

Impact of Real-Time CGM Data Sharing on Quality of Life in the Caregivers of Adults and Children With Type 1 Diabetes

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Abstract

Background: To examine caregivers' experiences with real-time continuous glucose monitoring (RT-CGM) data sharing and its impact on quality of life (QoL) and health outcomes.

Methods: Parents of children with type 1 diabetes (T1D) ($N=303$) and spouses/partners of T1D adults ($N=212$) using the Dexcom G5 Mobile or G6 RT-CGM system and who were actively following their T1Ds' RT-CGM data completed a survey examining their perceived value of data sharing, the impact of sharing on their own QoL and their child/partner's health, and how they used RT-CGM data to support their T1Ds' diabetes management. Regression analyses examined whether their actions were linked to reported changes in QoL and health outcomes.

Results: Respondents were predominantly non-Hispanic White (91.1% parents; 88.7% partners), female (78.2% parents; 54.7% partners), and college-educated (65.3% parents; 61.8% partners). The majority reported that data sharing had enhanced hypoglycemic confidence (97.7% parents; 98.1% partners), overall well-being (60.4% parents; 63.2% partners), and sleep quality (78.0% parents; 61.3% partners). Of note, three positive caregiver actions were broadly consistent and significant predictors of QoL and health benefits for both parents and partners: celebrating success related to glycemic control, providing encouragement when glycemic control is challenging, and teamwork discussions about how the caregiver should respond to out-of-range values.

Conclusions: RT-CGM data sharing was associated with a range of QoL and health benefits for caregivers. Degree of benefits was influenced by the collaborative actions taken by caregivers to support their child's or partner's diabetes management. To determine the most effective strategies for collaborative data sharing, longitudinal trials are needed.

Keywords

type 1 diabetes, continuous glucose monitoring, quality of life, real-time data sharing, parents, spouses

Introduction

Emotional stresses and strains are common among caregivers of people with type 1 diabetes (T1D). This includes both parents of T1D children as well as spouses/partners of T1D adults. In particular, worries about hypoglycemia are often predominant, and these concerns can contribute to significant conflict between the caregiver and the T1D individual.¹⁻³ Now that real-time continuous glucose monitoring (RT-CGM) systems allow for remote data sharing, the caregiver (if granted access by the T1D individual) can view the user's real-time data on their smartphones or other smart devices. Also, with certain systems, the caregiver can be alerted if the user's glucose values reach specific thresholds (eg, indicating severe hypoglycemia or hyperglycemia). But how are these systems affecting people with T1D and their data-sharing followers? Are relationships helped or harmed? While there is growing use of CGM and remote data sharing, little is known about how sharing is being used and how it may be affecting quality of life

(QoL) for T1D caregivers and their relationships with their T1D children or spouses/partners.

Even before remote data sharing was available, it was becoming clear that RT-CGM could serve as a boon to families while at the same time potentially leading to interpersonal conflict. Ritholz and her colleagues interviewed a series of T1D adults and their spouses, observing that RT-CGM use contributed to greater comfort and collaboration between partners, but that many of the couples also noted greater conflict around how best to talk about and respond to RT-CGM data, especially when hypoglycemic events occurred or

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seemed likely to occur.⁴ In a recent qualitative study reviewing 39 blogs since the introduction of RT-CGM data sharing, this functionality was associated with greater feelings of safety for the individual with T1D as well as their data following caregivers; however, interpersonal challenges were also apparent.⁵ Semi-structured interviews with 20 parents of T1D primary school children pointed to broad benefits resulting from RT-CGM data sharing, including improved sleep quality and reductions in anxiety for the parents, but the potential for family disagreement was noted.⁶

How does remote data sharing affect people with T1D and their caregivers? What exactly is the value here? Given the potential for interpersonal conflict, might the specific ways in which these data are discussed and responded to in the family setting be of importance and thereby contribute to the resulting impact of remote sharing on key outcomes? To investigate these issues, we surveyed three large cohorts of current users of remote RT-CGM data-sharing systems: T1D adults, spouses/partners of T1D adults, and parents of T1D children. For each group, we explored how data sharing was being used, the reported reactions and behaviors in response to remote CGM data, the perceived value of remote data sharing, and the impact of data sharing on key aspects of QoL and health.

We have previously reported on the survey results from the cohort of T1D adults, concluding that RT-CGM data sharing was associated with a range of reported health and QoL-related benefits, and that the observed benefits were—from the perspective of the T1D adults—influenced by the ways in which they and their caregivers responded to those data.⁷ In the current report, we focus on the survey results from the cohort of T1D caregivers: specifically, spouses/partners of T1D adults and parents of T1D children.

