

Improving Communication and Social Support for Caregivers of High-Risk Infants through Mobile Technologies

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ABSTRACT

Upon leaving the hospital, parents of high-risk infants experience a variety of challenges in providing care at home. In this work, we present results from a qualitative study to understand the role of social interaction and information-sharing surrounding high-risk infants among both home caregivers and health professionals. These results demonstrate challenges in communication and social support for caregivers of these infants. Based on these results, we present design guidelines for collaborative communication technologies for this population and a prototype system design that demonstrates how these design guidelines might be met in a mobile application. Finally, we discuss how collaborative technologies can serve to improve communication with professionals as well as provide much-needed social support.

Author Keywords

Collaborative health technologies, communication, infants

ACM Classification Keywords

J.3 Life and Medical Sciences (Health); H.5.3 Group and Organization Interfaces (collaborative computing, computer supported cooperative work)

General Terms

Human Factors

INTRODUCTION

Over the past two decades, the incidence of preterm births has increased dramatically and in 2002 accounted for 12% of live births in the US [14]. Furthermore, advances in perinatal care have improved the chances for survival of low birth weight infants [13]. Children with extremely low birth weight (ELBW) have been found to show significantly

higher rates of functional limitations compared with those in the normal birth weight range for eight year olds in the US [13] and Australia [2] and for six year olds in the UK [18]. Thus, an improvement in care for these high-risk infants is likely to reduce the incidences and burdens of other chronic conditions over time.

The birth of a high-risk infant can be traumatic for the families involved. Many are at high risk for complications, because they are born prematurely (<37 weeks total gestation) despite being otherwise healthy. In these cases, parents are often unprepared for the early birth. Some infants are born prematurely after showing signs of distress throughout the pregnancy culminating with a difficult birth. In other cases, the families learn only at the time of the birth that a substantial medical issue is apparent, either due to some inherent disability or to some occurrence during pregnancy or delivery. Immediately following the birth of a high-risk infant, the infant is taken from the parents and cared for in the Neonatal Intensive Care Unit (NICU) or some other hospital unit, depending on the nature of the illness. Stays in these units can last days or months, with parents returning to the hospital as visitors of their sick children and anxiously awaiting the day they can bring their children home. Upon discharge, the message of their children's fragility is once again driven home to parents as they are told what to do to care for them and how to document this care for the many specialists, pediatricians, and social workers they will see over the next several months [12].

The sheer volume of people, procedures, and data involved in the care of these infants after they leave the hospital creates challenges in communication amongst caregivers. Large amounts of health information are often stored and recorded by individual clinicians who cannot or do not share records. Thus, parents must bear the responsibility for sharing information between clinicians. However, it can be important for the long-term health of both the infants and their families to share information with other caregivers, clinicians, and their social networks.

In this paper, we present the results of a qualitative study focused on understanding the social, communication, and

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collaboration needs of parents, other family caregivers, clinicians, and non-clinical professionals (e.g. social workers). Our findings indicate that balancing effective and efficient means of communication along with providing control and feedback to manage privacy are important in persuading the diverse network of caregivers to use a collaborative technology, communicate, and share information. Additionally, social support, particularly integrating and providing easy access to existing social networks, is imperative to helping this population of highly-stressed caregivers. Based on these results, we describe a set of design guidelines for collaborative technologies for high-risk infants that can also be relevant for other collaborative health technologies. We outline the design of our prototype system, Estrellita, to demonstrate how these design guidelines can be satisfied for this population.

RELATED WORK

Related literature suggests that communication and social support are important for parents of high-risk infants. Support and social connectedness, in any form, can be effective in contributing to happiness and contentment, as well as the social and psychological well-being of people in general [5].

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 [8, 10]. Another study identified various communication types used by parents who had more successfully coped with preterm experiences [12]. In this section, we outline previous research on tracking and sharing data about children and the existing tools for social support for chronic illness.

Baby Steps, an application designed to act as a child development milestone repository, can be used to collect data, which can be used to foster communication and understanding. However, Kientz *et al.* reported that full-term parents had problems, with parents failing to consistently enter data [20]. Parents of high-risk infants, who carry a greater amount of stress and anxiety, would probably see similar or exacerbated effects. Though it is necessary to track health data, Kientz *et al.* warned that tracking certain data might also cause unnecessary worry from parents [20]. For parents of high-risk infants, this can be compounded by the already fragile state of the infant.

