Using Data to Promote Healthy Behavior in Children

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ABSTRACT
Childhood offers a number of opportunities for parents to shape the health-related attitudes and behaviors of their children. The proposed research described in this paper aims to better understand the ways in which a child’s personal health data can be leveraged to educate and provide a transition to healthy adult behaviors. The target population for this project is children with Type 1 Diabetes and their parents, but many of the design issues may be relevant to the management of other chronic diseases as well as general health in childhood.

Keywords
H.5.2 [Information Interfaces and Presentation]: User Interfaces - User-centered design; J.3 [Computer Applications]: Life and Medical Science – Health; K.3.1 [Computers and Education]: Computer Uses in Education - Collaborative learning

INTRODUCTION
This dissertation research examines the aspects of human behavior that need to be considered when designing health-related technologies. It uses research from the fields of Human Computer Interaction (HCI) and Behavioral Science to explore the sustainable impact of technology aimed at managing disease and general health in children. Parents play a significant role in a child’s dietary and physical activity habits [21]. Therefore, understanding the ways in which technology can foster positive parent-child interactions around health data is important. Adolescence is a sensitive period in a child’s development during which parents must incrementally release control while still remaining engaged with decision-making and behaviors, creating tension [3]. The parent-child relationship is particularly strained for adolescent children with Type 1 Diabetes Mellitus (T1DM) as routine health behaviors and decisions can lead to serious complications and even death. The proposed research will examine the various tensions that arise between parent, child, and technology used to manage T1DM. The goal is to better understand the way in which parent-child interactions are influenced by the use of health related technology and to develop design considerations for this population.

Issues Related to Managing T1DM in Childhood
Children with T1DM and their parents live a data-driven life. Numbers including blood glucose values, carbohydrate content of food, urinary ketones, carbohydrate to insulin ratios, insulin basal rates, and many others are a matter of life and death for these children. “Constant vigilance” has been identified as a principle behavioral pattern for parents managing their child’s diabetes related “numbers” resulting from legitimate fears of life threatening metabolic changes and a deep sense of responsibility for the long term health of their child [18]. This situation creates a complicated interplay between parent and child as parents train their child to effectively handle the rigors of diabetes management, allowing their child to build effective coping skills and self-efficacy [22]. During these formative years parents must be cognizant of their child’s evolution towards independent self-care and support the journey through an incremental release of control. The road between childhood and adulthood is rocky for many children and parents, but the burden of intense data monitoring required for sustaining the health of a person with T1DM places additional strain on ordinary parent-child interactions. Like most of us, children with diabetes prefer their health issues fade in the background of daily existence. This desire becomes stronger during adolescence when adaptation to peers becomes a central focus, contributing to parent-child conflict related to diabetes management [2]. Teens, not wanting to appear different, may skip critical blood glucose checks exasperating parents who fear both the immediate and long-term negative impact on health.

The proposed research intends to explore the ways in which ubiquitous computing may serve to mitigate conflict and improve diabetes regimen compliance during adolescence. Research has clearly shown that parental involvement during adolescence improves diabetic outcomes [3,7,8,22] but there is a delicate balance that is difficult for many families to achieve without assistance. This dissertation research will focus on understanding how parent-child interactions are influenced by the use of technology that collects and displays the health information of children with T1DM. Two extensive user studies will be conducted to address gaps identified through a review of related literature. The objective is to define implications for design that help promote the balance of independence and dependence with diabetes management routines in families.

PROPOSED RESEARCH
Managing diabetes is highly individualized based on a child’s temperament, disposition, and age at diagnosis, socioeconomic status, cultural background, independence
with disease management, family dynamics related to diabetes management responsibilities, and the caregiver’s parenting style [1,2,3]. In addition, the goal of diabetes management – maintaining healthy levels of blood glucose – is incredibly delicate. There are a myriad of factors that influence blood glucose that the body of a non-diabetic amazingly handles on its own including stress, growth, emotional excitement, illness, physical activity, food consumption and environmental temperature. Using technology, medication and human intellect to manually replace this process is still extremely crude despite many recent technological advances such as insulin pumps and continuous glucose monitoring sensors. While there is already a considerable literature on resolving diabetes management issues in childhood there is much less on the efficacy of technological interventions. The proposed dissertation research will address the following gaps that have been identified through a review of related literature.