Participants and Methods

Participants

The two groups of T1D caregivers were recruited from the Dexcom database via an email invitation. Inclusion criteria for parents were age ≥ 25 years, and parent to a child < 19 years old with T1D ≥ 12 months, who was currently using the Dexcom RT-CGM (either the Dexcom G5 Mobile or Dexcom G6 Systems) and had been sharing with the parent respondent > 3 months. Inclusion criteria for spouses/partners were similar: age ≥ 25 years, and in an ongoing relationship ≥ 12 months with a spouse/partner with T1D ≥ 12 months, who was currently using the Dexcom RT-CGM (either the Dexcom G5 Mobile or Dexcom G6 Systems), and had been sharing with the spouse/partner respondent > 3 months.

Procedures

The invitation detailed that the study required the completion of an online questionnaire examining the feelings and experiences of caregivers of people with T1D regarding the

Dexcom data-sharing feature. All were informed that the study was a collaboration between Dexcom and the Behavioral Diabetes Institute, that questionnaire responses were anonymous, and that participation was voluntary. If respondents expressed interest, they accessed an online portal and completed seven screener questions. If found to be eligible, they then completed an informed consent document and an ~ 80 -item questionnaire. Completers received a \$25 electronic gift card for participation. All collected data were entered into a central database using a HIPAA-protected server, with no linkages to personal health information or personal identifiers. The research protocol was approved by Ethical and Independent Review Services, a community-based, institutional review board.

Measures

After a review of the available literature, we adopted a co-design approach by completing semi-structured interviews with five parents who were active RT-CGM followers (ie, receiving real-time data from their T1D child's Dexcom G5 or G6 RT-CGM system) and five spouses/partners who were similarly active RT-CGM followers (ie, receiving real-time data from their T1D partner's system). All interviews focused on attitudes toward RT-CGM data sharing, the interviewees' perspective on how they and the T1D individuals communicated about and responded to the shared data, and how they sensed that may have influenced their own QoL. As a result of these interviews, a multisection, self-report questionnaire battery was developed in concert with further advice from our group of interviewees.

The section on "Sample Characteristics" focused on demographic information for the caregiver respondent (eg, age, gender, ethnicity, years of education) and the T1D child or spouse/partner (eg, age, gender, ethnicity, years of education, number of years since T1D diagnosis, duration of RT-CGM use). The section on "Use of RT-CGM Shared Data" examined the caregiver respondent's perspective on how he/she typically responded to/acted on the shared data (the six items are listed in Table 2). The section on "Perceived Value" assessed the respondent's perspectives on the value of RT-CGM data sharing (the 11 items are listed in Table 3). For the sections "Use of RT-CGM Shared Data" and "Perceived Value", items were scored on a five-point Likert scale, ranging from "strongly disagree" to "strongly agree."

Section 4 ("Perceived Impact") examined respondents' perceptions of the impact of RT-CGM data sharing on four key aspects of their own QoL. Since there were no available validated scales that assess perception of change retrospectively, three existing instruments, most of which are well validated and previously used in previous RT-CGM studies, were adapted for use in the current study:

1. To evaluate overall well-being, we selected World Health Organization-5 scale (WHO-5; sample item: feeling "cheerful and in good spirits"). In this

modified version, respondents were asked to indicate how data sharing had affected them on a five-point Likert scale (“much less of the time,” “somewhat less of the time,” “no change,” “somewhat more of the time,” or “much more of the time”).⁸ The modified scale demonstrated acceptable reliability in the parent ($\alpha=0.80$) and partner ($\alpha=0.85$) samples.

2. To evaluate worries and concerns related to diabetes and its management, we chose the two caregiver versions of the Diabetes Distress Scale (DDS), the 21-item version for partners of adults with T1D (Partner-DDS; sample item: “feeling unclear about exactly how much I should be involved in managing my partner’s diabetes”)² and the 20-item version for parents of teens with T1D (Parent-DDS; sample item: “feeling that trying to help my teen with his/her diabetes is always a battle”).¹ Of note, the Parent-DDS was only completed by parents with T1D teens; no distress measure was administered to parents of T1D pre-teens. As before, the scales were modified such that respondents rated how data sharing had affected them on a five-point scale (“much more of a problem than before,” “somewhat more of a problem than before,” “no change,” “somewhat less of a problem than before,” “much less of a problem than before”). The modified scales demonstrated acceptable reliability in the parent and partner samples (both $\alpha=0.94$).
3. To evaluate change in feelings about hypoglycemia, spouses/partners completed the 12-item Hypoglycemic Confidence Scale (HCS) for partners of adults with T1D (Partner-HCS; sample item: “how confident are you that your partner can stay safe from serious hypoglycemia problems when he/she is alone?”), once again modified such that respondents indicated how data sharing had affected them on a five-point scale (“much less confident than before,” “somewhat less confident than before,” “no change,” “somewhat more confident than before,” “much more confident than before”).³ Parents completed a similar version of the HCS, which was developed for this study. The modified scales demonstrated acceptable reliability in the parent and partner samples (both $\alpha=0.89$).¹

Finally, respondents were asked to indicate on a five-point scale how data sharing may have affected their sleep quality, with response options ranging from getting “much more” to “much less” quality sleep than before.

