [Cox 1987]), stress levels (using the Perceived Stress Scale [Cohen 1983]), and a subjective mood indicator (using the Mood Map [Morris 2010]; see Figure 1, right). The validated clinical instruments enable Estrellita to summarize information quickly for clinicians and to flag parents in need of a referral. However, we also wanted to ensure that parents would have the opportunity to examine their moods themselves in a more casual way.

Fig. 1. (Left) Estrellita main menu as shown on the mobile device. (Right) Mood Map showing the heat map of this week's moods.

The Mood Map has been shown in previous work to encourage experimentation and reflection on the part of parents [Morris 2010].

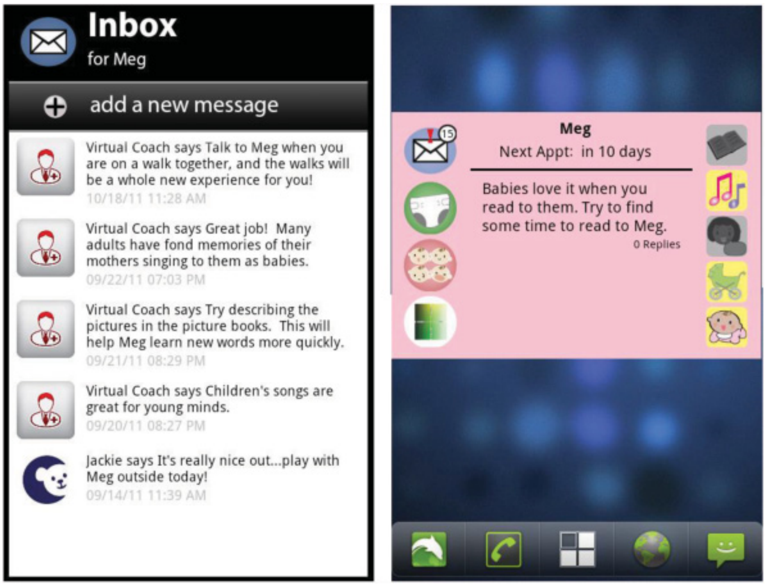
Estrellita also allows for the recording of nonclinical data that can be useful for assessing the infant's overall health, such as how "fussy" an infant is and parental caregiving activities. By monitoring child development–related activities (e.g., singing, talking, reading to one's child) and appointments, Estrellita subtly encourages healthy behavior while supporting parents in their caregiving practices.

> . . . It did have a little bit of an effect of, like, oh my gosh, I better read a book to him today so I can check that box! – Healthy Baby Pilot Participant J

Finally, Estrellita also supports tracking of custom data to reflect the individualized nature of each infant's health and development. These data might be agreed upon by both clinicians and parents together hoping to understand some concern or collect additional data about some important metric for that particular infant. Parents alone might also use such a tool to track data important to them but potentially not clinically relevant. Estrellita supports recording both numerical (e.g., tracking ounces of feeding formula) and free-form text-based data (e.g., food eaten by a breastfeeding mother).

> And so then, so I was thinking, what's important to me? Sleep. Sleep is a huge thing for me and it's something we struggle with so I thought let me create my own sleep chart. – Health Baby Pilot Participant I

To further support data collection by busy parents, Estrellita provides cascading reminders to fit varying levels of urgency and importance. The most overt reminder occurs at a set time each night if no data have been recorded and entails an audio and tactile (vibration) notification on the phone, a blinking LED, and a system tray notification with more detail. Although this reminder was a requirement of the researchers and clinicians to encourage daily data collection, the parents set its exact timing at the first home visit with the researchers. To complement notifications, Estrellita also has a dashboard-style widget on the phone's home screen containing information about



Virtual Coach says Talk to Meg when you are on a walk together, and the walks will be a whole new experience for you!
10/18/11 11:28 AM

Virtual Coach says Great job! Many adults have fond memories of their mothers singing to them as babies.
09/22/11 07:03 PM

Virtual Coach says Try describing the pictures in the picture books. This will help Meg learn new words more quickly.
09/21/11 08:29 PM

Virtual Coach says Children's songs are great for young minds.
09/20/11 08:27 PM

Jackie says It's really nice out...play with Meg outside today!
09/14/11 11:39 AM

Meg
Next Appt: in 10 days

Babies love it when you read to them. Try to find some time to read to Meg.
0 Replies

Fig. 2. (Left) Inbox filled with messages from both the virtual coach (automated system) and one of the nurses on the clinical care team. (Right) Home screen widget showing health indicators and other options on the left side, recent messages in the center, and progress on bonding activities on the right side.

upcoming appointments, system-generated tips, feedback cues for completing bonding activities, and shortcuts to some of the primary indicators logged every day (diapers, bonding, weight, and maternal moods). Finally, within the application, on the main dashboard, Estrellita provides subtle reminders in the form of highlighted data tiles (see Figure 1, left) for indicators that have not been updated recently.

4.2. Enable Empowerment and Consistency through Education and Reflection

Empowering parents to care for their preterm infants can lead to improved health outcomes for infants [Liaw 1995; Cockcroft 2011]. Many personal informatics tools incorporate principles of self-reflection into their designs (e.g., Chiu et al. [2009], Consolvo et al. [2006], and Li [2010]), which can lead to improvement in feelings of empowerment. However, in pediatric care, a caregiver, not the patient, is the predominant user of the tool. In these cases, special care must be taken to ensure that caregivers continue to be motivated and supported in their care routines.

In Estrellita, we facilitate caregiver empowerment in three ways. First, Estrellita includes a virtual coach, who provides basic feedback on data that parents are recording. The metaphor of the "coach" keeps parents in charge but provides them additional support and advice. This information is system generated but appears alongside human-generated messages from clinicians or other supporters in the application's "inbox." The messages help inform parents about the purpose of recording health data and strategies for supporting the shared goal of a healthy infant (see Figure 2). Parents can respond to these messages if they choose, but parent responses to the virtual coach—just like any other parent-initiated communication—is not answered by the virtual coach. Instead, the human clinician who monitors the inbox would respond. Second, Estrellita provides other automated (e.g., charts, alerts) and human-generated feedback (e.g., messages from clinicians) that can increase parents' awareness of their child's health status and potentially bolster parental feelings of self-efficacy as a caregiver. Finally, by streamlining data capturing to focus on a few, but important, data types as described earlier, the system provides a holistic view of the infant's health without too much detail that can be overwhelming. Of course, additional educational messaging can and should be explored beyond Estrellita's current capabilities depending on the needs of the family. For example, one parent of a healthy baby in the pilot study was very focused on sleep and so noted that the system should support education about sleep for families:

> If you want to use it to provide information I think that's fantastic. Like you could then look for patterns and say wow this baby is not going to bed until 11 every night, and this baby is 3 months old and an appropriate bedtime for a 3 month old is not 11. So, that could be something that the app does. . . . Hey baby is 3 months old and at 3 months is a time we start to shift bedtimes early and you know just provide that information because I think a lot of families just don't know. – Healthy Baby Pilot Participant I

4.3. Support Communication through Data Sharing

Our early work in this space demonstrates that communication practices vary widely among this population and that substantial barriers exist to effective communication with healthcare providers, family members, and other sources of social support. These barriers include challenges with gathering and communicating accurate information (an issue explicitly addressed through Estrellita's design), as well as concerns about health literacy (an issue inherent to any health information technology) [Liu et al. 2010]. Collaborative technologies, such as Estrellita, can address some of these barriers and challenges, thereby augmenting existing communication channels and creating new ones. Existing online resources[5] can provide information to concerned parents and allow them to share messages and experiences with each other. Studies have shown that mothers of both preterm and full-term infants who had more social support showed less stress and were more positive in attitude over the months following birth [Crnic et al. 1983; Eward 1979].

