

“What’s your number?”

A survey of how parents and teens cope with diabetes in the context of technology support

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Abstract—Teenagers make many transitions during adolescence toward adult lifestyles and responsibilities. Teens with Type 1 Diabetes (T1D) have the additional burden of assuming responsibility for disease management. The findings reported in this paper represent the perspective of parents and adolescents who are coping with T1D - uncovering various tensions that interfere with the effective use of technology to manage the disease. Predominant themes from a set of semi-structured interviews are used to construct implications for the design of new technology intended to support families coping with T1D.

Keywords—Design; Human Factors; Chronic disease; Parent-child conflict; Adolescence; Health Monitoring Technologies

I. INTRODUCTION

Parents are instrumental in shaping their child's health related attitudes and behaviors – a responsibility that has additional implications for parents raising children with chronic disease such as Type I Diabetes (T1D). Parents of children with T1D must be vigilant as they monitor their child's diabetes related health data due to the ever-present possibility of life threatening metabolic changes. Technology that collects and displays health data can be an aid to parents but can also create stress in the parent-child relationship, particularly for adolescent children. Therefore, understanding the ways in which technology can foster positive parent-teen interactions around health data is important.

II. BACKGROUND

Adolescents with T1D and their parents live a data driven life. Numbers including blood glucose (BG) values, carbohydrate content of food, urinary ketones, insulin dosage, and many others are a matter of life and death. Monitoring BG is particularly important in T1D as keeping levels in target range (70-120 mg/dl) reduces the incidence of life threatening medical complications including kidney failure, micro vascular disease and vision loss [2].

Research has demonstrated that teens with T1D have better medical outcomes when parents remain engaged in their routine management [1]. BG monitoring technology may help parents stay connected with their child's diabetes management but may also create tension (or emotional strain) in the parent-teen relationship. Tensions can also arise because teens with T1D face scrutiny when using technology to execute routine diabetes management tasks in public. People are naturally curious when they see a person checking BG, delivering an insulin injection, or wearing an insulin pump. This type of

attention can be particularly difficult as teens navigate adolescence – a period of development that includes heightened anxiety about appearance to peers and acceptance [3]. These intense emotions can push a young person into a phase of non-compliance with required diabetes management tasks, which increases the risk of complications and death. This aim of this study was to better understand these tensions from the perspective of both parent and teen. The findings can be used to inform the design of technology that facilitates BG monitoring and the transition to autonomous care.

A. Methodology

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. For example, Mamkina et al. examined the impact of technology on everyday life with diabetes based on two participants [4], Kientz used interviews of 8 families to understand the nature of office visit interactions between parents and their child's care providers [5], and Petersen et al. studied two families to explore barriers to technology use in the home [6].

Likewise, we conducted interviews with three teens with T1D and their parents. Our goal was investigate the ways in which technology designed to track and trend BG levels may contribute to or detract from the goal of independent effective disease management. Interview questions were designed to probe interview participants, uncovering the variety of issues that surround their personal use of technology for diabetes management and their perception of how new technologies might impact their lives during the transition period between high school and moving away to attend college.

Teenagers with T1D who were entering their senior year of high school and their parents were recruited through a letter sent to local school districts. A total of six, 60-90 minute semi-structured interviews were conducted, representing three families who volunteered. Three teenagers – one girl (P1) and two boys (P2 & P3), all age 17 – were interviewed individually and without their parents being present. P1 and P2 were diagnosed with T1D at age 8 and 7 respectively, while P3 was diagnosed one year prior to the interview at age 16. Parents were interviewed separately, but as a couple when available. All interviews were transcribed and prominent themes were identified during an iterative analysis of the conversations.

III. FINDINGS

There were two opposing emotional responses to BG monitoring technology: (1) Parental anxiety and struggle to release control related to fear of the impact of poor glycemic control on the long-term health of their child and (2) Teen frustration and desire for independence in managing their own life, including their disease. These emotional responses created a tension in the parent-child relationship that inhibited effective diabetes management.

A. Parental Anxiety & Struggle to Release Control

Anxiety was a tension shared by all of the parents we interviewed – 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 tricky patch of child development.

1) BG checking

Anxiety related to BG checking can interfere with the trust between parent and child. For example, one parent said:

"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]." <P1-mom>

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.

Anxiety related to checking BG before driving can also contribute to parent-teen tension. P3 shared a story about a time when he experienced a low BG while driving home after visiting his girlfriend. Stopping to treat the low BG caused him to get home past his curfew and he had to offer his glucometer results as evidence to his parents. P3 described this type of situation as one in which he would value having the capability of automatically sending a text message from his glucometer to his parents. The main benefit from his perspective is that it eliminates the need for conversation or judgment around the number. Without prompting and in a separate interview, P3's mother shared the same story from her context.

