

Impact of Type 1 Diabetes Technology on Family Members/Significant Others

Running Title: Diabetes Tech Survey for Family Members

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Novelty Statement:

- it is the first study that directly explores family members' perceptions of the impact of diabetes technology
- to ensure that such devices are used in a way that returns maximum benefit from a medical and psychological perspective, it is necessary to understand the personal experiences of users and their families
- Supporting users in using diabetes technology to achieve the best possible glycemic control, in the context of their own life, is crucial

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Abstract

Aim: To explore the impact of diabetes-related technology in order to ensure that such devices are used in a way that returns maximum benefit from a medical and psychological perspective.

Method: Spouses and caregivers of people with type 1 diabetes were invited to complete an online questionnaire about their experiences with diabetes technologies used by their family members. Participants were recruited via the Glu online community website. Questions explored impact on daily living, frequency and severity of hypoglycemia, and diabetes-related distress.

Results: One hundred parents/caregivers and 74 partners participated in this survey. Mean duration of living with a person with T1D was 16 years (SD 13) for partners; with mean duration of diabetes for children being 4.2 years (3.2). Mean duration of current therapy was 8.3 years (SD=7.3) for adults and 3.4 years (SD=2.9) for children. 86% partners and 82% parents/caregivers reported diabetes technology had made it easier for their family members to achieve blood glucose targets. Diabetes related distress was common, as was sleep disturbance associated with device alarms and fear of hypoglycemia. Reduced frequency and severity of hypoglycemia were reported by approximately half of participants.

Conclusion: There is little doubt about the medical benefit of diabetes technologies and their uptake is increasing but some downsides were reported. Barriers to uptake of technologies lie beyond the mechanics of diabetes management. Supporting users in using diabetes technology to achieve the best possible glycemic control, in the context of their own life, is crucial. Furthermore, understanding these issues will help innovation and design of new technology.

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Introduction

Research has demonstrated that technologies to support diabetes self-management for people living with type 1 diabetes (T1D) can have positive effects on medical and quality of life outcomes [1]. It also shows that there may be an additional burden of wearing and using these technologies [1]. The psychosocial impact of living with diabetes is complex and impacts both the person with T1D and the people that live with and support them. Experiencing hypoglycemia, for example, is challenging for both the individual with diabetes and their family members, with family members reporting not knowing what to do or what is happening [2].

It is well-established that diabetes and its treatment can impact the lives of people living with somebody with T1D in both positive and negative ways [1]. Continuous knowledge of glucose levels with an accurate, discrete device has been cited as a research priority by people with T1D [3] but CGM use has received mixed reports in the research. Improvements in glucose control are dependent on consistent CGM use however this is expensive and not always reimbursed by insurance or other healthcare provider. Furthermore, alarm fatigue, technical failure and accuracy problems limit ongoing engagement, with lack of trust in the devices and irritation with technological failure cited as primary reasons. A negative psychosocial impact of CGM use has been described [4] and, despite a high proportion of pump use, CGM use in the T1D Exchange cohort remains low with 6% of children <13 years old, 4% of adolescents, 13 to <18 years, 6% of young adults 18 to <26 years, and 21% of adults ≥ 26 years using CGM. Discontinuation rates are high, however at 41% of users having discontinued use by one year [5].

Currently, there is limited research on the impact of diabetes technologies on the lives of those people who live with someone with T1D and its role in helping them to support that person. The aim of the present survey was to explore the perceived impact of diabetes-related technology from the perspective of family members and partners of individuals with T1D, including impact of devices on the life of the individual with T1D and family members, diabetes related burden, impact on mood and well-being of family members and impact of technology on frequency/severity of hypoglycemia, and diabetes control.