Estrellita supports data sharing, and subsequent communication, in a variety of ways. First, all recorded infant health data are shared with clinicians through a web portal accessible by healthcare professionals who have expertise in caring for preterm infants or others with whom parents choose to share the data (see Figure 3). To be implemented fully in clinical practice, these kinds of data-sharing portals would have to be incorporated into the clinical workflow and have associated billing codes for their use. However, as part of our research, healthcare providers who were dedicated to the project engaged in these activities without that full integration. Estrellita's architecture (built on a combination of secure web servers and a backup connection of data through Microsoft HealthVault) also allows for the connection of nonclinical supporters, such as friends and family, either directly through the portal or through their own application to send messages to the Estrellita user. Finally, the mobile nature of Estrellita allows for parents to bring their data with them and access it during appointments. For clinicians who are unwilling or unable to access a portal, this solution allows for just-in-time reporting of data during appointments and is likely much more accurate than parent recollection during a clinical interview as is standard practice in pediatrics visits currently.

Finally, Estrellita supports parents in preparing questions for their providers through the appointment note feature. At the time of booking the appointment or anytime after, parents can access the notes field associated with a specific appointment to record relevant information or to note any questions they might have. This

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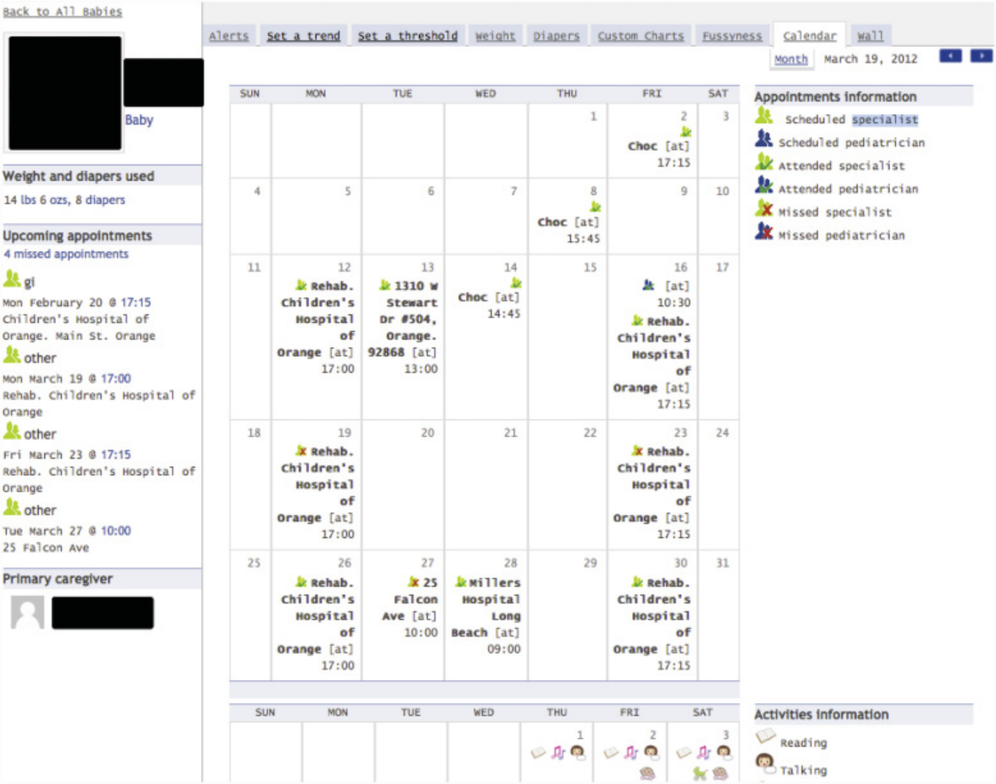
[5] Custom premature infant information, such as Yahoo! Preemie List (http://groups.yahoo.com/group/preemie-list) and Prematurity – Preemie Baby Preemie Child (http://www.prematurity.org) provide educational information and support as well as more general purpose websites like BabyCenter.com.



[redacted] Baby

Weight and diapers used

14 lbs 6 ozs, 8 diapers

Upcoming appointments

4 missed appointments

gi
Mon February 20 @ 17:15
Children's Hospital of Orange. Main St. Orange

other
Mon March 19 @ 17:00
Rehab. Children's Hospital of Orange

other
Fri March 23 @ 17:15
Rehab. Children's Hospital of Orange

other
Tue March 27 @ 10:00
25 Falcon Ave

Primary caregiver

[redacted]

March 19, 2012

SUN	MON	TUE	WED	THU	FRI	SAT
				1	2 Choc [at] 17:15	3
4	5	6	7	8 Choc [at] 15:45	9	10
11	12 Rehab. Children's Hospital of Orange [at] 17:00	13 1310 W Stewart Dr #504, Orange. 92868 [at] 13:00	14 Choc [at] 14:45	15	16 [at] 10:30 Rehab. Children's Hospital of Orange [at] 17:15	17
18	19 Rehab. Children's Hospital of Orange [at] 17:00	20	21	22	23 Rehab. Children's Hospital of Orange [at] 17:15	24
25	26 Rehab. Children's Hospital of Orange [at] 17:00	27 25 Falcon Ave [at] 10:00	28 Millers Hospital Long Beach [at] 09:00	29	30 Rehab. Children's Hospital of Orange [at] 17:15	31

Appointments information

- Scheduled specialist
- Scheduled pediatrician
- Attended specialist
- Attended pediatrician
- Missed specialist
- Missed pediatrician

SUN	MON	TUE	WED	THU	FRI	SAT
				1	2	3

Activities information

- Reading
- Talking

Fig. 3. Dashboard view of a patient's file viewed by healthcare professionals.

feature matches the activities already observed in many of the design and pilot participants:

> . . . I keep a notebook for my baby at home and I write down my questions for the doctor beforehand in there, and I bring it to him and I write down the answers in that. . . . I like that feature [appointment notes]. So I think that what I might do though is somehow even more actively encourage people that at least have questions for their doctor. – Healthy Baby Pilot Participant M

Based on their feedback, we also added a prompt to the appointment reminder to review any notes that have been saved prior to that appointment. These notes are not viewable through the clinician portal and so provide a private place for parents to express their concerns and make notes on clinician behavior, comments, and so on.

5. EVALUATION OF ESTRELLITA WITH PARENTS OF PRETERM INFANTS

In the second phase of our work, 14 mothers of preterm infants and 16 infants, recruited from the NICU at a large suburban hospital, participated in the deployment evaluation (Tables I and II).[6] The infants were all singletons or twins born between 23 and 32 weeks' gestational age. Eligibility was determined through chart review by one of the nurse case managers at the hospital's high-risk infant follow-up clinic.