For parents of high-risk infants, because their situation is in many ways unique among their social networks, it can be challenging to find others who can understand what they are going through and can support them through that understanding. We define “social support” in relation to Barrera *et al.*'s 6 categories: material aid, behavioral assistance, intimate interaction, guidance, feedback, and positive social interaction [4]. Online communities have often been a place where people dealing with other chronic illnesses can find that kind of support [19]. However, there is, especially, a lack of online communities for parents of

high-risk infants. The online communities that are actually available are not always active, and therefore, are not very helpful for these caregivers. Furthermore, lower socioeconomic status parents, who make up the majority of our sample, do not have regular Internet access at home and must instead rely on other means of communication, most often SMS, local phone calls, and face to face contact. While some existing online resources¹ can provide information to concerned parents and allow them to share messages and experiences. Although these tools help parents find resources and advice, they do not allow any integration with their different social networks.

Several social networking sites have been proposed to help people with chronic diseases share their experiences and problems providing community support, motivational reinforcement, or encouragement for healthy lifestyles. Such an example is the online patient community, PatientsLikeMe, through which people with chronic diseases have an online community for both resources and for support [6]. Another example, Facebook, is already popular among parents of newborn children [11]. Thus, leveraging these types of existing systems can enable people to stay connected with their support system.

Beyond work focusing on supporting infants and children, there are a wide variety of efforts focused on motivating healthy lifestyles and supporting adults with chronic illnesses. *UP Health* is a collaborative system that allows users to share information about physical activity and smoking cessation [27]. This application allows users to challenge each other, send messages, and consult health information to decrease their smoking habits. Similar applications have been proposed to support patients with cancer, Crohn's disease, and other chronic illnesses. For example, *HutchWorld* [12], acting as a Hutch “portal,” provides tools for social interactions, access to information, and diversionary activities in conjunction with an online community. This system helped patients stay connected with family and friends and paired patients up with others, with similar conditions, who had experienced transplant procedures. Similarly, the Facebook Connect platform helps catalyze social support for breast cancer patients [26]. This application uses social networking tools to allow sharing of health information, status information, advice and other forms of social support, freeing patients to focus their attention on treatment and recovery.

Although these applications have shown that social support is crucial for people in these conditions, they do not include health providers in the equation, and patients have regretted the absence of them. In this direction, Sá and Carriço proposed a tool where patients undergoing psychological treatment are able to register and visualize different types of data such as thoughts, exercises, images, and sounds [25].

¹ <http://www.sidelines.org>; <http://www.prematurity.org>; <http://groups.yahoo.com/group/preemie-list>

Such information helps patients improve their adherence to the post-consultation activities, increasing continuity. Also, the tool includes mechanisms that allow therapists to introduce comments or triggers, helping patients maintain their activities outside consultation settings [25].

By providing different communication channels between health providers, systems can be used to persuade patients. pHealthNet, a persuasive virtual community, aims at promoting a healthy lifestyle in patients with chronic degenerative diseases that participated in a national program for the prevention of diseases, education, and self-care [14]. Through these methods, pHealthNet helps persuade patients to change eating habits and to increase physical activity. LotsaHelpingHands² also provides ways for patients to ask for help from their friends and family. A coordinator can work on behalf of the patient to create the helping community. Coordinators can request help that members of the community can see and sign-up for.

While not explicitly considered record keeping or a social networking site (SNS), blogging and micro-blogging, similar to status updates in popular social networking sites, affords users an easy channel to keep viewers updated with their lives and establish a feeling of connectedness with their viewers [22, 32]. Through blogging, a history is created that can be used as well. However, with such informal methods, the extent for which they could be clinically relevant is uncertain. Considering the positive effects of SNS and blogging, it is necessary to determine how to make content both clinically relevant and appropriate for friends and family.

Taken together, this work suggests that social support can be important for people with chronic illness, but that there still exists open questions surrounding the needs and comfort with sharing data for different stakeholders. Furthermore, the substantial challenges associated with communication and collaboration among families and professionals must be further examined in light of the development of new communications technologies.

