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Designing for Positive Health Affect: Decoupling Negative Emotion and Health Monitoring Technologies

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Abstract—**Through various health-focused technology projects, we discovered that the emotional response to technology was related to uptake and sustained use of health monitoring technologies. In this paper we present a case study of how we synthesized constructs of social cognitive theory, technology as experience, and diabetes management guidelines as a framework for making design recommendations for blood glucose monitoring technology that address the emotional response of users. We suggest applying this theoretical lens for design may help attend to emotional responses of users in an effort to decouple strong negative emotions that are paired to health monitoring technologies that provide a single value health result.**

Keywords- theory; design; health monitoring technology; understanding users; user experience

I. INTRODUCTION

There is a proliferation of technologies available today that provide people a way to measure, record, and track their own health data. We focus on technologies that measure an internal body function and return to the user a single value that reflects an immediate state of health. This includes measures of blood pressure, heart rate, and blood glucose levels. Our research shows the importance of attending to the negative emotions that can be evoked by this set of technologies. In this paper we share how a synthesis of three different theoretical frameworks helped shape design recommendations to address negative emotional response to glucometer use in children with Type 1 Diabetes (TID) and their parents. Our research suggests that simple feedback can help decouple negative emotional response and technology that measures internal body processes.

II. BACKGROUND

A. Emotional Response

Blood glucose (BG) monitoring is central to maintaining the health of people with diabetes. Tightly controlling BG level – keeping glucose values within normal range of 70-120 mg/dl – greatly reduces the long-term complications of diabetes including cardiovascular disease, blindness,

Figure 1. Glucometer; "HI" reading indicates BG over 600 mg/dl

amputation, and kidney failure [1]. *'Tight glycemic control'* is accomplished by frequently checking BG level using a glucometer and correcting for abnormal levels – giving insulin to correct high or taking dietary carbohydrate to address low BG levels. The glucometer (Figure 1) is a device that determines BG from a small sample of blood obtained by the user when they prick their skin with a small needle (lancet). There are a number of glucometers from different manufacturers available that range from very simple display and storage of 180 days of readings to 'smart meters' that allow for annotation of BG readings with contextual data and/or communicate directly with insulin pumps. Checking BG with a glucometer can be an emotional, even hated task. The following scenario describes one example of what we consider to be *emotional response* to BG monitoring (BGM) technology that commonly occurs for adolescent girls with T1D.

Vanessa is a 13-year-old girl who has been living with T1D since she was seven. For the past two months she has been having a hard time managing her BG, which is not typical for her. In the past, Vanessa has been able to keep her numbers in normal range on most days. Now it seems that no matter what she does, her numbers are always high before dinner and when she gets up in the morning. Vanessa's mother has been nagging her with questions about what she has been eating after school and at bedtime, which makes Vanessa feel mistrusted and frustrated. Her glucometer has become a reminder of all she does that is wrong. This has caused Vanessa to periodically lie to her mother about her numbers and sometimes she doesn't actually test her BG.

This scenario demonstrates a characteristic of glucometer use that distinguishes it from other health monitoring technologies – e.g. a pedometer. The changes in Vanessa's BG control are likely a result of changes in her body that are out of her control and not a direct reflection of health behavior. Puberty strikes at an average age of 11 years for girls with an accompanying growth spurt that begins between 12 to 15 years [2]. During this period of development, girls experience a peak height velocity of 3.4 inches/year and peak weight velocity of 18 pounds/year [2]. 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. In addition to changes brought forth by physical maturation, children at this age experience many social issues that contribute to stress levels that alter metabolic control. Fleshing out the cause of dramatic shifts in blood glucose at this age requires context to supplement raw data to improve understanding and acceptance of unstable glycemic control. In the scenario above, a meter may take into account Vanessa's age and date of last menstrual cycle that would trigger a prompt or message i.e.) "If you think you are about to get your period, mark this BG reading now," that may help Vanessa understand her BG reading and mitigate negative emotions. Simple context such as this may also help put mother's mind at ease as she reflects on annotated BG trend reports and reduce parent-teen tension.

Understanding the emotional response to BGM technology is important because it can present a barrier to use – not only for children with T1D [1] but all people with diabetes. Polonsky [3] characterizes emotions experienced by people with diabetes in his book, *Diabetes Burnout*, and provides the top ten reasons why people with diabetes hate their glucometer. The number one reason is that "your meter makes you feel bad about yourself." Getting an 'out of range' BG reading can set off a trigger for negative self-talk about personal health behavior when in some cases the reading may not be related to behavior, creating misplaced guilt.