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[6] Seventeen families initially enrolled in the study, but two dropped out for personal reasons, and one family of twins was excluded from analyses because it was determined later that their infants were outside the eligibility criteria for the study.

Table I. Demographics of Participants for Intervention (I) and Control (C) Conditions

#	Condition	# births	Mat. age	Maternal ethnicity	Insurance	Education	Marital status**	# of communication partners in 2 weeks	
								Overall	Family, friends, and neighbors
1	I	1	34	African American	Private	Professional or graduate degree	Married/partner	14	6
2	I	2	25	Hispanic/Latino American	Private and Medi-Cal	Some junior high school or less	Married/partner	20	15
4	I	1	24	Hispanic/Latino American		Some college*	Married/partner	15	15
6	I	1	28	Caucasian		Some junior high school or less	Married/partner	15	13
7	I	1	32	Hispanic/Latino American	Private and Medi-Cal	Some college*	Married/partner	9	7
8	I	1	25	Hispanic/Latino American	Medi-Cal	Some junior high school or less	Single or never married	21	14
9	C	1	24	Hispanic/Latino American	Private and Medi-Cal	Some college*	Married/partner	25	15
10	I	1	28	Caucasian	Medi-Cal	Some college*	Married/partner	31	19
11	C	1	30	Asian/Asian American, Oriental, or Pacific Islander	Private	College degree	Married/partner	21	19
12	C	1	22	Hispanic/Latino American	Medi-Cal	Vocational or technical school	Single or never married	16	11
13	I	2	37	Hispanic/Latino American	Medi-Cal	Some junior high school or less	Remarried	10	10
14	C	1	41	Hispanic/Latino American	Medi-Cal	Some college*	Married/partner	15	15
15	C	1	20	Hispanic/Latino American	Private	Some junior high school or less	Married/partner	12	10
16	C	1	30	Caucasian	Private	Some college*	Married/partner	16	9

*Some college includes vocational school.

**Married/partner includes both married families and those living together.

Parents were recruited either in person at the NICU or over the phone. Just before the baseline assessment, parents were randomly assigned into either the experimental Estrellita condition or a control condition with standard care (i.e., they did not receive Estrellita but did receive the information that Estrellita reports in the usual manner, which includes books, pamphlets, phone calls, and other standard communications). Seven parents were randomized into the phone condition, and seven into the control condition. In some cases, the fathers actively participated in the recording of data on the phone and in the interviews. Parents in the control condition did not differ from parents in the intervention condition in age, number of children living at home, and other general demographics. In addition, characteristics of the infants did not significantly differ between the control and experimental conditions in terms of mean birthweight, gestational age, medical acuity, and perceived heath.

The study was conducted over the span of 10 months, with families enrolled for 4 months at a time on a rolling basis. To avoid the possibility of overburdening already stressed families with a high-risk infant, we presented Estrellita to enrolled families when the infants reached 2 months adjusted age.[7]

Our evaluation included a mix of quantitative and qualitative, subjective and objective, and observed and reported metrics. In this way, we were able to understand the results of the deployment of the technology more deeply. Furthermore, we placed particular emphasis on the parent experience while still reflecting upon the needs and responses of all those involved. Our overall approach to evaluation included deploying the technology for an extended time, measuring outcomes quantitatively, and obtaining a deep understanding of this impact using qualitative, contextualized inquiries into the practices of users involved. By following this approach, others may benefit from our experience in such difficult deployment and evaluation situations in the future.

All participants completed a baseline assessment, including a demographics questionnaire. Additionally, parents in the intervention condition received a T-Mobile G2 Android smartphone with Estrellita preloaded and a baby scale at baseline and were trained on how to use them. All of the parents had previous experience with mobile phones, but none of them used their own phones in the study due to our effort to control the platform. All participants were then interviewed 2 months after the baseline (midpoint interview) and 4 months after baseline (final interview). Interviews of the intervention participants addressed a variety of issues, including how Estrellita was used and integrated into daily life, perceived impact of entering and viewing the data on behavior, sharing of data from the phone with healthcare providers and other caregivers, concerns about privacy and data security, and general challenges experienced in the care of a preterm infant. Interviews of the control participants addressed strategies to manage infants' health information, communication with healthcare providers, and general challenges in caring for a preterm infant(s). Interviews were audio-recorded with permission of the participants. At the final interview, all participants also completed the Parenting Stress Index [Abidin 1990].

Participants were compensated $20 for each interview that they completed. In addition, intervention group participants were compensated $5 for each week that they entered data into the phone. They were given the G2 phone to use, with a fully paid phone and data plan, for 4 months, as well as the baby scale. At the end of the study, intervention participants were given the baby scale to keep as well as the option to keep the phone (service would be transferred to their name) or to receive an additional $75 compensation for returning the phone. Only one family chose to keep the phone following the study, having switched to it as a primary phone.

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[7] Adjusted age is calculated according to the date at which the baby would have been born at full term and typically corresponds roughly to the discharge date from the neonatal intensive care unit.

Table II. Summary of Maternal Demographics for Deployment Study

Characteristic	Control (n = 7)	Intervention (n = 7)	Combined (n = 14)
Mother's income[8]			
No income	7	3	10
< $30,000	0	3	3
$30,000–$49,999	0	1	1
Mother's education level			
Some junior high school or less	2	0	2
High school diploma or GED	1	2	3
Vocational or technical school	1	0	1
Some college (including associate degree)	3	3	6
College degree	1	0	1
Professional or graduate degree	0	1	1
Marital status			
Married or living with a partner	5	6	11
Remarried	1	0	1
Single or never married	1	1	2

All interviews were audio-recorded with participant consent and transcribed for analysis. In the one case in which the participant preferred not to be recorded, extensive notes were taken by two researchers conducting the interview and included for analysis. Data collection and data analysis occurred continuously throughout this project, and these activities overlapped and informed one another. The research team met biweekly to discuss trends in the data from both the control and intervention participants.

Throughout data collection and analysis, the research team met regularly to discuss trends in the data collected from interviews and in-home observations, particularly as they related to trends we were seeing in the logs and system usage. Dominant topics included any usability or technical challenges the families were having as well as more nuanced concerns around privacy and security of data, parent empowerment and communication with clinicians, parental behaviors and activities that relate to their infants, and the relationship of Estrellita to these phenomena. Additionally, we regularly discussed the trends we were seeing in the clinical use of the tools and other behaviors as well as perceptions of both the tightly integrated clinicians and those more remote to the project. Our overall analysis was a mix of inductive and deductive approaches. We examined the interview transcripts and field notes for data related to our initial hypotheses and goals relating to Estrellita's ability to support parents. Additionally, at the end of the study, we looked for explanatory qualitative data to help unpack the trends we saw in the quantitative results, analysis of which is described later. In terms of inductive analysis, we used coding, memoing, and affinity diagramming through the data collection and analysis process over the course of nearly 2 years [Charmaz 2006]. During the first round of open coding, codes focused on themes of health information and understanding, social support and interactions among the caregiver network, work practices of clinicians, and challenges to the collection and sharing of data. Based on the first round of coding, additional rounds of coding and analysis were conducted to examine further the challenges faced by both parents and clinicians in accomplishing their goals and in using Estrellita. We aggregated

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[8] Although some mothers had additional income in the household from the baby's father, other family members, or even close friends, the concept of "household income" is not a standard one for many participants, and so we report here only maternal income.

themes related to these challenges, detailing the ways in which our design choices supported or limited usage as well as emergent themes focused on empowerment of parents and the risks and rewards of data sharing.

