


Psychosocial Impact of the COVID-19 Pandemic in Racially/Ethnically Diverse Youth With Diabetes

Jessica M. Valenzuela,^{1,2} PhD, Karen Dimentstein ,¹ MS, MPH, Shanique Yee,¹ MS, Bernard Pan,³ BS, Meg C. Snyder,^{3,4} PsyD, and Risa M. Wolf,³ MD

¹College of Psychology, Department of Clinical & School Psychology, Nova Southeastern University, USA, ²Salah Foundation Children's Hospital, Broward Health Medical Center, USA, ³Division of Pediatric Endocrinology, Johns Hopkins School of Medicine, USA, and ⁴Department of Behavioral Psychology, Kennedy Krieger Institute, USA

All correspondence concerning this article should be addressed to Jessica M. Valenzuela, PhD, College of Psychology, Department of Clinical & School Psychology, Nova Southeastern University, 3301 College Avenue, Fort Lauderdale, FL 33314, USA. E-mail: jv637@nova.edu

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Abstract

Objective This study examined caregiver perceived impact of the Coronavirus Disease 2019 (COVID-19) pandemic on a diverse sample of U.S. youth with diabetes and their families.

Methods Caregivers of youth with diabetes completed an electronic survey in English or Spanish at two sites. Participants provided demographic and disease characteristics and completed the COVID-19 Exposure and Family Impact Scales (CEFIS). Glycemic health was assessed via Hemoglobin A1c (HbA1c) from medical chart review. Analysis of variance and analyses of covariance were utilized to examine racial/ethnic differences in glycemic health and in COVID-19 Exposure, Impact, and Distress scales. Hierarchical linear regression was conducted to predict HbA1c. Thematic analysis was conducted on open-ended responses regarding the effects of COVID-19 on youth and families' overall and diabetes-related well-being. **Results** Caregivers ($n = 114$) of youth with diabetes ($M = 12.6 \pm 3.5$ years) completed study measures. Mean HbA1c for Non-Hispanic White youth was lowest and significantly different from Hispanic and Non-Hispanic Black youth. Exposure to COVID-19 stressors differed by race/ethnicity ($p < .05$) with Hispanic caregivers reporting greatest exposure. CEFIS scales did not predict HbA1c after controlling for demographic/disease variables. Caregivers described child/family changes during COVID (e.g., more time together, health-related hypervigilance), as well as differences in diabetes management during COVID-19. **Conclusions** Findings indicate differences in COVID-19 exposure but did not demonstrate other racial/ethnic disparities in COVID-19 impact or distress. Household income was the most important predictor of glycemic health. Addressing structural inequalities experienced by youth with diabetes and their families is critical. Recommendations to support families with diabetes are made.

Key words: COVID-19; diabetes; endocrinology; health disparities and inequities.

Introduction

The impact of the current Coronavirus Disease 2019 (COVID-19) pandemic on children and adolescents

with chronic health conditions is not yet well understood. However, research has demonstrated a significant negative impact of COVID-19 pandemic-related

social isolation and quarantining on children, as well as high stress, anxiety, and financial burden on caregivers during previous pandemics (Fong & Iarocci, 2020). In addition, recent surveys of healthy youth during the COVID-19 pandemic found that youth were at increased mental health risk due to the current pandemic and pandemic-related stress (Gassman-Pines et al., 2020; McKune et al., 2021; Raviv et al., 2021). For youth with chronic health conditions, COVID-19 pandemic-related changes in access to health services, school closures, financial stressors, increased health anxiety, and disrupted routines may represent unique challenges beyond those experienced by the public (Serlachius et al., 2020).

Youth with diabetes and their families may be particularly vulnerable to the negative psychosocial impact of the COVID-19 pandemic. One study of 122 adolescents with type 1 diabetes (T1D) and elevated diabetes distress found far-reaching impact across family relationships, school changes, personal health/safety, social relationships, and mental health (O'Donnell et al., 2022). Other studies indicate that caregivers of youth with T1D had increased worries and greater COVID-19-related emotional burden compared to caregivers of youth without diabetes (Alessi et al., 2021; Zeiler et al., 2022). In addition, youth with diabetes and their caregivers experienced high rates of financial difficulty, loss of in-person school-based diabetes management support during school closures, and limited access to regular healthcare including in-person physician visits and regular laboratory screenings during the COVID-19 pandemic (Ismail et al., 2022; Jaswaney & Cerdena, 2020). It is notable that some studies also suggest resilience in youth with diabetes such that diabetes distress, which refers to “the worries, concerns, fears and threats associated with struggling with a demanding chronic disease like diabetes over time,” may have improved or stayed the same on average during the COVID-19 pandemic (Bassi et al., 2022; Fisher et al., 2019, p. 803).

