

# Psychosocial repercussions of the covid-19 pandemic for people living with or supporting others with diabetes

**Edited by**

Emma Berry, Andreia S. Mocan, Rossella Messina, Lene Eide Joensen and Mark Davies

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# Psychosocial repercussions of the covid-19 pandemic for people living with or supporting others with diabetes

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# Editorial: Psychosocial repercussions of the Covid-19 pandemic for people living with or supporting others with diabetes

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diabetes, emotional distress, depression, anxiety, COVID-19

## Editorial on the Research Topic

**Psychosocial repercussions of the Covid-19 pandemic for people living with or supporting others with diabetes**

The outbreak of the Coronavirus (COVID-19) pandemic has created a global health crisis and resulted in drastic changes in the way we perceive our world. Imposed restrictions such as lockdown and social distancing, and the promotion of safety behaviours were introduced to reduce the magnitude of infection (1). In-person appointments were suspended and people were encouraged to manage their diabetes largely by themselves often without the immediate support of the health care team. Both for people with diabetes and for the health care team, new problems emerged. In addition to the usual challenges of diabetes self-management, emotional stress and adaptation, the COVID pandemic added a larger and more inclusive problem: adaptation to a new world. A new world that incorporates a new type of social and work environment and relationships; new rules, habits and behaviours; new perceptions and emotions related to self-protection and protection of others against a new and unknown threat. Within this context, this special issue, entitled “Psychosocial repercussions of the COVID-19 pandemic for people living with or supporting others with diabetes”, focussing on COVID-19 impact on diabetes was conceived.

This Research Topic attracted thought-provoking and insightful manuscripts that fall into 4 categories: a) COVID-19 and healthcare providers; b) COVID-19 emotional burden in type 1 diabetes (T1D); c) self-care activities and diabetes distress in type 2

diabetes (T2D) and d) general aspects of diabetes management during the COVID-19 pandemic.

The first category of research includes papers on professionals working in the field of diabetes. [Hale et al.](#) captures the concerns expressed by endocrine specialists and primary care providers about the well-being, psychosocial functioning, self-care routine, and financial challenges faced by the people living with diabetes (PWD) they care for. Lifestyle management interventions *via* tele medicine were used by the participating healthcare providers to offer support. Moreover, some of the participants helped PWD access financial programs when needed. A cross-sectional study by [Wagner et al.](#) found that half of the participating health care providers (n=123, 27 countries) experienced moderate to severe levels of mental stress, burnout, or other mental health issues because of the pandemic. Significant concerns were expressed about the lack of clear public health guidelines, delays in or the lack of COVID-19 testing, COVID-19 work exposure, safety concerns for themselves/staff/PWD, and about how PWD use technology and manage their diabetes. Isolation from colleagues was reported to be a moderate to serious problem for many participants in this study.

A second category of research examined people living with T1D. A literature review by [Bassi et al.](#) showed that the majority of COVID-19 studies on T1D teenagers focused mostly on glycemic control. Protective or risk factors, specific prevention or/and supporting methods for psychological well-being were less likely to be considered. 'Positive lockdown effect' was discussed and was defined as a period of stable routine had a positive influence on glycemic control. Caregivers perceived increased burden in diabetes management and child-related worry during the pandemic. Telemedicine was suggested as a method to increase maintenance of healthy diabetes care and self-efficacy during pandemic. An ecological momentary assessment study by [Schmid et al.](#), spanning a 10-day period, showed no difference between pre-pandemic and during pandemic levels of diabetes distress and depression among middle-aged individuals living with T1D. Fears of COVID-19 and of becoming infected were associated with diabetes duration and were predicted by pre-pandemic diabetes distress and illness/diabetes acceptance. [O'Donnell et al.](#) investigated the psychosocial and diabetes management impact of COVID-19 on adolescents living with T1D and who had elevated diabetes distress. They found that social and family relationships, health practices, school routines, diabetes management behaviors, dietary behaviors, physical activity and medical appointments were all disrupted. Resilience, social support, faith and meaning making were all reported as being helpful and protective against pandemic impact.

A third category of research focused on people living with T2D. A Scoping Review by [Cummings et al.](#) showed that the pandemic was in some ways detrimental to people living with T2D. Decreases in physical activity and no significant change in

glucose monitoring and substance misuse were reported. However, positive effects were also found. Based on cross-sectional study of 1822 participants, [Amerson et al.](#) reported that during COVID-19 pandemic people living with T2D reported an increase in self-care activities, reductions in perceived distress and moderately lower diabetes distress, especially in vulnerable groups.

The fourth category of research concentrated on the impact pandemic lockdowns had on diabetes management in general. [Olesen et al.](#) found in a one year follow-up study that PWD reported both negative changes (i.e. lower physical activity, eaten unhealthier, diabetes management was more difficult; higher blood pressure and more glucose variability) and positive changes (i.e. more physical active, more healthy food and easier diabetes management) compared to pre-pandemic life. Moreover, the authors found that higher diabetes distress at the beginning of the pandemic was a predictor for both positive and negative aspects of diabetes management. [Holloway et al.](#) showed that PWD were feeling burned out by the constant effort to manage their diabetes during the pandemic and that easing/relaxing the pandemic restrictions might help with diabetes specific emotional problems such as worry about COVID-19 and diabetes.

For the members of the medical profession, the pandemic presented particular challenges about how to provide support to PWD to assist them to adapt whilst, at the same time, having to adapt themselves. Studies such as those published in this Special Issue, help to transform an unknown problem into a known one. Data derived from sound methodology, supports the development of conceptual frameworks upon which interventions to help PWD and healthcare professionals manage emotional struggles can be built. It should be noted that the studies presented in this issue tended to under-represent the views of men and of PWD from low and middle-income countries, where the experience of pandemic might be very different to those reported here. Nevertheless, the published studies are an important contribution to the understanding of the COVID-19 psychosocial and management impact on PWD.

## Author contributions

AM, EB, MD, LJ, and RM contributed to the conception of the editorial. AM redacted the draft of the present editorial All authors contributed to manuscript revision, read, and approved the submitted version.

## Conflict of interest

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## Reference

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# Diabetes Distress During COVID-19: Three Brief ‘Snapshot’ Surveys of Adults With Diabetes Calling the Australian National Diabetes Services Scheme Helpline