In addition to the qualitative interview data, we instrumented the Estrellita application to log additional usage patterns. This helped us better understand how parents were actually using Estrellita on the phone. All the data entered on the phone were logged. We also recorded (1) when and how Estrellita was launched and (2) which data were accessed and when they were updated.

Descriptive and inferential statistical analyses were conducted with Excel and with SPSS 17.0. Descriptive statistics were calculated for the frequency of using Estrellita overall and for each health indicator. The overall parenting stress score from the Parenting Stress Index was calculated according to scale instructions. Parenting stress scores of parents in the phone condition were compared with those in the control condition using independent sample *t*-tests.

6. EVALUATION RESULTS

The promise of interactive technologies for health often rests on their ability to provide access to meaningful health data for patients, as well as their caregivers and healthcare professionals. Gaining access to data requires the ability to collect and store these data, and making use of the information stored therein requires the consumer to both understand and be willing and able to take action based on these data. Thus, in this section, we detail the ways in which our prototype design met the goals of our design recommendations and accomplished the collection, storage, and sharing of personal health data for both preterm infants and their parents.

6.1. Flexibility and Limited Requirements Are Needed for the Capture of Necessary Data

Despite high levels of stress and heavy caregiving responsibilities, participants in the deployment study recorded data fairly frequently. Overall, they entered at least one piece of data nearly three-quarters of the days in the study (M = 74.86%, SD = 18.97%). We also calculated rates of data entry for each health indicator (number of days or weeks in which at least one entry was made, divided by the total number of days or weeks in the study), as different health indicators had different time frames for data entry. We found that diapers and bonding data were the most frequently entered in relation to their potential frequency of entry (see Figure 4).

As part of the study design, we debated how to compensate caregivers. On the one hand, compensating them based on compliance with regular use of the tool (analogous to adherence to a medication regimen in a clinical pharmacological trial) enabled us to test the efficacy of the tool in producing the outcomes we hypothesized would come. On the other hand, by doing so, we muddied our ability to test whether people would even use it at all outside of this compensation scheme. Ultimately, we decided to provide a small level of compensation for tool use with a larger amount of compensation for participation in interviews and in-home visits, a compromise that seemed appropriate for this initial study. After all, if the tool is not efficacious, there is no point to trying to get people to use it.

Though parents were generally consistent in logging data and their levels of data entry were fairly stable across the 4 months of the study for most indicators (infant fussiness is a notable exception; see Figure 5), there were still many days on which data were not entered. To address this gap, we interrogated the potential barriers to data entry in this study.

6.1.1. Prioritizing Data Collection for Particular Health Indicators. Ease of use and perceived importance of some health indicators over others may help explain the patterns of data

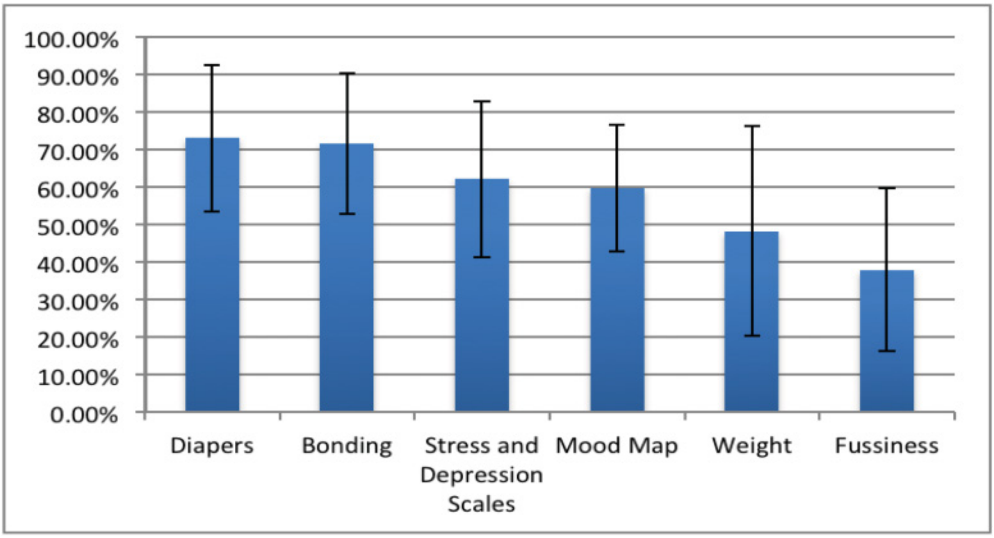

Fig. 4. Percentage of opportunities to enter data in which data were entered. For most indicators, this is a daily measure. However, the stress and depression scales were only delivered monthly, and weight could only be entered once per week. Additionally, in the cases in which twins are considered, if data were entered for one twin, the day is counted.

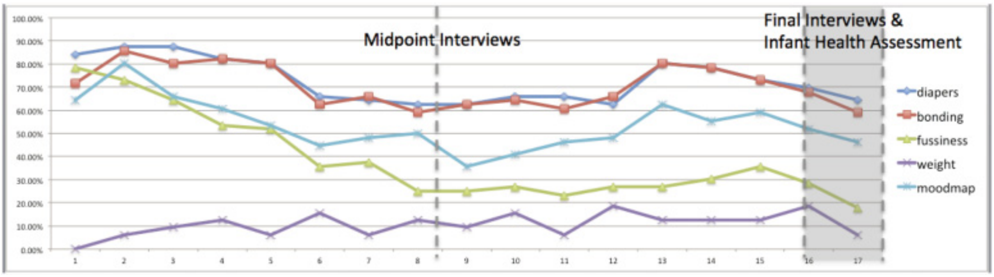

Fig. 5. Average rate of data entry for all the indicators and across the duration of the study.

entry. Parents tended to prioritize recording information for those indicators that they found easiest to use and most important to their assessment of their infant's health. The frequency of gastrointestinal problems among this population and the regularity with which pediatricians ask about diapering as a health indicator may explain some of the particular interest by parents in diapering.

> I usually go straight to the diaper part first. To me that's the, I mean her health is a little bit more important. . . . I've found it a priority to do her diaper stuff and that stuff more, because that's important.
> –P9

On the other hand, indicators like the infant's general fussiness level were considered less important to record regularly by parents. Though parents generally reported that fussiness ratings were helpful, they also reported that fussiness was not the most critical indicator of their infant's health. Thus, they tended only to record data when the infant was particularly fussy, leading them to be able to track which days were problematic but not days that went particularly well.

In our early work, weight was one of the most frequently expressed concerns by parents. It might be surprising, then, given the interest in this indicator, that parents only entered weight data about 50% of the weeks that they were in the study. We identified challenges to gathering weight data at home. First, even though parents and clinicians alike described weight as a major concern throughout the first year of life during interviews, weight might not have been as important of a factor 2 months following discharge, when the infants tend to start stabilizing, as immediately after discharge. Second, to meet clinician requirements about the reliability of the weight data, we provided parents a baby scale to use with Estrellita, showed the parents how to calibrate it, and required that a photograph of the infant on the scale be submitted with each weight entry. This was done to ensure that the infants were similarly clothed from week to week and that there were no other materials on the scale that could be affecting the weight. Weighing a baby is tricky under the best circumstances, given their tendency to squirm or roll away. Needing to take a picture with a squirming baby on the scale, however, further compounded things for parents.

