COVID-19 Pandemic Effects on Caregivers of Youth With Type 1 Diabetes: Stress and Self-Efficacy

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BACKGROUND | Little is known about the coronavirus disease 2019 (COVID-19) pandemic's psychological effects on caregivers of children with type 1 diabetes.

OBJECTIVE | This study aimed to investigate the experience of caregivers of youth with type 1 diabetes during the COVID-19 pandemic.

METHODS | A 49-item questionnaire using a 5-point Likert scale and open-response questions was distributed via e-mail and type 1 diabetes–related social media platforms from 4 May to 22 June 2020. Quantitative data were analyzed using SPSS v.25 statistical software. Descriptive statistics were used. Relationships were compared using Pearson correlation. Qualitative data were coded and categorized.

RESULTS | A total of 272 caregivers participated (mean ± SD respondent age 42.1 ± 7.8 years; 94.5% females; 81.3% with college degree or higher; 52.6% with annual income >$99,000; 80.1% with private insurance). The mean ± SD age of caregivers' children with type 1 diabetes was 11.0 ± 4.1 years, and their mean ± SD diabetes duration was 4.2 ± 3.5 years. Participants reported being diagnosed with or knowing someone with COVID-19 (24.6%), increased stress (71.9%), job loss (10.3%), and financial difficulty (26.8%) as a result of the pandemic. General self-efficacy scores were high (mean ± SD 16.2 ± 2.6, range 8–20) and significantly correlated with COVID-19–related self-efficacy (mean ± SD 12.6 ± 2.1; $R =$ 0.394, $P < 0.001$) and type 1 diabetes self-efficacy during COVID-19 (mean ± SD 17.1 ± 2.5; $R = 0.421$, $P < 0.001$).

CONCLUSION | Despite reporting high overall self-efficacy, caregivers of children with type 1 diabetes reported greater overall stress and challenges during the pandemic. Health care providers should be prepared to provide families with specific social and mental health support.

Caring for children with type 1 diabetes is stressful and demanding for parents and caregivers. Parents report emotional distress (often defined as a state of mental anguish) at the time of their child's diagnosis that does not diminish over time (1,2), with high parental emotional distress associated with worse psychosocial and physical health outcomes for both parents and children (2–7). Self-efficacy is defined as confidence in one's ability to successfully perform specific tasks or behaviors (8,9). Emotional distress associated with diabetes care can be further amplified during events such as the coronavirus disease 2019 (COVID-19) pandemic, and self-efficacy can be negatively affected, especially when caregivers experience disruptions in day-to-day life and uncertainty about potential added type 1 diabetes–related risks for their child.

Reports early in the pandemic suggested that people with diabetes were in the high-risk category for COVID-19 death and adverse outcomes (10,11). These reports contributed to confusion and anxiety, especially for caregivers of children with type 1 diabetes. Therefore, it is important to assess how parents/caregivers experience, manage, and cope during events such as the COVID-19 pandemic.

The main objective of this study was to investigate the experience of caregivers of youth with type 1 diabetes who

were <18 years of age during the COVID-19 pandemic. Using self-reported questionnaire data, we *1*) determined pandemic stressors and coping mechanisms and *2*) examined general, COVID-related, and type 1 diabetes care–related self-efficacy measures.

Research Design and Methods

Development and Description of the Questionnaire

A 49-item self-reported questionnaire, the "T1D-COVID-Care Questionnaire," was developed by a team of pediatric endocrinologists, nurse practitioners, certified diabetes care and education specialists, and clinical psychologists. Before dissemination, the questionnaire was pilot-tested among the members of the study team, who included one individual with type 1 diabetes and one parent of a youth with type 1 diabetes. The survey questions are provided in the Supplementary Material. Response options for most Likert scales used in the quantitative sections of the T1D-COVID-Care Questionnaire were as follows: 1 = not at all, 2 = a little, 3 = somewhat, 4 = quite a bit, and 5 = very much.