METHODS

Over the course of several months, we conducted semi-structured interviews with 29 participants in Southern California. These individuals included 18 home caregivers³ with primary responsibility for caring for a preterm or high-risk infant (17 mothers and one aunt), all of medium to low socioeconomic status. Interviews were conducted in English (n=16) or Spanish (n=2) according to participant comfort and lasted between one to four hours long.

² <http://lotsahelpinghands.com>

³ For simplicity of reading, we will regularly refer to these individuals as parents. In our sample, in nearly every case, the mother declared herself as the primary caregiver responsible for documenting the infant's health and communicating this information with professionals.

All parents were interviewed in their homes (n=15) or in the hospital where their infant was born (n=3), as individuals (n=16) or in a pair (n=2). Interview questions included concerns about caring for their infants, their strategies for preparing for the birth and discharge from the hospital, quality of communication with various providers, strategies for getting help or finding information when needed, and considerations for the design of technologies to support their needs. Interviews lasted approximately an hour and were audio-recorded and transcribed.

Interview participants also included 11 health professionals⁴: pediatricians, nurses, psychologists, social workers, etc. The professionals were recruited from a state-funded high-risk infant follow-up program (HRIF) housed in a children's hospital or from the Neonatal Intensive Care Units (NICU) of that hospital and another nearby. The HRIF is responsible for state-mandated monitoring of the developmental and medical milestones of all high risk infants in the local geographic area as well as attending to parental health and well-being. Approximately 600 new infants and their families are referred there each year. The two NICUs each hold 20-30 incubators and have more than 100 nurses and several physicians working in each. They each admit somewhere between 300 and 500 infants in any given year.

Professionals were interviewed in groups when possible to support varied discussion amongst professionals with different backgrounds and expertise. Interview questions and topics included their perceptions of parental concerns, how to integrate data collection and sharing into the clinical workflow, and any other concerns the professionals had while caring for these infants and their families. Eight participants were interviewed in two focus groups (n=6 and n=2) and the rest (n=5) were interviewed individually. Among the individual interviews, two participants had already participated in a group interview but had more to share; three were not able to attend a group interview and so were interviewed individually. Group interviews lasted multiple hours and individual interviews one hour. Interviews were recorded when permitted and transcribed (n=8). For three individuals (one pediatrician and two social workers), we were not able to record the interviews, but detailed notes were taken for analysis.

Three of the researchers coded all of the interviews looking for emergent themes, confirmation of the literature on familiar challenges in caring for children with chronic illnesses or high-risk infants, and design recommendations. Returning to the interview data, the entire team then discussed these issues in detail and developed the design guidelines and ultimate design of our prototype system collaboratively.

⁴ For simplicity of reading, we will regularly refer to these individuals as professionals.

RESULTS

Our results show that communication activities vary widely among different populations – between parents and other secondary caregivers (e.g., mother and father, or mother and grandparent) as well as between parents and professionals. This variation is inherently challenging for already stressed parents to overcome and can result in misunderstandings and missed information sharing opportunities. Additionally, our results indicate that parents have a substantial need for social support, especially immediately after discharge from the hospital and that the needed support is often limited or absent.

Types of Communication

Sharing health-related information can be important for the care of high-risk infants. This communication happens both within the home and between the home and clinical settings.

Within-family communication

Multiple people in one family may care for an infant (e.g., mother, father, grandparents) all with their own beliefs about what is important to document and communicate. For example, one mother mentioned that she cares the most about when the infant slept or ate. Her husband, “*sometimes asks whether the baby slept and ate, but he asks more about the bowel movements and as to why [the baby] is so constipated*” [P-15]. This disparity between what an individual finds to be important or interesting can also affect communication between parents and professionals. Parents share with professionals the information that parents find interesting and may neglect what the professionals want to know either because the parents did not know it was important or because they knew but were not interested.

Likewise, there are cases in which one parent is not physically present and thus, relies on the other parent to relay information. For example, “*If [the baby] does something, my husband lets me know right away.*” [P-16]. Much like patient hand-offs in a hospital [2], substantial information may need to be communicated within a family (or to and from a nanny or babysitter), but most families have developed at best *ad hoc* solutions for these challenges, occasionally putting their infants at risk for rehospitalization (e.g., when a medication dosage is missed or bowel movements have stopped without the caregivers recognizing it).