Management of pediatric diabetes is complex, with high rates of youth experiencing elevated blood glucose levels far above recommended glycemic targets; the SEARCH for Diabetes in Youth Study (Petitti et al., 2009) found 17% of youth with T1D and 27% of youth with type 2 diabetes (T2D) had Hemoglobin A1c (HbA1c) levels $\geq 9.5\%$ and these trends are worsening in youth and young adults (Malik et al., 2022). In addition, since youth with T2D are often treated with insulin therapy and glucose monitoring, they have a similar burden of diabetes management as youth with T1D (American Diabetes Association Professional Practice Committee et al., 2022). The impact of COVID-19 on glycemic health in pediatric diabetes is unclear. One study suggested that blood glucose levels had lowered in children with T1D

during the COVID-19 pandemic (Cusinato et al., 2021), while other studies showed no change (Danne et al., 2021; Nwosu et al., 2021). A small study in an underserved population in Baltimore showed increased average HbA1c levels in youth with T2D during the COVID-19 pandemic (Bharill et al., 2021). The complexity is highlighted by a study in youth with T1D showing that while average blood glucose levels were reduced during “lockdown,” high levels of anxiety and depression were reported and linked to reduced time-in-range on continuous glucose monitoring (Cusinato et al., 2021). Therefore, it is important to consider how the COVID-19 pandemic’s impact on glycemic health may vary across families based on their experience of stressors related to the pandemic. Furthermore, COVID-19 has likely exacerbated already existing disparities in diabetes management and outcomes for minoritized and underserved youth (Willi et al., 2015).

There is consistent and longstanding evidence that racially and ethnically minoritized¹ (REM) youth with diabetes experience significant disparities in access to diabetes technology (Lipman et al., 2020), diabetes distress (Agarwal et al., 2020), glycemic health (Kahkoska et al., 2018), and broader health outcomes (Hamman et al., 2014; Saydah et al., 2017). In addition, there is initial research in the general public to suggest that REM youth may experience greater negative impact from the COVID-19 pandemic such as increased risk of infection (Van Dyke et al., 2021), increased risk of loss of a parent or grandparent caregiver (Hillis et al., 2021), less access to full-time in-person learning (Oster et al., 2021), and greater exposure to multiple stressors that adversely impact health (e.g., housing insecurity, food insecurity, and extreme poverty; Abrams et al., 2022). There is no research to date specifically assessing REM youth with diabetes and their families’ experiences of specific COVID-19-related stressors and psychosocial impact. There is a need to better understand the impact of COVID-19 in REM youth with diabetes, as well as to better understand how COVID-19-related stressors and their psychosocial impact may affect glycemic health.

The present study assesses caregiver perceived psychosocial impact of the COVID-19 pandemic in the United States on youths with diabetes and their families. It specifically aims to address a gap in our current understanding of racial and ethnic disparities exacerbated by the pandemic in this population. We

1 Systems-centered language is used throughout to indicate that while variables such as race and ethnicity are incorporated in this study and in the studies referenced within, these variables must be considered within the context of systems of racial privilege and oppression. For example, the term “minoritized” is specifically used because it emphasizes that people are actively oppressed versus existing as a natural or numerical minority (see Milner & Jumbe, 2020).

hypothesized that there would be disparities in caregiver perceptions of COVID-19 exposure, impact, and distress for REM youth with diabetes and their families and that COVID-19 stressors and disruption would be related to reduced glycemic health in children with diabetes. Furthermore, caregiver perceptions of COVID-19 impact will be described based on their qualitative responses regarding the effects of COVID-19 on youth and families' overall and diabetes-related well-being.

Methods

Participants

The present study recruited caregivers of youth with type 1 or type 2 diabetes, ages 0–21, who received care at one of two pediatric diabetes centers in the Northeast and Southeast United States. English or Spanish-speaking caregivers were able to participate. Individuals with cystic fibrosis-related diabetes and maturity-onset diabetes of youth (MODY) were excluded. This study was approved by the Institutional Review Boards (IRB) of all institutions. Informed consent was obtained electronically in either English or Spanish, prior to proceeding with the survey. Data associated with the study will be made available within the confines of what the IRB allows by request to the corresponding author.

Study Procedures

The caregivers of pediatric patients who met eligibility criteria were invited to participate in the study by e-mail invitation. Study invitations were sent to 460 valid email addresses, with 57 caregivers completing the study via email. In addition, 67 eligible caregivers were invited to participate during scheduled in-person clinic visits with 9 declining to participate for a variety of reasons (e.g., limited time, privacy concerns) and one removed from the study after lab findings suggesting they met criteria for MODY. All participants completed the COVID-19 Exposure and Family Impact Scales (CEFIS; Kazak et al., 2021) electronically (on a home device or a tablet in clinic) via REDCap after completing eConsent. REDCap (Research Electronic Data Capture) is a secure, web-based platform designed to support data capture, manipulation, and integration across sites (Harris et al., 2009, 2019). Participants were given the option to complete the survey in English or Spanish. All surveys were completed between October 27, 2020 and June 10, 2021.