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The aim of this study was to take ‘snapshots’ of how people with diabetes are feeling emotionally during the coronavirus disease 2019 (COVID-19) pandemic. Three ‘snapshot’ surveys were conducted during May 2020, August 2020 and April 2021, each over a two-week period. Adults ( $\geq 18$  years) with diabetes calling the Australian Government’s National Diabetes Services Scheme Helpline (NDSS) were invited to participate. Those who accepted were asked three questions sourced/adapted from the Problem Areas in Diabetes scale. Responses were recorded on a 5-point scale (0=‘not a problem’, 4=‘serious problem’). Of interest were scores  $\geq 2$ , indicating this was at least a ‘moderate problem’. The survey was administered by NDSS Helpline staff via telephone. Basic demographic and clinical data were collected. In total, 1,278 surveys were completed over the three ‘snapshots’ (1<sup>st</sup> N=449; 2<sup>nd</sup> N=414; 3<sup>rd</sup> N=415). Participants were aged (median[IQR]) 62[47,72] years, 56% were women, and 57% had type 2 diabetes. At the 3<sup>rd</sup> ‘snapshot’, 21% had received a COVID-19 vaccine. Our findings show that feeling at least moderately ‘burned out’ by the constant effort needed to manage diabetes is salient, and consistently experienced by adults with diabetes calling the NDSS Helpline at three timepoints during the coronavirus pandemic. Those who participated in the 3<sup>rd</sup> ‘snapshot’ survey were less likely to report that feeling ‘alone with their diabetes’ or ‘worrying about their diabetes because of the COVID-19 pandemic’ were moderate or serious problems for them. Except for younger adults, findings indicate that the easing of restrictions may mitigate some of the effects of the pandemic on diabetes-specific emotional problems, including feeling ‘burned out’, ‘alone’ with diabetes, and/or worried about diabetes due to COVID-19. Prospective data are needed to improve our understanding of the emotional impact of COVID-19 on people with diabetes and to inform when and how to target support for those who need it most.

**Keywords:** diabetes, diabetes distress, emotional wellbeing, COVID-19, mental health, survey

## INTRODUCTION

The novel coronavirus disease (COVID-19) is associated with serious physical consequences (1). Mounting evidence highlights that the pandemic (and associated restrictions to personal freedoms) is having a detrimental impact on mental health in the general population (2). For people with diabetes, COVID-19 infection is associated with increased risk of serious complications and/or death (3, 4), while the pandemic and associated restrictions contribute to increased distress, stigmatisation and social isolation (5). Changes in the number of active cases in the community, levels of restrictions, and vaccination rates, may impact how people are coping with, and adapting to, the challenges of this novel virus at any given point in time.

Our aim was to obtain brief snapshots of how adults are feeling about their diabetes at three timepoints during the COVID-19 pandemic. Prior to the first 'snapshot' survey period (26 May to 9 June 2020), pandemic restrictions had been in place but were about to be eased nationally. During the second 'snapshot' (20 August to 3 September 2020), Melbourne had widespread community transmission, and a second lockdown, while all other states reported zero or few cases and minimal restrictions. During the third 'snapshot' (27 April to 13 May 2021), most states had no community transmission and minimal restrictions. Furthermore, the Australian Government's COVID-19 vaccination program had commenced, though only 2.9 million doses (11 per 100 people) had been administered at that time (6).

## MATERIALS AND METHODS

We conducted three cross-sectional 'snapshot' surveys of diabetes-specific distress, associated with feeling 'burned out', alone and worried because of the COVID-19 pandemic, among inbound callers to the National Diabetes Services Scheme (NDSS) Helpline. The NDSS Helpline service provides practical support for people with diabetes, including advice on diabetes self-management and information about NDSS services and products. Each 'snapshot' survey was conducted over two-week periods commencing May and August 2020 and April 2021. Adults ( $\geq 18$  years) with diabetes calling the NDSS Helpline (for any reason) were invited to take part in the brief telephone surveys.

Three brief questions were sourced or adapted from the Problem Areas in Diabetes (PAID) scale (7). Respondents were asked, "Which of the following are currently a problem for you?": a) Feeling 'burned out' by the constant effort needed to manage diabetes? b) Feeling alone with your diabetes? c) Worrying about your diabetes because of the COVID-19 pandemic? Participants rated each item (from 0=not a problem, to 4=serious problem). The three items demonstrated acceptable internal consistency (Cronbach's  $\alpha=0.733$ ). These items were selected given the salience of these issues for people with type 1 diabetes (T1D) and type 2 diabetes (T2D) (7, 8), particularly during the COVID-19 pandemic (9, 10); and also because NDSS factsheets offering support for these issues were readily available for those

experiencing problems in these areas (11). Thus, if the caller's responses indicated that any item was a moderate or serious problem (score  $\geq 2$ ), NDSS Helpline call operators recommended relevant NDSS emotional health factsheets (8): 'Diabetes distress' (item 1), 'Peer support' (item 2), and 'Managing worry about COVID-19 and diabetes' (item 3). The factsheets were recommended in addition to usual referrals and support suggested by Helpline staff, including the offer of referral to an 'on-call health professional'.

In addition to the three survey items, for each participant, the following data were recorded: NDSS registration number, age, gender, postcode, diabetes type and, for those with T2D: treatment type (typically, insulin versus non-insulin). Participants who completed the 2<sup>nd</sup> and 3<sup>rd</sup> 'snapshots' were asked if they had taken part in the 1<sup>st</sup> or 2<sup>nd</sup> surveys. Unique to the 3<sup>rd</sup> 'snapshot' survey, participants were also asked if they had received a COVID-19 vaccine.

## Statistical Analysis

We examined the proportion of participants, by diabetes type, who reported scores of  $\geq 2$ , indicating the item was at least a moderate problem, at each time point. We examined scores  $\geq 2$  given that moderate levels of diabetes distress are regarded to be clinically significant in the scoring of diabetes distress measures and can have a significant impact on how a person manages their diabetes (3, 4, 7, 8). Differences between timepoints were analysed using Pearson Chi-square tests or Fisher's exact tests. Between the three timepoints, item scores (0-4) were also compared using Kruskal-Wallis tests. *Post-hoc* pairwise tests with Bonferroni correction were performed on categories with significant ( $P < 0.05$ ) Kruskal-Wallis results.

All tests were 2-sided, with  $p < 0.05$  considered statistically significant. Analyses were performed using SPSS v26.

## RESULTS

During the 2-week survey periods, the NDSS Helpline received  $N=5,932$  inbound calls from people with diabetes:  $n=2,168$  (1<sup>st</sup>),  $n=2,119$  (2<sup>nd</sup>) and  $n=1,645$  (3<sup>rd</sup>). Of these callers, 479 (22%), 454 (21%) and 451 (27%) were invited to participate, respectively in the 1<sup>st</sup>, 2<sup>nd</sup> and 3<sup>rd</sup> 'snapshot' surveys. In total,  $N=1,278$  surveys were completed over the three 'snapshots' (1<sup>st</sup>  $N=449$ ; 2<sup>nd</sup>  $N=414$ ; 3<sup>rd</sup>  $N=415$ ) by 1,248 eligible adults ( $n=30$  completed a survey at 2 timepoints), representing a 94%, 92% and 93% acceptance rate among those invited. Demographic and clinical characteristics were similar across timepoints (Table 1). At the 3<sup>rd</sup> 'snapshot', 21% ( $n=88$ ) had received a COVID-19 vaccine dose. There were no differences (by gender, state or diabetes type) between those who had and had not received the vaccine. Of those who received a vaccine dose, 50% were  $>70$  years old and 39% were 50-69 years old.

During the 1<sup>st</sup>, 2<sup>nd</sup> and 3<sup>rd</sup> 'snapshots', 42% ( $n=530$ ) of respondents reported diabetes-specific distress related to at least one problem (i.e. score  $\geq 2$  on at least one survey item). This differed between timepoints: 48% in the 2<sup>nd</sup> survey, compared to 40% in the 1<sup>st</sup> and 37% in the 3<sup>rd</sup> 'snapshot' ( $p=0.004$ ). More participants in the



**TABLE 1 |** Participants' demographic and clinical characteristics in the 1<sup>st</sup> (May 2020), 2<sup>nd</sup> (August 2020) and 3<sup>rd</sup> (April 2021) 'snapshot' surveys.