Methods and Participants

Partners and caregivers of people with T1D were invited to complete an online questionnaire about their experiences with diabetes technologies. Questions included a mix of existing validated measures (PAID-5, WHO-5) and specific questions exploring the impact of technology. The survey was hosted on T1D Exchange's online patient community, Glu (myGlu.org). All study materials were approved by the Institutional Review Board at the Jaeb Center for Health Research (Tampa, FL). Each participant provided informed consent before participating in the study. The questions were developed by the multi-disciplinary research team including medics, psychologists, statistician and family members living with T1D, prior to piloting with potential participants. Minor revisions were made in line with feedback prior to 'going live'.

Emails were sent to registered Glu members who previously indicated a preference to be contacted about research studies. Additionally, information about the study was provided on Glu, Facebook, and Twitter. Eligible participants were required to be at least 18 years old. For the partner survey, participants were required to be living with their spouse, partner, or significant other with T1D. For the parent survey, participants were required to have a child with T1D under the age of 18.

The study was conducted in accordance with the Declaration of Helsinki.

Quantitative responses were analyzed using SPSS software (IBM SPSS Statistics for Windows, Version 23.0) and free text responses were analyzed using thematic coding and content analysis. Free text data were analyzed using constant comparison methodology with two researchers independently analyzing and coding the text, before consensus was reached on key themes and findings.

Results

Participant demographics and use of diabetes technology are presented in Tables 1 and 2. One hundred parents/caregivers took part as well as 74 partners. Mean duration of living with a person with T1D was 16 years (SD=13) for partners; with mean duration of diabetes for children

being 4.2 years (SD=3.2). Mean duration of current therapy was 8.3 years (SD=7.3) for adults and 3.4 years (SD=2.9) for children.

Table 1: Participant Demographics

	Partners (n=74)			Parents/caregivers (n=100)		
Age in years	<i>M</i>	<i>SD</i>	Range	<i>M</i>	<i>SD</i>	Range
Age	42.7	14.9	18-55	42.93	5.67	30-56
Child's Age	-	-	-	10.76	3.72	1-17y
Gender	<i>n</i>	<i>%</i>		<i>n</i>	<i>%</i>	
Male	42	57		15	15	
Female	32	43		85	85	
Race	<i>n</i>	<i>%</i>		<i>n</i>	<i>%</i>	
American Indian / Alaska Native	0	0		0	0	
Asian	2	3		3	3	
Black or African American	1	1		1	1	
Multiracial	0	0		0	0	
Native Hawaiian or other Pacific Islander	1	1		0	0	
White/Caucasian	68	92		96	96	
Other	3	4		1	1	
Current Work Status	<i>n</i>	<i>%</i>		<i>n</i>	<i>%</i>	
Working full-time	47	64		45	45	
Working part-time	6	8		21	21	
Homemaker	4	5		38	38	
Student	7	9		1	1	
Retired	10	14		0	0	
Unemployed	1	1		1	1	
On disability	2	3		0	0	
Military	2	3		1	1	
Other	2	3		2	2	

Table 2: Current Therapy and Diabetes Technology Used by Participants

	Adults (n=74)		Children (n=100)	
	<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>
Current Therapy				
Insulin pump	57	77	85	85
Injections using an insulin pen	17	23	15	15
Injections using a syringe	11	15	11	11
Inhalable insulin	1	1	0	0
Diabetes Technology Currently Used				
Insulin pump	53	72	83	83
CGM	46	62	66	66
Combined insulin pump and CGM (one device)	6	8	6	6

Blood glucose meter	56	76	87	87
Other	1	1	7	7

Some parents/caregivers reported dual use of injections using a syringe and an insulin pen

In addition, 62% ($n=46$) of partners and 66% ($n=66$) of parents/caregivers reported current CGM use (up to seven days a week) by their partner or child. Number of days wearing a CGM had a reported mean of 6.31 ($SD=1.8$) by partners and 6.53 ($SD=1.1$) by parents/caregivers.