Caregiver Report of Demographic and Disease Characteristics

Prior to completing the CEFIS, caregivers were asked to report on the following variables used in the present study: caregiver's relationship to youth (mother,

father, grandmother, grandfather, other), patient's gender (male, female, other), race (White, Black/African American, Asian, Native Hawaiian/Pacific Islander, American Indian/Alaska Native, Other), ethnicity (Hispanic, Not Hispanic), zip code, and approximate annual household income. Caregivers also reported on patient's current regimen including insulin regimen (Injection, Pump, No Insulin), continuous glucose monitor use (Yes, No), and oral diabetes medication (Metformin, Other, No Oral Diabetes Medications). Caregiver report of patient gender, race, and ethnicity was chosen over electronic medical record (EMR) data for these variables due to concerns about the validity of the data in the EMR.

Disease Characteristics Recorded from Medical Chart Review

Study consent included caregiver consent for medical chart review. The following variables were retrieved from the EMR in the present study: patient's date of birth, diabetes type, diabetes diagnosis date, and most recent hemoglobin A1c (assessed via point of care, $n=98$ or laboratory assay, $n=12$) available from June 2020 to October 2021. Mean interval between A1c assays conducted and survey completion was 1.17 months ($SD=2.21$).

COVID-19 Exposure and Family Impact Scales

The CEFIS (Kazak et al., 2021) was designed to be used in pediatric healthcare systems to assess the psychosocial impact of COVID-19 on families of youth with health conditions. It consists of three scores: (a) an Exposure score calculated as the sum of 25 items (Yes/No responses) that measures participants' exposure to COVID-19-related events and stressors (e.g., school closure, death of a family member); (b) an Impact score calculated as the average of 10 items (on a 4-point Likert scale) that measures the impact of COVID-19 on family functioning in specific domains (e.g., parenting; scores >2.5 are considered a "negative impact"); (c) a Distress score calculated as an average of 2 items (on a 10-point scale). Higher scores indicated greater exposure, greater impact, and greater distress. Finally, the CEFIS includes an open-ended question where participants could include additional details related to their experiences with COVID-19. In the present study, the question was adapted slightly to inquire about any changes specific to diabetes as follows "Please tell us about other effects of COVID-19 on your child/ren and your family, both negative and/or positive. If you noticed changes in your child's overall wellbeing or their diabetes, please tell us more about these changes."

The CEFIS Exposure ($\alpha=.76$), Impact ($\alpha=.93$), and Distress subscales ($\alpha=.78$) demonstrated adequate reliability in the current sample. The measure

has recently demonstrated support for its factor structure, convergent validity (with the PROMIS Global Mental Health Scale and Family Assessment Device), and a relationship to posttraumatic stress symptoms in a large, diverse sample of caregivers within a children's healthcare system (Enlow et al., 2022).

Statistical Analysis

Descriptive statistics are presented for demographic, disease, and COVID-19-related characteristics. Race/ethnicity were combined into a single variable due to sample size limitations. Racial/ethnic categories identified by $n > 10$ caregivers were maintained (Non-Hispanic Black [NHB], Non-Hispanic White [NHW], Hispanic). All analyses were conducted using SPSS (Version 28.0). A one-way analysis of variance (ANOVA) examining disparities in HbA1c by race/ethnicity was conducted. Four one-way analyses of covariance were conducted examining racial/ethnic disparities in COVID-19 Exposure, Impact, and caregiver and child Distress scale scores while controlling for clinic site. Clinic site was included as a covariate due to differences in how families might have experienced the COVID-19 pandemic due to state's different timelines for lockdown-related policies. These state-wide differences can be reviewed on the John Hopkins Coronavirus Resource Center website (<https://coronavirus.jhu.edu/>). Item standardized residuals were explored for scales with significant racial/ethnic group differences. A hierarchical regression analysis was conducted to examine the association between COVID-19-related Exposure, Impact, and Distress scales and HbA1c. Three blocks were entered in the analysis including disease variables (CGM, clinic site, and diabetes duration), sociodemographic variables known to be associated with glycemic health (race/ethnicity and household income), and CEFIS scale scores (Exposure, Impact, and Distress composites).