> So it was hard to get the picture in because the scale kept going up and you know, it was like I know it was an accurate one like 12 [or] 12.5 and it was, and he moved again and it went up two more or something but I'm like, "stop moving." – P4

In addition, some parents stored the baby scale in places that were not easy to access, making the weight data even more difficult to gather. A few of the parents lived in small homes and needed to put the scale away somewhere. However, putting the scale away often meant they could not easily access it when needed. Other parents stored the scale in its box, a strategy that became its own barrier to regular weight entries.

> [The scale] was in the box. (laughter) Like I would use it and put it back in the box, in her room. [Weighing] never happened. So now it's sitting on the table right next to me for a change. So I look at it and think, ok "got to remember, got to remember." – P1

Prioritization of infant health indicators above parental health indicators also explains to some degree why the Mood Map and the maternal mental health scales were not completed as regularly as diapers and bonding.

> If I had more time, I would definitely do the moods. . . . Like, I don't have time for anything, I don't have time, I barely have time to use the restroom. I have to take a shower at like 12 a.m. And I barely have time for breakfast, like at 12, so it's lunch and breakfast and, but it's really hard. Yeah, it's too hard. – P2

No requirements were made of the parents to enter mood information, and the system did not prompt them to do so; we had wanted it to be a time of reflection made by the choice of the parents. On the other hand, the maternal health scales were presented monthly and did generate system reminders. These reminders, of course, bring with them their own challenges. They can go unnoticed (P9) or trigger other anxieties, such as not wanting to take a measure for fear of the potential diagnostic information it might produce (P2).

Getting parents to remember the importance of their own well-being and mental health while caring for their children is a staple of parenting books and postpartum health brochures. Certainly, systems designed to support parents through this challenging time can and should be designed to more explicitly encourage parents to treat their own health as important, an issue we were not able to address fully in the design of Estrellita. By explicitly visualizing maternal and infant health together as well as proactively providing messages to support this prioritization, we can make some strides. Additionally, the use of sensors to detect parental stress or health challenges and feed those into the system is worth exploring.

6.1.2. Time and Household Pressures as Barriers to Data Collection. Encouraging parents to track data is a well-known challenge in pediatric informatics (e.g., [Hayes et al. 2011b; Kientz et al. 2009]). Parents may not be motivated enough to collect data if just the data clinicians requested are included. Past work has shown that including additional data or allowing parents to store these data in the form of artifacts important to them (e.g., photo albums) can remedy some of these challenges [Kientz et al. 2009]. However, as in our early work, in this larger evaluation study, we again saw the themes of time pressures and the general busyness of a household with a new baby emerge as major barriers to entry of health data. For example, a participant who described the data entry both boring but manageable mentioned pressures of other commitments:

> . . . I have other things to do. . . . [My typical day is] very busy. . . . That's why I skip it sometimes because . . . I know it doesn't take a lot of time. But to me, a minute is a lot because of the two kids. If I had one baby, I know for sure, for a fact, that I would put way more information in it, even notes of every detail. But since I do have four kids and two are the babies I kind of have to put what is most needed. – P2

Busy schedules and time pressures can create barriers to data entry no matter how motivated a parent is. Because of their busy schedules, parents often waited until the end of the day to enter data, particularly if they had other children in the household or were working.

> . . . I usually update it at the end of the day when she is in bed. I'm done with whatever I need to do and I'm just sitting on the couch hanging out by myself. – P6

In practice, a tension arose between our design choice to limit entry of data to the same day (in large part prompted by clinician concerns about data integrity and reliability) and the reality that the "day" with a newborn may not end at midnight, at the end of the calendar day.

> . . . Usually I do it really late. Like, almost 12, 11. Because that's the time when everything is calm and that's when I have, you know, all the information of the diapers and everything, after the day. . . . So I can focus. . . . So that's why when I have missed again, it's because. . . . Yeah, it's a "new day" and I haven't slept yet. – P2

In response to participant feedback, Estrellita now allows parents to enter data for previous days. However, designers and researchers should consider in their own work this tension between wanting the most recent data and the reality of trying to achieve that recency in practice in busy households. Some parents were even aware of this tension, such as P2, who described wanting to take the postpartum depression scale and the Perceived Stress Scale more frequently than the once per month it was offered to support her ability to reflect on the changes over time:

> . . . It should be more than every month though. I think it should be like every week or something. . . . It kinda makes you think about what you went through and makes you think how you did. . . . – P2

For parents who work outside the home, additional challenges emerge from the choice of the mobile phone platform and whether it was with the parents or the infants. Parents who used the study phone as their primary device took it with them to work, meaning that the caregivers with the infant were not able to track data or had to use other tools to collect data that were then transferred to Estrellita.

> [The nanny] writes it down. Yeah, she keeps a, like a sheet of paper on the refrigerator and she jots down her diapers and her, you know, she lets me know when she's extra fussy and maybe for what reason. – P6

Likewise, parents who left the phone with their infants' caregivers for data tracking were forced to use the web portal to follow up on any information that might be logged, which in practice was too cumbersome for regular use.

An obvious solution to this challenge is to make the system multiuser in a way that we had not for the research study. Certainly if multiple caregivers could all access the same mobile application, they could receive the benefits of a mobile device while sharing information. However, even with this solution, our experience indicates that there are still challenges to awareness and communication when multiple caregivers are involved. In some ways, the replacement with a more "efficient" system that allows multiple people to edit through their own interfaces could even cut down on the opportunities for communication and collaboration. For example, in one study of the implementation of electronic medical records in a hospital setting, important information that was previously exchanged verbally could be lost when staff were no longer required to physically transfer a patient's chart from one ward to another [Hayes et al. 2011a].

6.2. Empowered Parents and Behavior Change through Education and Reflection

Despite the barriers to entering data, the parents in our deployment study overall expressed that it was relatively easy, and their data entry rates stayed consistently high over time. Entering data has only limited value, however, if it is not accessed later for reflection, decision making, and behavior change. To encourage this kind of reflection, Estrellita embedded the access activities inside the capture activities [Kientz 2012] by requiring parents to move through a screen showing a visualization of recent data before they could update with new information. In practice, this resulted in reflection on their data as well as actionable responses to these data.

To support reflection at multiple levels, Estrellita includes a variety of visualizations at different time scales (e.g., daily, weekly, monthly). Parents reported enjoying use of the infant visualizations to see "that they're making progress" (P1) at a quick glance.

Perhaps unsurprisingly, those indicators parents described as most reflected upon were for the most part the same as those most recorded, indicating an overall strong interest in these indicators as well as the obvious limitation that one cannot reflect on data that have not been collected.