The questionnaire was divided into four sections. The first section (12 questions) collected demographic and COVID-19–related data on parents and their child with type 1 diabetes and COVID-19–specific variables such as job loss, financial difficulty, and general COVID-19 information-seeking or intrusive marketing (e.g., the receipt of COVID-19–related health information that parents did not try to find, such as news about higher risk for severe disease and mortality for people with diabetes).

The second section collected data related to caring for a child with type 1 diabetes during the COVID-19 pandemic and included six qualitative and seven quantitative questions rated on a 5-point Likert scale. These questions were specific to the COVID-19 pandemic and its effect on caregivers' lives, including its financial impact, as well as their related feelings (e.g., feeling stressed, scared, angry, or anxious).

The third section of the survey was designed to collect information on caregivers' self-efficacy (11 questions). Three five-point Likert scales were used to assess general, COVID-19–related, and type 1 diabetes care–related self-efficacy.

General self-efficacy was assessed using the Patient Reported Outcome Measurement Information System (PROMIS) four-item short-form questionnaire, which is validated to measure general self-efficacy from participants' perspective (12). Each question had five response options rated on a 5-point Likert scale as above. A summed score for responses to each question was then calculated, with the lowest possible raw score being 4 and the highest possible raw score being 20. Standard

scoring tables were then used to translate the total raw score into a T-score for each participant. The T-score rescales the raw score into a standardized score with a mean of 50 and an SD of 10. Therefore, a person with a T-score of 40 is one SD below the mean (12). A higher PROMIS T-score represents greater self-efficacy. The raw score, however, was used for comparison and correlations with other specific self-efficacy measures.

The second scale measured COVID-19–related self-efficacy. This scale was developed by the study team by modifying and adapting validated surveys used to measure self-efficacy during the H1N1 influenza pandemic (13). This scale had three scaled questions, as shown in the Supplementary Material. The total raw score was calculated using the sum of the values of the response to each question such that the range of scores for this measure was 1–15, with lower scores indicating lower COVID-19–related self-efficacy.

The third scale measured type 1 diabetes–related self-efficacy and included four questions that were developed by the study team (e.g., How confident are you that you can take care of your child with the added burden of social distancing?). The total raw score was calculated using the sum of the values of the response to each question, with a range of 1–20, with lower scores indicating lower levels of self-efficacy.

The final section of survey constructs included perceived threat, information receptivity, and prevention behavior. The 13 questions in this portion of the survey were also based on modified versions of questions from H1N1 influenza pandemic surveys (9). Each question had five response options rated on a 5-point Likert scale as above. For the open-ended questions, responses were categorized and the responses per category were counted.

Inclusion Criteria and Survey Distribution

This study was considered exempt from institutional review board approval (Indiana University IRB protocol #2004373820, University of Florida IRB protocol #202001064). Participation was voluntary, and participants were informed that their completion of the questionnaire indicated their consent to participate in the study. The participants could also stop answering survey questions at any time. There was no compensation offered for study participation. Information provided at the beginning of the survey also included the inclusion criteria: *1*) ≥18 years of age, *2*) residing in the United States, *3*) ability to read and understand English, and *4*) parent/caregiver of a child/children <18 years of age with type 1 diabetes. The survey was distributed electronically and advertised in several ways, including *1*) online invitations emailed to people

enrolled in a registry who had previously provided consent to be contacted for research opportunities and who had a child with type 1 diabetes, 2) advertisements posted to diabetes-specific social media groups and emailed to diabetes volunteer organizations (JDRF, Children With Diabetes, and American Diabetes Association camps) for distribution, and 3) an electronic flyer sent along with an invitation for a telehealth visit.

The questionnaire was administered online using the Qualtrics survey tool with anonymous links. Data collection took place during the first U.S. COVID-19 pandemic wave, between 4 May and 2 June 2020.

Data Analysis Plan and Statistical Methods

A total of 307 individuals started the survey, and responses from 272 were included in the analysis. Respondents were excluded for the following reasons: respondent did not answer "yes" in response to informed consent ($n = 6$); respondent provided consent, but no additional information ($n = 19$); respondent indicated that child had a diabetes duration >18 years ($n = 3$) and indicated "prefer not to state" on the question about the child's age; and respondent provided demographic data only ($n = 7$).