Parent-health professional communication

Many of the parents in the study expressed the desire to communicate with professionals in different ways. For example, one mother noted that it, “*would be convenient if the doctor had an email where you could just send a picture or a question*”, but recognizing that professionals also have demanding schedules, added, “*I’m not gonna’ call the doctor and sit and wait for them to call me back – sending an email, we’re all prepared to wait for an answer*” [P-13].

All parents we interviewed, spoke about wanting to be able to have some kind of communication with professionals when unanticipated problems arise. However, the professionals we interviewed, particularly pediatricians, described time and billing pressures, noting they do not have the time to respond to these alerts. Another challenge to communication between parents at home and professionals can be the pressure of the rapid synchronous conversations that occur during the appointment. For example, one nurse explained that a pediatrician, on average, sees 30 children a day and that:

“[In order to really assess them], you would have to spend half an hour to 45 minutes with each one of these kids...but they have to see five or six kids in that same hour” [P-22].

This has been echoed in previous work that has found that a visit duration of a patient with a family physician lasted for only 10 minutes [24]. This synchronous communication can only allow the parent to convey information that they remember at that specific time of conversation. Allowing for asynchronous communication, during which parents can communicate information to the professional when the activity is happening, may enable professionals to gather much more information to make better assessments.

Barriers to Communication

There are substantial challenges to communication and sharing of health-related information. Different stakeholders may have different expectations about the information being shared and even the sharing practices themselves. Furthermore, our results indicate that health literacy and language barriers are substantial challenges in pediatric care, particularly for high-risk infants.

Gathering and communicating accurate information

Professionals report that accurate and complete information about infants is essential to their ability to provide high quality care. However, massive amounts of data are generated and stored about these infants at home, in various clinical settings, and so on, making a holistic view of the health of the child very difficult to obtain.

The medical fragility of these infants necessitates that most see multiple professionals. Even in integrated healthcare systems, transferring of records and commentary among these professionals is imperfect at best. Thus, parents are often relied upon to communicate information from a specialist to a general pediatrician, and so on. This situation inherently engenders a sort of medical version of the game “telephone”, in which the end message after numerous transmissions can be quite garbled, making it difficult for a professional to trust the information and overwhelming parents who reported already feeling beleaguered by the amount of medical jargon and diagnostic and treatment information they are to remember. For example, one nurse mentioned that:

“the parents will just say, ‘The doctor said their eyes are developing fine’, but we don’t have proof and so we’re basically taking the parent’s report as fact” [P-19].

These results are in line with other studies in which clinicians reported being apprehensive to use patient-provided information due to potential discrepancies between prescribed treatments and parental knowledge of these treatments [7].

In our study, caregivers often described methods of recording information that may not match the expectations of the professional to whom they are providing the information. For example, one mother explained:

“if I know I’m going to the doctor and I know they’re going to ask me that question, then I start keeping track...sometimes, I try to feed right before [the appointment] so I can have an accurate [feeding] time” [P-11].

These data, then, suffer from recency effects of which the professional may have no knowledge.

Language and literacy

Health literacy and language can be significant barriers to parent-provider communication [23]. Approximately 30% of the high-risk infants in our geographic area are born into what are called Spanish-language households, meaning that no adult in the household speaks English well enough to have a medical conversation without a translator. Another large proportion of the households are English as a second-language households, in which the primary language is Spanish, Korean, Vietnamese, or some other language. Although mechanisms are in place to provide translation services when needed, parents may not request them. For example, one mother explained,

“[Clinicians] do explain [the terminology], but I don’t understand, and I’m embarrassed to ask, or sometimes the doctors don’t speak Spanish” [P-16].

This statement hits on two important points. First, the language barriers for this population are enormous, but second, even parents who speak English or have a translator may have low health literacy and not understand the medical jargon being used. This result echoes what is seen in the literature for other populations. For example, in one particular study, many patients (regardless of their native tongue) could not even read the instructions on their medication bottles, let alone explain how to take their medication correctly [24]. In another study conducted in a United States hospital, 42% of the participants could not understand instructions on a medication pill bottle, 43% did not understand some sections on a Medicaid application, and 60% could not understand a standard consent form [19].