> I went and looked back at her weight, what we started at and all that stuff. So yeah, I look back at them. Because you don't remember and you know, you want to see her progress and how she's doing and everything, so it's a good thing. – P6

> . . . I'll go in and look and check his diapers, because sometimes our day gets really busy so it's like, it's hard to remember, did he go poop today . . . so by checking and there's missing days, I'll be like maybe I need to call the doctor now because it's already been two, three days that he hasn't went to the restroom. But I know if I didn't have the app, I wouldn't remember that. Because there's just so much stuff going on, so it would be hard to remember that. – P12

Below are some specific examples of how reflection enabled parents to change their behaviors in positive, health-promoting ways.

6.2.1. Empowering Parents to Improve Their Mental Health. Despite prioritizing their infants' health over their own health in data access and capture, parents described reflecting on their mood data positively as a tool for coping with emotional challenges:

> Yeah, like during the end of the night [I see I was] saying like happy all day. I know, because right now, me and his dad are going through a separation, so, it's like, I'm like, it's good that I'm not letting it keep me down. . . . It helped me remind myself I'm not gonna let anything get me down. – P12, describing daily review of her Mood Map data

One parent took this dichotomy even further by explicitly stating that her mood data was not important to her and then following up with a story of its power in motivating her to train for a half-marathon.

> [The Mood Map was] not really [useful] for me. I don't know, most of the time I'm stressed out. . . . I did notice that when I exercised more I have more energy and you know, I noticed that the times that I had more energy it's like after I exercised. . . . – P1

While the Mood Map is intentionally ambiguous and encourages reflection [Morris et al. 2010], the maternal mental health scales used in Estrellita are clinical indicators to help our clinical collaborators monitor the safety of research participants. The strongly clinical language of the validated scales gave some parents a sense of safety in the face of their own fears for their mental health. Likewise, the simple act of tracking, for others, was a comfort. For example, P4 was told that she was likely to experience postpartum depression (PPD) upon leaving the hospital:

> . . . I think that helps because like at first when I first left the hospital I was kind of scared of . . . post partum so that was kind of freaking me out and a lot of people were like oh you might get it for a little bit. So for me it just kind of helped me because I would know if I was fussy or not, you know just keep track of myself. – P4

For others, this language coupled with the carefully vetted advice to get help may have contributed to mistrust or displeasure with using the system, particularly in light of stigma surrounding mental health generally and PPD particularly. For example, even though P6 began mental health treatment in response to getting an alert from Estrellita indicating she was at risk, she was loathe to use the PPD label:

> I don't have postpartum. . . . I do have some sort of depression, but not post partum. . . . I mean, just because I don't have post partum depression, I do have a slight case of it, but I wouldn't have called anybody, if I didn't have [Estrellita], if I didn't get that message [to call a healthcare provider], so, it was a good thing. – P6

These results indicate that even when parents do not prioritize their own health, they can be encouraged to collect data about themselves and to learn and act on important indicators.

6.2.2. Enabling Parents to See Connection between Maternal and Infant Health. Additionally, helping parents to see the connection between maternal and infant health [Holditch-Davis et al. 2007; Muller-Nix et al. 2004; Wijnroks 1999] may encourage them to collect and use these data even more. Most parents in the deployment study were not clear about the impact of their own well-being on their infants, even when explicitly asked about it after using Estrellita for 4 months.

> . . . I think when she's not doing good it affects me, obviously. I don't think it, I don't think my moods affect her health in anyway. – P6

Although Estrellita does not allow parents to visualize maternal and infant health together, they can quickly flip between indicators, which allowed some to begin to see important connections.

> . . . If I'm logging her mood and my mood I've noticed that we go along together, so it's kind of, it's nice. – P9

> I think [the app] motivates you to keep track of what's going on and then also my moods too. It tells me if my moods and how I'm feeling about things, which is kind of, you know, you don't really, it's not in the forefront of your mind. It should be, you know, you have to take care of yourself and make sure your health is ok and so, I think it is motivating to help you keep track, in terms of, that would be the word I would use to describe it. – P1

Certainly, visualizing these data together might help parents to see these patterns even more easily, a design choice we considered. However, on a small screen, our early designs with all of the data visualized together were largely unusable. Additionally, we were particularly interested in supporting families in reflecting on their data as they enter new information, which in our design occurred one indicator at a time. Thus, for this initial prototype and deployment, all of the indicators were graphed individually.

6.2.3. Changing Behavior Requires Education.

Certainly reflection takes us the first several steps toward parent empowerment and action. However, just viewing and interpreting data are not enough. Our results clearly indicate that for action to take place, the parents must also be educated about how to interpret the data, in particular in relation to the specific needs of the individual child. As just a simple example, understanding the visualizations requires some basic graph literacy. Likewise, one of the design goals of Estrellita focused on encouraging behaviors and activities thought to be particularly important for child development. Overall, the system encouraged greater awareness of these activities, which may indicate greater performance of these behaviors, in the intervention group compared to the control group:

> [The homescreen widget] kind of helps with our, what is it, our activities. Yeah, it kind of helps me during the day, like, oh what we should get done and what we haven't got done. – P12

> I like, I really like entering the bonding time, because then it makes me want to do it. Which are things that I should be doing, and so I think about it every day even without thinking about that. There's these things that I just have to do, so I really like that. – P1

In contrast, during interviews and in-home observations, control participants appeared to be less aware that these behaviors were beneficial for their infants. Additionally, they more often dropped one of the activities from their routine when challenges were present. For example, even though all parents were given information on these activities at the time of discharge, one participant, when asked whether she did tummy time with her baby, responded: "What's tummy time? [After interviewer explains,] No I haven't done that." – P8

Another participant was able to maintain some of the activities but dropped reading when her infant's changing sleep schedule made it difficult to maintain the reading.

> [I] talk and sing, yes, because anything I am doing in the kitchen he kind of wants to see and be heard. So I just talk and sing to him so part of the time so when he gets upset I just talk to him. Reading is not happening, because he recently he has changed his nap times and he dropped his third nap and now we in the evening he is really cranky. – P11

However, many of these educational and persuasive elements were not customized to the particular infants in the study. This kind of customization can be important, particularly in paying attention to how the messages are framed as potential gains or losses [Rothman 1997]. This lack of customization could at times create frustration when the details of the infant's condition were not considered:

> I don't do much of [the recommended tummy time] because the doctor told me because of the gtube, that it's ok, you know, to wait. – P2

Overall, these results indicate that personal informatics tools like Estrellita can empower patients and their caregivers to become more informed, take action, and create healthful behavior routines. However, a lack of understanding of the connection between the data and health status as well as a variety of barriers to data collection can impede use of these tools.

6.3. Rewards and Risks of Sharing Data

Parents using Estrellita shared data with both professionals and friends and family. This sharing was accomplished with varying degrees of success and using a variety of strategies. Responses to the sharing varied as well, from positive and supportive to indifference.

6.3.1. Sharing Data to Enhance Clinical Communication. Overall, everyone who used Estrellita in both the pilot and full deployment studies described liking and prioritizing messages from clinicians that appeared on the Estrellita "wall," a finding consistent with the kinds of communication preferences noted in our preliminary work [Liu et al. 2011]. Likewise, the primary nurse tasked with viewing data and communicating with parents via the wall described this communication as making the families more "real" rather than "numbers on a medical record." Even though the communications were happening in short text-based formats, knowing a clinician was the source of them felt more comfortable for many parents than the system-generated alerts. For example, one mother described wanting the system-generated PPD alert to have been more like the messages sent directly by a nurse.