Section 5 (“Perceived Impact on T1D Health Outcomes”) examined respondents’ perspective on the impact of RT-CGM data sharing on their child’s or partner’s frequency of severe hypoglycemic episodes and glycemic control.

Throughout the questionnaire battery, respondents were frequently reminded that they were not being asked to evaluate how their spouse/partner or child’s RT-CGM use overall had affected them, but only how that one specific aspect of

RT-CGM use—their spouse/partner or child’s *data sharing*—had influenced them.

Data Analysis

Descriptive statistics (N , %, mean, standard deviation) were used to describe caregiver respondents’ demographics, and their T1D child/partner’s diabetes history and use of RT-CGM and data sharing. Frequencies, reported as N (%), were obtained to summarize how RT-CGM data were used, the perceived value of RT-CGM data sharing, and the perceived impact of RT-CGM data sharing on respondents’ QoL (HCS, WHO-5, DDS, and sleep quality) and their T1D child/partner’s diabetes (severe hypoglycemia frequency and A1C). Multiple linear regression analyses were conducted to evaluate whether the ways in which the caregiver respondent used the RT-CGM data influenced their own QoL and their T1D child/partner’s health. Specifically, the six RT-CGM relevant skills and behaviors were entered as independent variables in separate multiple regressions for each of the QoL outcomes (HCS, WHO-5, DDS, and sleep quality) and each of the T1D’s health outcomes (severe hypoglycemia frequency and A1C). Key demographic variables (age, gender, education, and ethnicity) were included as covariates in each of the regression models. Separate analyses were conducted for parent and partner respondent samples. As there were no statistically significant differences in the reported impact of data sharing on QoL and health outcomes between parents of T1D pre-teens (<13 years of age) versus T1D teens (≥ 13 years of age), the parent group was analyzed as one coherent group for parsimony. IBM SPSS Statistics 25 was used for all analyses.

Results

Sample Characteristics

Of the 330 parents and 214 partners who began the survey, most completed it satisfactorily—303 parents (91.8%) and 212 partners (99.1%). Respondents were predominantly non-Hispanic White (91.1% parents; 88.7% partners), female (78.2% parents; 54.7% partners), and well educated (65.3% of parents and 61.8% of partners were college graduates). Mean age was 43.3 ± 6.7 years (parents) and 49.7 ± 15.6 years (partners). The majority of the T1D children (86.1%) and T1D partners (76.4%) had been using RT-CGM >1 year. Of note, approximately half (47.5%) of the T1D children were teens (≥ 13 years). Descriptive statistics are presented in Table 1.

Use of RT-CGM Shared Data

The majority of parents (94.4%) and partners (72.6%) reported that they typically checked their T1D child’s or partner’s CGM readings multiple times/day. Most respondents agreed

Table 1. Sample Characteristics.

| | Partners (n=212) | Parents (n=303) | P-value |
|--|------------------|-----------------|---------|
| <i>Respondent characteristics</i> | | | |
| Age, in years (mean ± SD) | 49.7 ± 15.6 | 43.3 ± 6.7 | <.001 |
| Female | 116 (54.7) | 237 (78.2) | <.001 |
| Non-Hispanic White | 188 (88.7) | 276 (91.1) | .368 |
| College graduate | 131 (61.8) | 198 (65.3) | .409 |
| Lives with T1D child full-time | – | 278 (91.7) | – |
| Duration of relationship with T1D partner | | | – |
| ≤5 years | 34 (16.0) | – | |
| 6-10 years | 35 (16.5) | – | |
| 11-20 years | 43 (20.3) | – | |
| >20 years | 100 (47.2) | – | |
| <i>T1D partner/child characteristics</i> | | | |
| Age | | | |
| In years (mean ± SD) | – | 12.00 ± 4.0 | – |
| 21-34 | 48 (22.6) | – | |
| 35-44 | 39 (18.4) | – | |
| 45-64 | 80 (37.8) | – | |
| ≥65 | 45 (21.2) | – | |
| Female | 93 (43.9) | 144 (47.5) | .413 |
| Non-Hispanic White | 198 (93.4) | 272 (89.8) | .151 |
| College graduate | 131 (61.8) | – | – |
| Duration of T1D | | | <.001 |
| ≤5 years | 23 (10.8) | 194 (64.0) | |
| 6-10 years | 18 (8.5) | 76 (25.1) | |
| >10 years | 171 (80.7) | 33 (10.9) | |
| Duration of CGM use | | | .001 |
| 3-6 months | 22 (10.4) | 19 (6.3) | |
| 7-12 months | 28 (13.2) | 23 (7.6) | |
| >1 year | 162 (76.4) | 261 (86.1) | |
| Duration of data sharing w/ partner/parent | | | .013 |
| 3-6 months | 29 (13.7) | 25 (8.2) | |
| 7-12 months | 32 (15.1) | 29 (9.6) | |
| >1 year | 151 (71.2) | 249 (82.2) | |

CGM, continuous glucose monitoring; SD, Standard deviation; T1D, type 1 diabetes. N (%) presented unless otherwise noted.

