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Best Intentions: Health Monitoring Technology and Children.

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Health Monitoring Technology and Children

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ABSTRACT

In this paper we describe findings from two studies aimed at understanding how health monitoring technology affects the parent-child relationship, examining *emotional response* and *barriers* to using this type of technology. We present suggestions for the design of health monitoring technology intended to enhance self-care in children without creating parent-child conflict. Our recommendations integrate the study findings, developmental stage specific concerns, and prior HCI research aimed at children's health.

Author Keywords

Pervasive technology; health monitoring; understanding users; children; parents; diabetes; design; user experience

ACM Classification Keywords

H.5.2 [Information interfaces and presentation]: User Interfaces – User-centered design;

INTRODUCTION

Parents guide their children through various developmental milestones to help shape behavioral choices – social, fiscal, academic, health, and others. Technology can be an aid to parents, providing a virtual window into their child's life. For example, parents can remotely monitor their child's choice of food items purchased in the school cafeteria, homework assignment submissions, and grades through school websites. Social activities can be tracked through Facebook accounts and text message activity on mobile phones. Driving decisions can be tracked with pervasive technology embedded into motor vehicles. Credit card transactions and bank activity can be monitored using web-based portals. These technological developments create a situation where parents with the best intentions of remaining connected with their child, in order to provide effective direction, can cross a personal boundary and create conflict in the relationship [4]. The focus of our research is on how new technologies can impact the *health* behavior of children. While intended to reassure, health monitoring technologies may actually exacerbate bad feelings and parent-child conflict in certain contexts. Our

research looks at this potential concern from the perspective of children with Type 1 Diabetes (T1D) and their parents.

Blood glucose monitoring (BGM) is central to maintaining the health of people with diabetes. Thus, parents of children with T1D are likely to want a technology that helps collect, track and relay blood glucose (BG) values to them. In this research we sought to expose what – if any – emotional response is provoked by the use of BGM technology, and in turn, if this response affects the parent-child relationship. We conducted two different kinds of study to examine this central concern. First, we conducted an *interview study* to uncover the differing needs of children with T1D and their parents across three phases of development – Older Elementary (8-11 years), Early Adolescence (12-15 years) and Late Adolescence (16-19 years). This study was designed to gain a better understanding of stage-based concerns surrounding the use of technology for routine diabetes management. Our aim was to identify ways in which BGM technology could be designed to lower barriers to use and curtail negative emotional response. Second, we analyzed the findings from a *12 month controlled trial of a BGM technology* that automatically collects, tracks, and then sends BG information to parents. This study focused on the older elementary age group and was designed to determine if the technology impacts affective response to BGM, in addition to the health outcomes and self-care of children with T1D.

While the two studies were carried out separately, they complement each other by addressing the core research question from different perspectives – how does the emotional response to BGM technology impact disease management and the family dynamic? The interview study examines parents' and children's emotional concerns surrounding BGM usage while the technology trial uses a validated instrument to measure changes in emotional response to BGM during 12 months of use. Importantly, both sets of findings suggest how technology can be designed to increase reflection on BG trends without creating problems in the family dynamic.

BACKGROUND

Many of the personal decisions to take a particular health action (e.g. exercise) or use a technology to monitor health (e.g. Nike+iPod to track exercise) are the same whether managing chronic disease or wellness – a person may realize that they should take action to benefit their health,

yet they choose not to. Despite how it may help our health, few of us enjoy stepping on a scale to monitor weight because it can make us feel bad about ourselves, out of control, or discouraged. Likewise, few people with diabetes enjoy using technology to monitor their BG control. Designing health promoting technologies aimed at a single user is challenging but this becomes even more complex when the technology must simultaneously meet the needs of two individuals with differing emotions – namely, parent and child.

Managing Diabetes in Childhood

T1D is one of the most common chronic childhood diseases with more than 15,000 young people diagnosed every year in the United States [1]. The disease occurs when the body's immune system attacks and destroys the beta cells in the pancreas, halting the production of insulin. The main function of insulin is to allow glucose to move from the blood into the cell for energy, growth and healing. A lack of insulin, therefore, causes a rise in BG levels, or *hyperglycemia*. Once diagnosed, individuals with T1D will have to replace natural levels of insulin for the rest of their lives. Insulin can be delivered either by multiple injections throughout the day or continuously with an insulin pump. T1D differs from Type 2 Diabetes (T2D), insofar as the latter can be treated with diet and exercise, and where the pancreas still produces insulin, but the body cannot effectively use it.

Dietary intake, physical activity, stress, and physiological processes, such as growth or illness affect BG levels. Dietary intake of carbohydrates is the primary contributor to BG levels, and thus insulin must be delivered in direct relation to the amount of dietary carbohydrates consumed. Children with T1D must, therefore, carefully determine the grams of carbohydrates of anything they eat including meals, snacks, beverage, and medications. Physical activity contributes to an increased utilization of BG and can cause low BG, or *hypoglycemia*, if insulin delivery and carbohydrate intake are not properly adjusted. Tight glycemic control – keeping glucose values within normal range of 70-120 mg/dl – greatly reduces the long-term complications caused by hyperglycemia, which can include cardiovascular disease, blindness, amputation, and kidney failure [1]. Tight control can be accomplished by frequently checking BG levels using a glucometer and correcting for abnormal levels. The glucometer is a device that determines BG level from a small sample of blood obtained by the user when they prick their skin with a small needle (lancing device). Reflecting on BG patterns is necessary to properly adjust insulin therapy for tight glycemic control [1].