In this paper we argue that designers must give serious attention to the potential for this type of negative emotional response of users when developing technology that monitors internal body function. These devices, e.g. glucometers, heart and

Figure 2. Heart rate monitor vs. pedometer: different opportunity for design

blood pressure monitors, can be distinguished from other health monitoring technologies – such as food diaries, pedometers, or activity/sleep sensors – because values can be affected by things outside of an individual's health behavior (Fig 2). For example, in the scenario above, Vanessa's BG was likely being affected by growth and/or shifts in hormones due to puberty. Aside from potential malfunction, the feedback from a pedometer is directly reflecting walking behavior. We believe technologies that monitor bodily functions – e.g. BG, blood pressure, and heart rate – present unique opportunities to design technology that reduces the negative emotional response that can follow feedback.

III. DESIGNING FOR POSITIVE HEALTH AFFECT

Two theoretical frameworks were leveraged in the analysis of data from our two studies of T1D children: 1) Social Cognitive Theory [5] was used as a framework to code qualitative data obtained from both studies and to form design concepts; and 2) the Technology as Experience framework presented by McCarthy and Wright [6] helped to identify tensions around the use of technology, uncovering the complexity of social interactions that interfere with adoption and sustained use. In the next section, we will explain how these two theories and the American Diabetes Association's guidelines were used to develop design guidelines for BGM technologies that better meet the emotional needs of children with T1D and their families.

A. *Work with Children with TID*

Our research with children living with T1D 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. Two different kinds of studies were carried out to examine this central concern. First, an interview study was conducted 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 developmental stage-based concerns surrounding the use of technology for routine diabetes management. The aim was to identify ways in which BG monitoring technology could be designed to lower barriers to use and curtail negative emotional response. Second, a 12-month controlled trial of a technology that automatically collects, tracks, and then sends BG information to parents was conducted. This study focused on the *older elementary* age group and was designed to determine if the technology impacts affective response to BG data, in addition to health outcomes and self-care of children with T1D. While the two studies were carried out separately, they complement each other by addressing the research questions from different perspectives. The interview study examined parents' and children's emotional concerns surrounding BGM, while the technology trial used a validated instrument to measure changes in emotional response to BGM during 12 months of using a new technology. Findings from both studies where analyzed using the same theoretical lens and synthesized to suggest how BGM technology can be designed to attend to the emotional needs of child and parent. The methodology and findings from these studies have been described elsewhere [4]. In this paper we show how we leveraged frameworks from different fields to identify opportunities for designing BGM technology that mitigates negative emotional response.

B. Therapeutic Guidelines

The foundation for the design of technology aimed at disease management must begin with the standards for medical care. Diabetes self-care encompasses a large variety of things including routine BG testing, delivering insulin injections, inserting insulin pump infusion sets, knowing when to check BG (e.g. before meals, school exams, driving, etc.), changing the settings on the insulin pump, managing BG during illness, and more. In fact, there are over 600 tasks that must be mastered for independent, routine management of T1D – 53 for blood glucose checking alone [7]. In our design work, we built on the ADA's guidelines for the *Care of Children and Adolescents with Type 1 Diabetes* [1], which outlines target values for tight BG control, milestones for diabetes self-care and corresponding family issues across three stages of childhood development. This document informed our interview strategy and expectations for BGM behavior (glucometer use).

We found that *older elementary* school age children (8-11 year olds) can assume basic self-care tasks including BG testing with supervision and support of knowledgeable adults [1]. Children in this age group often report feeling different from their peers because they have to complete diabetes management tasks (BG testing) at school. Anxiety is also brought on by fear of having a hypoglycemic episode and not being near a parent or someone else who knows how to handle this medical emergency. These social anxieties present a problem during a period when children are forming self-esteem in relation to their peer group. It has also been shown that children who are given too much responsibility for independent care of diabetes too soon, have bad medical outcomes [8]. Thus, technology should be designed to keep parents engaged with their child's diabetes management. This not only preserves the child's sense of "being normal" while they engage in social activities with peers but also helps relieve the anxiety of independent diabetes management.