Similarly, one professional described the challenges faced by parents who need to feed their high-risk infants a special formula for their particular needs:

“they get taken off their premature formulas because [the parents] don’t know how to get the formula, or they don’t really understand why they need to have that different formula” [P-22].

The challenge of finding and procuring the special formula may prove to be too great for already stressed parents, and their limited understanding of the differences between it and “regular formula” can result in the infants being misfed, which can negatively affect the infant’s weight gain.

Effective care requires effective communication between the professionals and parents. However, our results indicate that substantial language and literacy barriers prevent communication among these groups from being effective. Thus, there is an opportunity for collaborative technologies to provide support for multiple languages and multiple levels of health literacy.

Social Support

In addition to needing effective communication with professionals, caregivers often need additional social support from their existing social networks, emergent networks of peers who also have high-risk infants, and professionals. In this section, we outline the current practices and challenges surrounding social support.

Support from existing social networks

A substantial challenge for parents is overcoming their feelings of fragility and “differentness” about their infants. The complexity of the infant requires them to incorporate substantial medical care at home along with more typical parent-infant bonding activities. However, this situation can lead to parents focusing too much on one piece of this care at the cost of another. For example, one parent explained how fixated she was on her infant’s weight,

“everyday you’re asking ‘What’s their weight? What’s their weight? What’s their weight?’ because you want them to gain weight” [P-13].

For these parents, receiving social support from others can help overcome these concerns. As one clinician pointed out, sometimes “[caregivers] hear everything that’s wrong with their child, and they don’t have enough of the [support]” [P-20].

Despite being told to reach out for social support, parents in our study often described struggles to reconnect with existing social networks. Parents can simply be too busy and overwhelmed with care for their newborn, and though they want to be able to share information about their infants, it can be too time-consuming. For example, one mother delegated the task of sharing information with her family onto her father:

“my guys were in the NICU, and my dad sent out a daily email to all my family and friends about, kinda, what was happening, and the status and everything, but now, actually, he still does that for me because I don’t have time” [P-18].

Many parents resisted support from local friends and family in the form of visits out of fear of exposing their infant to germs from the outside world. Furthermore, geographic distance and unfamiliarity with the specific concerns of caring for a high-risk infant can further limit the amount of support that can be provided by friends and family. In some cases, families were spread across multiple countries, but the parents still described wanting to stay in touch regularly, creating workarounds if access to their family was not simple. For example, one parent described the challenges in communicating with her family in another country:

“Our family is far away – we are from Oaxaca [Mexico]...the town has no phone except for one in a little store, so I call the store to my mother, and she goes to the little store and I have to dial again...I tell [the baby’s progress] to my mother, and she tells the rest of my family” [P-15].

This issue demonstrates the necessity that many parents feel, regarding the support they receive from their family members. This also shows that many parents may not feel the support that they need where they are located, pushing them to try to receive the support in other familiar places, even if that requires a great deal of work. Many parents also feel that the social support should be a two-way street, stating that communicating often with their family keeps the family calm and can help the parents at the same time. Finally, parents also used this communication for social support as a way to ask family members for advice. For example, a parent explained that the reason for communicating with their family was *“to give them peace of mind and also to listen to their advice”* [P-16].

These results indicate that despite numerous challenges, both caregivers and professionals recognize the importance of support from existing social networks. Thus, collaborative technologies can in part meet these needs through integration with existing tools and practices.

Support from peers

Parents also receive support from other parents who are in similar situations. For example, at one of the hospitals in this work, there is

“a group called Mommy and Me...we make sure that [the caregivers] are connected because these kids do have disabilities. It’s better that they’re paired up with other families who are really a support system” [P-20].

With these kinds of hospital-based programs, parents can meet other parents who are in similar but often somewhat unique situations. For example, fathers may be absent

entirely from the household or if present, feel less central to the care process. For those who do become highly involved, their relative uniqueness can cause discomfort. One professional described such a case surrounding a man involved in a support group for nursing mothers:

“A couple months later, we had another dad that came into the clinic. So, very informally, we were able to connect the two together and they had their own way of supporting each other” [P-20].