**Gap 1 – Who, What, When**

There exists a gap in understanding what type of technological intervention will work best for what type of child/family and at what developmental stage the intervention would be most effective [10,20]. The proposed research is focused on addressing this gap with regard to adolescent children with T1DM. Previous research has shown that adolescent children enjoy using mobile technology to aid in their diabetes management in favor of web-based solutions [4,9,12] so this will be the medium of technology (what type of technology) examined in the proposed research. Parent-child conflict surrounding diabetes management is common in adolescence and teens are resistant to sharing BG data with their parents [2], however children who have parents engaged in their daily care have better medical outcomes [7,8]. An outstanding research question is what is the right way to navigate this sensitive period with remote BG monitoring devices? To date, there have been no studies that clearly examine the impact of remote BG monitoring on the child and/or parents’ attitude toward the routine diabetes management task of checking BG. That is, does remote monitoring increase or decrease the negative feelings that surround check BG? Is more data always better or is there some measure of family dynamics that can aid in the design and selection of appropriate technologies based on the family context? Answering these questions are therefore part of understanding what family characteristics and timing (who and when) are best suited for specific interventions. Prior research from the HCI literature related to health behavior of children and families [11,13,14,16,19] provides a foundation for design implications that evolve from the proposed research.

**1.2.2 Gap 2 – Barriers to Adoption & Sustained Use**

Much of the research dedicated to the use of technology for children with diabetes is focused on medical outcomes as demonstrated by improved Hemoglobin A1C (Hgb A1C). This biometric marker is a reflection of blood glucose control over a 3-month period of time. The deeper issues that present barriers to technology adoption have not been well described in the literature. Research that strictly focuses on improving Hgb A1C may overlook important issues related to technology design that influences adoption and sustained use. There are many emotions elicited by health monitoring technology. A single BG reading can create a visceral response by the receiver that influences their desire to continue engagement with BG monitoring technology. Consider a BG value that is higher than normal range. The diabetic child may see this number after taking all the correct diabetes management steps and still feel frustrated, ashamed, afraid, or angry. The child’s parents may experience similar emotions, as they are integrally involved with routine management. What influence do these feelings have on continued use of BG monitoring technology? Are these feelings important to consider in the design process?

There are many known issues with acceptance and continued use of various technologies designed to aid with diabetes management. Web-based solutions have not garnered much success with changing health related behavior in general due to large drop out rates [6,20]. Recent studies that target children with T1DM have identified similar issues with website retention [4,12]. There has been success with text message systems that offer reminders to adolescent T1DM [9,12] but the impact of the messages were shown to dwindle with time. Further, most of the research looks at the impact of sending messages to the person with diabetes, not their support system. The ADA recommendations for care of adolescents with diabetes state appropriate levels of parental involvement, that are acceptable for both parent and child, is critical for good health outcomes [1]. This delicate balance is undoubtedly influential in the uptake and sustained use of diabetes management technology and therefore an important research question.

There is little research that focuses on the parental response to increased provision of additional information, either educational or BG trending values. Gammon et al. [10] found that some parents were more likely to nag their children about diabetes management issues if they had more information and that “surveillance technology” used to track BG values created a negative parent-child relationship. In the most comprehensive trial of technology and adolescents with T1DM (Sweet Talk), none of the participants elected to share goal related information with parents or friends and the authors concluded future research should evaluate the “personal and contextual factors influencing the adoption of such technology” [9]. In the field trial of a cell phone device with embedded glucometers by Carrol et al. [4], teens reported no positive impact to their relationship with parents or healthcare providers from technology that allowed sharing of BG data.

Emotion related to interactions with BG monitoring technology is not well understood and may be an important factor related to technology acceptance. Further, it is not
known whether parent-child conflict can be mitigated with technology by designing it to target the parent’s reaction vs. the child’s. For example, could the parent or caregiver be given instructional messages along with the data that facilitated appropriate diabetes management related conversations? Gammon’s [10] study findings also lacked a reflection of the child’s feelings related to tracking BG values. None of the existing literature related to technology trials with children have used survey instruments from behavioral science that detect negative response to checking BG values. These instruments may be an important means for defining the acceptable level of parental involvement with adolescents dealing with T1DM and understanding the ways in which technology can conform to this user need will be addressed in this research.