Pervasive technologies offer much potential to support children with TID and their families, in particular, providing real time data that can help them cope with the complex, daily routines of diabetes care. For example, a system that automatically records and displays BGM data can be an aid to parents by heightening awareness of BG trends and sustaining engagement with their child's diabetes management. Prior research has established the value of parental involvement in the care of children with T1D [1, 2]. A technology that makes it easy to collect and reflect on BGM data also stands to improve diabetes self-management in children, which has been correlated with better glycemic control [6]. However, there is also the danger that these types of monitoring technologies can create a negative attitude towards BGM due to an increased focus on BG values and constant surveillance [4]. Negative BGM affect has been linked to poor glycemic control [8], underlying the importance of understanding the emotional response of user in the design of this type of technology. However, there is a paucity of research that demonstrates the range of changes in attitude and behavior among children and their parents when using such pervasive monitoring technologies. There is a significant HCI literature dedicated to understanding how best to design health promoting technology. What follows is an overview of some of the work that has inspired the research presented in this paper.

Health Behavior Research in HCI & UbiComp

Many studies aimed at managing the health of children have emphasized the importance of understanding the influence of technology on family dynamics. Kientz et al. examined the record keeping needs of parents as they track their child developmental milestone progress [9]. Themes that evolved from focus groups and interviews revealed that the choice to use the technology may be based on *emotions*. For example, some parents were not interested in collecting milestone data because they felt it may trigger feelings of paranoia about their child's development. Maitland et al. [11] conducted a field study that examined the ways in which technology might be used to improve dietary behaviors in families with low socioeconomic status, highlighting the importance of considering *cultural values* related to particular health behavior when designing technology. Grimes et al. [5] conducted a field study to explore the implications of collecting, analyzing and sharing health information (diet and exercise) within families. This study of 15 families found that understanding the *potential impact to the family dynamic* is essential in the design of health related applications aimed at children. From her extensive work designing technology for autistic children, Hayes [7] suggests that emotions such as *perceptions of surveillance* be attended to in design by balancing the control of data with social needs such as trust.

Some researchers have sought to address the *data capture needs* of people as they manage health. Mamykina et al. studied three prototype technologies that focused on diabetes management in adults with T2D [12, 13]. The central arguments in this body of work is that simply providing data does not ensure the user will know how to use it for behavior change. Thus, data capture technologies should *encourage users to engage with the data collection to promote reflection and understanding*. Though not

specific to diabetes, Hayes et al. [7] have conducted many studies to understand the use of data capture technologies as an aid to children with autism. One design suggestion from this body of work is that data capture technologies must *reduce the burden of collecting and analyzing data* to a point where it does not interfere with ordinary activities of daily living. In a series of experiments with technology that collects physical activity data of adults, Consolvo [3] found that participants experienced many breaks in their exercise routine due to various life events (e.g. minor illness, work commitments, holidays). She suggests technology be designed with the goal of *sustaining the user's interest in the device* so there is motivation to resume use after breaks.

Our research builds on prior work on health monitoring technologies, focusing on the ways in which emotional response to it affects user engagement with BG data, family interactions, and health outcomes.

INTERVIEWS WITH CHILDREN AND PARENTS

An interview study was conducted to better understand tensions that occur between children with T1D and parents as they use technology to cope with diabetes across the continuum of childhood development. This study focused on children, aged between 8 and 18, which is the peak time of T1D diagnosis [1] and a stage of development when key interventions can make a life-long impact upon health behaviors. The age range encompasses three specific stages of development for which unique diabetes management issues have been defined [1] – *Older Elementary* (8-11 years old), *Early Adolescence* (12-15 years old), *and Late Adolescence* (16-19 years old). While the interaction between parent and child evolves over time, research has shown that children with T1D who have parents who are engaged in diabetes management throughout these stages of development, ultimately have better health behaviors and outcomes [1]. Thus, it is important to design technology that supports parent engagement.

Interview Method

Qualitative research has been found useful for understanding the nuances and complexities of a particular research question. One approach is to use a small number of participants in order to reveal these with respect to technology adoption, appropriation and resistance [12, 10, 14]. Likewise, we reached data saturation by conducting interviews with seven families. The goal of the interviews was to investigate the ways in which technology, designed to track and trend BG levels, may *contribute to or detract from* the goal of independent and effective disease management. The study protocol was approved by the institutional review board (IRB) of Indiana University.