“somewhat” or “strongly”) that they knew what to do when they observed glucose values in the hypoglycemic range (97.7% parents; 96.7% partners) (Table 2). The majority had discussed with their T1D child/partner about how best to respond (and how not to respond) when seeing out-of-range glucose values (“Clear Discussion”—55.4% parents; 68.4% partners). Having such a discussion was significantly more common in partners than parents ($P=.003$). The majority also reported offering encouragement when noticing that their T1D child/partner was struggling with glucose management (“Offers Encouragement”—82.2% parents; 89.2% partners) and celebrated with them when seeing that their glucose management was going well (“Celebrated”—81.2% parents; 79.2% partners). Significantly more partners than parents indicated that they offered encouragement ($P=.029$). Of concern, almost one-third of respondents agreed that they were now

“bugging” their T1D child/partner too frequently about glucose values (31.7% parents; 29.2% partners).

Perceived value of RT-CGM Data Sharing

Most agreed that data sharing gave them peace of mind (88.4% parents; 87.7% partners), contributed to lowering their anxiety (84.8% parents; 86.3% partners), and helped them feel confident about their ability to help their child/partner (92.1% parents; 94.3% partners) (Table 3). Also noteworthy was that the majority agreed that they now felt more understanding about the personal challenges of managing T1D (87.1% parents; 90.6% partners). Many agreed that data sharing had contributed to a better relationship with their T1D child/partner, though this was significantly more common among partners (57.1%) than parents (38.6%) ($P<.001$). A

Table 2. Use of Shared RT-CGM Data.

| | N (%) agreed | | P-value |
|--|---------------------|--------------------|---------|
| | Partners (n=212) | Parents (n=303) | |
| Celebrates: When seeing my partner/child's numbers, I celebrate him/her when things are going well | 168 (79.2) | 246 (81.2) | .585 |
| Lack of Understanding: I do not really understand how best to respond when seeing my partner/child's numbers | 13 (6.1) | 8 (2.6) | .049 |
| Offer Encouragement: I offer my partner/child encouragement when I see he/she is struggling with his/her numbers | 189 (89.2) | 249 (82.2) | .029 |
| Hypoglycemic Knowledge: I know just what to do if I see that my partner/child's blood sugars are getting too low | 205 (96.7) | 296 (97.7) | .496 |
| Bug him/her: Because of data sharing, I now bug my partner/child too much about his/her numbers | 62 (29.2) | 96 (31.7) | .555 |
| Clear Discussion: My partner/child and I have had a clear discussion about how I should best respond (or not) when seeing that his/her numbers are out of range. | 145 (68.4) | 168 (55.4) | .003 |

Data presented reflect N (%) of partner/parent respondents who (somewhat or strongly) agreed with each item.

All items were rated on a five-point Likert response scale: 1 = "Strongly Disagree," 2 = "Somewhat Disagree," 3 = "Neutral," 4 = "Somewhat Agree,"

5 = "Strongly Agree." Items were analyzed as continuous variables for significance testing; however, response categories 4 and 5 were collapsed to reflect "Agreed" for data presentation purposes.

Table 3. Perceived Value of RT-CGM Data Sharing.

| | N (%) agreed | | P-value |
|---|---------------------|--------------------|---------|
| | Partners (n=212) | Parents (n=303) | |
| Data sharing gives me peace of mind | 186 (87.7) | 268 (88.4) | .805 |
| Because of data sharing, I am more critical about the choices my partner/child is making about his/her diabetes | 122 (57.5) | 163 (53.8) | .399 |
| Thanks to data sharing, if my partner/child needs help, I have his/her back | 196 (92.5) | 287 (94.7) | .294 |
| Using data sharing with my partner/child makes me feel like a member of his/her diabetes team | 196 (92.5) | 266 (87.8) | .086 |
| Data sharing has improved the relationship with my partner/child | 121 (57.1) | 117 (38.6) | <.001 |
| Because of data sharing, I feel more understanding about how challenging diabetes can be | 192 (90.6) | 264 (87.1) | .228 |
| Using data sharing, I now feel more confident about helping my partner/child with his/her diabetes | 200 (94.3) | 279 (92.1) | .322 |
| Because of data sharing, I now feel less anxious about my partner/child | 183 (86.3) | 257 (84.8) | .634 |
| Because of data sharing, I now feel more anxious about my partner/child | 23 (10.8) | 41 (13.5) | .364 |
| Data sharing has caused more tension in my relationship with my partner/child | 20 (9.4) | 38 (12.5) | .272 |
| Data sharing has given me too much information. | 18 (8.5) | 28 (9.2) | .769 |

Data presented reflect N (%) of partner/parent respondents who (somewhat or strongly) agreed with each item.