**Gap 3 – HCI Perspective**

While the management of diabetes has been discussed in a handful of projects in the HCI literature [15,17], there has been no study that specifically looks at people with T1DM. The management of T2DM and related design issues are distinctly different. Hayes [13] and Grimes [11] have looked at the impact of health data monitoring technology on children and caregivers, but the impact to the parent-child relationship from introducing BG monitoring technology has not been discussed in the HCI literature. The proposed research is focused on addressing this gap with regard to adolescent children with T1DM.

The HCI perspective offers an additional lens to the medical and behavioral science approach, focusing on the human experience with the technology vs. the medical outcomes related to the technology intervention. The findings of the proposed research will result in implications for design that go beyond a goal of improved Hgb A1C, instead it will look at improved experience with the technology and resultant self-efficacy with disease management. HCI research that is grounded in behavior change theory is especially well suited to approach the problems related to research questions identified above and existing research in HCI [5,15] serves as a model for examining the problems related to BG monitoring will serve as a model for further examining the value of behavior theory based design. The perspective taken in the proposed research will help contextualize problems with adoption and continued use of health related technology.

**METHOD**

The proposed research will address the identified gaps in knowledge through analysis of two studies. The first includes the analysis of semi-structured interviews with children who have T1DM and their parents. Children, ages 10 – 18 years old, and parents will be interviewed separately; parents will be interviewed as a couple when available. Both parents and children will complete validated survey instruments from behavioral science research that reflect the child’s independence with self-care and perceived parental involvement with care. One goal of the interview study is to identify the barriers to using commercially available technology. The interview transcripts will be analyzed using a grounded approach and relevant themes will be used to define design implications for this target population. Analysis of the survey instruments will be used to assess possible relationships between diabetes management in the family context and barriers to technology use.

The second study includes the results from a controlled technology trial to evaluate the impact of a patient/family-centered diabetes care program utilizing the Automated Diabetes Management System (ADMS) from Diabetech®, LP. The ADMS, comprised of the GlucoMON® and GlucoDYNAMIX™, are wireless technologies that work together to provide automated self-monitored BG data retrieval, analysis and reporting. The system communicates BG readings immediately parents via text message and email. Additionally, it sends a three-week BG trending report via email each night. In this study, the ADMS was provided to patients and families of children (age 10 – 14 years) with established T1DM to determine if the system significantly improves long-term glycemic control, diabetes self care knowledge, patient and family satisfaction, reduces diabetes health care provider work load and improves provider satisfaction compared to conventionally managed patients. Forty-nine families from a diabetes clinic participated in a 12-month trial – 25 used ADMS and 24 received traditional therapy. The children and parents of both control and experimental groups completed validated survey instruments from behavioral science research that reflect anxiety related to checking BG levels and independence with self-care. The surveys were completed before beginning the trial, at 6 months and at the end of the trial period. Hgb A1C data was collected at each of these time intervals as well. Analysis of the data from this study will be used to understand the impact to family communication and emotions from the introduction of technology that provides intense BG data monitoring. Follow-up interviews will be conducted with participants as design concepts and questions emerge from the data analysis of both studies.

**SUMMARY**

The proposed research is directed at understanding the influence of ubiquitous computing technologies that become integrated into ones life. Managing a child with T1DM is a rigorous daily responsibility that involves vigilance and must evolve as the child moves through different stages of development. The addition of technology to aid in this routine is still quite crude but has clear potential value. This thesis is concerned with understanding both the child and parent experience with ubiquitous technology that monitors health. To this end, three gaps identified in the literature will be addressed: *Gap 1 – Who, What, When: The themes that evolve from the interview study will be integrated with the results of the technology trial in order to better understand the influence of diabetes management in the family context; Gap 2 – Barriers to Adoption & Sustained Use: The interview findings will*
As technology continues to evolve and play a larger role in the management of children’s health, research is needed that examines the impact of the use of such technology on the parent-child relationship. While this dissertation research is focused on children with T1DM, the findings may be generalized to the management of other childhood health issues.

REFERENCES