All quantitative analyses were performed using SPSS v. 25.0 statistical software. Descriptive statistics (means, SDs, and ranges) were used to describe demographic and COVID-19–specific variables. Pearson correlations were calculated between the self-efficacy measures, including the PROMIS self-efficacy short form, the COVID-19–related self-efficacy scale, and the type 1 diabetes–related self-efficacy scale; self-efficacy measures and perceived COVID-19 threat; and perceived COVID-19 threat and COVID-19–related stress. P values <0.05 were considered significant.

For the qualitative data, responses to open-ended questions were coded using thematic analysis (14) by three study team members (B.L.H., R.O., and P.Y.S.), and data were coded and grouped into categories and themes during iterative meetings until consensus was achieved. These categories were then analyzed quantitatively.

Results

The mean ± SD respondent age was 42.1 ± 7.8 years, 94.5% were female, 81.3% had a college degree or higher, 52.6% had an annual income >$99,000, and 80.1% were privately insured. The mean ± SD age of respondents' children with diabetes was 11.0 ± 4.1 years, with a mean ± SD duration of type 1 diabetes of 4.2 ± 3.5 years. Table 1 summarizes the demographic data of participants.

During the pandemic, 10.3% of respondents reported job loss, 26.8% reported financial difficulty, and 24.6% reported either having or knowing someone who had COVID-19.

TABLE 1 Demographic Characteristics of Survey Respondents	
Caregiver age, years, mean ± SD (261 respondents)	42.1 ± 7.8
Caregiver sex, % female (271 respondents)	94.5
Caregiver education, *n* (%) (272 respondents)	
High school or less	14 (5.1)
Some college/vocational training	35 (12.9)
Associate's degree	32 (11.8)
Bachelor's degree or higher	189 (69.5)
Other*	2 (0.7)
Insurance type, *n* (%) (271 respondents)	
Medicare/Medicaid	36 (13.3)
Private insurance	217 (80.1)
Tricare	11 (4.1)
No insurance/self-pay	3 (1.1)
Other*	4 (1.5)
Household income, *n* (%) (272 respondents)	
<$20,000	10 (3.7)
$20,000–$50,000	32 (11.8)
$50,000–$75,000	38 (14.0)
$75,000–$99,000	44 (16.2)
>$99,000	143 (52.6)
Other*	5 (1.8)
Age of child, years, mean ± SD (range) (261 respondents)	11.0 ± 4.1 (1–17)
Child's diabetes duration, years, mean ± SD (range) (272 respondents)	4.2 ± 3.5 (0.5–16)

*"Other" indicates either no response or respondents indicating that they did not want to share this information.

Self-Efficacy

General PROMIS self-efficacy scores during the pandemic were high (mean ± SD raw score 16.2 ± 2.6, mean ± SD T-score 49.5 ± 3.6). The same was observed for measures of COVID-19–related self-efficacy and type 1 diabetes care–related self-efficacy, indicating high self-efficacy in these areas as well (12.6 ± 2.1 and 17.1 ± 2.5, respectively) (Table 2). Most respondents reported being quite or very confident in "managing to solve difficult problems, dealing efficiently with unexpected events, thinking of a solution if in trouble, and handling whatever comes their way." General self-efficacy raw score levels correlated positively with COVID-19–related self-efficacy ($R = 0.362$, $P < 0.001$) and type 1 diabetes care–related self-efficacy ($R = 0.427$, $P < 0.001$) during the pandemic.

Stress, Anxiety, and Perceived Threat

The majority of caregivers (71.7%, $n = 195$) reported experiencing increased stress levels during the pandemic, with 20.4% ($n = 53$) indicating that their anxiety had increased "quite a bit," and 13.8% ($n = 36$) responding that it had increase "a lot." When asked how much they agreed with the prompt: "I believe we are all at risk for getting COVID-19," 26.5% responded "quite a bit," and 12.7% responded "very much." When asked, "Do you think your child is at increased risk for getting COVID-19?," 24.8% ($n = 64$) responded "somewhat," 13.4% ($n = 35$) responded "quite a bit," and 12.6% ($n = 33$) responded "very much." Table 2 shows stress and perceived COVID-19 threat response data.

