FitBaby: Using Observations of Daily Living to Improve the Health of Preterm Infants and Their Caregivers

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Abstract
Capture and access technologies to collect and report Observations of Daily Living (ODLs) can strengthen support of caregivers at home. We present a mobile capture and access application for parents of newborns conducting in-home assisted exercise routines: FitBaby. This system enables parents to log ODLs through input forms on SmartPhones and automatic collection of sensor-based data. The system allows for real-time prompting and feedback to caregivers. This paper describes the challenges to caring for preterm infants and how ODLs, specifically those collected by FitBaby, can support these activities and improve health outcomes.

WISH 2010 April 11, 2010, Atlanta, Georgia, USA.

Keywords
FitBaby, Preterm Infants, Capture and Access

ACM Classification Keywords
J.3 Computer Applications.Life and Medical Sciences; H.5.2 Information Systems.Information Interfaces and Presentation

Introduction
Over the past two decades, the incidence of preterm births (born at less than 37 weeks of gestation) has increased dramatically and in 2002 accounted for 12% of live births in the US [8]. Premature birth is associated with long term health impairments including neurological and cognitive deficiencies, chronic lung disease, and altered growth patterns of lean, fat, and bone tissues [6]. Furthermore, in Hack et al's study, 64% of low birth weight (LBW) children at age eight demonstrated one or more limitations, including conditions such as asthma, impaired vision, and

cognitive disabilities [7]. Other studies suggest that an improvement in care for these LBW infants in the early months is likely to reduce the incidences and burdens of their chronic conditions over the lifespan [14, 15].

A primary barrier to care to LBW children is ensuring the continuity of care from hospital to the home. Upon discharge, standard procedures are to educate caregivers about how to care for their LBW infant and then to discontinue all support and care from NICU providers to the caregiver and the infant. Responsibilities for clinical care are transferred to the child's pediatrician, who will often request a visit within the first three weeks after discharge. In addition, county regional centers have responsibility for monitoring the progress of these at-risk children after discharge, but it is common for regional centers to take up to six weeks to initiate contact with families.

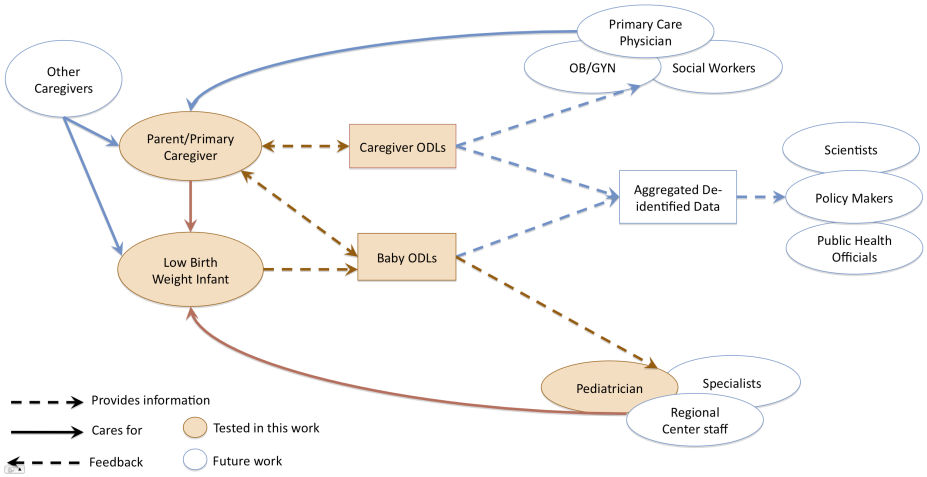

fig 1: information transfer model for ODLs for LBW infants and their caregivers

The transition to home can be very stressful for caregivers (called parents from here on). They suffer from greater sleep deprivation than caregivers of non-LBW babies, because LBW babies have particularly challenging feeding schedules and needs [16] and sleep for shorter durations at a time [4]. The physical demands of caring for an LBW baby is compounded by the stress of not knowing whether they are properly caring for their baby. Caregivers are also more likely to experience depression and isolation from their social support networks, at least in the short term [5]. The lowered emotional well-being of parents may impact their ability to give quality care to the baby.

Related Work

Mobile and ubiquitous computing solutions for healthcare have become prevalent in both research and commercial efforts. These systems and applications have the potential to improve patient care in a variety of locations for a variety of ailments, improving the level of care offered and the efficiency with which it is delivered. In response to this growing concern about chronic health, major research efforts have focused on "smart home" technologies.