Participant characteristic	1 <sup>st</sup> snapshot (N = 449)	2 <sup>nd</sup> snapshot (N = 414)	3 <sup>rd</sup> snapshot (N = 415)
<b>Age, years<sup>#</sup></b>	60+16.99, 19-93	60+16.68, 19-91	58+16.92, 18-90
18-34 years	63 [49, 73]	62 [47, 72]	61 [44, 72]
35-49 years	48 (11)	46 (11)	53 (13)
50-69 years	68 (15)	70 (17)	80 (19)
≥70 years	167 (37)	156 (38)	159 (38)
	166 (37)	138 (33)	123 (30)
<b>Gender: Women</b>	249 (56)	234 (56)	237 (57)
<b>State<sup>~</sup></b>			
Australian Capital Territory (ACT)	1 (<1)	7 (2)	7 (2)
New South Wales (NSW)	129 (29)	116 (28)	136 (33)
Northern Territory (NT)	1 (<1)	0 (0)	2 (<1)
Queensland (QLD)	111 (25)	74 (18)	89 (22)
South Australia (SA)	22 (5)	22 (5)	30 (7)
Tasmania (TAS)	9 (2)	5 (1)	7 (2)
Victoria (VIC)	146 (33)	168 (41)	118 (29)
Western Australian (WA)	25 (6)	19 (5)	23 (6)
<b>Diabetes type</b>			
Type 1 diabetes	149 (33)	150 (36)	215 (52)
Type 2 diabetes	279 (62)	252 (61)	192 (46)
Gestational diabetes	14 (3)	11 (3)	7 (2)
Other or unknown	7 (2)	1 (<1)	1 (<1)
<b>Treatment type (Type 2 diabetes only)<sup>^</sup></b>			
Insulin	77 (28)	98 (39)	45 (24)
Non-insulin	197 (71)	153 (61)	146 (76)

Data are n (%) or mean±SD, range or median [IQR].

<sup>#</sup>Age: data missing for 4 participants at 2<sup>nd</sup> survey.

<sup>~</sup>State: data missing for 5 participants (1<sup>st</sup> survey), 3 participants (2<sup>nd</sup> survey), 3 participants (3<sup>rd</sup> survey).

<sup>^</sup>Treatment type: data missing for 5 participants (1<sup>st</sup> survey), 1 participant (2<sup>nd</sup> survey), 1 participant (3<sup>rd</sup> survey) with type 2 diabetes.

2<sup>nd</sup> 'snapshot' reported that all three survey items were at least a moderate problem (11%) compared to participants in the 1<sup>st</sup> (8%) and 3<sup>rd</sup> (6%) 'snapshots' (p=0.029).

## Feeling 'Burned Out'

During the 1<sup>st</sup>, 2<sup>nd</sup> and 3<sup>rd</sup> 'snapshots', 30%, 41% and 38% of adults with T1D and 24%, 29% and 23% of adults with T2D, respectively reported feeling at least moderately 'burned out' by the constant effort needed to manage their diabetes (Table 2). Item scores were not significantly different between timepoints (Kruskal–Wallis test: T1D, p=0.476, T2D, p=0.316).

## Feeling Alone With Diabetes

During the 1<sup>st</sup>, 2<sup>nd</sup> and 3<sup>rd</sup> 'snapshots', 26%, 26% and 16% of participants with T1D, and 17%, 18% and 8% of adults with T2D, respectively, reported feeling 'alone' with diabetes was at least a moderate problem for them (Kruskal–Wallis test: T1D, p=0.044, T2D, p=0.020). *Post-hoc* comparisons, adjusted by the Bonferroni correction comparing differences in item scores between timepoints (Table 2) found that feeling 'alone with your diabetes' was less problematic at the 3<sup>rd</sup> 'snapshot' compared to the 1<sup>st</sup> (T1D, p=0.033; T2D, p=0.010) and 2<sup>nd</sup> (T1D, p=0.040; T2D, p=0.019).

## Worried About Diabetes Because of COVID-19

During the 1<sup>st</sup>, 2<sup>nd</sup> and 3<sup>rd</sup> 'snapshots', 29%, 38% and 18% of participants with T1D, and 22%, 27% and 11% of adults with

T2D, respectively, reported feeling at least moderately 'worried about their diabetes because of COVID-19' (Kruskal–Wallis test: T1D, p<0.001, T2D, p=0.001). *Post-hoc* comparisons, adjusted by the Bonferroni correction comparing differences in item scores between timepoints found that 'worrying about diabetes because of COVID-19' was less problematic at the 3<sup>rd</sup> 'snapshot' compared to the 1<sup>st</sup> (T1D, p=0.014; T2D, p=0.003) and 2<sup>nd</sup> (T1D, p<0.001; T2D, p<0.001) (Table 2).

## Differences by Demographic Characteristics

Younger participants (18-34 years) were more likely to report feeling at least moderately 'burned out' during the 3<sup>rd</sup> 'snapshot' (47%), compared to 17% and 30% during the 1<sup>st</sup> and 2<sup>nd</sup> surveys, respectively (p=0.004; Table 3).

Overall, men and women with T1D and T2D reported feeling less worried about their diabetes due to COVID-19 during the 3<sup>rd</sup> 'snapshot' compared with earlier surveys (Table 3). However, during the 1<sup>st</sup> 'snapshot', women with T2D were more likely to report feeling worried about their diabetes due to COVID-19 compared with men (p=0.043).

During the 3<sup>rd</sup> survey, there was a trend towards a higher proportion of women with T1D feeling at least moderately 'burned out' compared with men (p=0.047).

Within state comparisons over time showed that feeling at least moderately worried about diabetes due to COVID-19 was more likely at the 2<sup>nd</sup> than the 3<sup>rd</sup> 'snapshot' among participants residing in New South Wales (2<sup>nd</sup>: 28% vs 3<sup>rd</sup>: 13%; p=0.008) and

**TABLE 2 |** Proportion of participants with type 1 diabetes and type 2 diabetes who reported each issue as 'a moderate-to-serious' problem during the 1<sup>st</sup> (May 2020), 2<sup>nd</sup> (August 2020) and 3<sup>rd</sup> (April 2021) 'snapshot' surveys.