Perceived COVID-19 threat scores did not correlate with COVID-19–related stress scores ($R = -0.89$, $P = 0.152$). Caregivers who expressed the belief that their child was at increased risk for COVID-19 had lower COVID-19 type 1 diabetes care–related self-efficacy ($R = -0.168$, $P = 0.007$). COVID-19–related feelings of anxiety correlated negatively with the general and type 1 diabetes care–related self-efficacy measures ($R = -0.182$, $P = 0.003$, and $R = -0.140$, $P = 0.02$, respectively) but did not correlate with COVID-19–related self-efficacy measures ($R = -0.095$, $P = 0.125$). General, COVID-19–related, and type 1 diabetes care–related self-efficacy were not associated with history of exposure to or knowing someone with COVID-19, education level, income level, job loss, or financial difficulty during the pandemic.

Open-Ended Responses

Qualitative survey responses revealed that 87.6% of caregivers (184/210) had one or more worries. An example of a COVID-19–related health worry was "My child will become gravely ill and die" (Table 3). Nearly all (90.9%) of the caregivers (190/209) reported having at least one challenge,

including concerns about social isolation and mental health. Examples included "He . . . greatly misses the social aspect of school as well as his main passion, which is soccer that he plays daily usually." And ". . . She has been very depressed, and I feel that is contributing to her [blood sugar] fluctuations." Three-fourths of the caregivers reported talking to someone about COVID-19 and type 1 diabetes as a coping mechanism, and 30.4% reported coping by taking care of their own physical and mental health. On the other hand, 39.7% reported social isolation, and 20.4% reported lack of support.

Information-Seeking Behaviors

Half of respondents reported COVID-19–related information-seeking behavior (50%, $n = 136$), and 79.8% ($n = 217$) described receiving unsolicited information passively, mostly through television, social media, or e-mail. More than half (50.8%) reported actively seeking information regarding COVID-19 and type 1 diabetes.

Of those who actively sought information, a range of sources of information about type 1 diabetes and COVID-19 were identified, with most using more than one source for information about COVID-19 and diabetes, including nonprofit diabetes volunteer organizations (43.9%), with JDRF cited most often (41.5%), followed by health care professionals (30.0%); government medical sources such as the Centers for Disease Control and Prevention (CDC), National Institutes of Health, U.S. Food and Drug Administration, and World Health Organization (28.8%); social media (19%), the news (19%); and online medical sources such as WebMD, PubMed, and UpToDate (18%). The American Diabetes Association was cited as a source 10.2% of the time. A majority of respondents (76.1%) reported that they were able to identify reliable sources, and some noted trust in official sources (e.g., the CDC), but not in social media (e.g., Facebook).

Discussion

This study investigated self-efficacy and stress experienced by caregivers of children <18 years of age during the early months of the COVID-19 pandemic. We described general, COVID-19–related, and type 1 diabetes care–related self-efficacy and identified perceived threats, knowledge-seeking behaviors, prevention behaviors, and stressors. Although respondents reported high general, COVID-19–related, and type 1 diabetes care–related self-efficacy levels, they also identified significant stress, worries, and challenges related to diabetes care. Most respondents believed that they had found reliable sources of information on COVID-19 and type 1 diabetes; yet, the concern that their child had a