Items were rated on a five-point Likert response scale: 1 = "Strongly Disagree," 2 = "Somewhat Disagree," 3 = "Neutral," 4 = "Somewhat Agree,"

5 = "Strongly Agree." Items were analyzed as continuous variables for significance testing; however, response categories 4 and 5 were collapsed to reflect "Agreed" for data presentation purposes.

significant fraction of respondents indicated more negative perspectives on data sharing, including an increase in anxiety about their T1D child/partner (13.5% parents; 10.8% partners) and heightened tension in their relationships (12.5% parents; 9.4% partners).

Perceived impact of RT-CGM Data Sharing on Quality-of-Life and Health Outcomes

Improvement in hypoglycemic confidence due to data sharing was reported by almost all respondents (97.7% parents;

Table 4. Perceived Impact of RT-CGM Data Sharing on QoL and Health Outcomes.

| | N (%) improved | | P-value |
|---|---------------------|--------------------|---------|
| | Partners n = 212 | Parents n = 303 | |
| Respondent's QoL and health outcomes | | | |
| Partner/Parent Hypoglycemia Confidence Scale ^a | 207 (98.1) | 296 (97.7) | .084 |
| WHO-5 Well-Being Scale ^a | 134 (63.2) | 183 (60.4) | .245 |
| Partner/Parent Diabetes Distress Scale ^{a,b} | 169 (79.7) | 76 (52.8) | – |
| Sleep ^c | 130 (61.3) | 234 (78.0) | <.001 |
| T1D partner/child's health outcomes | | | |
| HbA1c ^d | 132 (77.2) | 231 (85.6) | .025 |
| Severe hypoglycemic events ^e | 164 (77.4) | 235 (77.6) | .958 |

HbA1c, hemoglobin A1c; QoL, quality of life; T1D, type 1 diabetes; WHO, World Health Organization.

Data presented reflect N (%) of partner/parent respondents who reported improvement in the QoL or health outcome due to RT-CGM data sharing.

^aQoL measures were analyzed as continuous variables for significance testing. However, for data presentation purposes, mean QoL score thresholds were used to indicate an improvement (versus no change/worsening) in the caregiver respondent's QoL due to RT-CGM data sharing.

^bDDS scores available for parents of children older than 12 years (n = 144). Significance testing not conducted as parents and partners completed different diabetes distress measures.

^cPartner/parent respondents reported the perceived impact of RT-CGM data sharing on their own sleep quality on a five-point Likert scale: 1 = "much more than before," 2 = "somewhat more than before," 3 = "no change," 4 = "somewhat less than before," 5 = "much less than before."

^dPartner/parent respondents used a five-point Likert scale to indicate the perceived impact of RT-CGM data sharing on their T1D partner/child's HbA1c: 1 = "has dropped a lot (at least 0.5%)," 2 = "has dropped a little (but less than 0.5%)," 3 = "has not really changed," 4 = "has risen a little (but less than 0.5%)," 5 = "has risen a lot."

^ePartner/parent respondents reported the perceived impact of RT-CGM data sharing on the frequency of their T1D partner/child's severe hypoglycemic events on a five-point Likert scale: 1 = "many fewer than before," 2 = "somewhat fewer than before," 3 = "no change," 4 = "somewhat more than before," 5 = "many more than before."

^{c,d,e}Response categories 1 and 2 were collapsed to reflect "improved" for data presentation purposes.

98.1% partners) (Table 4). The majority also noted that data sharing added to their own well-being (60.4% parents; 63.2% partners), contributed to better sleep quality (78.0% parents; 61.3% partners), and reduced diabetes distress (52.8% parents of teens; 79.7%, partners). Note that diabetes distress was not assessed in parents of pre-teens. Finally, the majority indicated that their T1D child/partner enjoyed beneficial outcomes in response to data sharing, including a reduction in severe hypoglycemic events (77.6% parents; 77.4% partners) and A1C improvement (85.6% parents; 77.2% partners). Of note, significantly more parents than partners reported A1C improvement ($P = .025$).

Are Caregivers' Behaviors in Response to Data Sharing Associated with the Perceived Changes in Quality of Life and Clinical Outcomes?