Impact of device use on partners and parents compared to their family members

Tables 3 and 4 present data on the impact of diabetes technology on participants' lives and the lives of their family member. Impact of each device, on both the person filling out the survey and the impact on their family member with type 1 diabetes was reported on a scale of -2 (extremely negative) to +2 (extremely positive). Partners reported that devices had a less positive impact on their own lives than on the person living with type 1 diabetes. This was true for use of insulin pumps (effect on self, $M=1.3\pm.8$, effect on partner with type 1, $M=1.7\pm.6$; $t(69)=-3.9$, $p<.001$) and CGMs (effect on self, $M=1.1\pm1.2$, effect on partner with type 1, $M=1.4\pm.9$; $t(57)=-3.3$, $p<.01$). Due to insufficient numbers, paired sample t-tests were not conducted for other devices.

Parents, on the other hand, reported that pump use benefitted both themselves and their child equally ($M_{\text{parents}}=1.8\pm.5$, $M_{\text{children}}=1.8\pm.5$, $p=n.s.$), and that CGM use was more beneficial to themselves than their child ($M_{\text{parents}}=1.6\pm.8$, $M_{\text{children}}=1.0\pm1.2$, $t(72)=5.6$, $p<.001$). When comparing partners to parents, there was a significant difference in the impact of both insulin pump ($t(153)=4.6$, $p<.001$) and CGM use ($t(130)=3.1$, $p<.01$). In both cases, parents report a more positive impact of device use on their own life than partners (means reported above).

Table 3: Impact of Device on Your Life (not the person with diabetes)

	Adults ($n=74$)		Children ($n=100$)	
	<i>n</i>	%	<i>n</i>	%
Insulin Pump				
Extremely negative	1	2	0	0
Somewhat negative	1	2	1	1
Neutral	5	9	0	0
Somewhat positive	20	34	13	15
Extremely positive	31	53	71	84
CGM				
Extremely negative	0	0	0	0
Somewhat negative	5	10	4	5

Neutral	6	12	1	1
Somewhat positive	8	16	14	19
Extremely positive	31	62	54	74
Combined Insulin Pump and CGM				
Extremely negative	1	8	1	8
Somewhat negative	1	8	3	23
Neutral	3	23	2	15
Somewhat positive	3	23	3	23
Extremely positive	5	38	4	31
Blood Glucose Meter				
Extremely negative	0	0	0	0
Somewhat negative	1	1	1	1
Neutral	12	17	11	11
Somewhat positive	14	20	18	19
Extremely positive	42	61	66	69

Insulin pump *n* (partners = 58; parents/caregivers = 85); CGM *n* (partners = 50; parents/caregivers = 73); combined *n* (partners = 13; parents/caregivers = 13); BG meter *n* (partners = 69, parents/caregivers = 96); two partners also report artificial pancreas impact, one was neutral and the other extremely positive

Table 4: Impact of Device on Your Partner's/Child's Life

	Adults (<i>n</i>=74)		Children (<i>n</i>=100)	
	<i>n</i>	%	<i>n</i>	%
Insulin Pump				
Extremely negative	0	0	0	0
Somewhat negative	1	2	1	1
Neutral	1	2	1	1
Somewhat positive	10	17	15	17
Extremely positive	46	79	69	80
CGM				
Extremely negative	2	4	4	5
Somewhat negative	1	2	8	11
Neutral	3	6	8	11
Somewhat positive	10	20	16	22
Extremely positive	35	69	38	51
Combined Insulin Pump and CGM				
Extremely negative	0	0	2	14
Somewhat negative	0	0	2	14
Neutral	1	8	5	36
Somewhat positive	5	42	2	14
Extremely positive	6	50	3	21
Blood Glucose Meter				
Extremely negative	0	0	0	0
Somewhat negative	4	6	8	8
Neutral	5	7	16	17
Somewhat positive	14	20	25	26
Extremely positive	46	67	47	49