Participants

Children with T1D and their parents were recruited from two school districts in mid-western United States. School nurses sent recruitment letters to 35 families and a total of seven volunteered to participate. Table 1 presents personal characteristics of each participating family, including the

Participant	P1	P2	P3	P4	P5	P6	P7
Age [a]	8	9	12	12	17	17	17
Duration of T1D [a]	3	6	7	6	9	1	10
Gender [b]	F	M	F	F	F	M	M
Insulin pump [c]	Y	Y	Y	Y	Y	Y	Y
CGM [c]	n	n	n	Y	n	n	Y
BG trend software [c]	Y	Y	Y	n	n	n	Y
Smart glucometer [c]	n	Y	n	n	Y	n	Y

Table 1. Characteristics of Interview Study Participants.

[a] in years; [b] F = female; M = male; [c] Y = yes used; n = not used.

diabetes management technologies they have used. All of the parents interviewed had completed college. There was one participant (P4) whose parents were divorced; all other parents were married. The mothers from all of the families were interviewed, as well as the fathers of P1 and P7. Written informed consent was obtained from all parents and children before the interview.

Procedure

Children 10 years of age and older were interviewed individually, without their parents being present. Children under the age of 10 were not interviewed because the IRB did not grant permission to utilize the planned interview questions for this younger age group. Instead, we relied on the older children interviewed, asking them to reflect on issues around diabetes management that might have occurred when they were younger.

In total, 12 one-hour semi-structured interviews were conducted. The interview questions solicited the types of diabetes technology used, barriers to use, and perceptions about how BGM technologies affect the parent-child relationship. Parents and children were asked the same questions but to answer from their own perspective. At the end of each interview, participants were shown a video demonstrating a technology called the Automated Diabetes Management System (ADMS), by Diabetech®, in use. The video served as a probe to stimulate the participant's thoughts about a general category of technologies that automatically track, trend and communicate BG readings. After viewing the video, parents and children were presented with various scenarios of use to identify how this type of technology would or would not be useful for diabetes care at their (their child's) current phase of development, as well as when they were younger, and how it might impact their relationship with their parent (child).

Analysis

The interviews were audio recorded and later transcribed to text. The transcripts were analyzed using an iterative approach. Participant comments were pulled out from each interview and grouped together in categories. These were refined after each review of the data until prominent themes emerged. Stage specific differences in diabetes care concerns and family division of responsibility, as defined in the

American Diabetes Association guidelines for care [1] were used to help organize the findings and identify ways in which technology might be best leveraged to impact diabetes self-care behavior.

Interview Findings: Older Elementary

The following is a summary of relevant themes from the interviews with the parents of P1 and P2.

Frustration with data collection and reflection

Barriers identified in the interview study of older elementary age children include frustration from the difficulty collecting BG values and engaging the child with the data. Both families interviewed in this study used multiple glucometers, keeping one in their child's bedroom, kitchen, in the family car, and in the nurse's office at school. Multiple meters present a barrier to reflecting on BG trends because there is no device that can collect, consolidate, and display information gathered from glucometers in different locations or glucometers of differing types. One mother described her experience using an online tool to track and trend her son's BG values.

"I liked being able to track the numbers, but it was a lot of time … it was a hassle because we use multiple meters too. I don't really know how to get around that. I usually use pencil and paper to log BG values, because we use so many different meters." <Mom of P2>

There exists a tension between the desire to reflect about BG trend data – as a means to improve glycemic control as well as train the child in diabetes self-care – and the burden of collecting the data. Both of the families interviewed felt that existing technology was not an effective training tool for their child. One participant described a creative way in which parents in his support group get their children with T1D engaged with BG monitoring, by making it fun.

"We have a little contest sometimes, [all the children] come and check their [blood] sugar at the same time and they get a lot out of that. Who is going to be highest and who is going to be lowest? Just to make a game out of it. It is no big deal, it is just a number, but let's have some fun with it." <Dad of P1>

Fear associated with loss of diabetes management control

Diabetes management is a 24-hour responsibility; parents or trained caregivers must be nearby to provide care and ensure safety of late elementary age children. This can be challenging when allowing children to participate in 'normal' activities such as slumber parties and school sports teams. The impulse to keep a young child safe and close to oneself is a natural response in parents, particularly when there is fear about putting the responsibility for diabetes management in the hands of another caregiver. Equally, children seek the security of having a parent nearby. One parent described this type of transition that had recently taken place for his eight-year-old daughter.

"We are just getting past the point where she was afraid if she knew that mom and dad were going to be out [of sight] and the concept of overnight was scary to her. We are now at a point that we have built that independence in her that she knows she can be away from us … but she still needs that connection through our cell phone." <Dad of P1>

Parent, child, and temporary caregivers, alike, value the connectedness that remote monitoring technology can offer. None of the parents we interviewed felt that this type technology would provoke a negative sense of surveillance for their child.

Although we were unable to interview children in the older elementary age group, several of the adolescent participants shared experiences, which support the perspective of the parents we interviewed. P7 mentioned a time when he was in elementary school and the school secretary had to track his mother down while she was shopping to address a BG that was too high. He concluded that a technology like the ADMS *"would have been cool and would have made things easier."* P5 concurred stating *"When I was a little kid [the ADMS] would have helped so much. If we had that technology when I was 8, I probably would have had a cell phone. I think my parents would have probably got me one for that sole purpose."* P3 felt it would have been helpful during sleepovers with friends when she was younger.