Parents often look for social support from their peers online. One mother explained,

“There’s actually a lot of [forums] on, like, Babycenter.com. They have tons of the forums for the mothers of premature babies, and they give their experiences, as well as their opinions, on different things that they did in the unit for them. But everybody has their different opinion mainly because premature babies are different” [P-13].

While some parents are able to find these people, it can also be difficult for others to find people that are in similar situations. For example, a parent of an infant with a vision condition may not find the experiences and opinions of a parent of an infant with a digestive problem useful.

Support from hospitals and professionals

Because of the vast amount of time spent in the hospital, parents often receive support through the hospital and through professionals as well. Every parent interviewed mentioned getting to know the hospital professionals well during their stay. Most also noted that they either already had or would not hesitate to call the professional if there was a problem with the infant. Similarly, one NICU social worker mentioned this practice as a problem for the professionals in their unit. They prefer the parents to try to foster new relationships with regional centers and not to remain dependant on the NICU:

“You gotta know you have limits... and people have to move on. Right behind them, we get new patients” [P-27].

These results indicate that collaborative health technologies for this population should help ease the move from the hospital to outpatient caregivers.

Current Social Media and Communication Practices

Parents described using a wide variety of communication channels currently to share information and milestones with family and friends, regardless of their location. Unsurprisingly, all parents said that they regularly shared photos of their infant with their family and friends, either online or printed. Many parents also reported using social networking sites (e.g., Facebook, MySpace, My Yahoo!, etc.) to stay connected with their friends and family.

However, parents often have varying audiences in their social networking sites. Privacy, control of data, and self-

presentation can be important issues when sharing and communicating personal information [25]. In particular, a child's personal health information is protected legally in many countries and could have bearing on future consequences for the infant that cannot yet be predicted. Therefore, the ability to control the information being shared, based on the parents' preferences, is important. For instance, one parent mentioned that she would want control over the videos shared, saying, "you don't want to send all the videos [via Facebook]" [P-17].

In another example, a parent mentioned that she used Facebook as well as MySpace, but noted that MySpace was, "only for friends, so then I'll post what his latest accomplishments have been" [P-13]. Using these social networking sites allows parents to stay in touch with friends and family even during the early weeks of having an infant at home when they are often wary to go outside or let many people into their homes for fear of infection.

As mentioned in the previous section, for those families with computing at home, email and Skype were additional tools for staying in touch with their families at a distance. For example, one parent mentioned: "my family is in Russia, so they're not anywhere close to me, so most of the information that we share is through Skype" [P-17]. Through this approach, grandparents were able to see videos of the infants. These different forms of media provide the ability for the parent to share information about their infants to their friends and family, while also receiving the crucial social support that they may often need.

DESIGN IMPLICATIONS

Collaborative technologies have the potential to improve both communication and social support for parents of high-risk infants. The results of this work lay a foundation from which many further research questions around communication between the home and the (multiple) clinicians' offices, and between the caregiver and their social network (e.g. family, friends, etc) can be addressed. In this section, we present the key design requirements for these types of technologies as well as an example prototype system, Estrellita, derived from the design guidelines. This prototype design demonstrates a possible solution for the needs of this population and makes concrete the design guidelines presented. Estrellita includes a mobile application that parents use to track and share information and a web interface parents and health professionals use to view and analyze the resulting data.

Using Social Networks for Motivation, Reinforcement, and Advice

Caring for a high-risk infant is an emotional and stressful undertaking for parents, which can disrupt existing personal relationships and negatively impact their own health. Chronic illness in children, such as high-risk infants, typically requires the family to play a more significant role than in other kinds of chronic illness [13]. Family members jointly suffer from time spent away from school and work,

loss of sleep and time spent in transit to or at physicians' offices and hospitals [29]. From our study, we found out that new parents of high-risk infants need social support for motivation, reinforcement, and advice. Estrellita focuses on motivating parents to collect information and giving them the ability to easily share that information with social networks and professionals. Collaborative systems used for sharing information (e.g., photographs, milestones, etc.) should provide communication tools allowing parents to share information with their social network, including both parents and others who may be geographically near or far, who can then provide these forms of social support. In order to address the issue of sharing with the appropriate audiences, we integrated several services into Estrellita: social networking sites such as Facebook or Twitter, personal health record systems, and our own databases to separate the appropriate information. Parents can change settings that govern what information to forward to the various connected services, and optionally send any non-shared item to wherever they want.