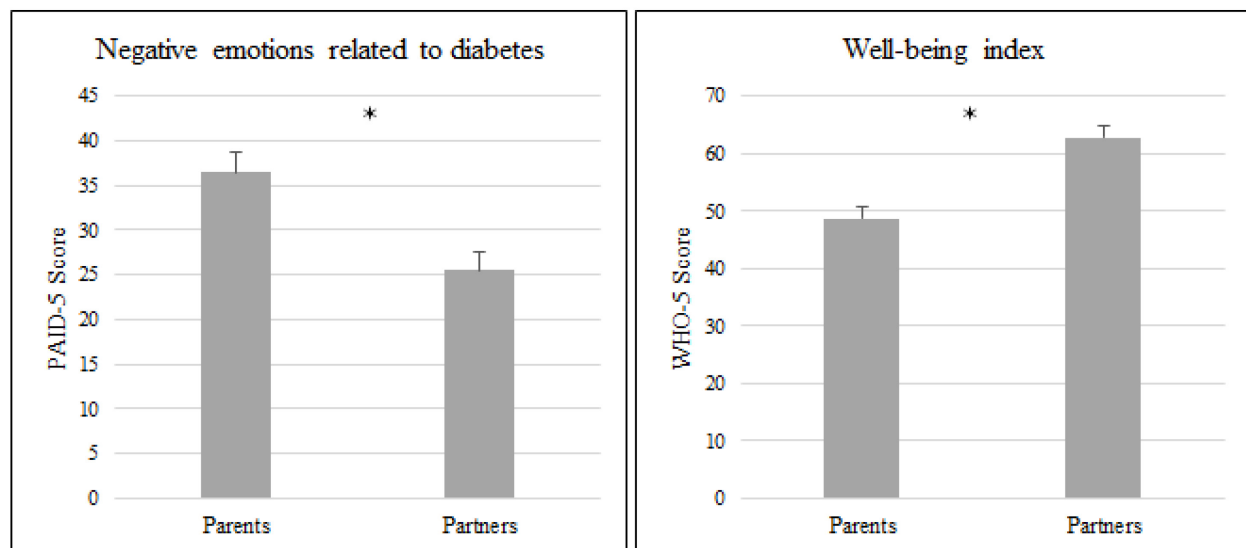
Insulin pump *n* (partners = 58; parents/caregivers = 86); CGM *n* (partners = 51; parents/caregivers = 74); combined *n* (partners = 12; parents/caregivers = 14); BG meter *n* (partners = 69, parents/caregivers = 96); three partners report artificial pancreas impact, one was neutral and two were extremely positive

In response to whether glycemic control had changed due to their use of diabetes technology, 86% (*n*=64) partners and 82% (*n*=82) parents/caregivers said that it had made it easier to achieve blood glucose targets. Table 5 below shows frequency and severity of hypoglycaemia.

Table 5: Frequency and Severity of Hypoglycemia

	Adults (<i>n</i> =74)		Children (<i>n</i> =100)	
	<i>n</i>	%	<i>n</i>	%
Frequency of Hypoglycemia				
No, number of episodes has not changed	13	18	20	20
Yes, number of episodes has increased	8	11	10	10
Yes, number of episodes has decreased	40	54	51	51
Unsure	13	18	18	18
Severity of Hypoglycemia				
No, severity of episodes has not changed	17	23	25	25
Yes, episodes are more severe on average	4	5	4	4
Yes, episodes are less severe on average	38	51	55	55
Unsure	15	20	15	15

Fig. 1



Psychosocial impact of T1D on family members

Perceived burden was scored on a 5-point Likert scale ranging from no burden (0) to very large burden (4). Parents reported higher perceived burden (*M*=2.2, *SD*=1.3) than partners (*M*=1.2, *SD*=1.1; *t*(184)=5.7, *p*<.001).

Negative emotions were measured on the PAID-5, and this scale had good internal consistency (Cronbach's $\alpha=.84$). Overall, participants reported a relatively low degree of negativity related to diabetes ($M=31.24 \pm 21.8$, range 0-100). However, parents reported more negative emotions related to diabetes on the PAID-5 scale than spouses ($M=36.4$, $SD=22$, versus $M=25.4$, $SD=20.1$; $t(187)=3.55$, $p<.001$; see Fig. 1).

