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ORIGINAL ARTICLE

Supporting the transition from hospital to home for premature infants using integrated mobile computing and sensor support

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Abstract This paper reports on the requirements for, design of, and preliminary evaluation of a novel pervasive healthcare system for supporting the care of premature infants as they transition from hospital to home. In support of this system, we report the results of gesture sensing in a clinical setting and of interviews and focus groups with caregivers and clinicians who are involved in the postnatal transition to the home. From these results, we developed prototype systems for monitoring and tracking observations of behavioral and health-related data in the home, including a mobile phone-based capture and access system for caregivers, a sensing platform, and an activity recognition algorithm for automatically documenting infant movement. We describe the results of preliminary trials of both systems with an emphasis on the synergistic importance of bridging this transition. The results of these trials indicate that clinically relevant monitoring can be accomplished in the home, but there is still more to do to integrate these approaches into a comprehensive monitoring system for this population.

Keywords Capture and access · Activity recognition · Premature infants

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1 Background and introduction

Mobile and ubiquitous computing technologies can be applied to the care of preterm, low-birth-weight infants to reduce the burden of chronic illnesses over their lifespan. This line of research follows directly from a trend in the ubiquitous computing community to apply mobile and ubiquitous computing technologies to chronic healthcare (for example, [2, 33, 34, 45, 53]. Chronic health conditions typically include all impairments or deviations from normal [58] that last three or more months [55]. The long-lasting nature of these illnesses makes record-keeping and long-term analysis of diagnostic and evaluative measures both important and challenging. Not only must symptoms, interventions, and progress be documented over very long periods of time, but also they must often be recorded in the middle of everyday life, while accomplishing other goals and doing a wide variety of other activities. For parents of high-risk newborn infants, such as those born with low birth weight, these activities include the mundane (e.g., bathing, diapering, feeding, and so on) as well as the remarkable (e.g., use of specialized breathing machinery for infants with poor lung development, visits to numerous specialist physicians, and so on). Capture and access [1, 68] and activity recognition technologies [54] are particularly promising for lifelong diagnosis and monitoring of chronic conditions [2], because they automate aspects of data collection and interpretation that can be particularly challenging for parents and other caregivers. Furthermore, health and behavioral data can be captured, analyzed, and mined over the life of the child, providing valuable evidence for tracking the progress of behavioral and pharmaceutical interventions [33].

In this work, we were interested in how these technologies might usefully be applied to the care of infants at high risk for chronic illness. Many definitions are used for chronic health conditions in childhood [69], but for the purposes of this paper, a chronic health condition is one that is physical or neurological in origin, lasts for an extended period of time, brings about significant change in the life of the child, and requires more than the usual amount of care (Council for Children and Adolescents [19]). Children born with low birth weight (LBW)—typically, born prematurely (born at less than 37 weeks of gestation)—are an important population to consider as a step in tackling the broader issues of chronic childhood illness. As a broader healthcare trend, over the last three decades, the incidence of preterm births has increased dramatically in industrialized countries [29] and in 2002 accounted for 12% of live births in the US [32]. Furthermore, advances in perinatal care have improved the chances for survival of low-birth-weight infants [8], thereby placing us on a trajectory to have an even greater number of sick infants need to successfully transition from a hospital than ever before.

These infants present four substantial challenges. First, they are at higher risk for lifetime chronic illness [31]. Second, chronic illness, if contracted and survived in childhood, is with the patient for many more years than chronic illness that begins in adulthood. Third, chronic illness in children typically requires the family to play a more significant role than in other situations [26]. This effect, while seen in children of all ages, is particularly profound in newborns, who have minimal communication and self-care skills. 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 [65]. Finally, children who were born prematurely show significantly higher rates of functional limitations [8, 31]. Furthermore, in Hack et al.'s study, 64% of LBW children at age eight demonstrated one or more limitations, including conditions such as asthma, cerebral palsy, impaired vision, and cognitive and social disabilities [31]. Weight gain is a critical determinant of healthy outcomes in premature infants, and many researchers and clinicians argue that improving weight gain and other measures early can lead to long-term improvement in health status. Assisted movement can improve outcomes related to weight gain in the hospital setting [42]. Movement and massage studies in humans and handling experiments in rats suggest that these types of interventions lead to a more general increase in physical activity and thereby help explain the accompanying effects on body composition [70]. Thus, in this work, we were interested in using technologies that would support increased movement as infants move from the clinical to the home environment.

One of the primary limitations in delivering care for this population, however, is the pressure for discharging these very expensive patients from the hospital to the home. Time spent in the hospital and away from home is a burden to parents who want to bring their new children home, to the healthcare system with its limited resources for clinical care, and to the infants who may have trouble bonding with parents and other caregivers in the hospital environment [16]. Once home, parents can find caring for their children challenging and communicating with clinicians, friends and family about their children even more so. Thus, advances in the design, development and deployment of ubiquitous computing technologies that support the treatment and monitoring of infants as they move between formal and informal care environments are critical to quality long-term care while also supporting efforts to reduce hospital stay length.

In this work, we focused on addressing two major challenges associated with caring for premature infants. First, the development of novel capture and sensing technologies that enable improved record-keeping in terms of both the burden of collecting records by parents and clinicians and the reliability and accuracy of collected data. Second, novel visualization and analysis techniques that support the understanding of these interventions both in the short-term, to support testing of clinical efficacy, and over the lifetime of these patients whose chronic conditions can span several decades. In this work, we focused on addressing these challenges for one specific domain to demonstrate the potential that continuous data collection technologies have for addressing the chronic healthcare needs of children generally. Although we only address the synergy between one clinical and one home application, the creation of this platform is an enabling step toward understanding and addressing the potential of mobile and ubiquitous technologies for bridging clinical and home healthcare.

The remainder of this paper is structured as follows. In section two, we outline some of the related work in ubiquitous computing technologies for monitoring home health, including those specifically focused on children. In section three, we outline the methods we used in this method for collecting and analyzing empirical data as well as for designing our prototype solutions. In sections four and five, we describe our prototype systems and preliminary evaluations of their use. Finally, we close with a discussion outlining an integrated path forward for technologies that focus on home sensing of clinically relevant health data.