> ... I think that would have been nice [for the messages to be] like the [Nurse's Name] thing, like that. Instead of "go call, you're crazy." That's how I felt once the number came up, like oh my gosh, they think I'm nuts now. They want me to call that number. ... Usually that person will not call, because they are afraid. They don't want to feel like they need to do that or they're embarrassed or whatever, but I know for sure or in my case, I know for sure if somebody called me, and they told me "honey how are you doing? I'm just here to have a little chat with you, how you're feeling, it's all confidential" ... and then I would have totally told them everything and it would have totally helped. – P2

For most parents, the text-based short communication with clinical staff was simply more efficient and convenient than other mechanisms. This mode of communication could augment other clinical contact the parents had, as well as reinforce their positive caregiving behaviors:

> ... It's like the other source right there. If I need someone, like, I can just text them instead of having to call then waiting for the doctor to call me back. ... – P12

> It kind of reinforces that you are doing a good job, because somebody's actually paying attention to it and looking at it, and giving you feedback. Which you know is real feedback it's not just a standard message. – P6

Likewise, easy-to-access visualizations can provide an easy way to communicate with healthcare professionals during appointments, either through physically sharing the visualizations with the clinical staff or by referencing them during the visits.

> ... I think it's just always good for you to have to show something, you know, because if they ask you and you don't know, you are like ohh, I mean they still want you to give them exact details. You know and it's always like that with doctors, you have to show them. – P4

All of the primary care pediatricians for the intervention families were contacted to be interviewed and offered access to their patients' data through Estrellita. None of them created accounts to access the data, and despite expressed interest from three in being interviewed, only one was able to find the time in her schedule to participate in the interview. She responded positively to Estrellita's features and emphasized that it would be most useful for high-risk infants:

> I mean, it's not for everybody but, you know, for high-risk babies ... especially early on ... you know, those first couple months, yeah, I could see it having some value. – HP2

Six of the seven families reported sharing Estrellita data directly from the phone with their clinicians during at least one visit. The level of engagement of the physicians during these visits appeared variable based on family reports.

> I showed the doctor, she said it was great and I gave her [a letter from the study team]. I showed her everything. And she said "Oh, this is great. This is so great. I'm totally glad they're doing" that's what she said. She didn't take much time to look in detail, but what she saw she liked. – P2

On the other hand, some participants tried to share data and were ignored or actively rebuffed. For example, P9 tried to share diapering information at her first appointment after receiving Estrellita in response to a question about how many diapers were being used each day but never shared data again after "it didn't really seem like the doctor was really interested."

P4 regularly showed her son's providers information from Estrellita. She described most of them as thinking the application was "neat" but became frustrated when the pulmonologist refused to view the data on the phone while asking her questions answerable through the system:

> . . . He was just kind of like "I really don't need any of it" and I was like "Ok, but I was just letting you know I'm updating stuff." . . . Not interested or, I don't know, but he was like, well, he does ask me how many diapers he has, how many feeds has he taken and stuff I put in there. So, then after the surgery too he had asked me, like, "how is his, is he fussy, does he go enough?" But I am like, "everything is in here." . . . But, if he just didn't have time for it or whatever, but I'm like, well, everything that he asks me is pretty much stuff that I put in there. – P4

In response to these kinds of negative responses to sharing the Estrellita data, some parents made a practice of referencing the information on the phone to answer clinician questions but not actually sharing the information directly from the system:

> I would kind of check it on my phone so when I went into the appointment rather than showing him the phone. – P7 husband

> I entered all her flu shots and RSV [respiratory syncytial virus] and all her appointments and then it makes you look like you know everything. [The app] is just very helpful . . . and the doctors, it makes their jobs a whole lot easier. Especially the PMD [primary medical doctor], because they have to keep track of all the appointments. . . . I did use it to tell [the doctors] when her appointments were and they really appreciated it. – P1

Parents can feel more confident about the information they are giving and receiving during clinical encounters when they have records to support their beliefs and memories. For example, one family (P7) disputed a clinical measurement based on the data they had collected themselves. Specifically, the weight being measured by the nurse during an office visit was substantially different from the weight that had been checked just the day before at home. It turned out that the clinic's scale was slightly miscalibrated (a result of having been "zeroed out" improperly), and a new measurement was taken in the office that more closely aligned with the parents' measurement. Given the potential for errors in both electronic and personal health records as well as erroneous measurements on both clinical and consumer devices, this is not to say that only Estrellita data should be considered valid. The benefit we see here, rather, is enabling parents to feel confident in their abilities to converse with and sometimes question clinical data and advice. Ultimately, no one is likely to care as much about one's health as oneself or closest caregiver. Thus, ensuring that these individuals are as involved in the discussions as possible could improve health outcomes. Likewise, policy changes might be made to support paying physicians for the time that they spend examining these kinds of data. Finally, improvements in both the visualization and decision-support aspects of both consumer and clinical health information systems might support improved integration into clinical workflow.

6.3.2. Gaining Social Support through Sharing with Nonclinicians. These kinds of discussions—and disagreements—over data are certainly not limited to clinical encounters. Many families have multiple caregivers, including two parents, grandparents, and others, attending to the needs of the infants, and most commercial tracking applications allow for some kind of data sharing among nonclinical care providers. In all but one of the Estrellita households, the mother was the primary data recorder, despite so many people engaging in the care of the infant. Thus, data sharing among these caregivers became an important part of Estrellita's role in the households. At the same time, its design as an app on an individual's smartphone limited its ability to support that role as described earlier.

Given the general trend toward recording and sharing data being the purview of the mother, it makes sense that many of the mothers using Estrellita described wanting to connect with other mothers and to share information about their children, a finding from the deployment study that supports the preliminary results obtained from our early work [Liu et al. 2011]. Despite this ever-present desire to share, sharing too much has its own risks, including being thought inadequate as a mother or just simply boring one's friends. Instead, parents described wanting to connect particularly with others who have the same challenges they do rather than potentially inundating people who have not had similar experiences with information they may not want.

> . . . On Facebook, like right after I get out of a doctor's appointment or anytime I weigh her I'll be like [Child's Name] weighs blah blah blah, or she, you know, this is how long she is. I'm so excited about her and all the things she's been doing, so I have to share with everyone. They're like "come on lady, stop talking about your kid already." – P9

> I like to see other moms with twins. I love it because we have so much in common. . . . It really, really helps to know people with twins that have the same thing your baby has because you can share your feelings, and we give each other advice and stuff like that. So, it would be cool if [Estrellita] had something that the moms could talk to each other. I would love that. – P2

Personal disclosures are especially commonplace on Facebook [Nosko et al. 2010], and lab studies of disclosures to friends versus strangers have found strangers to be more empathetic and to offer more acknowledgments of disclosures than friends [Barker and Lemle 1987]. This phenomenon bore out in our discussions with Estrellita users as well. For example, in describing her ideal social support through Estrellita, P2 began talking about people she knows but quickly turned to the idea of anonymous, or at least stranger-based, support.