Interview Findings: Early Adolescence

Next, is an overview of the tensions, discussed by P3 and P4 and their parents, during their separate interviews.

Frustration with rapid growth & metabolic complications

Puberty strikes at an average age of 11 years for girls and 13 years for boys with an accompanying growth spurt that begins between 12 to 15 years and 14 to 17 years of age respectively [16]. Growth brings about increases in the amount of insulin required for glycemic control, not just by virtue of the increase in food consumption, but also due to hormonal changes. Both of the mothers we interviewed felt software to track and trend BG was especially important now because their daughters' blood sugars had become abnormal due to the onset of puberty. Parental concerns about unusually high BG dominated the conversation and the following quote is a representative example.

"She has always run usually under 200, well this year was different and I am sure it was hormonal. She started her period and she was just running high all the time and today it is nothing for her to be in the 200s." <Mom of P4>

When glycemic control takes a turn for the worse in adolescence, simply the act of checking BG can create tension because the numbers may inexplicably and rapidly rise, leading to a battery of questions to the child about what may have happened. Both mothers explained that collecting contextual data surrounding the BG reading, e.g. food consumed, illness, emotional stress, physical activity,

would be an aid for reflection and retrospective problem solving with their daughters.

Shame and burgeoning self-esteem

Health monitoring technologies have the potential to produce shame in the people who use them, as they are often a direct reflection of success towards a personal health goal. The adolescents and parents we interviewed discussed examples of 'shameful feelings' produced by interacting with diabetes-related technology. One mother described how her daughter went through a period of being dishonest when questioned about checking BG values;

"There was a period where she was lying that she tested. She has even been on the phone with me and said 'Okay I will test.' I waited on the phone and [she said] 'I am 122 Mom' and when I check later I found she didn't even test and later we found her blood sugar had been high, it was just one lie after another [during that period of time]." <Mom of P4>

Conflict can occur when parents are trying support their child toward independent self-care but the child is pulling them back in for assistance. It can be frustrating to children as they search for independence within established parent-child interactions. Simply checking in with a child about a glucometer reading can create feelings of frustration, as was described in the following;

"Sometimes we will forget and say 'Did you test yourself?' [Her Dad] and I will both ask. By the third time she is like 'Yes…I told you!' You hear it so often from them; it is in one ear and out the other sometimes." <Mom of P3>

It is hard to break old habits that have been established during elementary school years. The younger a child is diagnosed, the more transitions a parent must successfully endure. Responsibilities must shift but it is often easy to slip back into old routines. Both of the girls interviewed shared the same conflicting attitude toward parental assistance, for example one child said:

"I usually know everything, but once in a while I will wonder how much something is [the grams of carbohydrate in food] and I will call her." <P3>

Children in this stage of development are becoming more independent and make statements to push a parent away from their care. However, this age group still needs significant parental assistance, especially with the more complicated diabetes management tasks (e.g. interpreting BG trends and knowing when an intervention is required).

Interview Findings: Late Adolescence

The teens (P5, P6, and P7) and their parents that were interviewed had opposing needs related to the use of BGM technologies. This difference in perspective contributed to tension in the parent-child relationship, inhibiting the use of certain diabetes management technologies.

Parent perspective: Anxiety and lack of trust

Anxiety was a tension shared by all of the parents – particularly the need to know if their child routinely checked BG. Each parent also described their struggle to release control of diabetes care to their teenagers and expressed a need for suggestions about how to successfully navigate this difficult stage of child development. Anxiety related to BG checking can interfere with the trust as one parent describes:

"Sometimes I feel like I have to nag, because sometimes I don't see her test [her BG] and she says 'Yes I have already done it!' and when she is not looking I will look at her meter [to confirm]." <Mom of P5>

This tension can lead to significant parent-child conflict, especially when either the teen gets caught lying and/or parent gets caught looking at their child's glucometer. Another parent describes suspicions that her son may only share BG information when it works in his favor:

"He is supposed to test before he drives, I am sure he doesn't test every time. In fact, I don't think he tests ever, but if he feels weird, he will call me and say I am going to be late, my sugar is low. I have said well just wait, get your sugars up and then come home. One time though I have to say that it was awfully convenient. He was at his girlfriend's but supposed to be home, hmm." <Mom of P6>

All of the parents were empathetic to their child's desire for independence and expressed a need for guidance on how to transition their adolescent to autonomous self-care. Trust issues can interfere with a parent's best intentions to release control of disease management to their child. All of the parents had conflicted feelings similar to the following:

"I don't like not knowing what [his BG values] are. I probably could just go in at night and take his meter and write them down, but I am trying to give him control and let him deal with the doctors." <Mom of P7>

The parents placed value in a technology that would help them keep track of their teenager's BG monitoring activity as a means to reduce anxiety and help build the trust.