2 Related work

Over the last decade, mobile and ubiquitous computing solutions for healthcare have become increasingly prevalent in both research and commercial efforts. These systems and applications have the potential to improve patient care and the efficiency with which it is delivered. In practice, the majority of research in pervasive computing technologies for healthcare has been focused on hospital work (e.g., [3, 4, 7, 10, 11, 15, 20, 23, 59, 61, 62, 66]. However, hospitals are just one of many locations where novel technological interventions for healthcare are needed. In particular, when considering chronic healthcare management, opportunities exist for extending applications and systems outside of clinical settings.

Of particular interest to this work are projects related to enabling families to cope better with the chronic illness of a child [37]. Findings indicate that families are better able to manage their joint healthcare when they are educated about a condition and involved with the management of it [21, 71]. In part, this education may decrease stress and anxiety for the caregivers as they become more expert and involved in the care [21, 38]. Furthermore, greater education and involvement in care correlates with higher rates of compliance with treatment regimens [21]. These results are compatible with research that suggests adult diabetes patients believe themselves to be more in control of their disease and are more compliant toward treatment when better educated and able to test data about their health themselves [45]. They also further support our interest in developing recording and analysis technologies that integrate parents, families, and other caregivers in understanding and treating the conditions of pediatric patients. Thus, in our work, we sought not only to involve parents in the care of their children and documentation of their children's progress but also to develop technologies that could be understood by parents while being clinically relevant.

In response to this growing concern about chronic health and the forces that are moving care out of the clinic and into the home, major research efforts have focused on "smart home" technologies (e.g., [22, 36, 40, 44]. Many of the home applications of these ubiquitous computing systems center on concerns about medication compliance and adherence (e.g., [39, 43], or monitoring and logging daily behaviors [47, 56] to support wellness over time (e.g., [5, 17, 48, 50, 60, 67]. Across all of these application areas is a general research question about the acceptability and usability of these technologies in homes and other personal areas necessary for healthcare monitoring [12], Consolvo and [67]. In this work, we build on these related projects to develop and apply ubiquitous computing solutions to the problem of caring for premature infants from the time they are discharged from the hospital through the toddler years, including monitoring specific behavioral interventions that may have begun in the hospital setting in an effort to decrease the barriers in transitioning from hospital to home shortly after discharge and between home and clinical settings throughout the first years.

3 Methods

We used a mixed methods approach to understanding the needs of parents, family members, and clinicians caring for premature infants. We began our investigations by interviewing mothers of premature infants. We then designed and tested various concepts with an expanded set of stakeholders using a participatory design approach [49]. This entailed bringing computer scientists, designers, nurses, an occupational therapist, a pediatrician, and a medical student together for working meetings. We interviewed caregivers and clinicians to assess their comfort with our approach, understanding of the technologies, and considerations for future designs, including that of an integrated comprehensive monitoring system for preterm infants moving from hospital to home. Finally, we developed our prototype systems and tested them for preliminary understanding of their efficacy and appropriateness for measuring and documenting particular concerns in this domain. In this section, we describe the details of the methods we used during each of these phases.

3.1 Initial interviews

Thirteen mothers, ranging in age from 19 to 47 years old, with infants of mean gestational age of 30 weeks were interviewed (2 Spanish, 11 English). In these interviews, we were concerned with not only understanding how novel technologies might enable the transfer of interventions from the hospital to the home, but also how these technologies might be designed in a culturally and personally sensitive manner. Only mothers were interviewed, because in all of the cases, the mothers described themselves as the primary caregivers, a situation that is typical for infants but particularly for premature infants. All interviews were conducted individually for approximately 45 min and were later transcribed and analyzed. The interviews were semi-structured in nature and covered a range of topics including feelings about various physical and behavior interventions, monitoring of their activities in the home, fears and concerns about bringing home their premature infants, and other considerations in daily life.

We also conducted interviews with eleven professional caregivers spread across two focus groups and one phone interview, emphasizing their comments and concerns with regard to their role in an assisted exercise intervention. These caregivers included researchers, three nurses, two physicians, an occupational therapist, and two social workers. They were all recruited through association with the neonatal intensive care unit (NICU) at the University of California, Irvine Medical Center (UCI MC).

3.2 Participatory design

Following these interviews, professional caregivers were integrated into a participatory design team focused on developing prototype technologies for the concerns that were most prevalent in our initial interviews. Over the course of several months, we iteratively designed technologies to address two primary problems associated with the care of premature infants:

(1) Tracking and measuring infant movement without manual observation and record keeping, because spontaneous infant movement can be a significant indicator of infant health in the clinic and at home; and.
(2) Enabling parents and other non-professional caregivers to track and measure a variety of data about infants at home, because data collected after discharge can demonstrate long-term health indicators and risks for chronic conditions.

The team, including both clinicians and computing researchers, met nearly weekly discussing a variety of issues related to infant health and care at home and in the NICU. The technological systems were discussed in particular at one meeting per month, during which time, the designers would present new versions of the systems that had been developed throughout the month in cooperation with various members of the team. Brainstorming new solutions, critiquing, and designing new versions of existing solutions were encouraged during these meetings. Extensive notes were taken and design artifacts collected both to supported continued design and for analysis of the process and in particular, the clinician roles in that process. These design sessions ultimately resulted in two functional prototypes, which we describe in this paper and which were evaluated individually but analyzed collectively as part of this work.

3.3 Evaluation of prototype systems

We evaluated two prototype systems—one focused on automated gesture recognition of infant movement and one focused on home-based record-keeping—in the hospital or in the home as appropriate for the particular applications. The details of these evaluations are described in the following sections in relation to the specific solutions. We conducted a component-based analysis for each issue (automatically sensing infant movement and home-based record-keeping) and have left the validation of the end-to-end system and hypothesis testing to future work. We evaluated each system with 10 infants (non-overlapping samples). Following our evaluations of these prototype systems, the research team collectively analyzed the results of the formative studies, records from design sessions, and newly collected health and interview data from these evaluations to define a set of design guidelines for a comprehensive home monitoring solution for premature infants, described in section six of this paper.

4 Automated involuntary gesture recognition

In newborns, levels of motor activity may reflect neurological development and/or integrity. Both decreased spontaneous movement (hypotonia) and excessive spontaneous movements (seizures) in newborn infants are associated with poor long-term outcomes [14]. A major concern to all pediatricians and parents regarding the introduction of any new intervention for premature infants will be to what extent the intervention influences neurobehavioral development. The Automated Involuntary Gesture Recognition (AIGR) System allows for quantitative measure of infant movement.