Thematic Analysis

Finally, caregiver responses to the CEFIS open-ended question were analyzed using thematic analysis (Braun & Clarke, 2006). Microsoft Excel (Version 2205) was used by the third and fifth author to independently review caregiver responses and identify initial codes inductively. Two responses provided in Spanish were translated to English prior to review. The authors reviewed these initial codes together, reached agreement on codes and their definitions (sometimes adding, collapsing codes), and iteratively applied these codes to caregiver responses while seeking any additional codes or changes in codes until saturation. When the authors agreed on a final list of specific relevant codes, the authors worked together to organize the codes into potential themes based on similar response patterns. Quoted responses were then collated by themes

independently by each author. Themes with extracted codes were reviewed and agreed upon by both authors.

Results

One hundred and fourteen participants completed the CEFIS across 2 sites (Table I). Caregivers were mostly mothers (84.2%) of youth ($M = 12.6$, $SD = 3.5$, range 5–19 years old) with T1D (85.1%). The sample included predominantly NHW (46.5%) and NHB (32.4%) youth, with a range of household incomes. Mean HbA1c for youth with T1D was 8.4% ($SD = 1.9\%$) and many participants with T1D were pump (66%) and/or CGM (58%) users. Mean HbA1c for youth with T2D was similar, 8.3% ($SD = 2.7\%$), and many participants with T2D were prescribed insulin (72.2%) and/or oral medication (77.8%).

COVID Exposure, Impact and Distress

Caregivers of youth with diabetes endorsed experiencing an average of 8.05 COVID-19-related events/stressors on the Exposure scale (out of 25 possible events). This was similar to the initial normative sample for the measure ($M = 8.71$). Exposure items endorsed by over 50% of caregivers included: school/childcare closure (91.2%), education disruption (76.3%), unable to visit family (66.7%), essential worker status (57.0%), and missed family events (69.3%). In addition, 49.1% of caregivers reported that their family income decreased and 38.6% reported that "someone in the family was exposed to COVID-19." Caregivers most frequently reported themselves, the patient, their spouse, and the "entire family" were exposed. Fewer caregivers reported difficulty accessing medicine (7.9%), healthcare (12.3%), or other essentials (19.3%; e.g., toilet paper, cleaning supplies).

The mean COVID Impact score in our sample was 2.52, slightly over the cutoff for negative valence (i.e., > 2.5). Caregivers reported the following areas as negatively impacted on average: ability to care for older/disabled family, caregiver and child exercise, caregiver and child diet, caregiver and child sleep, caregiver anxiety and caregiver mood. The mean caregiver Distress score (range = 1–10) was 5.8, and caregiver report of their children's distress was 5.1. In the initial normative sample, these mean Distress scores were 5.95 and 5.44, respectively.

Racial/Ethnic Differences During COVID-19

Mean HbA1c for NHW youth was lowest ($M = 7.8$, $SD = 1.1$) and significantly different from Hispanic ($M = 8.0$, $SD = 1.7$) and NHB ($M = 9.6$, $SD = 2.8$) HbA1c averages in the present sample. The ANOVA for racial/ethnic disparities in HbA1c was significant with a large effect size, $F(2, 100) = 10.3$, $\eta^2 = 0.29$, $p < .001$, even after controlling for diabetes type.

Table I. Characteristics of the Study Sample (*N* = 114)

Characteristics	Type 1 (<i>n</i> = 97)	Type 2 (<i>n</i> = 17)	Total (<i>n</i> = 114)
Sociodemographic factors			
Age, years (<i>M</i> ± <i>SD</i>)	12.2 ± 3.5	15.1 ± 1.9	12.6 ± 3.5
Child's sex (female)	52 (54.2%)	6 (33.3%)	57 (50.0%)
Participating caregiver type			
Mother	83 (86.5%)	13 (72.2%)	96 (84.2%)
Father	10 (10.4%)	4 (22.2%)	14 (12.3%)
Other	3 (3.1%)	1 (5.6%)	4 (3.5%)
Child's race/ethnicity			
Non-Hispanic, White	53 (54.6%)	0 (0.0%)	53 (46.5%)
Non-Hispanic, Black	23 (23.7%)	14 (82.3%)	37 (32.4%)
Hispanic	15 (15.5%)	2 (11.8%)	17 (14.9%)
Non-Hispanic, Asian	2 (2.1%)	0 (0.0%)	2 (1.8%)
Non-Hispanic, Multiracial	3 (3.1%)	0 (0.0%)	3 (2.6%)
Other (Not Identified)	1 (1.0%)	1 (5.9%)	2 (1.8%)
Household income (<i>n</i> = 90)			
<\$10,000	2 (2.1%)	4 (22.2%)	6 (5.3%)
\$10,000–\$29,999	10 (10.4%)	3 (16.7%)	13 (11.4%)
\$30,000–\$49,999	17 (17.7%)	2 (11.1%)	19 (16.7%)
\$50,000–\$69,999	5 (5.2%)	1 (5.6%)	6 (5.3%)
\$70,000–\$89,999	11 (11.5%)	1 (5.6%)	12 (10.5%)
\$90,000–\$109,000	6 (6.3%)	0 (0.0%)	6 (5.3%)
\$110,000 or more	28 (29.2%)	0 (0.0%)	28 (24.6%)
Clinical factors			
Duration, months (<i>M</i> ± <i>SD</i>)	50.8 ± 42.8)	23.4 ± 28.3	46.4 ± 41.9
Prescribed Insulin Regimen			
Injection	33 (34.4%)	13 (72.2%)	46 (40.4%)
Pump	63 (65.6%)	0 (0.0%)	63 (55.3%)
No insulin		5 (27.8%)	5 (4.4%)
Prescribed metformin			
Continuous glucose monitor	56 (58.3%)	14 (77.8%)	14 (12.3%)
HbA1c, % (<i>M</i> ± <i>SD</i>)	8.4 ± 1.9	8.3 ± 2.7	8.4 ± 2.1
CEFIS composites (<i>M</i> ± <i>SD</i>)			
Exposure	8.2 ± 3.4	7.4 ± 4.9	8.1 ± 3.7
Impact	2.6 ± 0.7	2.2 ± 1.1	2.5 ± 0.7
Caregiver distress	5.8 ± 2.4	5.7 ± 2.7	5.8 ± 2.4
Child distress	5.1 ± 2.7	5.1 ± 2.9	5.1 ± 2.7