"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. And 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...hmmm." <P3-mom>

This quote highlights the potential of technology to help mitigate parent-child conflict. A device capable of sending BG values directly from the testing instrument may reduce parental doubt about the validity of the reading. Further, the actual number need not be shared but rather the phrase "low," affording more privacy and control to the adolescent. All of the parents we interviewed explained that the primary concern was ensuring their teen was checking BG value. They felt confident the BG reading could be handled by the teen and did not always need to know the specific value. An exception would

be if there were repeated high or low BG readings indicating a pattern of problems that the teen was not addressing.

2) Fostering independence

All of the parents we interviewed were empathetic to their child's desire for independence but expressed a need for guidance on how to transition their adolescent autonomous self-care. Parents had a desire for more direction from the healthcare team during routine visits, which are typically consumed with changes in insulin regimen instead of addressing behavioral issues.

"It is a very grey area. How fast do you make them grow up? – Or – How long do you try to control it and let them be a kid?" <P2-mom>

Many parents described difficulty discussing long-term consequences of poor diabetes management without resorting to scare tactics – walking a fine line between educating and threatening their child.

"He is old enough that I have said to him if you want to kill yourself real slow, [ignoring diabetes] is the best way to do it. We have explained to him that when his blood glucose is high his blood vessels get nicked and they are going to clog up. I tried to bring the girlfriend into the conversation saying, 'Don't you want to be healthy for her?' " <P3-mom>

P2's parents struggle with how to transition their son to independent BG monitoring because he does not regularly check his BG without prompting. His parents shared their efforts to avoid a "diabetes management battle zone," noting that punishment has not been effective.

"You take away his cell phone – we have done that. You take away the car – yes we have done that. Eventually you realize [the diabetes] is not something that they did. It is something that they have and are trying to figure out how to deal with." <P2-mom>

3) Lack of trust

Trust issues can interfere with a parent's best intentions to release control of disease management to their child. All of the parents expressed conflicted feelings similar to those depicted in the following quote.

"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." <P3-mom>

Letting go is difficult for most parents and when it involves a life-threatening disease it can be even more challenging.

B. Teen Frustration and Desire for Independence

The teens we interviewed 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 [1].

1) What's your number?

The following is representative of what the teens described as constant BG "checking in," when parents pose the common phrase "*What's your number?*" One teen described his typical BG checking conversation with his Mom.

"Mom will say, 'What's your number?' I'll say, 'I am high.' She'll ask 'How high is high?' and I'll say' It is high...leave me alone.'" <P3>

P3 is clearly irritated by the question and his evasive response may fuel more distress in the interaction. This type of routine tension lead to a complete shut-down of communication related to BG values between P3 and his mother.

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." <P2>

Although P2 feels misunderstood, his parents were attempting to address their son's non-compliant BG checking behavior. In this case, it is easy to see both sides of the battle zone.

2) I can handle this myself!

All the teenagers expressed an appreciation for the fact that it was difficult for their parents to back away from their care – however, understanding did not prevent arguments related to BG checking.

"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." <P3>

Situations such as this, where teens want parents to completely disengage from their diabetes management, are common but studies have shown parents need to remain engaged [1]. Remote monitoring technologies may be useful to help parents in this type of situation back away to a point where the teen is comfortable, yet remain involved with their child's care. Mothers are typically the parent who assumes primary responsibility for their child's diabetes management and this was the case for each of the families we interviewed. P1 describes her Mom as a "stickler" in comparison with her Dad.

"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. It's not that she doesn't trust me, it's that she is scared of what is might happen." <P1>

The relationship between a teen with T1D and their mother is particularly important and was the most strained family relationship of the three teens we interviewed.

IV. DISCUSSION

The opportunities for design that emerged from our analysis are based on prominent themes from interviews with teens with T1D and their parents. It was not our intent to identify technological solutions for each of these themes as much as to characterize the prevalent issues in an effort to inform future work. We propose three general heuristics for designing technology to help mitigate tensions described in this study: parental anxiety and struggle to release control; and teen frustration and desire for independence.

A. Design Considerations

1) Offer support that fosters trust

Mistrust is at the heart of many parental anxieties related to BG monitoring and must be addressed if technology is intended to reduce parent-child conflict. Design efforts should be aimed at mothers in particular as they are most often the primary diabetes care providers and poor child-mother is associated with the worst outcomes in teens with T1D [3]. The teens we interviewed all reported their mothers as having the strictest approach to diabetes management and the parent having the hardest time backing away.