AIGR is an accelerometer-based logging system we developed that uses a custom light-weight accelerometer called the Eco [52]. The Eco can measure acceleration along three axes from −3 to +3 g and is light enough to be placed on a premature baby (<2 g) to measure changes in movement. The device is wireless and transmits its signal up to 10 m on the same band as Bluetooth but using considerably less power. One computer can receive the input from up to 50 devices, and the standard battery lasts 90 min while sensing at full capacity. Although not utilized in our studies, temperature and light sensing are also available on an Eco.

Current approaches to movement quantification and neurological examination involve directly observing or videotaping subjects for variable periods of time (up to 24 h) and qualitatively analyzing movement using validated movement scales. This method requires extensive expert time coding the video and is prone to observer fatigue. In our previous studies focusing on natural patterns of physical activity in 6- to 8-year-old children, it was shown that with 3-s observation, a typical observer needs a substantial break after approximately 20 min [9]. Moreover, attempting to quantify the seemingly chaotic activity of 4 limbs alone in a preterm infant by direct observation is a challenging task, even for the most focused and adept observer.

We hypothesized that AIGR could eliminate the need for low-level human analysis by using a computer algorithm to quantify and categorize the pattern, relative strength, and frequency of preterm infant movement during the period of observation that is as good as or better than human video coding. This system has the additional benefit of being deployable in a home setting as well, core to our goal of bringing clinically relevant sensing and record-keeping into the home post-discharge. To validate this system's value in a clinical setting, we collected a dataset of premature infant movement that could be subjected to a variety of analyses.

We screened the medical records of infants in the NICU at UCI MC and recruited preterm infants with a gestational age at birth of between 23 and 36 weeks and no skin disorders, which could be exacerbated by wearable sensors. The parents of 10 premature infants enrolled their children in the study.

All infants were monitored by 4 accelerometers and a video camera for 1 h at 30–43 weeks corrected gestational age in their isolette wearing only a diaper and with all swaddling removed (see Fig. 1). Each accelerometer measured 3 orthogonal axes of acceleration on the head and each of the 4 limbs, while a video camera was recording data for manual motion scoring. The accelerometers were embedded in cloth bands that were placed around the wrists, ankles, and forehead of the infants. The orientation and placement of the sensors is critical for inter-baby comparisons. Thus, we developed and enforced a consistent sensor orientation relative to the baby's limbs. This orientation was understandable by clinical staff who assisted in placing the devices on the infants, and our instructions for this placement are likely to be understandable by trained parents or community health nurses in a home setting. Accelerometer samples were made non-uniformly at approximately 19 Hz.

Fig. 1 Baby being monitored by 4 Eco accelerometers in the NICU (identified by the *white circles*)

We conducted two experiments using AIGR to collect data with the 10 enrolled infants. The first experiment involved confirming that AIGR was as good as human video assessors at assessing motion in the hospital setting. While this evaluation may seem counterintuitive to the ubiquitous computing community who might treat the sensors as being ground truth, the medical community established human video coding before sensing was available at this scale. Thus, using established, published, and validated procedures, a nurse manually scored the videos for periods of infant activity using the 4-point Giganti scale [28]. Annotations were made at 110 time points throughout the hour of data. At the top of every minute for 50 min, 50 annotations were made, and 60 annotations were made every 10 s for the remaining 10 min.

Using tenfold cross-validation, a Dynamic Bayesian Network was used to predict the nurse's score. A visual depiction of the model is shown in Fig. 2. We treated the Giganti score as a hidden variable ("True Motion") that was highly correlated with the nurse's trained annotation of motion ("Nurse Observed Motion"). This allowed flexibility for the model to treat the nurse's score as inaccurate when sensors indicated a nurse error. The observation came from the 4 limbs that each had a 3-axis accelerometer on them. These data were smoothed and normalized and then separated into four real-valued power scores. The full details of the feature smoothing are presented in [30]. We modeled the "True Motion" as a generative variable for the four limb scores with independent Gaussian distributions. We computed three additional features: the product of the arm scores, the product of the leg scores, and the product of all four limbs that also varied with independent Gaussian probabilities conditioned on the "True Motion."

We optimized the parameters of the model using cross-fold validation and Expectation–Maximization to smooth the data in between the sparse nurse annotations. As evidence that our system was performing adequately, we observed that when tested on held out data, the automated analysis matched the nurses' score to within 1 scale-point 100% of the time (see Fig. 3 for a visualization of a portion of the data).

This experiment established AIGR as a viable replacement for manual nurse video coding and at the same time provided much more high-resolution recording of infant movement than was previously available. This quantitative evaluation of movement is now being used as an outcome in home settings with the same technology to evaluate whether NICU exercise regimens cause increased spontaneous movement in infants, increased weight gain, and ultimately healthier outcomes for these high-risk patients.

As a demonstration of the multiple ways that such a record-keeping dataset can be used, we conducted a second