Survey item	Diabetes type	1 <sup>st</sup> 'snapshot' (N=428)	2 <sup>nd</sup> 'snapshot' (N=402)	3 <sup>rd</sup> 'snapshot' (N=407)	$\chi^2$ P-value	Kruskal-Wallis P-value <sup>#</sup>	Post-hoc test <sup>~</sup> (P-value)		
							1 <sup>st</sup> vs. 2 <sup>nd</sup>	1 <sup>st</sup> vs. 3 <sup>rd</sup>	2 <sup>nd</sup> vs. 3 <sup>rd</sup>
1. 'Burned out' by diabetes	T1D	45 (30.2)	61 (40.7)	81 (37.7)	0.149	0.476	-	-	-
	T2D	66 (23.7)	73 (29.0)	45 (23.4)	0.283	0.316	-	-	-
	Total	111 (25.9)	134 (33.1)	126 (31.0)	0.059	0.402	-	-	-
2. Feeling alone with diabetes	T1D	38 (25.5)	39 (26.0)	34 (15.8)	0.026	0.044	0.941	0.033	0.040
	T2D	49 (17.6)	47 (18.7)	16 (8.3)	0.006	0.020	0.834	0.010	0.019
	Total	87 (20.3)	86 (21.4)	50 (12.3)	0.001	0.005	0.971	0.004	0.006
3. Worried about diabetes due to COVID-19	T1D	43 (28.9)	57 (38.0)	38 (17.8)	<0.001	<0.001	0.154	0.014	p<0.001
	T2D	62 (22.2)	69 (27.4)	21 (10.9)	<0.001	0.001	0.344	0.003	p<0.001
	Total	105 (24.5)	126 (31.3)	59 (14.5)	<0.001	<0.001	0.072	0.001	p<0.001
Total diabetes distress score <sup>^^</sup>	T1D	2.00 (0.5-5)	3.00 (0-6)	2.00 (0-4)	-	0.022	0.247	0.140	0.006
	T2D	2.00 (0-4)	2.00 (0-4)	1.00 (0-3)	-	0.002	0.405	0.006	0.001
	Total	2.00 (0-4)	2.00 (0-5)	1.00 (0-3)	-	0.001	0.137	0.027	<0.001

Data are n (%) for proportion of participants who reported item was at least a moderate problem (score $\geq$ 2 on 0-4 scale).

<sup>^</sup>Median [interquartile range].

<sup>^^</sup>Total distress score is the sum of all three survey items (ranging from 0 to 12).

<sup>#</sup>Kruskal-Wallis test was used to compare differences between the three 'snapshots' on the 0-4 scale.

<sup>~</sup>Pairwise comparisons were conducted adjusted by the Bonferroni correction.

Victoria (2<sup>nd</sup>: 35% vs 3<sup>rd</sup>: 16%; p=0.001). No significant differences were found between the states on any of the three survey items.

At the 3<sup>rd</sup> 'snapshot', no significant differences were found on any of the survey items by vaccination status among adults with T1D and T2D (Table 4).

Table 5 summarises the rate of acceptance of relevant NDSS factsheets and uptake of a referral to an 'on-call' diabetes health professional (where item scores indicated at least a moderate problem). The rates of uptake when participants were offered a relevant NDSS factsheet were lower during the 3<sup>rd</sup> survey compared to the previous two surveys (p=0.022). Rates of uptake when participants were offered a referral to an 'on-call' health professional were comparable across surveys (p=0.064).

## DISCUSSION

Our findings demonstrate that adults calling the NDSS Helpline at three time-points during the COVID-19 pandemic were at least moderately distressed about their diabetes. On average, 42% (n=530) of respondents reported that at least one of the three issues explored was a moderate-to-severe problem for them. Participants were more likely to report feeling 'burned out', alone and worried about their diabetes because of COVID-19 during the 2<sup>nd</sup> 'snapshot' compared to other timepoints. During the 2<sup>nd</sup> 'snapshot', 6 months into the pandemic, a second lockdown was imposed in Melbourne (with some restrictions at a state level in Victoria). The state was also experiencing a peak number of daily new infections compared to the other timepoints.

Our findings suggest that, during the first year of the COVID-19 pandemic, adults with diabetes are more likely to report feeling 'burned out' and 'alone with their diabetes',

compared with pre-COVID-19 levels (8, 12–14). There is a paucity of data reporting on the longitudinal impact of the COVID-19 pandemic on diabetes distress. A longitudinal study of adults with diabetes in Denmark, found that diabetes distress and general loneliness reduced three months into the COVID-19 pandemic. Similarly, compared to 6 and 12 months prior, participants completing the 3<sup>rd</sup> 'snapshot' were feeling less concerned about their diabetes due to COVID-19. They were also feeling less alone with their diabetes. Our findings likely reflect a reduction in the number of COVID-19 cases in the community at this timepoint, the easing of restrictions and people re-engaging socially.

Younger adults (18-34 years) appear especially impacted emotionally and feeling 'burned out' was most common at the 3<sup>rd</sup> 'snapshot'. This is consistent with Australian findings among younger adults with type 2 diabetes (11).

The strengths of this study are that these novel 'snapshot' data have enabled examination of how people with diabetes are feeling during three timepoints during the COVID-19 pandemic. Participants were receptive to being asked by NDSS Helpline staff about their emotions related to diabetes, and referral options (i.e. factsheets and 'on-call health professionals') were in place for those experiencing distress. This is encouraging given that most callers were phoning the NDSS Helpline for practical support with the management of their diabetes.

Limitations include the cross-sectional study design, which precludes inferences about the impact of the pandemic on distress within participants over time. Around 20% of NDSS Helpline callers were invited to participate and most accepted. However, it is unclear whether their experience of diabetes concerns related to feeling 'burned out', 'alone', and 'worried due to COVID-19' can be generalised to those who were not invited to participate, nor to the general adult population living

**TABLE 3 |** Proportion of participants with T1D and T2D during the 1<sup>st</sup> (May 2020), 2<sup>nd</sup> (August 2020) and 3<sup>rd</sup> (April 2021) 'snapshot' surveys who reported each item as 'a moderate-to-serious' problem (score  $\geq 2$ ), by type of diabetes and demographic characteristics.