During *early adolescence* (12-15 years old), diabetes management responsibilities are increasingly transferred from parent to child. It is critical that there is clear communication between parent and child about division of diabetes management responsibility in order to mitigate conflict [9]. The parent-child relationship, which is often strained by normal developmental transitions toward independence, can be completely broken by the additional demands of diabetes management. Peers become increasingly influential and these relationships can affect decision-making, resulting in poor self-care. The primary goal for children in this developmental stage is developing a mutually respectful and balanced division of diabetes management responsibility with their parents. Technology aimed at this developmental stage should therefore foster communication related to diabetes management.

Late adolescence (16-19 years old) is a time of heightened parent-teen conflict. The burden of the intense data monitoring required to sustain the health of a person with T1D can place 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. 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. There are many barriers to communicating BG values and other related issues with diabetes management during adolescence, most related to burgeoning independence of the child [4]. Parents must remain vigilant with monitoring despite resistance [1].

While therapeutic guidelines provide a good starting point, we sought design guidance about how to encourage desired health behavior change.

C. Social Cognitive Theory

After review of the very large variety of theoretical frameworks that describe behavior, we elected Social Cognitive Theory (SCT) because is one of the most commonly used theories in behavior change research [5] and the constructs seemed to offer the best variety of mechanisms to impact the learned behaviors of diabetes management. SCT proposes a dynamic model of behavior in which personal factors (e.g. cognitions, perceptions) and environment factors (social and physical) are continuously interacting and influencing each other. It represents a departure from preceding learning theories, which suggested human behavior is purely a product of environmental stimuli, by emphasizing the importance of human cognition in behavioral choices. The constant interaction of a person's characteristics, a person's behavior, and the environment in which the behavior takes place is a foundational concept of SCT called reciprocal determinism. This concept reflects the complexity of human behavior showing that a change in one factor will result in a change to each of the others, which reflects the intricacy of our design challenge – the evolving learning needs of child and influence of parent-child interaction on the child's behavior.

1) Overview of Constructs
Self-efficacy [5] is defined as the confidence a person has in his ability to overcome barriers and perform a particular behavior. Self-efficacy can be increased by providing individuals with a series of small steps that break down a complex behavior. A child with T1D can build self-efficacy by gradually taking responsibility for diabetes management tasks.

Self-control [5] occurs when an individual self-regulates a targeted behavior (e.g. checking BG) related to an established goal (e.g. checking BG before each meal) and rewards one's self for goal related accomplishments. Parents must transfer this behavior to children as they transition to adulthood.

Emotional coping [5] is an individual's capacity to overcome intense emotions that interfere with the health-related actions. Problem solving and stress management skills are a central focus of this construct and integral to sustained behavior change. Children with T1D must learn how to maintain routine diabetes management despite life stressors.

Behavioral capability [5] is grounded in the idea that individuals must possess not only knowledge of the behavior but also the skill to perform the behavior. For example, a child may know it is important to adjust insulin coverage with exercise but not have the skill to complete the task independently.

Outcome expectations and expectancies [5] are related determinants of behavior. Expectations are a person's *anticipated outcomes* for a behavior, which can be learned from experience, observation, hearsay, or physiological arousal related to the behavior. Expectancies are the values an individual places on a particular expectation. This may be particularly important in the parent-child dynamic as expectations can be shaped by parental response to diabetes management, e.g. if a parent responds with negative emotion to a high BG it may create a negative expectation for BGM in the child.

Reinforcement [5] is the concept that suggests if a particular behavior is followed with a reward, performance of that behavior will increase. Reinforcement can be both extrinsic (external reward) and intrinsic (internal reward) and is either directly experienced, vicariously experienced, or self provided. For example, an individual with diabetes may observe a diabetic friend reduce his A1c level after following a walking program routinely for 3 months. This may vicariously reinforce the individual's decision to walk more. Similarly, if the individual experiences a reduction in A1c after instituting his own walking program, it will offer reinforcement by direct experience. Vicarious forms of reinforcement evolve from another concept in SCT, observational learning. Observational learning

happens when an individual watches the behavior of another person and observes the resultant reinforcement he receives. An individual's health-related actions may therefore be influenced by the behavior of others in their environment, as in the concept of reciprocal determinism.

Environment [5] can be described as things external to a person that may affect his behavior. This includes social environment, such as friends and family, and physical environment. Situation [5] refers to an individual's perception of his environment. This could be the real or distorted view of time, physical features, participants, and his or his role in the situation. Together, environment and the situation create a force for health behaviors. For example, a diabetic child's food preferences and exercise habits are in part a result of her home environment, including the behavior of her family and the access to specific foods and exercise opportunities. The child's situation is related to her age and dependency on her parents. Therefore, interventions must move beyond the person with diabetes and incorporate the social support system (family and friend) that is a critical part of constructing health behavior norms.