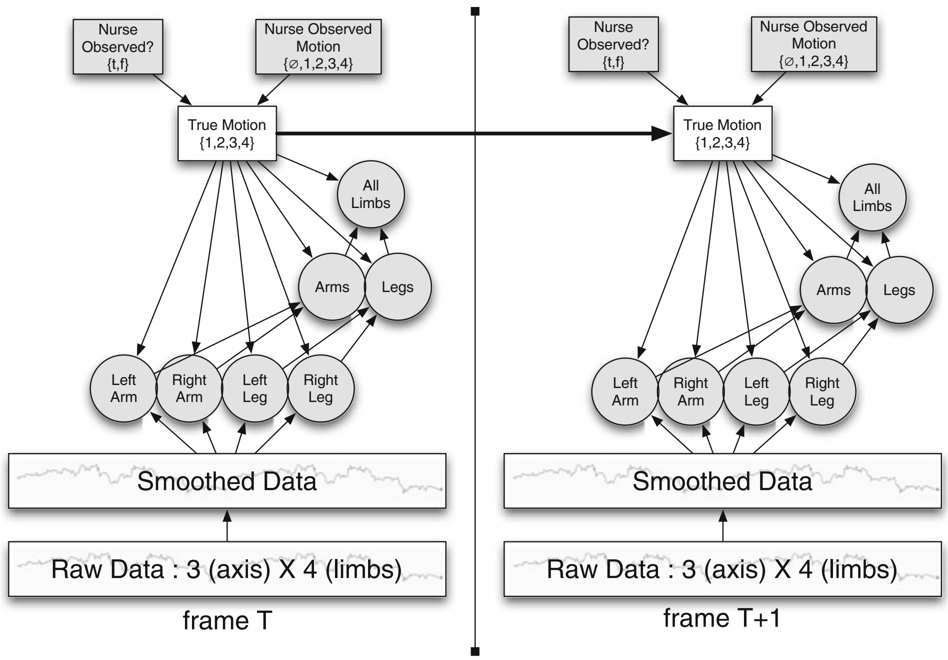

Fig. 2 Dynamic Bayes Net used to model and predict manual infant motion scoring

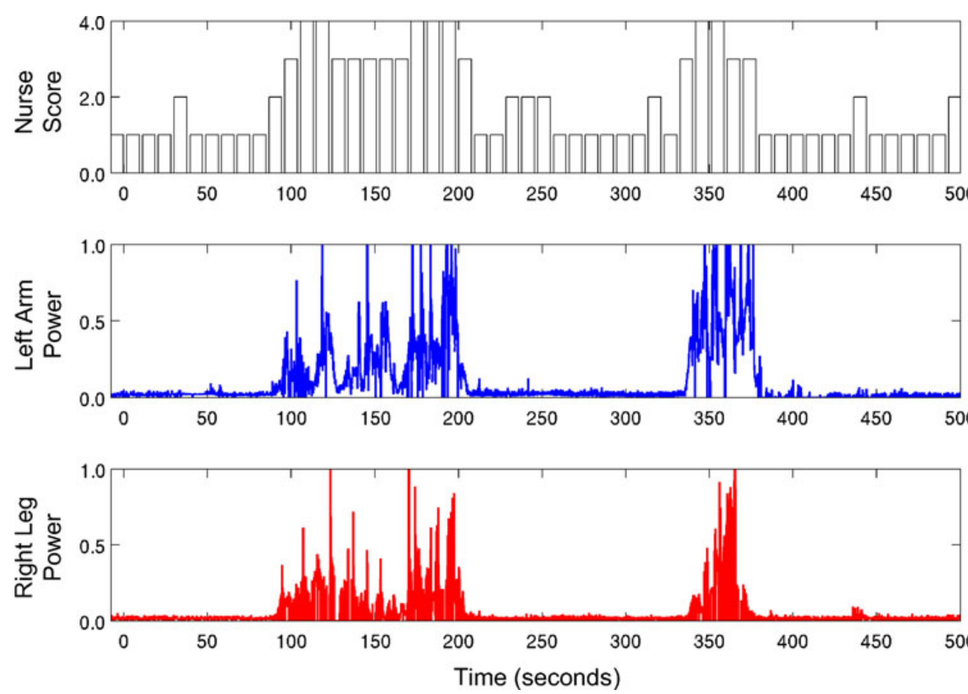

Fig. 3 A comparison of accelerometer data from two observed variables with manual Giganti video scoring by a trained nurse. 500 s of smoothed data from left arm and right leg are shown in the *bottom* 2 graphs with the nurse's scoring on the *top* graph

experiment in which we used more elaborate pre-processing to create additional features for statistical modeling. We modeled involuntary gestures by these babies that are predictive of cerebral palsy (CP). Current medical practice to diagnosis CP relies on a neurological examination conducted by a physician. However, in a study of more than 40,000 children conducted in 1992, only 23% of infants with CP ($N = 128$) had an abnormal neurological examination in infancy [51]. In practice, doctors end up diagnosing cerebral palsy by evaluating a child's motor skills and medical history over several years. Neuroimaging techniques, such as cranial ultrasound, CT scans, and MRI scans can also assist in diagnosis.

In the same way that manual video coding has been used to quantify infant motion, other clinically impractical examinations have been developed to diagnose CP. For example, Prechtl et al. developed an observational technique that evaluates the motor quality of an infant's movement also from 1 h video sessions [57]. The two key markers are involuntary gestures that are qualitatively identified as fidgety movements and cramped-synchronized general movements (CSGM). CSGMs look rigid and are characterized by all limb and trunk muscles contracting and relaxing almost simultaneously. The lack of the former and the presence of the latter are indicative of CP. Persistent CSGMs have been shown to predict CP with a specificity of 93% in preterm babies [24]. Evidence of such markers has been noted in a variety of settings [6, 51]. Unfortunately, due to the heavy reliance on manual video coding, they have not been widely used outside of research settings [64]. Our approach allows for use not only in non-research clinical settings but also in the home for early detection of potential disorders without additional visits to the clinic, a huge burden on parents of preterm and high-risk infants.

Using a similar approach as described for Giganti modeling, a trained nurse identified the portions of the videos in which the babies were displaying CSGMs. We treated those observations as ground truth and developed a suite of 166 features derived from the accelerometer readings with which we trained several machine-learning algorithms. Again, using tenfold cross–validation, we predicted for each of the approximately 700,000 samples that we collected whether it was indicative of a CSGM or not. The results are shown in Fig. 4. As a baseline we used a prediction of "Normal" meaning, no CSGMs were observed. This "most popular" guess formed one end of the ROC curve. The opposite prediction of "Abnormal" anchored the other end of the ROC curve. Various machine-learning algorithms were able to trade-off false positive and true positive rates in different ways. Both Support Vector Machines and decision trees outperformed the baseline. Decision trees were able to accurately predict CSGMs with 89.81% accuracy (Sensitivity: 0.10, Specificity: 0.94). Using a combination of Dynamic Bayes Networks with Random Forests, an accuracy of 70% was achieved but with a more balanced sensitivity and specificity trade-off (Sensitivity: 0.50, Specificity: 0.70). The full results of this study can be found in [63]. The most informative features compared the maximum and minimum power of the limbs over a 2-s window. Further work is required to understand why correlated features seem to provide additional predictive power.