Note. CEFIS = COVID-19 Exposure and Family Impact Scales.

Racial/ethnic differences in the COVID-19 Exposure scale indicated a medium effect (partial $\eta^2 = 0.06$) that was statistically significant ($p < .05$) with Hispanic caregivers reporting greater exposure than NHW ($p < .05$) and NHB ($p < .05$) caregivers. Differences in mean Impact and Distress scores demonstrated small effect sizes (partial $\eta^2 = 0.01$ – 0.04) and were not statistically significant after controlling for clinic location (Table II). Only items from the Exposure scale with standardized residuals ≤ -2.0 or ≥ 2.0 for Hispanic participants are reported in Table III with the frequency with which specific COVID-19-related events/stressors were endorsed by participants across three racial/ethnic groups.

Relationship Between COVID-19 Exposure, Impact, and Distress and Glycemic Health

The first step of the hierarchical linear regression analysis including CGM, site, and diabetes duration was significant ($F(3,73) = 3.095$, $p < .05$). Site was the

only statistically significant predictor in the first block ($B = 1.471$, 95% CI [0.457, 2.484], $p < .01$). The model remained statistically significant at the second step with patient race/ethnicity and household income added ($F(5, 71) = 3.108$, $p = .01$). Site and household income ($B = -0.364$, 95% CI [-0.666, -0.062], $p < .01$) were statistically significant predictors. The R^2 change value of .067 approached significance ($p = 0.06$). Finally, the R^2 change value and individual measures in step three adding CEFIS composite scores were not statistically significant after controlling for blocks 1 and 2 (Table IV). Of note, age was not a significant predictor in separate but identical analyses, and these findings remain when only participants with T1D were included in the analysis.

Caregiver Perceptions of COVID-19 Impact

Of 114 participants, 110 provided qualitative responses ($n = 17$ were caregivers of youth with T2D). Some caregivers responded indicating very little

Table II. Analyses of Covariance With Adjusted Means and Standard Errors for CEFIS Composite Scales by Race/Ethnicity

Measure	Full sample M (SD)	Adjusted mean and standard error by racial/ethnic group			F (df1, df2) p-value	Partial Eta ²
		NHW	NHB	Hispanic		
Exposure	7.99 (3.69)	7.43 (0.59)	7.77 (0.67)	10.22 (0.94)	$F(2, 103) = 3.28, p = .04^*$	0.06
Impact	2.52 (0.75)	2.58 (0.12)	2.34 (0.13)	2.74 (0.21)	$F(2, 97) = 1.83, p = .17$	0.04
Caregiver distress	5.81 (2.38)	5.83 (0.39)	5.42 (0.44)	6.61 (0.62)	$F(2, 103) = 1.44, p = .24$	0.03
Child distress	5.03 (2.67)	4.81 (0.43)	5.07 (0.49)	5.66 (0.71)	$F(2, 102) = 0.47, p = .63$	0.01

Note. CEFIS = COVID-19 Exposure and Family Impact Scales; NHB = Non-Hispanic Black; NHW = Non-Hispanic White. Estimated marginal means are presented after adjusting for clinic location.

* $p < .05$.