TABLE 2 Survey Responses

Question	Measures of Stress and Perceived Threat During the Pandemic				
	Much Less Than Before	Less Than Before	The Same	More Than Before	Much More Than Before
How would you compare your stress level during the COVID-19 pandemic to your stress level before the pandemic started? (290 respondents)	3 (1.1)	16 (5.9)	56 (20.6)	148 (54.4)	47 (17.3)
Sample COVID-19–Related and Type 1 Diabetes Care–Related Survey Items	Not at All	A Little	Somewhat	Quite a Bit	Very Much
How much does COVID-19 affect your life? (272 respondents)	5 (1.8)	19 (7.0)	48 (17.6)	135 (49.6)	65 (23.9)
Does COVID-19 make you feel anxious? (260 respondents)	28 (10.8)	70 (26.9)	73 (28.1)	53 (20.4)	36 (13.8)
Do you think your child is at increased risk of getting COVID-19? (260 respondents)	65 (24.8)	64 (24.4)	65 (24.8)	35 (13.4)	33 (12.6)
If your child were to get COVID-19, how sick would your child get? (260 respondents)	1 (0.4)	19 (7.3)	99 (38.1)	106 (40.8)	35 (13.5)
I believe my child is at risk for getting COVID-19. (260 respondents)	21 (8.1)	83 (31.9)	86 (33.1)	49 (18.8)	21 (8.1)
I believe we are all at risk for getting COVID-19. (respondents)	4 (1.5)	59 (22.7)	95 (36.5)	69 (26.5)	33 (12.7)

Data are n (%).

higher risk of contracting COVID-19 remained common. In addition, social isolation and lack of support were reported by some caregivers.

Caregivers of children with type 1 diabetes carry a high cognitive load and mental health burden, including responsibility for securing access to health care services, establishing a secure supply of insulin and other diabetes supplies, and day-to-day diabetes management (15,16). The pandemic created additional concerns, including the need to adhere to social distancing recommendations, supervise children who were attending school virtually, attend health care visits via telehealth, remotely upload diabetes data, and deal with changes in methods for obtaining laboratory results. People in the general public have reported fear of contracting the disease, and this fear, combined with mandated quarantine early in the pandemic, manifested itself as acute panic, anxiety, obsessive behaviors, hoarding, paranoia, and depression and later as post-traumatic stress disorder (17,18). Furthermore, the recent COVID-19 delta variant caused further confusion among the caregivers of children with type 1 diabetes similar to what was seen during the early days of the pandemic. This confusion and concern was especially apparent for families with children <12 years of age, who remained ineligible to receive a COVID-19

vaccine at the time this article was written. In addition, although children in general appeared to be at lower risk for contracting the disease, the same did not appear to be true of the delta variant.

Early reports lumped all people with diabetes into a high-risk category for COVID-19 death and adverse outcomes, citing poor outcomes for adults with diabetes and other comorbidities who had contracted COVID-19. These reports contributed to increased confusion among caregivers of children with type 1 diabetes. In addition, the terms "immunosuppression" (predisposing to severe infections such as COVID-19) and "autoimmune" were often conflated, leading to further misconceptions. However, thus far, most data have suggested that children with type 1 diabetes who are infected with COVID-19 have similar disease outcomes as their peers without diabetes (19–21). Some studies have suggested worse outcomes for those with type 1 or type 2 diabetes; however, the majority of those studies were performed in adults or included very few children (10,11,22). Furthermore, spending more time with caregivers and having more stable schedules may have had short-term benefits on glycemic control. Christoforidis et al. (23) found that children with type 1 diabetes who were on insulin pump therapy and used continuous glucose monitoring during the COVID-19 lockdown showed less glucose variability

TABLE 3 Responses to Open-Ended Questions Related to Worries and Challenges

Category	Frequency, % (n)	Themes and Examples
What are your worries about COVID-19 and type 1 diabetes?		
Described worries	87.6 (184)	"I am worried that if my daughter would get [COVID-19], managing her blood sugars would become exponentially harder."
		"That my child will become gravely ill and die."
		"That she will get sicker than a child without type 1 [diabetes]."
No worries	12.4 (26)	"None really. Our doctors have reassured us that as long as we manage her insulin correctly, she has the same risk level as [other children]."
What has been the most challenging part of the COVID-19 pandemic with regard to your child's type 1 diabetes?		
Described challenges	90.9 (190)	Social isolation: "He is very frustrated with online school and greatly misses the social aspect of school, as well as his main passion, which is soccer that he plays daily, usually."
		Mental health: "Her numbers have been very unstable, and with the sudden loss of school and the isolation, she has been very depressed, and I feel that is contributing to her fluctuations."
No challenges	9.1 (19)	"I don't think diabetes has been challenging with COVID-19."

compared with before the pandemic, albeit with similar overall glycemic control.