Survey item	'Burned out' by diabetes				Feeling alone with diabetes				Worried about diabetes due to COVID-19			
'Snapshot' period	1 <sup>st</sup> n (%)	2 <sup>nd</sup> n (%)	3 <sup>rd</sup> n (%)	P-value	1 <sup>st</sup> n (%)	2 <sup>nd</sup> n (%)	3 <sup>rd</sup> n (%)	P-value	1 <sup>st</sup> n (%)	2 <sup>nd</sup> n (%)	3 <sup>rd</sup> n (%)	P-value
<b>Type 1 diabetes</b>												
<b>Age</b>												
18-35 years	5 (17)	11 (31)	23 (49)	<b>0.013</b>	3 (10)	7 (20)	13 (28)	0.173	4 (13)	12 (34)	11 (23)	0.142
35-49 years	12 (41)	21 (64)	23 (45)	0.150	9 (31)	10 (30)	11 (22)	0.553	8 (28)	12 (36)	12 (24)	0.441
50-69 years	20 (38)	21 (40)	28 (40)	0.955	18 (34)	16 (31)	4 (6)	<b>&lt;0.001</b>	24 (45)	27 (52)	9 (13)	<b>&lt;0.001</b>
$\geq 70$ years	6 (19)	8 (29)	7 (15)	0.355	8 (26)	6 (21)	6 (13)	0.327	6 (19)	6 (21)	6 (13)	0.571
<b>Gender</b>												
Men	18 (27)	24 (39)	28 (30)	0.282	16 (24)	14 (23)	11 (12)	0.083	15 (22)	22 (36)	12 (13)	<b>0.003</b>
Women	27 (33)	37 (42)	53 (44)	0.283	22 (27)	25 (28)	23 (19)	0.243	28 (34)	35 (39)	26 (22)	<b>0.015</b>
<b>State*</b>												
NSW	16 (35)	19 (39)	20 (32)	0.741	12 (26)	9 (18)	9 (14)	0.297	16 (35)	35 (37)	11 (18)	<b>0.043</b>
QLD	14 (38)	14 (54)	22 (45)	0.453	11 (30)	10 (39)	9 (18)	0.154	8 (22)	26 (35)	9 (19)	0.291
VIC	9 (20)	19 (36)	23 (37)	0.120	11 (24)	14 (26)	12 (19)	0.629	12 (26)	24 (45)	15 (24)	<b>0.030</b>
<b>Type 2 diabetes</b>												
<b>Age</b>												
18-35 years	1 (25)	3 (38)	2 (100)	0.194	1 (25)	2 (25)	0 (0)	0.727	0 (0)	2 (25)	0 (0)	0.417
35-49 years	3 (10)	10 (35)	5 (19)	0.068	1 (3)	6 (21)	1 (4)	<b>0.037</b>	7 (23)	9 (31)	3 (12)	0.220
50-69 years	29 (27)	40 (39)	25 (28)	0.150	20 (19)	29 (28)	12 (14)	<b>0.041</b>	28 (26)	37 (36)	15 (17)	<b>0.013</b>
$\geq 70$ years	30 (23)	18 (16)	13 (17)	0.397	24 (18)	8 (7)	3 (4)	<b>0.002</b>	25 (19)	20 (18)	3 (4)	<b>0.008</b>
<b>Gender</b>												
Men	27 (21)	33 (28)	18 (22)	0.364	19 (14)	17 (14)	7 (8)	0.379	22 (17)	30 (25)	9 (11)	<b>0.028</b>
Women	39 (27)	40 (30)	27 (25)	0.634	30 (20)	30 (23)	9 (8)	<b>0.008</b>	40 (27)	39 (29)	12 (11)	<b>0.001</b>
<b>State*</b>												
NSW	17 (22)	16 (25)	16 (23)	0.863	13 (17)	11 (18)	5 (17)	0.159	15 (19)	14 (22)	7 (10)	0.155
QLD	13 (19)	11 (24)	12 (32)	0.351	8 (12)	6 (13)	6 (16)	0.841	14 (21)	12 (26)	8 (21)	0.768
VIC	25 (26)	35 (32)	10 (19)	0.193	21 (22)	22 (20)	3 (6)	<b>0.029</b>	25 (26)	35 (32)	4 (7)	<b>0.003</b>
<b>Treatment type</b>												
Insulin	22 (29)	35 (36)	16 (36)	0.568	19 (25)	20 (20)	8 (18)	0.638	21 (27)	32 (33)	8 (18)	0.181
Non-insulin	43 (22)	37 (24)	29 (20)	0.665	30 (15)	27 (18)	7 (5)	<b>0.002</b>	39 (20)	37 (24)	13 (9)	<b>0.002</b>

\*Respondents from New South Wales (NSW), Queensland (QLD) and Victoria (VIC) comprise 84-87% of the sample across timepoints. Due to small numbers, respondents were excluded from these analyses from the following states and territories: Australian Capital Territory (ACT), Northern Territory (NT), South Australia (SA), Tasmania (TAS), Western Australian (WA). Items in bold are considered statistically significant.

**TABLE 4 |** Proportion of participants who reported each issue as 'a moderate-to-serious' problem during the 3<sup>rd</sup> 'snapshot' survey (April 2021), by diabetes type and vaccination status.

Survey item	Diabetes type	Vaccinated <sup>^</sup> (N = 88)	Unvaccinated (N = 327)	$\chi^2$ P-value	Mann-Whitney* P-value
1. 'Burned out' by diabetes	T1D	18 (40.9)	63 (36.8)	0.620	0.844
	T2D	7 (15.9)	38 (25.7)	0.179	0.063
	Total	25 (28.4)	101 (31.7)	0.559	0.157
2. Feeling alone with diabetes	T1D	4 (9.1)	30 (17.5)	0.246	0.320
	T2D	1 (2.3)	15 (10.1)	0.125	0.068
	Total	5 (5.7)	45 (14.1)	<b>0.042</b>	0.066
3. Worried about diabetes due to COVID-19	T1D	7 (15.9)	31 (18.2)	0.827	0.846
	T2D	2 (4.5)	19 (12.8)	0.170	0.079
	Total	9 (10.2)	50 (15.7)	0.233	0.345

Data are n (%) for the proportion of participants who reported item being at least a moderate problem (score  $\geq 2$ ).

<sup>^</sup>Vaccinated means at least (and typically) one vaccine dose.

\*Mann-Whitney Test was used to compare differences between vaccinated vs. unvaccinated groups on the 0-4 scale.

Items in bold are considered statistically significant.

with diabetes. This is particularly pertinent given the higher number of adults with T1D who participated in our surveys and the under-representation of adults with T2D. Another limitation is the selection of only three PAID items, which limits insights into diabetes distress typically captured by a 20-item measure. It

is possible that participants may have been experiencing general or diabetes distress or mental health problems not captured by these survey items.

In conclusion, the three 'snapshots' suggest that diabetes distress, specifically associated with feeling 'burned out',

**TABLE 5 |** Referral type and uptake by participants who reported 'moderate-to-severe diabetes distress' in the 1<sup>st</sup>, 2<sup>nd</sup> and 3<sup>rd</sup> 'snapshot' surveys.

Type of support offered	1st Snapshot (N = 180)		2nd Snapshot (N = 198)		3rd Snapshot (N = 152)	
	Offered n (%)	Accepted n (%)	Offered n (%)	Accepted n (%)	Offered n (%)	Accepted n (%)
Health professional referral	136 (76)	40 (29)	148 (75)	47 (32)	141 (93)	31 (22)
NDSS factsheet(s)	117 (65)	65 (56)	132 (67)	65 (49)	120 (79)	37 (31)
Diabetes distress	72/116 (62)	39 (54)	91/132 (69)	48 (53)	101/126 (80)	35 (35)
Peer support	57/88 (65)	36 (63)	61/87 (70)	31 (51)	44/50 (88)	19 (43)
Managing worry about diabetes and COVID-19	77/109 (71)	48 (62)	88/128 (69)	45 (51)	48/59 (81)	19 (40)

1st snapshot (May) survey: 180 participants had a score of >2 on at least one survey item; 2nd snapshot (August) survey: 198 participants had a score of >2 on at least one survey item; 3rd snapshot (April) survey: 152 participants had a score of >2 on at least one survey item.

'alone', and 'worried due to COVID-19', are significant issues for adults with diabetes in Australia during COVID-19. Prospective data are needed to improve understanding of the trajectory of the emotional impact of COVID-19 on people with diabetes and to inform when and how to target support for those who need it most.

## DATA AVAILABILITY STATEMENT

Data was collected by the Australian National Diabetes Services Scheme (NDSS). De-identified raw data was provided to the co-authors. Requests to access the data would need to be approved by the NDSS. Requests to access the datasets should be directed to eholloway@acbrd.org.au.