Table III. Exposure Items Reported by Caregivers of Hispanic Youth With Significantly Greater Frequency Than Expected.

Exposure scale item	Frequency by race/ethnicity; n (%)				Standardized residual (Hispanic)
	Full sample	NHW	NHB	Hispanic	
We had to move out of our home.	4 (3.7%)	1 (1.9%)	0 (0.0%)	3 (17.6%)	3.0
We had difficulty getting medicine.	9 (8.5%)	2 (3.8%)	3 (8.1%)	4 (23.5%)	2.1
We had difficulty getting healthcare when we needed it.	12 (11.3%)	3 (5.8%)	2 (5.4%)	7 (41.2%)	3.7
A member of the family lost their job permanently.	17 (15.9%)	4 (7.5%)	7 (18.9%)	6 (35.3%)	2.0
We lost health insurance benefits.	3 (2.8%)	1 (1.9%)	0 (0.0%)	2 (11.8%)	2.2
Someone in the family died from COVID-19.	6 (5.6%)	1 (1.9%)	2 (5.4%)	3 (17.6%)	2.1

Note. CEFIS = COVID-19 Exposure and Family Impact Scales; NHB = Non-Hispanic Black; NHW = Non-Hispanic White.

impact of the COVID-19 pandemic on their family ($n = 36$). Analysis of the remaining responses led to identification of two emergent themes described below with subthemes and examples.

Family Changes During COVID-19

Many caregivers noted changes in youth's functioning related to the impact of the COVID-19 pandemic on their family ($n = 46$). Three subthemes were identified: First, caregivers reported experiencing heightened anxiety and hypervigilance regarding family health ($n = 21$). One mother of a 12-year-old son with T1D indicated, "he was very scared that if he got COVID he would die." Another mother of a 14-year-old boy with T2D shared "COVID has changed our whole family in a way that makes us more aware of what's happening around us but also more nervous." Second, caregivers reported reductions in physical activity for family members ($n = 8$). A mother of a 17-year-old boy with T2D stated "my child gained more weight and could not exercise enough." Another mother of a 9-year-old girl with T1D shared:

The lack of recess, gym, and other interactions has helped the BG (blood glucose) rise as well. Kids are more sedentary now that they have to sit in front of a computer for 6+ hours a day.

Finally, caregivers highlighted the impact of limited social interaction for youth during the COVID-19

pandemic ($n = 17$). One father of an 18-year-old boy with T1D shared:

...the lack of social interaction with peers and the loss of sports for varying periods of time has been the hardest part for all three children.

A minority of caregivers ($n = 8$) described strengthened family connection during the COVID-19 pandemic. One mother of a 16-year-old girl with T1D reported, "On a positive note we have spent more time just talking and joking around as a family unit." Another mother of a 16-year-old boy with T1D, shared:

COVID brought us all together more often. We have more time to spend together, shorter commutes, more flexible workdays, and healthier eating habits.

Changes in Diabetes Management and Outcomes

A small number of caregivers reported that they have noticed increases in diabetes management ($n = 6$) and/or are more able to supervisor/monitor their child's regimen ($n = 5$) while family members have been home during the COVID-19 pandemic. One mother of an 8-year-old girl with T1D reported:

A positive is [being home] ... I could see her going into DKA because the [school] nurse would have just contacted me but would have not known what to do.

Table IV. Hierarchical Linear Regression Model Predicting HbA1c Percentage During COVID-19 Pandemic

Factors	R^2	ΔR^2	B	β	95% CI for B	
					Lower Bound	Upper Bound
Step 1	.113*	.113*				
CGM			-.180	-.042	-1.217	.858
Site			1.471	.345**	.457	2.484
Disease duration (months)			.005	.106	-.007	.017
Step 2	.180*	.067				
CGM			-.069	-.016	-1.093	.956
Site			1.210	.284*	-.013	2.432
Disease duration (months)			.007	.149	-.005	.019
Race/ethnicity			-.469	-.156	-1.394	.456
Household income			-.364	-.346**	-.666	-.062
Step 3	.189	.010				
CGM			-.151	-.035	-1.239	.937
Site			1.069	.251	-.229	2.368
Disease duration (months)			.008	.168	-.005	.021
Race/ethnicity			-.369	-.122	-1.348	.611
Household income			-.350	-.333*	-.683	-.017
COVID exposure score			.005	.008	-.168	.177
COVID impact score			-.095	-.031	-1.029	.838
COVID caregiver distress			-.013	-.014	-.308	.282
COVID child distress			-.067	-.081	-.357	.223

Note. CI = confidence interval.

* $p < .05$; ** $p < .01$.

Another mother of a 7-year-old boy with T1D stated that their spouse “is now working from home 100%... So now he is home more to help with the other kids and the diabetes management.”