One of the striking findings of this study was that 90.9% of the participants reported at least one challenge, including social isolation and concerns about mental health. In a similar U.S. survey, the majority of parents expressed concerns about social isolation in addition to the emotional experiences of sadness and loneliness affecting their parenting (24). Therefore, these mental health concerns are relevant to most parents/caregivers and underscore the added burden experienced during the pandemic.

Data from this survey provide valuable information to clinicians who care for children with type 1 diabetes and their caregivers. Although general, COVID-19–related, and type 1 diabetes care–related self-efficacy levels were high among caregivers during the COVID-19 pandemic, levels of stress and perceived threat were also high, indicating that caregivers may require additional support to sustain their self-efficacy over an extended period of time.

Clinicians can mitigate stress and anxiety by addressing knowledge gaps during these times. Indeed, one study in which researchers surveyed 515 adults across the United States to assess whether knowledge of COVID-19 made people feel more or less stressed found that the more factual information adults knew about COVID-19, the less stress they experienced (25). In addition, clinicians can help caregivers by providing information on proactive coping mechanisms.

Our study also identified a subset of caregivers with low general, COVID-19–related, and type 1 diabetes care–related self-efficacy during the pandemic (Table 2). This group would benefit from targeted support programs and enhanced outreach. For isolated caregivers with minimal support, exploring and creating social support systems is vital, especially if there are financial difficulties or other outside stressors. Finally, access to credible data sources is extremely valuable. Knowing the information sources preferred by caregivers permits a targeted approach to providing caregivers of youth with type 1 diabetes with reliable, high-quality information about type 1 diabetes and COVID-19.

No study is without limitations. We captured responses from an online convenience sample of caregivers who had high levels of income and education, were based in the United States, and had internet access, thereby reducing the generalizability of our results to other populations (26). However, this survey was distributed via two independent clinical centers as well as nationwide to capture as representative a sample as possible. The study also captures sentiments during a limited time frame (May 2020) that was early in the pandemic, when uncertainty was high and information scarce. Performing this survey in other type 1 diabetes caregiver populations not represented here (e.g., underserved or underinsured [populations) using printed and translated copies distributed through community centers, in clinics, and at religious institutions and repeating the survey during and after the pandemic would be informative. Finally, we used the T1D COVID-Care Questionnaire in the correlational analysis, and this instrument has not been validated. To mitigate this concern, we used content experts when developing the questions and pilot- and pre-tested the questions. In addition, the timeliness of the questionnaire and collection of responses during a certain period of the pandemic was a priority, as is often the case during disasters (27).

In summary, during the early days of the COVID-19 pandemic in the United States, self-efficacy levels were high among caregivers of youth with type 1 diabetes, as were stress levels, the frequency of worries, and the number of new challenges being faced. There was concern that children with type 1 diabetes had higher risk of contracting COVID-19, in addition to worries about social isolation and lack of support. These results speak to the need for clinicians to address such concerns during clinical encounters and consider ways to support families with coping strategies to prevent burnout. This need was especially apparent and applicable to the uncertainty surrounding the COVID-19 delta variant at the time this article was written.

As the COVID-19 pandemic continues, communicating accurate information about prevention, including the benefits of COVID-19 and influenza vaccination, is essential. Furthermore, COVID-19 is unlikely to be the last worldwide pandemic. Therefore, health care providers should be aware of these findings and continue their efforts to provide accurate information, as well as social and mental health support for children with type 1 diabetes and their caregivers, during future health emergencies.

DUALITY OF INTEREST
No potential conflicts of interest relevant to this article were reported.

AUTHOR CONTRIBUTIONS
H.M.I. and A.A.-O. conceptualized the study. H.M.I., B.L.H., and A.A.-O. analyzed and interpreted the data and wrote the manuscript. B.L.H., R.O., and P.Y.S. categorized and coded the qualitative responses. L.A.D., R.O., P.Y.S., J.A., S.W., and K.D. contributed to the design, interpreted the data, and reviewed/edited the manuscript. H.M.I. and A.A.-O. are the guarantors of this work and, as such, had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis.

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