Teen perspective: Intense desire for independence

The teens shared feelings of frustration surrounding the interaction with BG monitoring technologies due to their desire to be independent. Vigilant 'checking in' with a child about BG level is an understandable, and to a certain extent desirable, parental behavior, but it can lead to unhealthy tension in the parent-child relationship. One teen explained how the tension in this interaction led to a complete shut-down of communication of any BG results to his parents:

"I basically want a complete removal from [my parents]…absolutely with no information at all going to them or from them. I [tell them] 'I know what I am doing, I can do this by myself' kind of thing and for Mom that is really, really difficult, because she wants to be there to protect me and keep everything good." <P6>

Feeling trusted in independent self-care was an important acknowledgement for teens to receive from their parents:

"My Dad kind of leaves it up to me, he will remind me like make sure you do your blood test and give yourself insulin. My Mom is the real stickler. I think my dad trusts me and knows that I am growing up and can do whatever, but my mom still thinks I am a baby." <P5>

Another teen complained about feeling misunderstood because he often gets distracted and forgets to check his BG but feels his parents and doctor don't accept this reality:

"Well my mom bugs me a lot about checking my level, I just honestly forget. I guess nobody really understands that I honestly forget. People are just like … you didn't forget, you just didn't want to. It's like no, I really forget." <P7>

The teens placed considerable value on the freedom to make their own health decisions and felt remote BGM technologies were unnecessary and would feel invasive.

### Summary of Interviews with Children and Parents
The primary contributor to tensions across all of the age groups was checking BG with a glucometer. Parents of older elementary children experience a sense of fear as they leave their child's diabetes management in the hands of another caregiver, who then takes over responsibility for checking BG. The lack of access to this data creates a loss of control and associated discomfort. Glucometer use can create shame in early adolescence because blood sugars are extraordinarily variable due to puberty and growth. This can contribute to parent-child conflict as children may be dishonest about checking BG to avoid bad feelings associated with high values. Non-compliance with BG monitoring is the principle source of parent-teen conflict.

Our study has revealed two core aspects of a technology that could address the emotions surrounding BGM: (1) *Remote access to data when parent and child are not co-located;* and (2) *easy collection of meaningful data that enhances reflection and awareness*. Each of these general functionalities would be designed differently based on the development stage-based needs identified in this study. Next we describe the findings of the second study that investigated the emotional responses to families using a specific health monitoring technology, the ADMS.

TRIAL OF A NEW PERVASIVE TECHNOLOGY
The needs of families with children in the *older elementary* stage of development, as identified in the interview study, were further explored through the analysis of data from a 12 month trial of a technology that automatically collects, tracks, and trends BG values. Although this study was not designed by the authors (see [18] for more details), it was completed after the interview study, enabling the themes identified to be explored in more detail, in particular, the changes in emotional response to BGM by the participants.

The technology used in this trial possesses the two core features identified in the interview study as having the
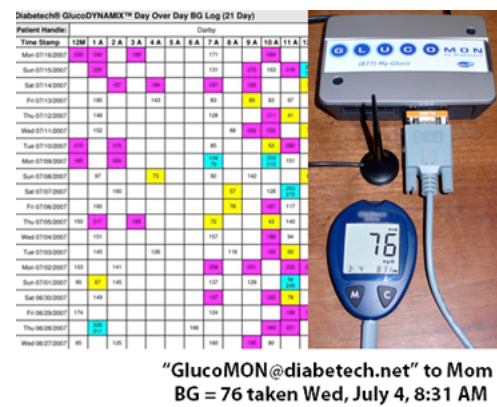
Figure 1. 21-day trend report, GMON, & real-time alert

potential to address emotions surrounding BGM. The focus of this study was to investigate whether actual use would affect the child's and/or parents' emotional response towards BG checking and health outcomes such as glycemic control and diabetes self-care skills. BG trending information and the heightened attention to BGM has the potential to trigger bad feelings for both parent and child. Parental monitoring may also contribute to negative feelings of surveillance for a child [4]. Thus, the technology trial addresses important questions about the potential of remote BGM, identified in the interview study.

Technology Trial Method
The interview study used a *qualitative* approach to understand the variety of parent and child perspectives about the use of diabetes technology. In this experimental study, *quantitative* measures of improved glycemic control, attitude toward BG testing, and attainment of diabetes self-management skills were collected for a BGM technology – the Automated Diabetes Management System (ADMS).

Intervention
The ADMS comprises two components: the GlucoMON® and GlucoDYNAMIX™; these are wireless technologies that work together to provide automated BGM data retrieval, analysis, and reporting. The participants taking part in the experimental study had access to two features within GlucoDYNAMIX including: (1) *'Real-time alerts'* – notification to parents, by text message to cell phones and/or email, of the last BG result immediately following the docking of the glucometer to the GlucoMON device; and (2) *'Trend analysis reports'* – parents received a *daily email* including the system generated 21-day BG log attached as a PDF document (see Figure 1). The report is color coded and arranged by date (on the y-axis) and time (on the x-axis). Elevated BG values are red; low blood sugar results in yellow; readings 'within range' are white.

Participants
Study participants were children with T1D under the age of 12 and their parents, who were recruited from an outpatient diabetes clinic associated with a children's hospital in the Southwestern United States.