There were no consistent associations between any of the parent/partner demographic covariates (age, gender, ethnicity, and education) and their own QoL (HCS, WHO-5, DDS, and sleep quality) or health outcomes (severe hypoglycemia frequency and A1C). With control for these demographics, distinct skills/behaviors of the parent/partner respondents emerged as significant independent predictors of their QoL and their T1D's health outcomes in a coherent pattern (Table 5a and b).

For both parents and partner, "Celebrated" was independently associated with data-sharing-related improvements in overall well-being (WHO-5; parents, $P < .05$; partners,

$P < .01$) as well as their T1D child's/partner's glycemic control (A1C; parents, $P < .05$; partners, $P < .01$). Furthermore, "Celebrated" was also linked to enhanced hypoglycemic confidence for parents (HCS, $P < .05$) and to reductions in diabetes distress for partners (DDS, $P < .01$).

Another important link was with "Offers Encouragement." For both parents and partners, this factor was independently associated with reductions in diabetes distress (DDS; parents of teens, $P < .05$; partners, $P < .001$) and greater hypoglycemic confidence (HCS; parents, $P < .001$; partners, $P < .01$) as well as reductions in their child's/partner's severe hypoglycemia rates (parents, $P < .01$; partners, $P < .05$). "Offers Encouragement" for parents was also associated with improvements in their child's glycemic control (A1C, $P < .05$), while for partners it was linked to enhanced well-being (WHO-5, $P < .001$).

"Clear Discussion" was independently linked to improved well-being (WHO-5) for both parents ($P < .001$) and partners ($P < .05$). For parents only, "Clear Discussion" was also associated with improvements in hypoglycemic confidence (HCS, $P < .001$) and reductions in their child's severe hypoglycemia rates ($P < .01$). For parents of T1D teens, "Clear Discussion" was also linked to reductions in diabetes distress (DDS, $P < .01$).

For both parent and partners, "Lack of Understanding" (not knowing how best to respond to glucose data) was independently associated with reduced hypoglycemic confidence (HCS; parents, $P < .001$; partners, $P < .05$) and overall well-being (WHO-5; parents, $P < .01$; partners, $P < .05$) as well as

Table 5a. Associations of Use of Shared RT-CGM Data with Caregiver Respondents' QoL.

| | Partners (n = 212) | | | | Parents (n = 303) | | | |
|--|-----------------------|-------------------------|-----------------------|-------------------------|-----------------------|-------------------------|-------------------------|-------------------------|
| | HCS ^a β | WHO-5 ^a β | DDS ^b β | Sleep ^b β | HCS ^a β | WHO-5 ^a β | DDS ^{b,c} β | Sleep ^b β |
| <i>Covariates</i> | | | | | | | | |
| Age | 0.02 | 0.04 | -0.08 | -0.12 | -0.03 | 0.04 | 0.07 | -0.04 |
| Gender (1 = female, 0 = male) | -0.01 | -0.10 | 0.05 | -0.11 | 0.10 | 0.10 | 0.03 | -0.11 |
| College graduate (1 = yes, 0 = no) | -0.02 | -0.11 | 0.06 | 0.16* | -0.06 | -0.08 | 0.22** | -0.01 |
| Non-Hispanic White (1 = yes, 0 = no) | -0.09 | -0.10 | 0.06 | -0.06 | 0.11 | -0.03 | 0.04 | 0.10 |
| <i>Caregivers' use of Shared RT-CGM Data^d</i> | | | | | | | | |
| Celebrate: "When seeing my partner/child's numbers, I celebrate with him/her when things are going well." | 0.11 | 0.18** | -0.23** | -0.10 | 0.14* | 0.15* | -0.13 | -0.05 |
| Lack of Understanding: "I do not understand how best to respond when seeing my partner/child's numbers." | -0.14* | -0.15* | 0.10 | -0.01 | -0.24*** | -0.18** | 0.24** | 0.10 |
| Offer Encouragement: "I offer the encouragement I think is needed when I see my partner/child is struggling with his/her numbers." | 0.23** | 0.32*** | -0.32*** | -0.13 | 0.22*** | 0.09 | -0.21* | 0.07 |
| Hypoglycemic Knowledge: "I know just what to do if my partner/child's blood sugars are getting too low." | 0.18** | 0.23** | -0.17* | -0.09 | 0.09 | 0.03 | -0.11 | 0.01 |
| Bug My Partner/Child: "Because of data sharing, I now bug my partner/child too much about his/her numbers." | -0.08 | -0.09 | 0.12 | 0.10 | -0.09 | -0.14* | 0.22** | 0.13* |
| Clear Discussion: "My partner/child and I have had a clear discussion about how I should best respond (or not) when seeing that his/her numbers are out of range." | 0.09 | 0.18* | -0.12 | -0.07 | 0.21*** | 0.22*** | -0.22** | -0.17 |

DDS, Diabetes Distress Scale; HCS, Hypoglycemic Confidence Scale; QoL, quality of life; RT-CGM, real-time continuous glucose monitoring; WHO, World Health Organization.