The increased prevalence of chronic health conditions, however, is not just at the older end of the lifespan. As survival rates from acute events in very young children rise, chronic health conditions in children have also increased. Thus, researchers have begun to examine particular issues surrounding chronic health conditions for children. Of particular interest to this work are projects related to enabling families to cope better with the chronic illness of a child (e.g., [9]) and to documenting early milestones for child development (e.g., [12]). Findings indicate that families who are educated about a condition and involved with the management of it can better cope [3]. In part, this education may decrease stress and anxiety for the

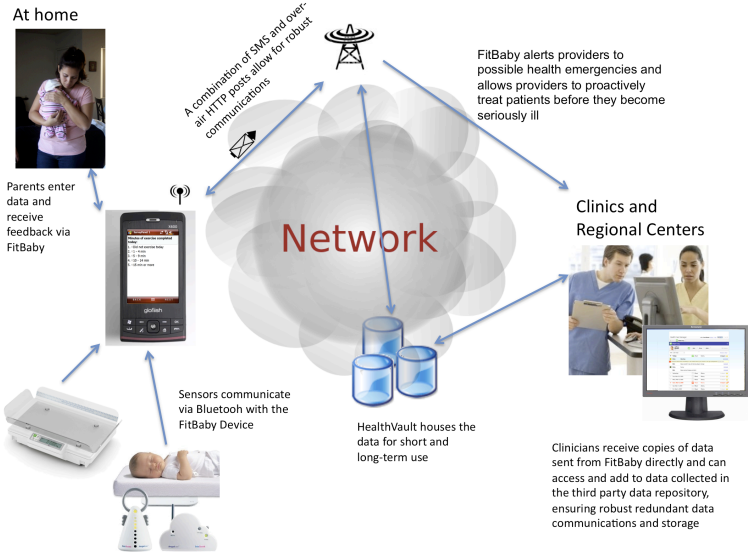

fig 2: (above) technical architecture for FitBaby system (below) sample screen of a log entry.

caregivers as they become more expert and involved in the care [10]. These findings also indicate that greater education and involvement in care correlates to higher rates of compliance with treatment regimens [3]. These results mirror findings with adult chronic diabetes patients who showed increased locus of control and increased compliance when better educated and able to test data about their health themselves [13]. They also further support our interest in developing recording and analysis technologies that will directly involve parents and their families in understanding and treating the conditions of pediatric patients.

FitBaby

FitBaby is a mobile system for collecting observations of daily living (ODLs) for premature infants and their caregivers after release from the hospital. ODL data is collected by both manual (diary entries, photos and videos recorded using the mobile phone) and automatic means (wireless sensors, including scales and crib monitors connected to the phone). These data are recorded both on the phone and over the network to enable clinicians to view data at a distance.

FitBaby supports collection of ODLs in several ways. The system generates an alert if a log has not been completed by a prescribed time. This feature was found to be very useful during an initial pilot study of FitBaby and improved the frequency of parents completing the logs. We are currently developing new features that will reflect the exercise data back to the caregiver through simple visualizations. These interfaces will include glanceable displays [2] on the mobile phones as well as the ability to "drill down" into the data on a more traditional desktop platform. Reflecting this kind of information back to them can enable greater feelings of self-efficacy and influence on the health of their babies [13].

This combination of automatically and manually collected data will enable us to record a significant amount of information about infant progress without substantial burden on the families. Furthermore, our innovative visualizations and reporting to the parents and clinicians will enable both overview and detailed reporting on infant progress and development.

Conclusions and Future Work

This work provides multiple significant contributions, both in terms of research results and the software systems themselves. First, through interviews and fieldwork, we have begun to understand the design requirements for supporting preterm and typical infant care at home. Second, the FitBaby system itself serves as a potential model for enabling other computing researchers to design and develop new related systems for the chronic care of children. Our current and future work focuses on the refinement and iterative design of the FitBaby system and its evaluation *in situ* through deployment to families and clinicians of LBW infants.

Acknowledgements

We are grateful to the nurses in the Neonatal Intensive Care Unit at UCI MC, whose work with an earlier prototype has proven invaluable to our new designs. We thank the participants in the various studies that have led to this work. This work was supported by an NSF CAREER grant #0846063. We thank Sheba George and Khai Truong for comments on earlier versions of this paper.

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