## ETHICS STATEMENT

Ethical review and approval were not required for the study on human participants in accordance with the local legislation and institutional requirements. Written informed consent for participation was not required for this study in accordance with the national legislation and the institutional requirements.

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## AUTHOR CONTRIBUTIONS

JS and CH conceived of the project with input from TS, EH, and GC. EH and GC coordinated the surveys. EH conducted the data analysis. EH prepared the first and subsequent drafts of this manuscript, following co-author review. All authors reviewed and approved submission of the final manuscript.

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**Conflict of Interest:** GC is the manager of the NDSS Helpline, and JS is the Leader of the NDSS Mental Health and Diabetes National Priority Area.

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# “It Just Kind of Feels Like a Different World Now:” Stress and Resilience for Adolescents With Type 1 Diabetes in the Era of COVID-19

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**Purpose:** The COVID-19 pandemic has been a major stressor for adolescents. Given the unique implications of the pandemic for youth with type 1 diabetes (T1D), who already navigate multiple stressors as a function of their chronic condition, we aimed to describe the impact of the pandemic on adolescents with T1D and describe their coping strategies and resilience resources.

**Research Method:** In a 2-site (Seattle WA, Houston TX) clinical trial of a psychosocial intervention targeting stress/resilience, adolescents 13–18 years old with T1D  $\geq$  1 year and elevated diabetes distress were enrolled August 2020 – June 2021. Participants completed a baseline survey about the pandemic, including open-ended questions about the effects of the pandemic, what was helping them navigate, and how it impacted T1D management. Hemoglobin A1c (A1c) was extracted from clinical records. Free text responses were analyzed using an inductive content approach. Survey responses and A1c were summarized using descriptive statistics and associations were assessed by Chi-squared tests.

**Results:** Adolescents (n=122) were 56% female. 11% of adolescents reported diagnosis of COVID-19 and 12% had a family member/other important person die from COVID-19 complications. Adolescents described Social Relationships, Personal Health/Safety Practices, Mental Health, Family Relationships, and School to be primary areas affected by COVID-19. Helpful resources included: Learned Skills/Behaviors, Social Support/Community, and Meaning-Making/Faith. Among participants indicating that the pandemic had an impact on their T1D management (n=35), the most commonly described areas were: Food, Self-Care, Health/Safety, Diabetes Appointments,



and Exercise. Compared to adolescents who reported minimal difficulty managing T1D during the pandemic (71%), those reporting moderate to extreme difficulty (29%) were more likely to have  $A1C \geq 8\%$  (80% vs. 43%,  $p < .01$ ).

**Conclusions:** Results underscore the pervasive impact of COVID-19 on teens with T1D across multiple major life domains. Their coping strategies aligned with stress, coping, and resilience theories and suggest resilient responses in the face of stress. Despite experiencing pandemic-related stressors in many areas, diabetes-related functioning was relatively protected for most teens, highlighting their diabetes-specific resilience. Discussing the pandemic impact on T1D management may be an important focus for clinicians, especially for adolescents with diabetes distress and above-target A1C.

**Keywords:** type 1 diabetes, COVID-19, stress, resilience, diabetes management

## INTRODUCTION

Adolescents with type 1 diabetes (T1D) are disproportionately affected by stress. Over one-third report high stress about their diabetes (1), with serious implications for mental and physical health. High diabetes distress is associated with higher A1c and an increased risk of developing psychological disorders (2, 3). The COVID-19 pandemic is widely recognized as a global and potentially traumatic stressor (4) and has been linked with high rates of stress, loneliness, and increased risk of depression for teens (5). Little is known, however, about the impact for teens managing a chronic health condition, such as T1D.

While there is no existing literature on the impact of the COVID-19 pandemic on the psychosocial well-being of adolescents with diabetes, research in adults with diabetes (both type 1 and type 2) suggests a significant impact on psychosocial health and diabetes management. Due, likely in part, to the increased risk of morbidity and mortality from COVID-19 (6, 7), adults with diabetes were more worried about contracting COVID-19 than their peers without chronic disease (8, 9). Increased pandemic worry, in turn, was associated with poorer psychosocial health and feelings of isolation and loneliness (10). Further, nearly half of adults with diabetes reported that the pandemic made diabetes management more difficult (11), and higher A1c was observed in those who reported less physical activity and an unhealthy diet during the pandemic (12). Increases in diabetes-related stress during the pandemic were also linked with higher A1c (11). To date, similar information has not been reported in teens, which represents a critical gap in the literature considering that prior to the pandemic over 80% of U.S. adolescents with T1D were not meeting glycemic targets (13).

The current study was designed to describe the impact of the COVID-19 pandemic on psychosocial health and diabetes management in an adolescent population with T1D and elevated diabetes distress. Specifically, we aimed to explore the effects of the COVID-19 pandemic on teens with T1D, to understand what coping strategies they used to manage stress, and to describe the impact of the pandemic on diabetes management. We anticipated that teens with T1D would

report that the COVID-19 pandemic significantly impacted various aspects of their lives and their T1D self-management.

## MATERIALS AND METHODS

Data for this study were part of a larger set of baseline measures for a psychosocial intervention trial for teens with T1D and elevated diabetes distress that was ongoing during the start of the COVID-19 pandemic (clinicaltrials.gov registration: NCT03847194). Quantitative and qualitative data were collected using REDCap electronic data capture tools hosted at the University of Washington (14, 15). This research was approved by the relevant Institutional Review Boards.

## Participants

Participants were eligible for the trial if they: 1) were aged 13-18 years old, 2) had a duration of T1D  $\geq 12$  months, 3) reported elevated diabetes distress within the prior 12 months (Problem Area in Diabetes Scale-Teen Version [PAID-T] (16) score  $\geq 30$ ), 4) spoke English fluently, and 5) were cognitively able to participate in intervention sessions and complete written surveys. Participants were screened through the diabetes/endocrinology clinics at their respective institutions, and recruitment primarily occurred *via* phone/video chat, although there were options for recruitment during outpatient or telehealth visits as was desired/appropriate. For participants under 18, written assent from the participant and written consent from the parent/legal guardian was provided. For participants aged 18, written consent was provided. We added a questionnaire related to the COVID-19 pandemic to baseline surveys in August 2020 and administered it to all newly enrolled study participants through June 2021. Participants were provided 6 weeks to complete their baseline survey and A1c. Participants received a monetary incentive (\$20) for completion of their baseline survey and were eligible for further incentives for subsequent surveys (up to \$80). Participants ( $n=122$ ) completed the COVID-19 questionnaire as part of baseline measures prior to randomization and intervention.

## Measures

Demographic data were collected *via* a self-report survey that participants completed as part of baseline measures. Health insurance, diabetes duration, A1c, insulin pump use, and CGM use were abstracted from electronic health records.

The Problem Area in Diabetes Scale-Teen Version (PAID-T) was utilized as a screening measure to assess the self-perceived emotional burden of living with diabetes (16, 17). The 14-item scale is the only measure of diabetes distress developed and validated purposely for use with teens. Patients responded on a 6-point Likert scale (1=not a problem, 6=serious problem), and higher scores represent greater distress.