The WHO-5 was used to obtain an index of well-being, with higher scores indicative of greater emotional stability. This scale had good internal consistency (Cronbach's $\alpha=.89$), and scores were mostly in the mid-range of the scale ($M=55.3 \pm 21.0$). Parents reported significantly poorer well-being than partners ($M=48.7$, $SD=21.2$ versus $M=62.7$, $SD=18.7$, $p<.001$; see Fig 1). Scores on the PAID-5 and WHO-5 were correlated for both parents ($r=-.46$, $p<.001$) and spouses ($r=-.35$, $p<.01$), indicating that those who had decreased well-being also reported a higher frequency of negative emotions related to their loved one's diabetes.

Overall, 87% ($n=64$) of partners and 66% ($n=66$) of parents/caregivers rated their own quality of life as good over the past two weeks as assessed by the WHO-5 well-being index [7]. 5% ($n=4$) of partners and 11% ($n=11$) of parents/caregivers reported their quality of life as poor or very poor. Parents/caregivers reported significantly poorer well-being than partners ($M=48.7$, $SD=21.2$ versus $M=62.7$, $SD=18.7$, $p<.001$).

Impact of Technology on Sleep

Disrupted sleep was commonly reported with 73% of parents/caregivers and 59% of partners reporting waking because of diabetes technology. Of these, 54% of parents/caregivers and 12% of partners report waking at least 4 times a week. The main reasons reported were CGM alarms (38% parents/caregivers, 36% partners) and fear of hypoglycemia (19% parents/caregivers, 4% partners). False alarms were uncommon with 26% and 23% respectively reporting rare false alarms; however 10% of parents/caregivers and 9% of partners reported false alarms occurring more than once a week. This is having a negative impact on most social functioning activities. Interestingly, participants report the impact of diabetes technology for their partner/child as generally positive.

Open Questions

Reported involvement in partner's diabetes management did not appear to vary irrespective of duration of diabetes, gender or diabetes related complications according to the free text responses. The online appendix with Tables 7-10 presents data on impact of diabetes technology on lived experience, daily functioning, nocturnal waking and satisfaction with training provided for device use.

Free text responses were coded into key themes, based on how participants reported helping their loved one with T1D. Key themes, listed in order of frequency of occurrence, were:

- Reminders and monitoring
- Practical support, such as ordering supplies, delivering insulin boluses if BG levels were high, booking medical appointments, and counting carbohydrates
- nocturnal BG testing (parents/caregivers)
- Treating hypoglycemic events
- Team work – teaching, transition (parents/caregivers)
- Providing moral support

Responses included:

‘If I notice him acting strangely, I’ll ask him to check his CGM to see if he needs a correction’

‘I am a constant assistant to my wife. I help with site changes and BG checks on a daily basis. I help treat highs and lows and always keep a watchful eye over her’.

‘My partner is very independent and private with diabetes management, so aside from support and providing snacks to help with low blood sugar, I do not contribute significantly’.

‘Be encouraging and patient’.

‘I encourage, support and enable her ability to exercise and eat properly. I support her desire to explore and research new technology. I listen’.

‘When he is sick or tired, I take over. Sometimes I offer just to give him a break. I also get his kit anytime he is home and needs it just to take the burden off of him’ [parent]

‘Guide and coach’ [parent]

‘I order all supplies for her, I attached her CGM to the back of her arm If she is sick or had an unusual amount of exercise, I get up at night to check on her’ [parent]

‘Cheerleading. Encouraging. Reminding. Everything that a teenager considers nagging’ [parent]

‘By approaching her care as a team’ [parent]

‘Trying to achieve normal values without affecting their normal lifestyle to the extent possible’ [parent]

‘Helping to get some sugar into him with severe hypoglycemia’ [partner]

Discussion

Unsurprisingly, there was a high use of CGM in both groups - partners and parents/caregivers with a high number of male partners participating. This finding is consistent with reported CGM use within the Glu community, in which 64% of people who provided this information were current or former CGM users.