There are no commercial devices that formally support a teen with T1D as they strive to become independent with diabetes management. Teens have many competing interests in life and *forgetting* to complete routine tasks can be expected. Reminder systems, such as "Sweet-Talk" [7] may improve compliance with basic tasks and appointments but do not help teens (or parents) navigate the "*diabetes management battle zone*." Technology designed with this normal and expected adolescent drive for independence in mind may help mitigate tensions related to parental struggles to release control. A hypothetical example is a tailored SMS based system designed to counsel/educate parents, helping them back away in order to preserve a healthy level of involvement with diabetes management and trust in their teen's diabetes decision making.

2) Support respectful communication

The parents we interviewed had an express need for advice on how to handle the release of diabetes management control to their teen. The challenges brought forth by the transition to adult self-care cannot be adequately dealt with in the doctor's office once every three months. In a recent study of 785 health care professionals providing care to children with diabetes, "providers estimated that they are able to provide adequate psychosocial support for little more than half of the young people in their care who have psychosocial problems" and only 20% routinely evaluate the psychosocial needs of their patients using a structured assessment tool [8], p. 12]. Technology could be leveraged to fill this gap. Survey instruments could easily be incorporated into technology and used to identifying specific areas in which parents may adjust their involvement in the management of their child's diabetes. With the support of the diabetes health care team, such tools could be used to facilitate respectful parent-teen communication.

The parents we interviewed were more interested in simply knowing that their teen is checking BG, rather than the actual number. The phrase "*What's your number?*" is really just a prompt to encourage the teen to check BG vs. a request for

information. This has important implications for design, suggesting that existing technologies could be modified to empower teens with more control of their data. For example, BG data could be presented to parents in an alternate form to render a general representation of BG checking behavior. It may be helpful to use this type of high level information in conjunction with behavioral contracting established by the family's diabetes health care team [1].

3) Provide parent warnings about extremes in data

There are many opportunities for teens in this stage of development to slip into harmful behaviors and it is essential that parents remain engaged with their child's diabetes management – receiving warnings when an intervention may be required. In order to afford teens the desired independence and privacy, warnings would only be triggered based on extreme circumstances. For example, teenage girls with diabetes are at much greater risk of developing an eating disorder such as anorexia. In the case of girls with T1D, they can manipulate their insulin delivery in order to lose weight. In short, they do not deliver insulin to cover the food eaten and it is not converted in the body to produce weight gain. Of course, this means that their BG values will run dangerously high causing devastating health complications. In this scenario, a parent may be warned with a "red flag" generated by the technology after days of high BG readings would be able to intervene before their daughter (or son) develops severe, life threatening health issues.

B. Conclusion

In this study, we have explored the range of tensions that occur between parents and teens as they use technology to cope with T1D. The conflicting needs of parents and teens must be addressed because the consequence of parents not staying engaged with their teen's diabetes management is poor health outcomes. Our findings have outlined several opportunities

where technology might help foster *positive* parent-teen interactions around BG data.

By drawing attention to tensions (emotional strain or pressure) that prevents the effective use of diabetes-related technology, we have uncovered ways in which technology might facilitate the transition to adulthood. Emphasizing the needs of adolescents does not have to be in conflict with the needs of their parents. Our findings suggest that addressing parents' desire to improve diabetes-related communication will help in diffusing the technology-enabled conflict.

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REFERENCES

- [1] B.J. Anderson, L. Vangsness, A. Connell, D. Butler, A. Goebel-Gabbri, L.M. Laffel, "Family conflict, adherence, and glycemic control in youth with short type 1 diabetes," *Diabet Med*, vol.19, pp. 635-642, 2002.
- [2] ADA Position Statement. "Care of Children and Adolescents With Type 1 Diabetes," *Diabetes Care*, vol. 28, pp. 186 -212, 2005.
- [3] J. Weissberg-Benchell, H. Wolpert, B.J. Anderson, "Transitioning from pediatric to adult care: a new approach to the post-adolescent young person with type 1 diabetes." *Diabetes Care*, vol. 30, pp. 2441–46, 2007.
- [4] L. Mamykina, E.D. Mynatt, D.R. Kaufman, "Investigating health management practices of individuals with diabetes." In Proceedings *CHI '06*, pp. 927-936, 2006.
- [5] J.A. Kientz, "Understanding parent-pediatrician interactions for the redesign of health technologies." Proceedings *IHI '10*, pp. 230-239, 2010.
- [6] M.J. Petersen, K.H. Madsen, A. Kjaer, "The usability of everyday technology: emerging and fading opportunities" In Proceedings *TOCHI*, vol. 9 (2), pp. 74-105, 2002.
- [7] V. Franklin, A. Waller, C. Pagliari, S. Greene, "Sweet Talk": text messaging support for intensive insulin therapy for young people with diabetes," *Diabetes Technol Ther*, vol. 5(6), pp. 991-996, 2003.
- [8] M. Peyrot, "How is diabetes perceived? The results of the DAWN Youth survey," *DiabetesVoice* vol. 53, pp. 9-13, 2008.