These two experiments demonstrate the potential for a non-invasive, pervasive computing approach to monitoring gestures in infants. The first study provided a quantitative dataset that is valuable for longitudinal evaluation of weight gain, which is known to correlate with healthier outcomes and is a particular concern of both parents and clinicians even well after discharge from the NICU. The second study used the same dataset to recognize involuntary gestures that have a high correlation with cerebral palsy. Early detection, particularly that can be done unobtrusively, can lead to much earlier intervention than

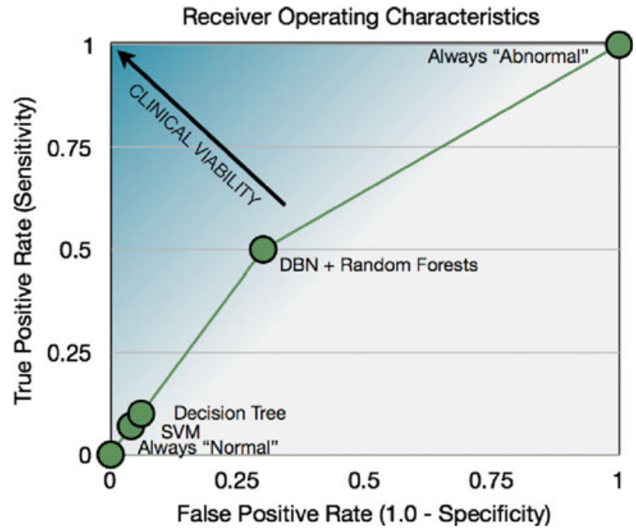

Fig. 4 Comparing machine-learning techniques' ability to predict cramped-synchronized general movements (CGSMs)

possible with existing methods. This approach also holds promise for helping to improve earlier diagnosis of other neurological disorders with movement symptoms such as seizure disorders and autism, a shared goal of other research projects (e.g., [41]. The fine-grained nature of the measurements opens the doors to even more detailed insight into regions of the brain that may be injured, based on different nuances in the observed movement.

This approach is of particular interest, because it need not be restricted to use within the hospital. If battery life can be appropriately managed, the same monitoring can continue after the baby has been discharged, allowing for continuous and comparable health monitoring of high-risk infants in the home. As a first step in understanding how these kinds of sensing applications might feasibly transition into the home, we also conducted a preliminary evaluation of a necessary additional component: a mobile phone-based home capture and access system. We describe a prototype of such a system in the following section and our preliminary evaluation of it.

5 Support for record-keeping and treatment at home

We uncovered several challenges to caring for preterm infants when this kind of care and documentation are transitioned into the home. As we anticipated, during interviews, parents reported being concerned that they might forget how to do the various prescribed behavioral interventions, such as an exercise routine or particular feeding or medication regimens. They were also concerned that they might hurt their babies even when doing activities they had often seen nurses doing and had been trained to do themselves. Additionally, they were concerned that they often did not know how to record requested data properly. Even when parents were confident in their ability to conduct interventions and record data, they were not always clear on why these activities should be conducted. Thus, a further design challenge that came up during discussions with the nurses and research staff at the NICU as well as with parents is to understand the long-term impacts of these home interventions. Clinicians in particular then worried about how to guarantee regular compliance with the routine, or at a minimum, documentation of when and how they were completed. Thus, in this work, we designed and tested tools for (1) augmenting home sensing with manual data entry, (2) prompting caregivers to complete prescribed interventions, and (3) enabling simple communication with the research and medical staff.

As an additional challenge, the majority of the patients admitted to the NICU of the hospital at which this work was conducted are of lower socioeconomic status, and many are not native English speakers. The majority of mothers interviewed echoed nationwide trends identified in the English-speaking Hispanic population [35]—not having Internet access at home but being willing and able to access information, email, and text messaging from mobile phones. Unfortunately, many commercial devices (e.g., HealthBuddy [13]) require an Internet connection and custom device. In this work, we were interested in incorporating the monitoring and prompting caregivers needed into a device they were already comfortable using. Thus, we focused the design of the FitBaby application for a mobile phone platform that could be used to communicate anytime anywhere without broadband Internet access or a computer (see Fig. 5).

Our initial FitBaby prototype included a mobile phone-based application for parents entering observations about their children's health as well as a networked database in which these data were stored for clinician access. FitBaby runs on Windows SmartPhones and was built on the MyExperience framework [25] to leverage various features of that toolkit, including the simple survey interaction model as well as the underlying communication mechanisms and ability to set alarms to prompt caregivers.

Through FitBaby, caregivers can manually begin a log entry, in which they are taken through a branched series of questions about the completion of their prescribed interventions, the baby's responses to those activities, and how the caregivers themselves feel. If no entry has been completed by a predetermined time each day, the system prompts the caregivers through standard configurable phone alerting features (e.g., lights, ringing, vibration). At that time, the caregivers may "snooze" the request or dismiss it entirely if they do not want to complete a log entry for that day. The questionnaires are delivered in either English or Spanish per caregiver choice.

Upon completion of each entry, all collected data are transmitted to a database accessible by clinicians, through an SMS message sent to an email address and then parsed into a database. If the mobile phone network is unavailable at the time of log completion (e.g., weak signal strength or incompatible networks), the request is stored on the mobile phone and resent when service is restored. This regular transmission of observations about the infants allows for real-time or near real-time prompting, feedback, and support. Specifically, the daily alert generated by FitBaby if a diary entry has not been completed for the day was designed to encourage completion of prescribed interventions and communication with clinicians about these activities.

We evaluated the use of FitBaby compared with paper-based documentation in the homes of 10 newly released preterm infants for 3 weeks at a time. Nurses and physical therapists trained nine mothers and one aunt of preterm infants to care for their infants, including instructions for documenting infant health indicators, daily activities, and compliance with prescribed interventions. Caregivers were instructed to use the system daily for 3 weeks, starting on the day of discharge from the NICU. We conducted home visits for observations and interviews at the end of the first week and at the end of the third week. Half of the caregivers used traditional methods of paper-based logging to record their daily information. The other half used FitBaby to log data about their activities and to stay in touch with the researchers. Regardless of condition, participants were compensated for each day in which they were in the study and completed a log entry. FitBaby was intentionally simple in its design and its scope of functionality. This simplicity enabled an easy path to adoption, encouraged caregivers to describe other advanced features they might like in a future iteration, and demonstrated the feasibility of ubiquitous computing technologies for monitoring health status and behavioral interventions at home.

During this study, parents were able to interact with the device with one hand, leaving the other free to hold the baby or perform other tasks. Additionally, the solution was robust in the face of challenging infrastructure capabilities. For example, occasionally, parents were out of mobile phone range, but the approach of storing and forwarding the information when they were in range again worked well in practice. Furthermore, although the devices require charging, they consistently ran the application for 2–3 days without a charge, and the system alerted parents when the battery was within a few hours of running out.