The COVID-19 questionnaire is a 26-item self-report questionnaire developed for this study to assess perceived impact of the COVID-19 pandemic on participants. These items were adapted from other measures of COVID-19 stress and impact that were newly developed at the start of the pandemic, including the COVID-19 Exposure and Family Impact Survey (18) (CEFIS-19) and the COVID-19 Impact Measure (19). Items from these measures most relevant to the study aims were utilized, and minor wording changes, as were appropriate for the target population, were made by content knowledge experts on the study team.

In the first 11 questions, items assess worry/anxiety related to COVID-19, life events as a result of COVID-19 (e.g., missed school), lifestyle changes, and known COVID-19 symptoms/diagnosis for self, family, and important others. Sample items included: *"Overall, how worried or anxious have you been about the COVID-19 pandemic?"* and *"How have changes in your life caused by COVID-19 impacted you?"* Two open-ended question allowed for participants to comment on their general experiences of the COVID-19 pandemic, including: 1) *Tell us about other effects of COVID-19 on yourself and/or your family, both negative and/or positive;* 2) *What is helping you through the COVID-19 pandemic?* The following 15-items focused on participants' appraisal of how the COVID-19 pandemic had affected their T1D management. 14 of the items were on a 5-point Likert scale (1=not at all; 5=extremely) and pertained to key domains of diabetes management. Items included the same stem (*"Since the COVID-19 pandemic, I..."*) and were phrased in both negative (*"...have struggled to properly manage my diabetes."*) and positive directions (*"...have found it easier to manage my diabetes."*). Domains included overall management, food/eating, physical activity, diabetes supplies, blood glucose variability, access to healthcare team, and family management. The remaining question was open-ended and asked participants: 3) *In what ways has COVID-19 impacted your T1D management?*

## Analysis Plan

Following the Standards for Reporting Qualitative Research (SRQR) (20), the qualitative study team included researchers with training in psychology (MO, MH, VC, JYF), endocrinology (FM, DD), medical anthropology and global health (KR), and health services science with expertise in qualitative research (KB, FM). Three members of the study team (MO, VC, KR) were

trained to code the qualitative data under the supervision of the team's qualitative lead (KB). The lead coder (MO) met with the qualitative lead to discuss a data analysis plan, to share codes, and to get feedback on the process. The lead coder periodically shared results, received feedback about codes, and identified themes with members of the investigator team (JYF, MH, FM, DD). The full writing group provided input into interpretation of codes to assure clinical relevance.

At the time of data analysis, existent literature on the COVID-19 pandemic's impact on teens with T1D was lacking. As such, we decided to take an inductive qualitative approach and used conventional content analysis (21). Each question was individually analyzed and open coding was conducted to create a codebook for each of the three questions. The lead coder generated initial codebooks from the response data. The three coders (MO, VC, KR) independently applied the codebook categories to all of the responses in separate Microsoft Excel spreadsheets and the coding team met regularly to identify discrepancies among coders and refine the codebook (e.g., by adding new codes for ideas that were not captured by existing codes). Multiple codes could be applied to a single response. Since both Question 1 (Effects of COVID-19) and Question 3 (COVID 19's Impact on T1D management) generated both positively and negatively worded responses, after primary codes were applied, responses were coded with sub-codes of "positive" or "negative" if the participant added a decipherable valence to their response.

After each iteration, each coder independently recoded the transcripts using the updated codebook. This process continued until there were minimal (<5) discrepancies across all three coders for both codes and sub-codes. Any discrepancies that could not be resolved within the coding team were escalated to the team's qualitative lead for adjudication. Once final coding occurred, codes across all three questions were tallied to identify the most widely endorsed code categories within each response set. The full research team then considered how the codes related to one another, to theories of resilience, and to team members' clinical experiences with teens with T1D during the pandemic to identify meaningful themes.

Survey items regarding COVID-19 impacts on diabetes management were collapsed from a 5-point Likert scale to 3 categories (Not at all/Slightly, Moderately, Very/Extremely) based on distributions for ease in interpretation and presentation. Two questions (*"I have struggled to properly manage my diabetes"* and *"I have noticed more fluctuations/variability in my blood glucose levels"*) were dichotomized as Not at all/Slightly versus Moderately/Very/Extremely because the distribution suggested a natural division between people who experienced little to no difficulty versus those reporting greater impact. A1c at enrollment was categorized as <8% vs. ≥8% as an indicator for elevated A1c. Participant demographics, A1c and survey responses related to general impacts of COVID-19 were summarized descriptively using frequencies and percentages for categorical variables and means with standard deviations for quantitative variables. Associations between survey responses and A1c levels (<8% vs. ≥8%) were assessed using Chi square tests.

## RESULTS

### Participant Demographics

Participants (n=122) were 56% Female, 2% American Indian/Alaska Native, 5% Asian, 11% Black/African-American, 1% Native Hawaiian/Pacific Islander, 80% White, and 7% Other (participants could endorse multiple racial identities). 18% of the sample indicated Hispanic/Latino ethnicity. Participants had a mean A1c of 8.5% (2.1%), 71% used an insulin pump, and 76% used a CGM (**Table 1**).

### General Impact of COVID-19

**Prevalence of COVID-related events.** Regarding incidents related to COVID-19, 11% (13/122) of teens in this sample reported a diagnosis of COVID-19 themselves, and 2% (2/122) were hospitalized. One half (63/122) of teens had a family member or other important person diagnosed, 19% (23/122) had a family member or other important person who was hospitalized, and 12% (15/122) of teens reported that they had a family member or other important person in their life die due to COVID-19.

**Personal impacts and responses to COVID-19.** On the quantitative survey, 44% (54/122) of teens reported that they were not at all or slightly worried/anxious about the COVID-19 pandemic, 37% (45/122) reported that they were moderately worried/anxious and 19% (23/122) reported that they were very or extremely worried/anxious. In response to the open-text question regarding negative or positive effects of COVID-19 on the teen or their family (Q1), there were 14 code categories (**Table 2**). The most frequently observed code categories were: Family Relationships (n=37), School Changes (n=21), Personal

Health and Safety Practices (n=21), Social Relationships (n=18), and Mental Health (n=17) (**Figure 1**). Changes in family relationships was a widely endorsed effect of COVID-19, although some teens found both positive and negative effects. For example, one 13-year-old gender non-binary teen noted, “Staying at home together all the time has caused tension between my family, but we have also grown closer.” Several teens noted the changes to their schooling, which were described as overwhelmingly negative. A 14-year-old male teen simply described, “School in my opinion is worse now (with it being online)...” Participants also discussed negative effects to their social relationships and mental health. One 13-year-old female teen described both noting, “There are not any positive effects. I can’t see my friends and my dog got an ... injury that we can’t get treated because of COVID. There is nothing to look forward to. Every day is the same ... my mental health has worsened...”

In response to the question of “What is helping you through the COVID-19 pandemic?” (Q2), there were 12 code categories (**Table 2**). Most commonly, teens reported that Relationships (n=65) and Stress Management *via* Entertainment, Hobbies, and Exercise (n=43) were helping them through. For example, a 14-year-old female teen described that “being able to still talk to people I love through facetime and text” was helping them get through, while another 16-year-old female teen described multiple behavioral strategies, “Increased free time to do more exercise and hobbies. Running and hiking have been good stress-relievers. I have also had more time for baking and reading.” Six participants noted that there was nothing that was helping them through the COVID-19 pandemic.