In Table 1 we share implications for design of a few select SCT constructs that were relevant to our design process for children with T1D. While SCT provided structure around which we could create ideas for technology design, there were still gaps in understanding how to design technology to address the tensions that occur between parent and child surrounding BGM. The emotional coping construct of SCT does consider the intense emotions that individuals might experience with diabetes management, however, it lacks the dimension needed to address the more complex emotions surrounding the ways in which an individual *frames* the experience of BGM. For example, we needed a way to think about intertwined feelings of shame and fear of parental disapproval that children can experience when checking BG. This is not an intense emotion that triggers problem solving but rather a chronic build up of experiences that leads to a bad emotional framing of BGM. We addressed this gap by using a framework from the field of human-computer interaction design that provided a more detailed account of how a user (child with T1D) constructs their experience using BGM technology.

TABLE I. IMPLICATIONS FOR DESIGN FOR SELECT SCT CONSTRUCTS

Construct	Implications for Design of BG Monitoring Technology
Behavioral capacity	Provision of **education and training** to develop specific skills aimed at a particular health behavior; Leverage benefits of interactive capabilities of computing systems for learning; Utilize video capability for skills training.
Emotional coping	Provide **problem solving training** for stress management. Offer features that **enhance social networks** for support during difficult times from others who have had similar experiences.
Expectations	Provide **real-time feedback** in response to desired health action in a manner that reinforces healthy and realistic expectations.
Expectancies	**Tailor feedback** so it is personalized to an individual's values or incentives for a particular outcome. Use interactive learning to **correct health misperceptions** and construct healthy behavioral norms.
Reinforcement	Provide **rewards** for goal achievement or acknowledgement of effort despite goal attainment.
Environment & Situation	Provide information and education to the child's social support system to help promote an **environment** that fosters healthy habits.

D. User Experience

While there are many approaches to explore user experience [10] we used the *Technology as Experience* framework presented by McCarthy and Wright [6]. It offers a language for thinking and talking about experience, building on practice-based approaches that have already been used in HCI but giving more attention to felt experience. The framework is used here as a mechanism for analyzing the experience children and parents have when using health related technologies because it most effectively describes the learning, or sense making, of disease management that occurs through the interaction with the technology. The pragmatist perspective suggests, *"experience is as much a product of what the user brings to the situation as it is about the artifacts that participate in the experience"* [6] pg. 52]. This is useful lens to apply to better understand emotional response to health monitoring technologies, i.e. glucometers.

In their framework, McCarthy and Wright [6] begin with the premise that people are actively engaged in constructing their experience versus being passive participants. They provide a metaphor of the various aspects of experience as four intertwined threads. The compositional thread

describes the structure of an experience; the <u>sensual</u> thread involves the sensory engagement with an experience such as thrill, fear, awkwardness and excitement; the <u>emotional</u> thread includes aspects such as anger, joy, and frustration that are part of our experience or that we relate to by empathizing with the experience of others; and the <u>spatiotemporal</u> thread which describes the specific time and location in which the experience takes place.

The four threads of *'felt experience'* contribute to the following actions that create meaning. People enter into an experience with existing expectations and ways of making sense of an episode. This <u>anticipation</u> is continually revised as an individual engages with actuality and it is this interaction that creates the space of experience [6]. A person <u>connects</u> with a situation when it first impacts their senses, before meaning is actually assigned [6]. As individuals connect in an experience they <u>interpret</u>, or give meaning to, a situation by reflecting what has happened or what may happen based on prior experience [6]. <u>Reflection</u> allows individuals to make judgments about the experience and appropriate value to it as the experience unfolds [6]. <u>Appropriating</u> is a key part of making sense of an experience as it allows an individual to relate the

TABLE II   *FELT EXPERIENCE* WITH BG MONITORING TECHNOLOGY

Thread	Interaction Experience
Compositional	Vanessa is very used to sharing her BG numbers with her mother after 6 years of living with T1D. Vanessa is starting to take more responsibility for her diabetes management as she moves into adolescence. She expects to continue to have the same glycemic control she has experienced in the past. Vanessa's mother also expects the same level of glycemic control as in the past.
Sensual	Vanessa fears disapproval of her mother. She may feel excited about becoming more independent, which includes managing diabetes.
Emotional	Vanessa is frustrated when she sees a high BG value she cannot explain – does not remember missing an insulin dose or miscalculating carbohydrate value in food. The glucometer is reminding her of how she has failed in other areas of her life.
Spatiotemporal	Vanessa's gets home from school and is alone until dinner. She relaxes in the kitchen reading the newspaper and eating a snack or in her bedroom with a good book. Checking her BG before dinner with the full family present and evaluating her number.

current situation to previous or future experience [6]. The act of <u>recounting</u> allows a person to go beyond the current situation and consider within the context of other experiences [6].