There was a considerable difference in perceived burden of diabetes management support for partners versus parents/caregivers. Again this is perhaps unsurprising considering that parents/caregivers take responsibility for a younger child’s diabetes management rather than simply providing support. There was a broad range of involvement in the partner’s diabetes care which may point to factors such as personality characteristics of the respondent and/or the partner living with T1D

Interestingly, not all participants reported currently using a standard BG meter, however this may be a function of it being ‘taken as given’ rather than lack of use. Even with consistent CGM use, a standard BG meter remains necessary for calibration and to confirm glucose readings before dosing insulin. Generally, technological devices were reported as having a neutral or positive impact on participant’s lives, however combined insulin pump and CGM devices fared less well.

A reported benefit of insulin pump therapy, CGM and artificial pancreas use is reduced severity and frequency of hypoglycemia [8,9]. This outcome was reported by half of participants, who believed their family member experienced fewer hypoglycemic events, and similarly half reported reduced severity of hypoglycemic events. These results could perhaps be attributed to tighter glycemic targets that the technology can facilitate, or perhaps a requirement for greater utilization of the specific features of the technology eg temporary basal rates. Most participants reported achievement of glycemic targets to be easier for their partner/child with T1D as a consequence of using diabetes technology.

The ability to target tighter glycemic control whilst beneficial medically, may in fact add to the burden of disease management. Diabetes related distress, including fear, feelings of guilt, anxiety, depression and being overwhelmed by diabetes management were commonly reported, both by parents/caregivers and partners. The challenge of helping to manage diabetes was reported as a large or very large burden by 45% of parents/caregivers and 11% of partners, which may contribute to the high numbers of participants reporting elevated diabetes related distress.

Parents/caregivers reported a more negative impact on family relationships than did partners. There was widely reported negative impact on relationships, more so for parents/caregivers than partners. Family conflict is commonly associated with diabetes [10], as the additional pressure of managing diabetes alongside other daily tasks takes its toll.

Fortunately, research is ongoing to develop more robust CGM alarm algorithms that will reduce false positive alarm rates by modeling physiology [11], compensating for frequent perturbations such as pressure [12]. Furthermore, the integration of multiple diabetes technologies, such as automatic dose capture (e.g. Smart Pens), more accurate and reliable CGM [13], and robust physiological algorithms that include insulin on board estimates [14], are also further expected to increase CGM alarm reliability, reducing intrusiveness and disease reminders.

The strength of the current study is that it is the first study that directly explores family member perspectives of the impact of diabetes technology, which informs potential uptake and sustained successful use thereof. The study is limited however in that it reaches only participants who are members of the Glu community and so may not be representative of the wider diabetes community, e.g. Glu membership may be more tech savvy as an online community. That being said, Glu is an open community of persons with T1D and is one avenue where greater understanding of the disease and supporting improved experiences for those living with T1D is actively pursued. Exploring concerns about accuracy of devices in greater detail would have been useful in terms of explaining whether this is a contributing factor for discontinuation of CGM devices.

It could be argued that the experiences of partners and parents/caregivers are different in terms of levels of responsibility and experience. We would argue, however, that within these cohorts the

experiences of individuals vary hugely, as seen in the results. It is our opinion that there are both similarities and differences between and within the groups and these are explored from a personal perspective in the current study. This could be argued as both a strength and a limitation and debate is welcomed in this regard.

Conclusions

There is little doubt about the medical benefit of diabetes technologies and their uptake is increasing. In order to ensure that such devices are used in a way that returns maximum benefit from a medical and psychological perspective, it is necessary to understand the personal experiences of users and their families. Barriers to uptake of technologies lie beyond the mechanics of diabetes management. Supporting users in using diabetes technology to achieve the best possible glycemic control, in the context of their own life, is crucial.