* $P < .05$. ** $P < .01$. *** $P < .001$.

^aHigher scores reflect higher QoL.

^bHigher scores reflect lower QoL.

^cDDS scores available for parents of children older than 12 years ($n = 144$).

^dItems were rated on a five-point Likert response scale (5 = "Strongly Agree," 4 = "Somewhat Agree," 3 = "Neutral," 2 = "Somewhat Disagree," 1 = "Strongly Disagree").

more frequent severe hypoglycemia in their loved ones (parents, $P < .01$; partners, $P < .01$). "Lack of Understanding" for parents was also linked to less improvement in their child's overall glycemic control (A1C, $P < .05$) and, for that subset of parents with T1D teens, greater diabetes distress (DDS, $P < .01$).

Discussion

In parallel to the findings from the earlier survey of T1D adults,⁷ we found that T1D caregivers, both parents of T1D children and partners of T1D adults, reported similarly broad health and QoL gains due to RT-CGM data sharing. More than three-quarters of respondents indicated that their T1D child/partner had experienced beneficial reductions in A1C and in severe hypoglycemic episodes, thanks to data sharing. The majority reported improvements in their own sleep quality, overall well-being, and levels of diabetes distress. The most striking affective changes due to data sharing were associated with hypoglycemic concerns—almost all caregivers reported improvements in their hypoglycemic

confidence, while the majority agreed that they now had greater peace of mind and less anxiety. In total, these data are consistent with the caregiver benefits resulting from data sharing described in earlier qualitative studies.^{4,5}

Patterns of (small to moderate) associations pointed to four caregiver skills as independent contributors to the observed health and QoL benefits. These included when the caregiver acted to celebrate with their T1D child/partner when seeing positive changes in his/her glucose values (linked to improvement in A1C, HCS, and WHO-5 when the parent celebrated; and in A1C, DDS and WHO-5 when the partner celebrated), when the caregiver offered encouragement when seeing that their T1D child/partner was struggling with his/her glucose readings (linked to improvement in A1C, rates of severe hypoglycemia, HCS, DDS, and WHO-5 when the partner was the encourager; and in rates of severe hypoglycemia, HCS and DDS when the parent was the encourager), and when the caregiver and their T1D child/partner had discussed clearly how best to respond to out-of-range values (linked to improvements in rates of severe hypoglycemia, HCS, WHO-5, and DDS, though for parents only). In contrast, caregivers

Table 5b. Associations of Use of Shared RT-CGM Data with Clinical Outcomes.

| | Partners (n = 212) | | Parents (n = 303) | |
|--|-------------------------|---------------------------------------|-------------------------|---------------------------------------|
| | HbA1c ^a β | Severe hypoglycemia ^b β | HbA1c ^a β | Severe hypoglycemia ^b β |
| <i>Covariates</i> | | | | |
| Age | 0.18* | -0.05 | 0.03 | -0.04 |
| Gender (1 = female, 0 = male) | -0.05 | -0.02 | 0.03 | -0.05 |
| College graduate (1 = yes, 0 = no) | 0.02 | 0.09 | 0.02 | -0.01 |
| Non-Hispanic White (1 = yes, 0 = no) | -0.01 | -0.06 | -0.03 | 0.01 |
| <i>Caregivers' use of shared RT-CGM data^c</i> | | | | |
| Celebrate: "When seeing my partner/child's numbers, I celebrate with him/her when things are going well." | -0.24** | -0.11 | -0.13* | -0.08 |
| Lack of Understanding: "I do not understand how best to respond when seeing my partner/child's numbers." | 0.08 | 0.20** | 0.20** | 0.17** |
| Offer Encouragement: "I offer the encouragement I think is needed when I see my partner/child is struggling with his/her numbers." | -0.11 | -0.15* | -0.16* | -0.19** |
| Hypoglycemic Knowledge: "I know just what to do if my partner/child's BG is getting too low." | -0.05 | -0.21** | -0.10 | -0.07 |
| Bug My Partner/Child: "Because of data sharing, I now bug my partner/child too much about his/her numbers." | -0.10 | -0.08 | 0.01 | 0.02 |
| Clear Discussion: "My partner/child and I have had a clear discussion about how I should best respond (or not) when seeing that his/her numbers are out of range." | -0.07 | 0.10 | -0.11 | -0.23** |

RT-CGM, real-time continuous glucose monitoring.

* $P < .05$. ** $P < .01$. *** $P < .001$.