Other caregivers described how changing routines made diabetes management more challenging ($n = 7$). A mother of a 9-year-old girl with T1D stated that it “made our schedule more unpredictable ... more difficult to manage her diabetes ... she might go out..., grab a snack, watch a movie, all at odd times.” Another mother of a 14-year-old boy with T1D described the impact of changes in a child’s mood on diabetes management:

COVID-19 has not been kind to my child. He went from being a happy, bubbly, self-motivated kid, to being lazy, combative, and having absolutely no motivation to care for his diabetes...

A few caregivers noted changes in health outcomes during the COVID-19 pandemic ($n = 9$). One mother of a 9-year-old girl with T1D stated, “We have more highs and lows than in the past because her days are not similar.” Another mother highlighted disrupted care with telehealth leading to poor outcomes for her 16-year-old daughter:

It has been difficult to obtain in-person medical and especially mental health care which has affected her greatly as she is very resistant to telehealth visits. Her overall glycemic control is worse. She’s had to be in ER twice for simple things as regular doctor visits could not be accessed.

Discussion

The present study aimed to examine disparities in the psychosocial impact of the COVID-19 pandemic on

youth with diabetes and their families in the U.S. Caregivers reported frequent exposure to stressors related to the COVID-19 pandemic, negative impact on child and caregiver functioning, and moderate distress. However, the study found limited support for racial/ethnic disparities in the experience of youth with diabetes during the COVID-19 pandemic and no evidence that COVID-19-related stressors impacted youth glycemic outcomes above and beyond family’s household income.

Overall caregiver ratings were similar to ratings of COVID-19 exposure, impact, and distress in the measure’s initial normative sample, which consisted of a variety of patient populations (hematology/oncology, chronic pain, community-based patients, and others; [Kazak et al., 2021](#)). In the present study, the average Impact score was indicative of a negative psychosocial impact of the COVID-19 pandemic similar to other recent studies with families of youth with spina bifida ([Stiles-Shields et al., 2021](#)), rheumatic disease ([Durcan et al., 2021](#)), and solid organ transplant ([Forner-Puntonet et al., 2021](#)). The most impacted domains reported on the CEFIS measure include caregiver mood, anxiety, and health behaviors for children and caregivers such as physical activity, diet, and sleep. Qualitative themes overlapped with survey results highlighting caregiver perceptions of youth and family anxiety, social isolation, and reduced physical activity during the COVID-19 pandemic. Caregiver report in this study is consistent with recent findings by [Burkart and colleagues \(2022\)](#) indicating that integrated heart rate and accelerometry data show worsening physical

activity and sleep trends for healthy children during the COVID-19 pandemic. Furthermore, initial studies from the UK indicate that changes in these lifestyle behaviors are associated with poorer mental health outcomes for children during the COVID-19 pandemic (Ingram et al., 2020). In addition to impacted mood and anxiety, caregivers in the present study also reported frequent disruption to themselves and their family, with over 50% of the sample experiencing common COVID-19-related events like school closures. While fewer caregivers reported difficulty accessing care, medicine, and other essentials, there was evidence of a racial/ethnic disparity in exposure to some of these disruptive COVID-19-related experiences.

Hispanic caregivers in the present study reported significantly greater exposure to COVID-19-related stressors and events than other caregivers. It is important to note that these results are based on a small subset of the overall sample, with only 17 caregivers identifying child ethnicity as Hispanic. In addition, few qualitative responses were provided in Spanish suggesting a possible need for further inclusion of less acculturated caregivers in the qualitative analysis. However, present survey findings did suggest a disproportionate experience of disruptive COVID-19-related stressors among Hispanic caregivers: more frequent report of having to move from their home, difficulty accessing medicine and healthcare services, permanent loss of employment, loss of health insurance benefits, and experiencing the death of a family member from COVID-19. These findings are consistent with recent findings from Wang and colleagues (2021) demonstrating that caregivers of REM youth with diabetes reported greater diabetes-specific negative experiences during the COVID-19 pandemic (e.g., reduced access to a diabetes team).

While there were differences in exposure to COVID-19-related stressors for Hispanic youth and families, the present study did not find significant racial/ethnic differences in caregiver report of COVID-19 impact or distress. This finding was surprising given existing evidence of disparities in COVID-19 infection and mortality rates (Mackey et al., 2021). Others have demonstrated that scores on the Impact and Distress scales are associated with global mental health and post-traumatic stress symptoms (Enlow et al., 2022). Therefore, a lack of disparity in caregiver report for REM youth with diabetes and their families is clinically significant and future research should examine relevant protective factors that may limit impact and distress. It is also important to note that greater confidence in this result may require further evaluation of the cross-cultural validity of the CEFIS measure (Kazak et al., 2021) particularly for responses on the Impact and Distress scales which

are more subjective than the Exposure scale (where caregivers report on the presence or absence of specific stressors). Enlow and colleagues (2022) note the need for future studies to examine the CEFIS measure's criterion validity with "culturally sensitive tools."