Participants reported performing the prescribed interventions on nearly every day in the study, and those in the FitBaby condition used the application daily, even on those

Fig. 5 The FitBaby prototype delivered questions in both English (*left*) and Spanish (*top*) to meet the needs of the target patient population. Mothers could use the phone one-handed while conducting exercises with their infants (*bottom*)

days when they did not complete the exercise intervention. FitBaby was initially viewed with apprehension by some of the nursing staff and caregivers. The hardware value, quite high for the income of most of the participants, and its advanced design produced some anxiety around use. For example, one mother noted, "I liked the PDA, but I was like being cautious with it, like I wasn't playing with it… I was just like set it here and leave it" (ID6). Most of the caregivers in the FitBaby condition experienced temporary problems with the prototype system at some point (e.g., mobile data service unavailable), during which time they used paper records. Despite these challenges, those caregivers in the FitBaby condition all unanimously preferred using it. They described it as easy and enjoyable to use. For example, one mother commented "It was easy, just ding, ding, ding, and done fast" (ID3).

Many of the parents enrolled in the study had met each other during their time in the NICU and occasionally talked with one another during the study. Parents enrolled in each condition generally reported that their method of reporting was simple, but in some cases, knowing each other led the participants to describe their perceptions of what being in the other experimental condition would be like. For example:

> So I just filled out the paper, it was easy. I thought this paper log was going to be like a lot to do on it was just like, that's it… it was just like the PDA (ID5; paper-based condition).

> I think the PDA was so much easier…'cause I saw [ID7, paper-based condition] doing the paperwork and then I was just like staring at her and I was like, thank G-d I have the PDA! (ID6, FitBaby condition).

From the clinical view, one of the primary goals of the FitBaby system was to remind caregivers to deliver the prescribed interventions and to be able to monitor adherence at a distance. The reminders generated by FitBaby were reported to be useful by all users. Parents described the reminders as helping them to adhere both to the documentation requirements from the clinicians as well as the exercises themselves, a primary goal of the clinicians with whom we were partnering. For example, one mother who had logged her entries every day on the phone for the first several days of the study was forced to use paper backup during a 2-day service outage. She commented that without the reminders, "… sometimes I can forget to enter the paper" (ID3). All of the caregivers in the experimental condition made use of the reminders at some point during their 3 weeks of use; most used the reminders daily rather than completing the entries manually. Additionally, one mother described forgetting to conduct the intervention on several days but being reminded by the alerts from FitBaby, thereby improving her adherence to the regimen.

Caregivers in the paper condition often completed their log entries from memory days later, an issue likely to reduce the quality of the information given the high likelihood of forgetting the details of their behavior in the ensuing days. In the FitBaby condition, this behavior was not possible, necessitating data capture to align more closely with the actual activities, thereby likely increasing the accuracy of those self-reported data. However, the data capture in FitBaby was built with the assumption that all data for a given day would be submitted in one log. Most of the mothers completed all of their prescribed exercises in close temporal proximity to one another, making this approach appropriate. However, one mother in the paper condition (ID9) liked to interweave the subparts of the intervention with her other activities throughout the day. She would look at the paper records she was keeping and check off each prescribed activity as she did it, using the documentation as a reminder of what she had left to do. Using FitBaby, a mother could complete multiple logs as each different activity is completed, but no visual feedback was available to allow them to see what they had already sent. This issue indicates that immediate daily feedback to support parents adhering to interventions may be as important as longer-term visualizations of trends.

FitBaby opened a new communication channel between parents and clinicians by sending the logs automatically to the clinicians at the hospital as they were completed. A researcher or nurse would call caregivers in the FitBaby condition if they did not complete logs 2 days in a row or if any data of concern were reported in the logs. Both parents and clinicians described this additional connection as a positive influence. In particular, parents of preterm infants tend to be told repeatedly about the fragility of their infants while in the NICU and their high risk for long-term health conditions upon discharge. In our initial interview study, they described fear at conducting prescribed interventions and in generally caring for their infants. During the deployment of FitBaby, however, caregivers described interventions as helpful to their infants and as allowing them to feel more relaxed, in particular because they knew they were “connected” to clinicians even if no additional communication acts (e.g., telephone calls, clinic, or home visits) occurred as a result of this connection. Clinicians did note the caveat that they were only able to review these data, however, as part of a research study. In terms of their regular clinical workflow, they would not have time nor be able to be reimbursed for reviewing these data in their practices. These results indicate that communication between parents and providers must be supported but in a way that is both useful and realistic in terms of the constraints of clinical practice.

During the initial interview study, the mothers described not particularly being interested in collecting nor monitoring health data. During the deployment study, however, families in both the pen and paper condition and the FitBaby condition showed an interest in how their infants were progressing and in monitoring how well they were complying with their prescribed interventions. Parents satisfied this interest by leafing through old paper log entries in the pen and paper condition, because they were only picked up from the parents during the home visits at the end of the second and third weeks of the study. Because the logs were sent automatically each day in the FitBaby condition, the researchers and clinical staff experienced closer to real-time data collection than the paper-based system allowed, but the parents were not able to leaf through the paper-based data and reflect on it themselves. Reflecting this kind of information, such as through glanceable displays [18] can help patients and caregivers to believe they are in more control of events that affect them, including their illnesses, an important goal in supporting behavioral interventions [45, 46]. Furthermore, clinical summarizations, alerts, and visualizations should be developed in conjunction with such systems to support healthcare providers being able to quickly grasp salient information without having to dig through the massive quantities of data created by these kinds of personal health systems. These results also indicate that as we integrate substantial sensor-based data, such as that from the AIGR system, that may be difficult for humans to interpret, we must pay particular attention to visualizations and their potential clinical utility.

Parents and healthcare providers requested a variety of additional features for any home-based monitoring system for this population. In particular, the phone was seen as a promising platform for delivering new educational interventions to a population stressed and unable to grasp the variety of complex medical information being given to them at discharge. For example, many caregivers reported being confused about what to do during a prescribed behavioral intervention:

> …once they [the NICU nurses] showed me to do it [the exercise intervention] different… That same [nurse], but they showed me how to do it different…a better position (ID3).

Furthermore, the caregivers described challenges in making use of the educational materials and training provided to them. It was not that they did not want to learn the interventions prescribed for their children. Quite to the contrary, they very much wanted to learn and wanted to follow the instructions correctly. In the moment, however, they could be “scared of like hurting and then like just remembering like what exercises to do” *[sic]* (ID5).

The caregivers enrolled in this study used a variety of strategies to address these concerns. Some attempted to memorize the instructions for their interventions. Many participants also reported wanting different kinds of materials available to them, such as videos demonstrating how to perform the exercises and something more "mobile" than the big notebook provided. These results indicate that more consistent, interactive, and engaging educational materials should be made available in a more comprehensive system.