Sixty-four families were invited to participate in the study. Fifty-four (84%) volunteered and were randomly assigned to one of two groups: 27 families in a *control* condition (conventional care without ADMS); and 27 families in an *experimental* condition (conventional care with ADMS). Three families from each group dropped out of the study leaving a total of 48 families – 24 in the experimental and 24 in the control condition of the study. Analysis revealed no statistically significant difference for demographic and clinical characteristics between the experimental and control groups (see Table 2).

Procedure

Participants in both conditions were seen five times during the 12-month study period, beginning with an initial baseline screening appointment during which demographic, glycemic control, and psychosocial data were collected. Families were seen quarterly for routine diabetes clinic visits during which relevant information was gathered. Neither group was asked to monitor BG any more or less frequently than other patients with T1D in the practice. Families in both groups received two registered BG meters and agreed to use only these devices during the study.

Both groups were seen by the same health care team and provided the same level of care without bias. BGM information collected by the ADMS was not monitored by the diabetes team outside of routine clinic visits. The health care team did not explicitly encourage use of the ADMS. Participants enrolled in the experimental group were provided the ADMS equipment and service, free of charge for the study duration. As an incentive, participants in the control condition were offered use of the ADMS for 6 months after the completion of the study. No other incentives for participation were provided to either group.

Participants were free to utilize data from the ADMS as they saw fit for diabetes management purposes. They were advised to dock their meter(s) daily or more often if they wish but at a minimum, they should dock weekly. One family had no Internet access so their trend analysis reports were mailed to their home each week. Reports were not automatically sent to the diabetes care team and no specific health care provider initiated action was triggered by ADMS reports. It was left to the family to decide what (if any) action should be taken.

Measurements

(1) *Glycemic control*. HbA$_{1c}$ was collected at enrollment and at 3-month intervals for every participant in for the duration of the study. This blood value is a reflection of how well BG has been kept in normal range during the prior 3 months, and is the clinical standard for measuring glycemic control. The risk of microvascular complications, – including eye, kidney and nerve disease – increase exponentially with higher HbA$_{1c}$ values [81]. A 10% reduction of HbA$_{1c}$ (e.g. going from 8 to 7.2) has been associated with a 43% reduction in the occurrence of complications [17]. The ADA suggests a target

		Experimental	Control
n		24	24
Age in years [a]		8.7 ±2.2	8.3 ±2.7
Duration T1D in months [a]		47 ±28	44 ±24
Baseline diabetes control HbA$_{1c}$ [a]		7.9 ±0.8	8.1 ±1.3
Gender	Male	13 (54.2)	15 (62.5)
Family	Two parents/guardians	21 (87.5)	17 (70.8)
	One parent/guardian	3 (12.5)	7 (29.2)
Ethnicity	White, non-Hispanic	15 (62.5)	14 (58.3)
	Hispanic	8 (33.3)	10 (41.7)
	Native American	1 (4.2)	0
Language	English	22 (91.7)	23 (96.8)
	Spanish	2 (8.3)	1 (4.2)
Insurance status	Insured	19 (79.2)	15 (62.5)
	Medicaid	5 (20.8)	9 (37.5)
Education level [b]	≤ High School	6 (25.0)	7 (30.4)
	Partial College	8 (33.3)	8 (34.8)
	Bachelor	7 (29.2)	6 (26.1)
	Master	3 (12.5)	2 (8.8)

Table 2. Characteristics of Technology Trial Participants.

Values are *n* (percentages) unless stated otherwise. [a] mean ± standard deviation. [b]Education level is for parent/guardian and represents highest level attained out of the two parents or guardians (no information for one control group participant).

HbA$_{1c}$ <8 for 6-12 year olds and <7.5 for teens 13-19 years old [1].

(2) *Diabetes self-management*. Participants from both study groups completed a Diabetes Self-Management Profile (DSMP) at the baseline, 6-month, and 12-month visits. The DSMP is a semi-structured interview that is a validated measure of diabetes self-management [6]. Parents were interviewed in this study as prior work has shown little difference between child and parent responses [6]. The questions are grouped into subscales related to each area of self-care and have a range of possible points as follows: exercise (0-12), management of hypoglycemia (0-11), diet (0-17), BG checking (0-33) and insulin administration and adjustment (0-16). Higher scores indicate more rigorous diabetes self-management along the five subscales.

(3) *Affective response to BGM*. Both parent and child completed separate Blood Glucose Monitoring Communication (BGMC) questionnaires at the baseline, 6-month, and 12-month visits. The BGMC questionnaire is a validated eight-question survey that gauges emotional response to BGM [8]. Children are asked to reflect on how it feels when their BG is out of range. Similarly, questions aimed at parents ask them to report the level of concern they have for their child in such situations. The total score of the survey is used to evaluate BGM affect, where a minimum score of 8 reflects a more positive emotional response and higher scores up to a maximum of 24 points are indicative of negative feelings towards BGM.

Technology Trial Findings

The findings presented here summarize the quantitative data showing the emotional responses to the use of remote BG monitoring technology (see [18] for more details).