Scales measuring COVID-19 exposure, impact, and distress were not predictive of HbA1c levels within our sample. Annual household income remained the most important factor associated with glycemic health as measured by HbA1c. Nearly 50% of caregiver respondents on the CEFIS reported a decrease in total family income during the COVID-19 pandemic. The U.S. Bureau of Labor Statistics (2020) has reported that COVID-19 pandemic unemployment rates rose to levels not seen since the Great Depression, reaching a rate of 14.7% in April 2020. Several studies have highlighted the disproportionate economic impact of the COVID-19 pandemic on low-income workers in the United States, including decreased access to child-care and increased financial and psychosocial stressors (Ettman et al., 2020; Kantamneni, 2020; Samuel et al., 2021). Changes in income during the COVID-19 pandemic were associated, in at least one study, with decreased parenting quality, increased parental depression, and child internalizing and externalizing disorders (Feinberg et al., 2022). Prior to the COVID-19 pandemic, numerous studies highlighted the impact of socioeconomic status on youth diabetes management and resulting glycemic health (Drew et al., 2011; Fegan-Bohm et al., 2020; Liese et al., 2022; Sutherland et al., 2018). Future research examining glycemic trajectories for youth during the COVID-19 pandemic should carefully assess the role of employment, income, and barriers to accessing care on diabetes management and outcomes. Clinical recommendations to screen for social needs, such as those made by Butler and colleagues (2020), may be exceedingly important to address disparities following the COVID-19 pandemic. In addition, there is a significant need for policies that reduce economic marginalization and its impact of youth and families.

Qualitative findings from the present study highlight how experiences during the COVID-19 pandemic have varied for youth with diabetes and their families. Many families described heightened anxiety and hypervigilance, as well as limited access to resources to engage in healthy lifestyles (e.g., going to the gym, using community centers such as YMCA). However, there were surprising benefits for some families during COVID-19 including increased parental monitoring of diabetes care, more home-based meals, and more time together for family members. These benefits appear to be especially relevant for caregivers with more flexible employment. In other pediatric chronic conditions (e.g., cancer), advantages of the COVID-19 pandemic (e.g., increased family cohesion) were also noted;

Fisher et al., 2021). Findings from the present study are consistent with O'Donnell and colleagues' (2022) findings and highlight the need to further examine benefits of "lockdown" for youth with diabetes and their families, especially to better understand which families were most likely to benefit, whether or not benefits continue as the COVID-19 pandemic evolves, and how these findings may help us better prepare for future adverse events youth and families might experience.

The strengths of this study include the diverse patient population from multiple diabetes clinic sites in the United States and the use of a validated assessment tool. However, the study is limited by the focus on only caregiver-report, the sample's wide age range, and the modest sample size, particularly for youth with type 2 diabetes. Therefore, findings may not be generalizable to youth-onset type 2 diabetes. Furthermore, study recruitment included participation from October 2020 through June 2021, which may have included different waves of the COVID-19 pandemic, and may not be reflective of ongoing stress and fatigue associated with the prolonged COVID-19 pandemic. In addition, it is important to note that patient HbA1c assays were available less frequently during the pandemic due to a transition to predominantly virtual visits. Therefore, HbA1c values were sometimes only obtained 1–2 times per year instead of the usual every 3 months resulting in a wider range of time around survey completion than ideal. Finally, while the study explored differences in the experiences of REM youth with diabetes and their families, it did not include assessment of experiences of discrimination that may be helpful to directly investigate as it relates to patient's health outcomes following the COVID-19 pandemic.

In summary, the COVID-19 pandemic had a negative psychosocial impact on youth with diabetes and their families. The present study did not find racial/ethnic differences in COVID-19-related impact and distress. However, there was evidence of increased exposure to COVID-19-related stressors in Hispanic youth and families affected by diabetes, as well as evidence of the importance of household income on glycemic health during the pandemic. Addressing the stress and impact of COVID by screening for social and mental health needs is of utmost importance within standard care for youth with diabetes. Advocacy for policies that increase access to needed services and reduce economic marginalization of youth and families is critical. Large multicenter studies (e.g., SEARCH, TODAY, T1D Exchange) should be leveraged to conduct much needed research to develop models that clarify the complex relationships between variables such as socioeconomic position and race/ethnicity (e.g., Liese et al., 2022), to understand the best

ways to address the needs of youth with diabetes, and to elucidate the full impact of the COVID-19 pandemic on youth with diabetes and their families.

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