The caregivers used the built-in camera features on the phone regularly, learning to take pictures with it independent of instruction from our team, often creating new effects and using advanced photographic features. This result suggests that home healthcare systems such as this one should integrate photo and/or video capture to support this natural inclination and to enable caregivers to gather even more evidence of their infants' progress for analysis by the study team. This kind of motivation to create memories through digital artifacts echoes previous work that found that parents were interested in documenting developmental milestones in large part due to these emotional and nostalgic impulses [41]. This kind of video collection is synergistic with our work in automated sensing of infant movement in which the goal is to reduce the amount of expert time needed to review video. Coupled with automatic gesture recognition, video with abnormal motion can be identified and flagged for expert review.

6 Implications for the design of a comprehensive system to support hospital to home transitions

Infants born early, with low birth weight, and at risk for long-term health complications, begin their lives in the NICU or other intensive hospitalized setting and continue to receive additional care and monitoring over time at home. Challenges for this care include issues related to the cost of administering the care both in the hospital and at home as well as how to document and understand the impact of interventions in both these settings. Thus, in this work, we were concerned with the ways in which ubiquitous computing solutions could usefully be deployed to support these activities. We conducted interviews and design sessions with parents and healthcare providers to develop initial understanding of the problem space. We then used our experiences with designing, developing, and evaluating two prototype systems for monitoring infant movement to further our understanding of how a comprehensive monitoring solution for this population might be developed. Several design principles emerged from this work, which we describe in this section.

First, solutions to support this population must be unobtrusive. Families caring for premature infants experience an enormous amount of stress, often do not sleep well, and can be under considerable emotional and financial strain. The addition of intense monitoring, in particular monitoring that requires human intervention, can be problematic. Thus, when possible, tools should automatically collect the data of interest. For example, rather than asking parents to record video or to observe and score infant movement, the accelerometer-based solution we tested in the NICU should be reengineered as a kit that can be sent home with parents, and which passes data through a mobile phone-based system to clinicians.

Second, solutions should provide access to collected data at various levels of abstraction appropriate for the different needs and audiences attempting to make sense of the presented information. For example, families may want daily indicators of infant progress. On the other hand, a pediatrician is more likely to want a summarized view of 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, either to make sense of errors in the data or to understand in more depth a phenomenon observed in the higher-level view. Automated tagging of abnormal sensor readings, such as provided by AIGR, can reduce the burden on clinical staff, and visualizations of both sensor-driven and manually entered data can provide the ability to understand these data and find patterns in them by both clinical and home-based caregivers.

Third, solutions should be cost-effective and off-the-shelf hardware and standardized interfaces must be used when possible. Caring for a premature infant, whether in the hospital or in the home, is an extremely expensive endeavor. Use of specialized devices (e.g., lung monitors or breathing supports) adds complexity both in terms of the retrieval of data from these devices and in terms of the cost and maintenance of the systems. Thus, new solutions should be designed not to add to this expensive and complex system when possible.

The presentation of data and alerting mechanisms should be balanced against the accuracy and reliability of the technology [27]. On the one hand, a sensor-based system that can provide alerts to caregivers when a baby is in danger can relieve caregiver stress. On the other hand, it may also inappropriately reduce vigilance on the caregiver's part. A well-designed visualization that does not simply alert but also incorporates presentation of uncertainty and technology reliability can help people make better decisions about how and when to rely on automated sensing.

Finally, solutions must account for dynamic infrastructure when deployed in the home. Certainly, it is not surprising that pervasive healthcare solutions for the home must account for a wide variety of homes—both large and small, connected and not. However, when dealing with premature infants, these challenges become more acute. As infants grow, both they and the space in which they live are ever-changing. For example, an infant who cannot yet roll over can be safely placed on any variety of surfaces throughout the day. During our fieldwork, we frequently observed parents swaddling their infants and laying them on the sofa, a chair, or even the floor. This practice of moving infants from place to place in the home can make monitoring their progress challenging. Different areas may have varying levels of network service or of noise in the sensor stream (e.g., accelerometers are unlikely to work well while the infant is in a swing; air quality sensors may greatly depend on whether the infant is placed near a window or vent, etc.). These circumstances need to also be noted so that the people who are analyzing the data can appropriately assess the contextual situation in which sensor data are collected. Again, well-thought-out design can accommodate these circumstances by including photographs, videos, and audio as part of the data collection process.

Based on these design guidelines and our experiences deploying and evaluating two prototype systems, we propose that an appropriate comprehensive solution to monitoring premature infants in the home would have to include modular sensing elements, the ability to collect data from these various elements and reflect it back to caregivers as well as to upload it to a space accessible by clinicians, and finally, functionality to enable clinicians to access and make sense of the collected data (see Fig. 6). This configuration allows for the addition or removal of various kinds of sensing depending on the particular diagnostic measure being examined (e.g., spontaneous movement, weight, etc.) or the particular needs of the individual infant (e.g., gastrointestinal or lung disorders).

7 Conclusions and future work

Premature infants have higher rates of chronic illness throughout life, but early interventions show promise in improving overall health. In particular, exercise and movement-based interventions can greatly improve weight gain, a primary indicator of health in low-birth-weight infants. While interventions initially start in the hospital setting and provide valuable data for diagnosis and wellness monitoring, eventually these infant patients are discharged. Caregivers can continue to conduct these interventions in the home, maintain communication about their activities with clinicians, and track progress through the use of novel technological solutions built on a combination of off-the-shelf (mobile phones) and custom (infant-sized accelerometer-based sensing systems) hardware and a combination of standardized (personal health record and electronic medical record) and custom (FitBaby and other applications) software.

Through our work in this area, we have uncovered design requirements for a home-based ubiquitous computing solution for monitoring the health of premature infants. We have also established the technical and clinical feasibility of development and use of such a system and evaluated portions of its components in individual studies. Our studies in the hospital demonstrated the value of lightweight motion sensing for high-risk infants for expert caregivers. Our studies in homes demonstrated that relatively novice caregivers from primarily low-income households not only can engage with the same interventions being used in the clinical setting but are also reflective about their children's progress and enthusiastic about the use of new technologies to remind them about the routines and connect them to clinicians. Furthermore, automated means of measuring progress over time can be effective with minimal impact to the infants themselves.