Usage Groups

ADMS usage was measured using system recorded docking events (glucometer docked with GlucoMON). Participants in the experimental condition were free to use the ADMS however they wished and 2 distinct groups of usage emerged – those who docked < 1 times each week and those who docked 1-3 times each week throughout the study. In addition to comparisons between the control and experimental, the ADMS usage groups (A) docking <1 time/week, (B) docking 1-3 times/week, and (C) the control group are used to categorize the study outcomes. There were no statistically significant differences in baseline demographic or clinical characteristics among ADMS usage groups (A), (B) and (C) – including characteristics listed in Table 2, baseline HbA$_{1c}$, BGMC or DSMP scores.

Glycemic Control

The results of the 12 month trial of the ADMS showed that children in the experimental group had significantly (p=0.01) lower HbA$_{1c}$ at 12 months (7.44 ±0.94, a reduction of 0.35 from baseline) when compared to the control group (8.31±1.24, an increase of 0.15 from baseline). Improvement was more profound in families using the ADMS more frequently. Participants in usage group (B), who docked 1-3 times/week, had a nearly 10% reduction in HbA$_{1c}$ from baseline (7.8 ±1.0) to 12 months (7.1 ±0.6).

Diabetes Self-Care

This study showed that participants who docked 1-3 times/week had larger improvements DSMP scores than both the control group (p=0.04) and the group docking <1 time/week (p=0.06). The largest gain for children in this group was in skills related to BG checking. This result occurred in a context where participants were simply given the ADMS and allowed to use it as desired. There was no additional prompting, educational messages, or connection with health care providers afforded by the technology.

Affective response to Blood Glucose Monitoring

As shown in Table 3, children in both the experimental and control conditions experienced no significant change in BGMC scores from baseline to 12-months. This indicates that the introduction of the ADMS had no impact on the BGM affect of children in the experimental group.

Table 3 also shows that parents in group B (those docking 1-3 times/week), had a significant (p=0.04) improvement in BGMC from baseline (13.1 ±3.6) to 12-months (11.3 ±2.3) when compared with the control group and those docking <1 time/week. The *mismatch* in BGMC scores (mismatch = BGMC-parent – BGMC-child) may reveal potential tensions around BGM. A *positive* mismatch indicates that the parent has more anxiety related to the results of their child's BGM. This discrepancy in emotional response may

	ADMS use			
	Group(A) <1x/week (n=13)	Group(B) 1-3xs/week (n=11)	Group(C) Control (n=24)	*p value^a*
BGMC-parent				
Baseline	13.6 ±	13.1 ± 3.6	13.5 ± 3.2	0.04
6 months	14.1 ±	11.5 ± 2.1	14.0 ± 3.8	
12 months	14.3 ±	11.3 ± 2.3	14.5 ± 4.1	
BGMC-child				
Baseline	12.2 ±	12.4 ± 2.2	12.7 ± 3.5	0.68
6 months	12.4 ±	11.2 ± 2.1	13.0 ± 3.5	
12 months	12.4 ±	12.5 ± 2.7	13.4 ± 3.4	

Table 3. Mean BGMC scores by ADMS usage group.
Values are reported as mean ± SD unless otherwise noted.
^{a}*p values* from analysis of variance model for change in BGMC scores for parent and children from baseline to 12 months.

create tension if an anxious parent over reacts to the results of a BG check, leaving the child frustrated because they have less anxiety related to BGM. Table 3 shows the mean BGMC scores of parents in Group B dropped below scores of children in that group after using the ADMS for 12 months (mean mismatch of -1.2). Mismatch for groups A and C became larger, more positive, by the end of the study.

Summary of Technology Trial

This study has shown a positive relationship between the use of the ADMS and health outcomes. Specifically, docking 1-3 times/week was associated with significant improvements in HbA$_{1c}$, DSMP, and BGMC-parent scores. Although the BGMC scores of children were not significantly different with the addition of the ADMS, it is a positive finding given that this technology has the potential to make bad feelings worse. We also found that families that used the ADMS more often had more comparable parent-child BGM affect by the end of the study.

DISCUSSION

The studies presented in this paper provide different perspectives to address the research question – how does the emotional response to BGM technology impact disease management and the family dynamic? The interview study revealed specific ways in which the evolving emotional needs of children and parents influence adoption and use. Our findings suggest that the two core functions of BGM technology must be addressed based on the differing needs of each age group. For example, *'Remote access to data when parent and child are not co-located'* must be addressed in the older elementary stage because parents and children, alike, fear separation when they must rely on others to properly respond to diabetes management concerns. Parents of children in early adolescence would benefit from remote monitoring in order to support their child as they navigate the complexities of managing diabetes during periods of rapid growth. In the later phase of adolescence, remote access to information could be used to foster trust and mitigate anxieties of parents who must back away gradually from their child's diabetes management. In the case of *'Easy*

collection of meaningful data that enhances reflection and awareness,' parents of children in the older elementary phase of development who are trying to interpret patterns in their child's BG readings may become frustrated and give up trying if the technology does not allow for easy data capture. In turn, parents without the full picture of BG trend information may react more strongly than needed to a single reading that is out of normal range. This type of negative, affective response can have emotional repercussions to both the parent and child. Children in early adolescence who are challenged by the changes brought about by puberty may benefit from contextualized BG readings to make the data more meaningful. Ease of data collection is essential to promote BGM reflection during late adolescence, but more important is identifying what aspect of collecting the data is most meaningful to teens in order to motivate routine BGM.