Accounting for the *'felt experience'* of interaction with pervasive health technology may help to clarify the more subtle barriers to the uptake and continued use of BGM technology. Consider the scenario from the beginning of the paper. After breaking down the scenario with the framework (Table II), key leverage points can be identified where the user's negative emotional response can be mitigated. Vanessa and her mother are *anticipating* BG numbers that they are use to seeing. When seeing a high BG value they are *connecting* and then *interpreting* it as misbehavior – missed insulin delivery or miscalculated carbohydrate content of food. *Reflection* on the experience causes a *misappropriation* causing Vanessa to feel bad about checking her BG. Ultimately she lies about checking her BG to avoid the negative feelings.

E. Leveraging Theory in Design

When designing technology for people with diabetes, emotions are certain to have an impact on uptake and continued use. As shown above, the technology as experience framework can be applied to scenarios of use as a means of identifying key leverage points where technology may better support users. Figure 3 shows how all three frameworks were integrated to devise design recommendations for adolescent girls with T1D experiencing problems like Vanessa. The tensions identified in the interview study [4] for children in this stage of development included frustration related to BG control and the lack of contextualized BG data which potentially contributes to feelings of shame. The context of use provoking these tensions was conceptualized using SCT as a model for health behavior which revealed 1) *the impact of prior experience with BG control*, 2) *the influence of both the parents' and child's emotional response as reinforcement*, and 3) *parental responsibility for establishing healthy attitudes towards checking and tracking BG*. Through this conceptual analysis it was apparent that technology may be able to influence the outcome expectations (glycemic control) of the target health behavior (BG checking and tracking) and that this may be best aimed at the parent whom the child looks to for reinforcement as
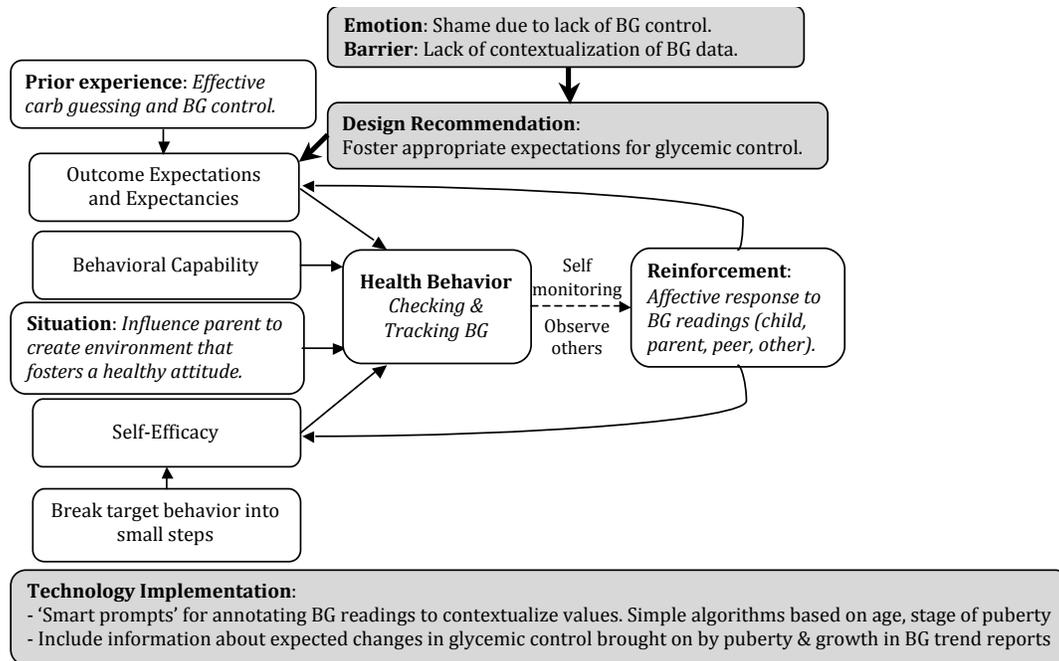
Figure 3. Integration of SCT Constructs & Felt Experience of Adolescent Girl with T1D