Our interview data demonstrated that our initial prototype systems were generally well received by both the clinicians and the parents in our study, and the interviews indicate that new technologies would be accepted—even embraced—by this population. In particular, data from caregivers supported the conclusion that they liked the reminders, ability to take pictures, ease of use, and connectedness to clinicians that the phone-based FitBaby application afforded. At the same time, the clinicians reported liking the ease of gathering large volumes of data without substantial clinician intervention and the ability to monitor behavior at a distance without the requirement for visits from home nurses. Furthermore, by automating as much record keeping as possible and moving self-report closer temporally to the activities being described, the fidelity and accuracy of these self-reports can be improved. Over time, a large corpus of data could be collected from many patients collecting these observations of daily living simultaneously. These records can be stored and mined for research or integrated into the individual patient's medical record for lifelong assessment of health. Data from our evaluations show that these improvements were accomplished while reducing the burden on caregivers who universally reported that the phones were simpler and more enjoyable than the paper records.

As with all early-stage designs, our initial prototype systems and their evaluation included several key limitations. First, the prototype systems were developed and tested separately. A comprehensive solution would require the connection of automatically sensed data, such as movement, into the self-reported data. Second, there were some features uncovered during our interviews and deployments that did not exist in our initial prototype systems. For example, FitBaby was not able to address issues around the consistency and interactivity of the educational materials and reflection on progress. Thus, we are currently creating new tools that include integrated sensing and manual data as well as more interactive

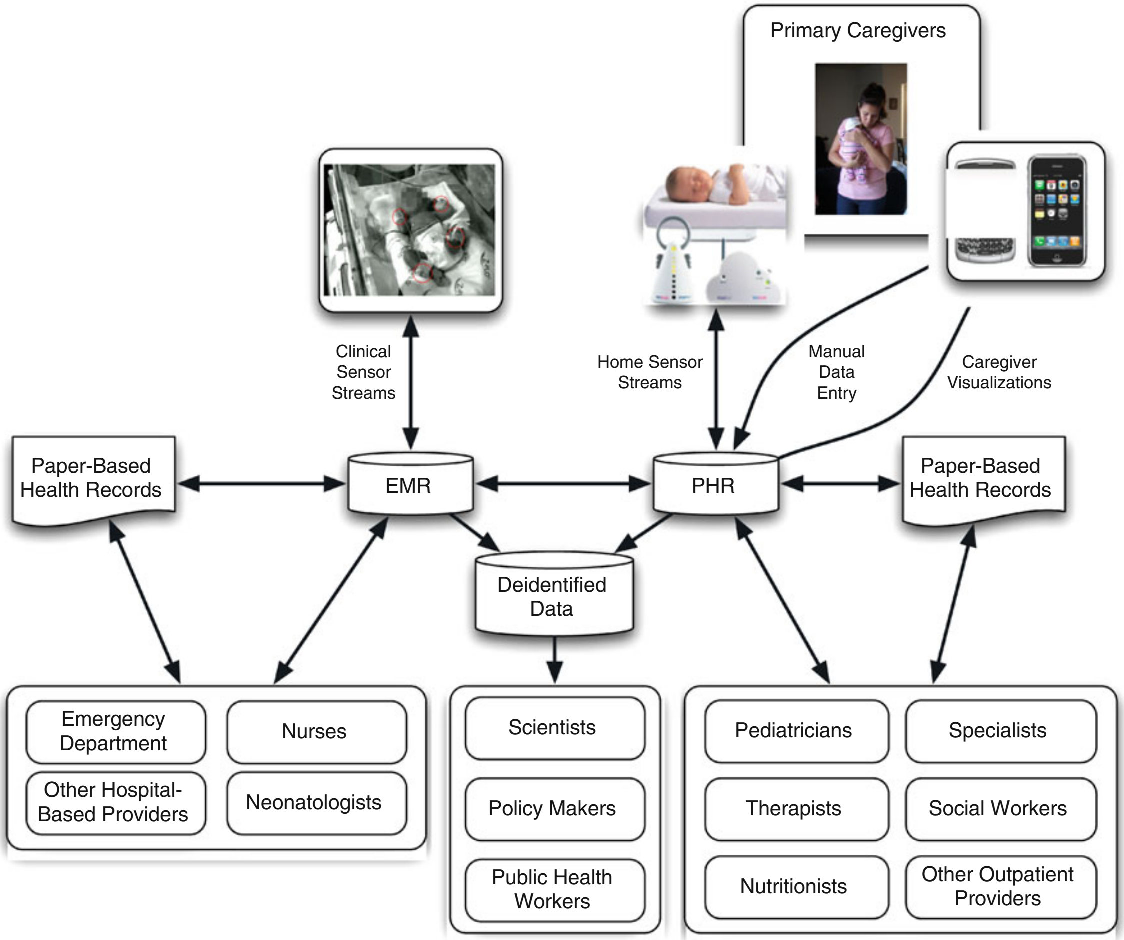

Fig. 6 Health data collected in the hospital and at the home should be integrated, allowing a variety of clinicians and researchers to diagnose and treat particular patients using identifiable data from provider-owned electronic medical records (*EMR*) and patient-maintained personal health records (*PHR*). Furthermore, over the long term, both researchers and healthcare workers responsible for larger population health can mine aggregated and de-identified data from a variety of patients to support creation of best practices and healthcare policies for use of Health IT

materials, progress indicators, and communication methods to enable personal and group reflection. Finally, although our current systems do a good job of monitoring infant behavior and progress, caregiver health can be intimately tied to the health of their infants. Thus, future systems should consider how caregiver health can be documented, caregivers can be made aware of their own health, and the connections between caregiver and infant health can be visualized and observed.

In conclusion, the results of our work demonstrate the promise of ubiquitous computing solutions for supporting the care for premature and at risk infants, particularly as they transition from the clinical to the home environment. Non-professional caregivers, such as parents, can use handheld devices to report accurate and timely data about the health and progress of their infants to clinicians and other care providers. Furthermore, clinicians can use automated sensing technologies to collect detailed clinically relevant data in novel ways with higher fidelity than previously possible. These data, both manually and automatically collected, in hospital and at home, can be mined by humans and machines to understand trends in the health of individual infants over time. In aggregate, even the trends of larger population can be monitored. Finally, clinicians are able to make use of these data both for clinical care and for further research on the impacts of various interventions. As the home increasingly becomes the site of healthcare delivery, the development and use of these types of technologies becomes more important, particularly during times of transition between clinical and non-clinical environments. Our future work will continue to examine how these integrated solutions can be developed to balance the needs of the hospital staff, general pediatricians and physicians, specialists, parents, and of course the infants themselves, to support a holistic view of infant health and development.

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