In answer to the research question, the technology trial has shown that a technology that pushes data to the parent can actually improve their emotional responses to health data without adversely affecting the feelings of the child. The results of this study confirm findings from the interview study, namely that attending to *emotional response* in the design of pervasive health technology can contribute to positive outcomes. The families who used the ADMS frequently enough to experience benefits had a *reduction* in parental anxiety around BGM. Moreover, the affective response of parents became more similar to that of their child, possibly lessening tension in their relationship. The ADMS also sustained the interest of roughly half of the experimental group who remain consistently engaged with the technology for 12 months – through the various life events that can cause a break in routine. This could be due to the system's ability to effectively address the anxieties of parents with children in the late elementary phase of development. The discussions we had with teens in early/late adolescence and their parents suggest that the ADMS (as currently designed) would not effectively meet the needs of families with older children. Furthermore, if not properly designed it could exacerbate parent-child conflict. However, given the significant positive impact to glycemic control and self-care skills it is important to consider how this technology can be modified to better meet the needs of teens and their parents.

The findings from this experimental trial suggest that, if properly designed, health monitoring technologies can support parents' *best intentions* without contributing to conflict. By focusing on *user experience* (emotions surrounding technology use) and the issues brought about by the stage of child development, we have identified following design implications for of health monitoring technologies like the ADMS:

Older Elementary: Children in this age group can assume basic self-care tasks including insulin injections and BG testing but still require the supervision and support of knowledgeable adults [1]. Parents also need to help their child understand diabetes management in order to set the stage for independent self-care. *Implications*: 1) Provide two-way communication, allowing parents to not only monitor BG but also offer remote support/cues to caregivers through the system; 2) Provide parents with a visualization of data that is meaningful to a child along with prompts to scaffolding conversations with child about diabetes care.

Early Adolescence: Puberty can result in average growth rates of 3.4-4 inches/year and 18-19.8 pounds/year [16], hormonal change, as well as stress related to social issues, all of which can alter metabolic control [1]. Providing context to supplement raw data might help sort out the cause of shifts in BG, improving acceptance of unstable glycemic control and reducing feelings of shame. Likewise, monitoring alternative aspects of diabetes management, aside from BG, may bolster self-efficacy during this time of variable control. *Implications*: 1) Provide context capture and alternative representations of successful diabetes management that build self-efficacy; 2) Provide parent warnings of potential problem behavioral patterns.

Late Adolescence: During this phase, children transition to independence and begin defining their ambitions for adult life. Research has shown that teens with T1D have better health outcomes when parents remain involved with diabetes care, despite resistance from teens [1]. Thus, technology should be designed to engage parents yet allow the teen to feel trusted to be independent. *Implications*: 1) Provide customizable display of data that affords a level of abstraction that can build parental trust yet respect the needs of teens to control their information; 2) Identify and connect design to teen values to motivate regular BGM.

Limitations

One limitation of this study was the lack of interviews with older elementary school age children. However, we have captured the needs of this group through the perspective of parents and the reflections of the older children we interviewed. We also leveraged the ADA's guidelines for diabetes care during this developmental stage and feel this has helped mitigate bias brought about by not interviewing younger children. Furthermore, because young children still require adult supervision, attending to parents' emotional response may also help meet the need of children to have parents who are less anxious about isolated BG readings.

CONCLUSION

The studies presented here show the potential of pervasive technologies to ease the tension in the parent-child relationship as it evolves over time, building on prior HCI research. Our work makes a new contribution by informing the design of remote monitoring technologies that take into account the diverse emotional needs of children and their parents. The trial of the ADMS has shown the potential of this type of health monitoring technology to enable positive outcomes for children with T1D and their parents. An important theme from the interview studies is the balance of control over data versus feelings of surveillance. This

discussion is needed to inform the proper design of technology aimed at health behaviors of children.

However, there is still much to understand about the impact of this kind of pervasive technology given the potential for adverse effects on the family dynamic. In addition, there may be certain aspects of learning and communication that are lost when moving to a purely technology driven form of monitoring. For example, teens might assume their parents are looking out for them when BG data is released and decide not to send an accompanying text message, explaining, for example, why they cannot drive home before their curfew. Temporary care providers may be disempowered by a technology that automatically communicates BG readings to parents – effectively cutting them off from opportunities to learn about diabetes care.

Monitoring the health of children with technology is a complicated design problem that requires a focus on the evolving needs of both child and parent as the child transitions through various stages of development. Rogers argued that in order to understand the more complex needs of users, researchers and practitioners must move beyond design efforts that focus on creating pleasurable experience and proactive computing to those that *uncover human desires, morals, and values that inspire technology use and proactive people* [15]. Our research has shown that focusing on what makes us human – in this case one's emotional response to health data – may help design technologies that inspire people to change health behavior.

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