In addition to the health related data that parents opt to share with their social networks, they are also able to enter specific information or milestones that they may want to share with their social networks through Estrellita to additional outlets such as Facebook or Twitter. Their social networks can give the necessary social support based on the shared information [Figure 1].

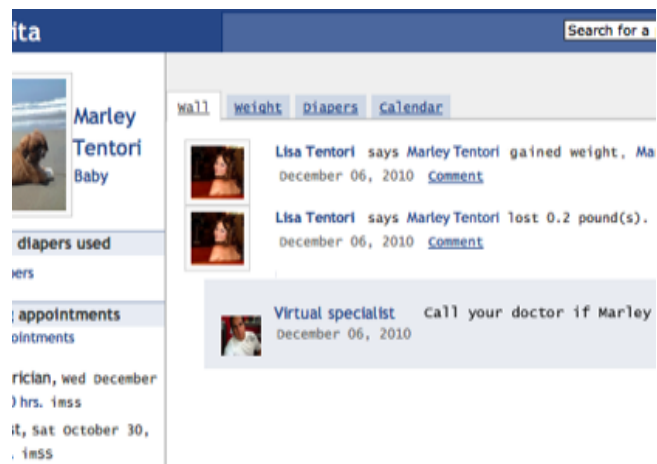


Figure 1. Prototype screenshot of Estrellita that allows parents to share specific information to their social network.

Balancing the Needs of Various Stakeholders

Collaborative systems for high-risk infants should provide access to the collected data at various levels of abstraction. We found out from our study that the information should be appropriate for the different needs of the audiences attempting to make sense of the data stored in these systems.

For example, parents might want to see a detailed daily summary of everything they did with the infant. On the other hand, a pediatrician is likely to want a summarized

view of the progress, set against gestational-age adjusted population charts. In both cases, the person viewing the information may also want to “drill down” into the details of the collected data and develop a deeper understanding of the information. Estrellita allows for multiple views to be generated, depending on the preferences and needs of parents and professional caregivers. For example, a parent may rather look at information daily whereas the professional may prefer seeing the information in a summarized manner [Figure 2]. To handle the varying needs of professionals as well, a variety of charts based on the data are available.



Figure 2. Prototype screenshot of Estrellita (in a professional caregiver’s viewpoint) of a summarized visualization of weight and diaper usage. Between 7 and 7.5 pounds is the “green” range to indicate success.

Our results show that while there are some online resources available to parents of full term and preterm infants such as Babycenter.com, it can be difficult for parents to find online resources that are more specific to their cases. Thus, we need to be able to support the wide variety of high-risk infants. By specifying certain requirements (e.g., five weeks premature with a vision condition) for online resources, parents will be able to find things that are more applicable to their certain situation.

Similarly, to help parents with finding the appropriate information, it would be useful for a system to automatically retrieve appropriate news, books, articles, and websites depending on each infant’s health needs to help caregivers discuss specific issues with their clinicians. This information can be used as an agenda for communication between parents and professionals.

Reducing Language and Literacy Barriers

Many families of lower socioeconomic status (SES) can have language barriers and reduced health literacy, which are significant challenges for parent-professional communication [23]. Language barriers can be detrimental to the communication between parents and professionals. Despite the existence of translators, these challenges continue to exist, particularly for parents who are embarrassed not to speak English. Collaborative technologies should be able to support the various

languages that make up the population being targeted. Low health literacy, regardless of language, creates additional challenges. Collaborative systems therefore must include some level of personalization that allows for translation of medical terminology into something understandable by the general public without diminishing the power of the systems for professionals. In Estrellita, one way we make the system more accessible to parents of low health literacy is to present data points using a traffic light analogy: red when an alert is urgent, yellow as a warning and green for success, as one way to address the issue (Figure 2). In this way alerts are highly visible and understandable to parents and in some cases, impossible to continue if unacknowledged.

Balancing Work and Benefit

The disconnect between who collects the data and who benefits from it can be profound in caring for high-risk infants, echoing the canonical challenge of balancing who does the work and who gets the benefit [16]. Parents may be tasked with collecting and reporting data but have no means for understanding it themselves. Thus, collaborative systems for collecting and reporting health information should enable automatic collection of data when possible and respectfully and flexibly schedule the frequency of data entry from parents.