well as guidance on diabetes management. Therefore, the design recommendation – *foster appropriate expectations for glycemic control* – could be realized in a BGM technology through two changes 1) Make it easier for the child to annotate BG readings to provide context and 2) give tailored information to the parent regarding the expectations for glycemic control during this stage of development. To demonstrate how one might operationalize this design recommendation in an implementation of a technology, we suggest the following changes to the BGM technology used in our prior research – the Automated Diabetes Management System (ADMS), by Diabetech®[4] which provides automated BGM data retrieval, analysis and reporting with two features: 1) *Real-time alerts*: notification via text message or email, BG result; and 2) *Trend analysis reports*: 21-day BG log pushed out daily through email. Since the time of our study, the ADMS platform has been further developed and commercialized as a wireless glucometer, Telcare (http://telcare.com). However, the design recommendations remain relevant.

1) Easy BG annotation to provide context

Existing technologies do not provide an easy way to collect and reflect on contextual information. Smart glucometers that allow for annotation of BG are a step in the right direction but still require manual entry of data that can be cumbersome. In addition, annotations are pre-wired into the glucometer and may not adequately reflect the contextual situation for an individual child. Providing a mechanism for voice-recorded information to be integrated into the ADMS BG trending reports may ease the process of capturing contextual data. There are many new glucometers that can connect directly to an iPhone (i.e. iBGStar http://www.ibgstar.us/) and would make it easy for a child to record her story as she is testing her BG. Recording contextual data could be encourage through 'smart prompts' that focus on issues specific to adolescence and are generated based on age, gender, and stage of puberty, e.g.) *" Did you know that stress can play a role in your blood glucose level all on its own? Look back at the last week of your blood glucose readings to see if there was a time you think this happened to you."*

2) Tailored information for proper expectations

The personally contextualized information as recorded by the child would then be embedded in the BG trend report sent to parents via email each night. The trending reports could also include tailored suggestions for the parent, e.g. *"It looks like your daughter has had high BG every morning this week. This may be due her menstrual cycle. You may want to check in with her to see how she feels about*

these changes." The email serves as a prompt and the report provides scaffolding for parents to have a thoughtful conversation with their child to discuss swings in BG. This process may help ease the minds of both parent and child, potentially reducing shame and conflict related to BGM.

IV. DISCUSSION

In this paper we suggest that it is critical to attend to the negative emotional response of users in the design of technologies that measure an internal body function – e.g. blood pressure, heart rate, blood glucose. We shared a case study of how theoretical frameworks from different disciplines could be used to generate design ideas that help decouple negative emotions and health monitoring technology. While we focused on the case of BGM in children with T1D and particular concerns for children in early adolescence as an example, the transdisciplinary approach employed is relevant to understanding emotional response to other health monitoring technologies. Because the parameters used to measure bodily function (e.g. BG level) can be affected by circumstances outside of one's behavioral control (e.g. growth), technology can be used in a unique way to help educate the user about her disease and thereby offer emotional relief.

It is our hypothesis that creating systems with smart, subtle feedback will ease negative emotional response that in turn will help sustain use. Our research showed that a technology that pushes data (simple 21-day BG trend reports from the ADMS) to the parent lead to a significant reduction in parental anxiety around BGM [4]. 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 need for *connectedness* [4].

Managing one's health can be reduced to a collection of small decisions made each day that culminates to a representative health behavior that leads to health outcomes. These small decisions are a result of people making sense of a particular context, personal goals, and emotional response to a particular choice (e.g. "...should I check my blood sugar because it is probably high and Mom will get upset?"). In this research, the *Technology as Experience* framework was useful for fleshing out the tensions surrounding interaction with diabetes specific technology. Although not applied directly, the framework presents a conceptualization of experience that lends necessary support to medical care guidelines and health behavior theory for the complex design problem of health behavior modification. HCI practitioners and researchers who are designing technology aimed at health behavior should attend to tensions surrounding interaction – specifically the emotional response generated by the value appropriated to interacting with a particular technology. Regardless of how enticing and fun it may be, if a technology does not help a person make sense of health data in a way that maps to their emotional needs it is likely to be abandoned over time. These needs include a user's expected outcomes from using the technology, which may or may not be directly related to the target health behavior, introducing complexity. Our work shows an example of how these design problems may be best approached in a transdisciplinary manner, leveraging a mix of theory from various domains.

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