> I would like it to be where you could connect to parents you already know, like FaceBook, sort of. But I would also like it for you to do, just chat with anybody and you don't know who it is. But they all have the same, like you all have the same, it's all about twins. . . . I think it is so cool because you can just talk about anything you want and you don't even know who it is but it's, and that's the good part. Because you can tell them, oh yeah today I did whatever whatever and oh did your twin do this and whatever, but you don't really have to know who they are necessarily, if you want to you know. – P2

For many parents, it would only be by accessing people currently unknown to them that they feel they would be able to find people with their same experiences:

> For me that was my issue because everybody that I knew had never had a preemie. And everybody was always like, no a baby is supposed to do this, I was like, we appreciated their, you know, opinions or whatever. . . . No, because it's different. – P4

> Because stay at home moms, I can't relate to. Although, you know, they might have a lot of tips they discover as stay at home moms that I would never have time to discover because I'm not staying at home. So, I wouldn't completely rule it out, I would prefer though the moms of the NICU grads, for me, that would be helpful. – P1

In particular, in sharing mental health information that can be stigmatizing, many participants described greater freedom in this kind of sharing with people outside their

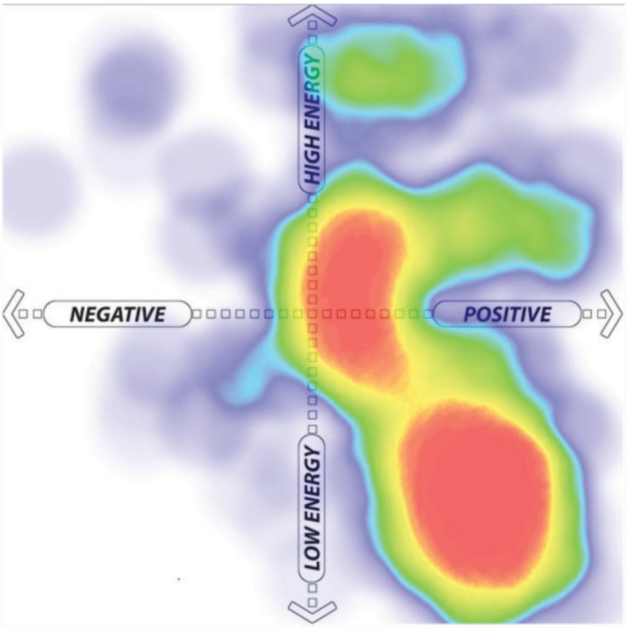

Fig. 6. Heat map of Mood Map data across all participants. Red is an indicator of more entries.

current social circles. For example, after getting a PPD alert, P6 described not wanting to share that information with anyone she knew:

> But, I think my main concern was I didn't want people to think I wasn't capable of taking care of her. So in the beginning I didn't want to say anything. Because I didn't want them to think she can't take care of her, we got to get her out of there. – P6

In addition to the clinical PPD scales delivered monthly, parents can record mood through Estrellita as a point on a two-dimensional graph formed by a horizontal axis of negative to positive valence, and a vertical axis of low to high energy as often as parents want to enter the data. Across the moods stored for all participants, we see a strong trend toward lower energy, positive scores, which may be more an indication of when data entry occurred (often at night, in bed, just before sleep when the household was "calm") than an overall indicator of participant mental health (see Figure 6 for the distribution of moods recorded as a heat map across all participants). In interviews, parents universally described the Mood Map as a tool for themselves and not for sharing information. It could then also be the case that lower energy, positive scores, such as were most commonly stored in the Mood Map, make a person less likely to want or need to share that information. Being angry (high energy, low valence) or depressed (low energy, low valence) or even ecstatically happy (high energy, high valence) are all situations in which one could logically imagine more of a drive to share mental health status than being somewhat content or mellow. Of course, without further study, we cannot be sure about the underlying mechanisms by which people chose not to share these data.

Overall, the ways in which people used the mental health tracking on Estrellita, chose to disclose these data or not, and responded to the idea of sharing indicate that substantially more work needs to be done to understand data-sharing practices around personal health data, particularly for mental health. Sharing information in Estrellita was seen to be a benefit in many cases but raised additional concerns, whether sharing with healthcare professionals or friends and family. The concept of and mechanisms for sharing this information with strangers and distant acquaintances must also be engaged further as these look to be promising approaches, particularly for emotionally fraught or stigmatizing discussions [Brubaker et al. 2010]. Additionally, examining situations in which multiple caregivers is more often the norm, such as multiple adult children caring for an aging parent, might bring up additional issues beyond those seen when only one caregiver takes such a dominant role.

7. CONCLUSIONS AND FUTURE WORK

Healthy home care for high-risk infants and their mothers can be augmented by improving what is known about the condition of these infants and their mothers in the fraught days and weeks following discharge from the hospital. Traditionally, this information can only be collected through clinical visits or, in extreme cases, home health workers. This process is difficult, time consuming, error prone, and expensive, leading to a patchwork of care practices and missed opportunities to intervene with a sick infant or mother showing signs of postpartum depression.

We developed an application to support these families called Estrellita and evaluated it in a pilot deployment study with three healthy infants followed by an intense 4-month deployment with seven families set against the experiences of an additional seven control families. Using multiple methods collectively to understand the design considerations for technology to support preterm infants, we developed key design principles for the creation of a system to support high-risk infants and their families at home. We then used these guidelines to design, develop, and deploy Estrellita. This case study demonstrates that the use of the design guidelines produces a successful system for caring for infants and families at home. Our evaluation shows the system is usable by parents with minimal training and does not add to their stress levels. Intervention participants and control participants showed equivalent levels of stress, as measured by the Parenting Stress Index, at the end of the study, $M = 208.00$ ($SD = 52.52$) versus $M = 195.29$ ($SD = 45.10$), respectively, $t(11) = 0.47$, $p = 0.65$. Despite the potential danger of being an invasive application, the system resulted in little intrusion to the home environment and was considered enjoyable to use by all participating families. To verify that these results are stable and to check for statistical significance for trends we observed that were not significant in this study, a large clinical trial would be necessary.

Too often iterative design is only used at the start of the design phase and stops at the deployment stage [Siek et al. 2014]. Beyond the research contributions stated earlier, this case study also demonstrates the importance of continuing the iterative design process throughout the research project. As a research prototype, the system had a few errors, which were minimal and eliminated by the end of the study. Although there was room for improvements with respect to how we designed, deployed, and evaluated, we benefited from sympathetic and highly motivated participants. This important driver to getting the work accomplished can also be seen as a limitation. Likewise, participants were compensated on a schedule that encouraged data collection at least once a week, potentially influencing how much data they recorded. Thus, future work requires not only the making of more robust systems for supporting pediatric care but also the evaluation of these systems over longer periods outside of an aggressive research study timeline and compensation schedule. Additionally, deployment of the system after 2 months at home missed a critical and extremely stressful time for families. In future studies, this time should be examined now that we have shown it to be feasible to deploy such a system when the families are relatively stable.

Finally, although use was sustained by participants across the 4 months of the deployment study, premature infants tend to stabilize over time even as their risk for long-term challenges remains high. Thus, one important goal of future work in this area must be to examine the potential for collection of data and support of early intervention on other disorders that can emerge later in childhood or even adulthood in the face of a context in which the urgency to engage in health-related activities and documentation has been diminished. Additionally, studying other transition situations in which caregivers must take a dominant role, such as in caring for older adults leaving the hospital and heading for hospice or home, might provide key insights into the generalizability of these designs.

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