Because these technologies will be used in the home by stressed and busy parents, they must be unobtrusive and be able to fade into daily life. Thus, when possible, tools should automatically collect the information of interest or provide easy methods to enter information. Estrellita uses two simple computer vision techniques to read the numbers from the scale when the parent weighs the baby and to read the feces percentage color when the parent takes a photo of a diaper. This solution provides an easy and automated method for information capturing.

These systems should also use data collection as a means to reduce parental stress and anxiety when possible. To help prevent fixation on unnecessary data capture the system should set and inform normal limits and acceptable fluctuations in data.

Provide control and feedback for managing privacy and uncertainty of shared information

Collaborative systems for sharing information about high-risk infants should provide mechanisms that allow parents to control the type of information shared, the mechanism by which it is shared, and the people to whom it is communicated. Control mechanisms can be incorporated that provide preset profiles or alternatively, real-time configuration to allow parents to make these decisions manually at the time of data capture.

Although unobtrusive sensing and monitoring can reduce the burden on parents to document information of interest to other stakeholders, automatic documentation can be error-prone. Therefore, applications for caring for high-risk

infants that automatically monitor information should take into account the level of uncertainty and display this information to caregivers and professionals. By understanding the potential margin of error, both professionals and caregivers can adjust their decisions and responses according to the potential implications of these values.

Uncertainty notification can be used to inform users of the level of uncertainty of a specific data point. One possible way to implement this principle is to manipulate the interface by including notification cues, conveyed in several manners such as sounds, visual cues, and the direction of gaze. These cues influence the users' perception of the information shown to them. Another way to provide awareness is through feedback. A system with *uncertainty feedback* can notify the user of the presence of uncertainty and provide mechanisms for them to deal with such uncertainty.

In Estrellita, to avoid errors, the estimated value is shown to parents so they can confirm if the data estimated by the system is correct. Alternatively, if parents detect an error, they can manually change the value. This approach opens an avenue of research for the potential to detect outliers automatically after a training period, which we will evaluate in the future to further automate this data collection.

CONCLUSIONS AND FUTURE WORK

Parents of high-risk infants face immense challenges while caring for their children at home. Although collaborative systems can be helpful in supporting this population, to date, little has been done to support their particular needs. In particular, in this work, we were focused on the design of mobile social and collaborative technologies that support channels of communication while building social support for parents of high-risk infants. We have presented the results of a qualitative study to understand the role of social interaction between parents of high-risk infants and professionals as well as among their social networks. Our results indicate that parents communicate with a wide variety of friends, family members, and professionals through a variety of channels. However, substantial barriers exist to making this communication as effective as they might like. At the same time, gaps in social network communication exacerbate feelings of isolation and loneliness for parents who already feel "different" due to caring for a "fragile" infant. Lack of communication between parents and professionals may also lead to mistrust, causing reduced quality of care for the infant. Collaborative technologies can address these issues by supporting health literacy, translation and language issues, and integrating new communication practices with existing tools and practices.

Based on the results of our empirical study, we presented design guidelines to support effective communication and promote social support for this highly sensitive and vulnerable population. These design guidelines were used

in our development of a prototype system, Estrellita, which we also present here. However, these guidelines can be useful in the development of related mobile social applications to support other caregivers of children with chronic illness and perhaps parents of healthy infants.

In addition to making contributions to our understanding of this population and the potential for the design of collaborative technologies to support them, this work opens new questions and avenues for research. There is still much more to be understood about the challenges of parent-provider communication, particularly for low-income and non-English speaking populations in the US. Furthermore, the personal and cultural context of use is likely to impact the way in which these technologies are adopted and used in homes. Thus, we must deploy these technologies and measure their effectiveness in promoting the kinds of health outcomes we envision as well better understand the ways in which they enable both existing and emergent communication and data sharing practices in use. Finally, these tools must inherently be embraced and used by both parents and professionals to be successful. However, many of the personal health information tools available have not yet been incorporated into the clinical workflow. Thus, open questions exist surrounding how professionals might actually use these applications and the health information they access in practice.

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