List of Abbreviations

T1D	-	Type 1 diabetes
CGM	-	Continuous glucose monitoring
<i>n</i>	-	Number (of participants)
SMBG	-	Self-monitoring of blood glucose
UK	-	United Kingdom
USA	-	United States of America
<i>M</i>	-	Mean
<i>SD</i>	-	Standard Deviation
WHO-5	-	World Health Organisation well-being index
PAID-5	-	Problem Areas in Diabetes short form

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Table 6: Impact of Partner's Diabetes Technology on their Life

Overall Mood	<i>n</i>	%
Much better	13	18
Somewhat better	38	51
No difference	17	23
Somewhat worse	5	7
Much worse	0	0
Overall Stress		
Much better	9	12
Somewhat better	33	45
No difference	25	34
Somewhat worse	6	8
Much worse	0	0
Diabetes-related Stress		
Much better	23	31
Somewhat better	32	43
No difference	9	12
Somewhat worse	9	12
Much worse	0	0
Energy Levels		
Much better	10	14
Somewhat better	30	41
No difference	29	39
Somewhat worse	4	5
Much worse	0	0
Anxiety Levels		
Much better	13	18
Somewhat better	31	42
No difference	24	32
Somewhat worse	4	5
Much worse	0	0

Table 7: Impact of Diabetes Technology on Your Daily Functioning

	Adults (<i>n</i>=74)		Children (<i>n</i>=100)	
	<i>n</i>	%	<i>n</i>	%
Impact on Daily Functioning				
Yes	22	30	76	76
No	45	61	16	16
Unsure	7	9	5	5
If Yes, is it Positive or Negative?				
Positive	10	14	32	32
Negative	2	3	0	0
Positive and negative	10	14	44	44

Impact on Their Diabetes-related Decision-Making				
Yes	47	64	72	72
No	16	22	11	11
Unsure	11	15	15	15
How Much of a Challenge is it for You to Help Manage your Partner's/Child's Diabetes				
Very large burden	2	3	16	16
Large burden	6	8	29	29
Moderate burden	16	22	29	29
Slight burden	28	38	10	10
No burden	22	30	15	15

Table 8: Nocturnal Waking

	Adults (n=74)		Children (n=100)	
	<i>n</i>	%	<i>n</i>	%
Do You Wake Because of Diabetes Technology?				
Yes	44	59	73	73
No	30	41	25	25
If Yes, How Often Do You Wake During the Night?				
Once a week	15	20	8	8
2-3 times a week	20	27	11	11
4-5 times a week	4	5	20	20
Every night	3	4	17	17
More than once per night	2	3	17	17
What Causes You to Wake?				
Fear of hypoglycemia	3	4	19	19
Your partner/child experiencing hypo low BG symptoms	1	1	1	1
Fear of hyperglycemia	0	0	2	2
Your partner/child experiencing hyper high BG symptoms	0	0	2	2
Your partner/child needs to test their blood glucose	2	3	8	8
CGM alarm	27	36	38	38
Insulin pump alarm	5	7	2	2
If CGM, How Often Does a 'False Alarm' Wake You in the Night?				
Rarely	17	23	26	26
1-2 times a month	11	15	17	17
Once a week	5	7	9	9
More than once a week	7	9	10	10
Not applicable	3	4	0	0

Table 9: Reported Satisfaction with Training for Diabetes Technology

	Adults (n=74)		Children (n=100)	
	<i>n</i>	%	<i>n</i>	%
My Needs				
Very dissatisfied	1	1	3	3
Somewhat dissatisfied	6	8	5	5
Neutral	16	22	8	8
Somewhat satisfied	19	26	27	27
Very satisfied	21	28	56	56
Partner's or Child's Needs				
Very dissatisfied	0	0	3	3
Somewhat dissatisfied	4	5	3	3
Neutral	6	8	16	16
Somewhat satisfied	27	36	25	25
Very satisfied	34	46	53	53

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