Higher scores on clinical indicators (HbA1c, severe hypoglycemia) reflect worse clinical outcomes:

^aItems assessed respondents' perceived impact of RT-CGM data sharing on their T1D partner/child's HbA1c, and was rated on a five-point Likert response scale: 1 = "Dropped a lot (at least 0.5% or more)," 2 = "Dropped a little (but less than 0.5%)," 3 = "Not really changed," 4 = "Risen a little (but less than 0.5%)," 5 = "Risen a lot (at least 0.5% or more)." The $n = 41$ partners and $n = 33$ parents who responded "I'm not sure" were excluded from the HbA1c outcome analyses only.

^bItems assessed respondents' perceived impact of RT-CGM data sharing on their T1D partner/child's severe hypoglycemic episode frequency on a five-point Likert scale: 1 = "Many fewer," 2 = "Somewhat fewer," 3 = "No change," 4 = "Somewhat More," 5 = "Many More."

^cItems were rated on a five-point Likert response scale: 5 = "Strongly Agree," 4 = "Somewhat Agree," 3 = "Neutral," 2 = "Somewhat Disagree," 1 = "Strongly Disagree."

reporting that they did not know how best to respond to shared RT-CGM data noted significantly fewer health and QoL benefits for their child/partner (for parents, linked to less improvement in A1C, rates of severe hypoglycemia, HCS, WHO-5, and DDS; and for partners, in rates of severe hypoglycemia, HCS and WHO-5).

While reports of health or QoL worsening were rare among study participants, adverse aspects of data sharing were evident. In particular, more than one-quarter of caregivers felt they were now bothering their child/partner too frequently about RT-CGM readings. Approximately 10% or more of caregivers noted that data sharing had led to an increase in anxiety about their T1D child/partner and greater tension in their relationships. This points to the potential difficulty that caregivers face when seeking to find the most appropriate role for themselves in a family member's diabetes management. Previous studies have documented that T1D parents and partners are commonly quite fearful about hypoglycemia,^{1,2} and in some cases they may be even more worried and frightened than the T1D

individuals in their lives. Therefore, while caregivers may appreciate the value of working together as a team and respecting the personal boundaries of their T1D family members when responding to RT-CGM data, this may at times feel too difficult to do when caregivers are overwhelmed by fear.^{4-6,9} Why this may be problematic in some families and not others remains an open, and important, question for future studies.

Taken as a whole, these findings are comparable to the findings from the T1D adult survey,⁷ where not only were similar health and QoL benefits due to RT-CGM data sharing reported and negative aspects of data sharing were seen to be uncommon (though not absent), but the same three positive caregiver actions were reportedly linked to QoL benefits for both T1D adults as well as T1D caregivers. The one exception is that significant associations between the "clear discussion" action and health and QoL benefits were observed in the parent sample, but not in the partner sample. We suspect that there may be important differences in how parents and partners may have experienced this "clear discussion" with their T1D family

member. Did such overt interactions about data sharing actually take place? One possibility is that parents may have found the conversation to be more comprehensive, productive, and satisfying than partners. It may be valuable to conduct further qualitative investigations to examine the nature and nuances of these family discussions about data-sharing conversations and to determine what actual agreements are reached.

Certain study limitations must be acknowledged, especially in regard to selection bias. While we do not know why only certain T1D caregivers responded to the study invitation and others did not, we suspect that those with less fervent appraisals of RT-CGM data sharing may have been less interested in participating. Less positive responses to data sharing for both parents and partners, therefore, may be more common than what is reported in the current findings. However, we believe that these data represent what is achievable when data sharing in the family setting is handled appropriately.

It is also important to recognize that caregivers were surveyed at only one moment in time; though the three main QoL-related measures were modified so that we could inquire retrospectively about changes due to data sharing, all findings are cross-sectional. Furthermore, reported results regarding QoL (as well as health) are all derived from self-reported data; they are based solely on respondents' memories and are therefore open to bias. Thus, no causal conclusions can be drawn with any confidence. Finally, though respondents were asked to judge how data sharing alone had influenced outcomes (not the pooled impact of data sharing in combination with the influence of RT-CGM), we suspect that a subset of respondents may have lumped together these features.

Conclusion

In conclusion, parents of T1D children and partners of T1D adults report substantial health and QoL-related benefits resulting from RT-CGM data sharing. Importantly, the characteristic ways in which caregivers responded to the observed RT-CGM data, especially supportive behaviors, influenced the reported benefits. To determine whether such actions are truly influential, longitudinal trials will be needed. Until that time, it may be of value to educate T1D caregivers who are remotely accessing RT-CGM data about how data sharing "etiquette" strategies could prove to be beneficial for themselves as well as their T1D family members.

Abbreviations

CGM, continuous glucose monitoring; QoL, quality of life; RT-CGM, real-time continuous glucose monitoring; SD, standard deviation; T1D, type 1 diabetes; WHO, World Health Organization; DDS, Diabetes Distress Scale; HCS, Hypoglycemic Confidence Scale.

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Note

1. Copies of all scales developed or modified for this study are available by request from the corresponding author.

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