From the codes, we identified overarching resilience themes consistent with stress and coping (22) and resilience theories (23, 24). These themes were: 1) Internal Resilience Resources, which referred to personal learned skills and behaviors (i.e., *what* helped the teen navigate COVID-19), 2) External Resilience Resources, which referred to social support and community resources (i.e., *who* helped the teens navigate COVID-19) and 3) Existential Resilience Resources, which referred to meaning-making, faith, religious, and spiritual resources (i.e., finding a *why* in navigating COVID-19) (**Figure 2**).

### Impact of COVID-19 on T1D Management

On the quantitative survey, the majority of teens (71%) reported that they were not at all or only slightly affected by COVID-19 in terms of properly managing their diabetes. Most teens endorsed that they had continued access to their diabetes care team (70%) and that they were not arguing with their parents more about diabetes during the COVID-19 pandemic (70%) (**Figure 3** and **Supplemental Table 1**). Of the 29% of teens who experienced increased (moderate to extreme) difficulty were more likely to have A1c  $\geq$  8% (80% versus 43%,  $p<.01$ ). The 42% of teens who reported greater fluctuations in blood glucose levels also were more likely to have A1c  $\geq$  8% (67% vs. 43%,  $p=.01$ ) (**Figure 4**).

In response to the open-text question of, “In what ways has COVID impacted your T1D management?,” there were 10 code categories (**Table 2**). Most commonly, when asked in an open-ended fashion, teens reported that there was no effect of COVID-

**TABLE 1 |** Sample characteristics (N=122).

<i>Demographic Characteristics</i>	
Age 13-17 years	88%
Age 18 years	12%
Age in years, median (IQR)	15 (14-16)
Gender	
Male	40%
Female	56%
Other	4%
Race*	
American Indian/Alaska Native	2%
Asian	5%
Black/African American	11%
Native Hawaiian/Pacific Islander	1%
White	80%
Other	7%
Ethnicity	
Hispanic/Latino Ethnicity	18%
Public Health Insurance	29%
Site	
A	52%
B	48%
<i>Diabetes Characteristics</i>	
A1c, mean $\pm$ SD	8.5 $\pm$ 2.1
Duration in years, median (IQR)	5.9 (3.4-8.9)
Pump use	71%
CGM use	76%

\*Participants could indicate multiple responses.

**TABLE 2 |** Code categories, code definitions, and number of times coded.

Codes	Code Definitions	Number of Times Coded
<i>Question 1 (Q1): Effects of COVID-19 (General)</i>		
Family	Included references to family relationships, both implied or explicit	37
School	Included references to school, school-related activities and/or extracurricular activities associated with school	21
Personal Health and Safety Practices	Included references to health and safety practices and not going out/leaving home	21
Mental Health	Included references to stress and/or any mental health symptoms	17
No Effect	Included language that suggests that COVID-19 has not made an impact on their lives	12
Cancellation	Included specific references to cancelled events (not including travel)	10
Physical	Included references to any aspect of physical health or fitness which cannot otherwise be accounted for as diabetes care	8
Perspective/Cognitive Shifts	Included references to changes in thinking and/or their outlook on the world	7
Financial	Included references to money/finances or implied financial changes	7
Comfort/Flexibility	Included references to flexibility, absence of routine stressors, and/or comfort related places	5
Maturation	Included references to growth and/or development	3
Diabetes Care	Included references to any aspect of diabetes management	3
Loss	Included references to mortality due to COVID-19 or other factors	2
Travel	Included specific references to travel	1
<i>Question 2 (Q2): What's Helping Them Through</i>		
Relationships	Included noted relationships, correspondence or connection with friends, family, pets, teachers, doctors, etc.	65
Stress Management via Entertainment, Hobbies, & Exercise	Included references to leisure activities (e.g., social media, video games, art, and exercise in any form)	43
School	Included references to school, school-related activities (e.g., studying) and/or extracurricular activities associated with school (e.g., band practice)	11
Looking Forward/Perspective	Included references to positively anticipating the future and/or thinking about the pandemic in a way that is beneficial to the individual	9
Personal Health and Safety Practices	Included references to health and safety practices and not going out/leaving home	8
Nothing	Included references to no coping resources/nothing is helping them get through	6
Comfort/Flexibility	Included references to flexibility, absence of routine stressors, and/or comfort related places	5
Distraction	Included references to not thinking about the pandemic or participating in activities to avoid thinking about the pandemic	5
Personal Development/Maturation	Included references to bettering oneself, growth, and/or accumulating knowledge	4
Work	Included references to work or work-related activities	3
Religion/Spirituality	Included references to religiosity, spirituality or god	2
Introversion/Appreciating being Alone	Included references to introversion and/or enjoying alone time	2
<i>Question 3 (Q3): Effects of COVID-19 (T1D Management)</i>		
No Effect	Included language that suggested that there has been no impact of T1D management as a function of COVID-19	50
Blood Glucose Management	Included references to managing blood sugar	18
Food	Included references to food and/or eating	14
Self-Care	Included references to taking care of the self (without any specific references to any one aspect of diabetes management)	13
Diabetes Appointments	Included references to diabetes appointments and diabetes care team (including telehealth)	13
Personal Health and Safety Practices	Included references to health and safety practices and not going out/leaving home	13
Exercise	Included references to exercise and/or physical activity	12
Mental Health/Stress	Included references to stress or any mental health symptoms	7
Motivation	Included references to their desire or willingness to manage their diabetes	5
Unknown	Included language that suggests that patient is unclear or does not know about the impact of COVID-19 on their diabetes management	3

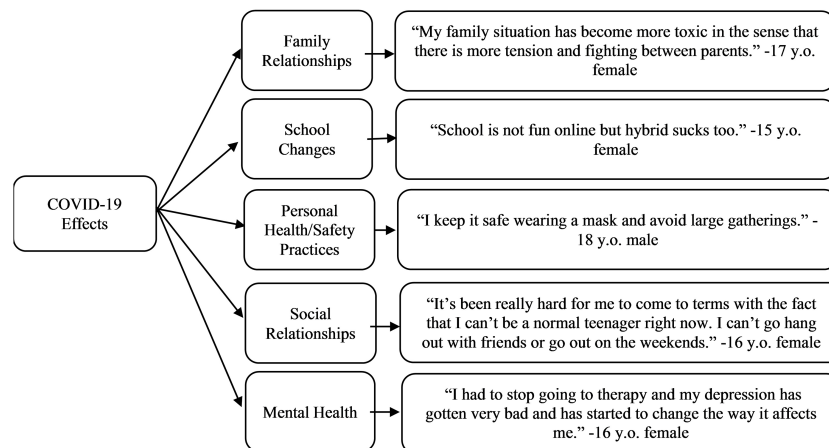
19 on their diabetes management (n=50). The next most widely endorsed domain was blood glucose management (n=18). For example, one 16-year-old male teen noted, “I’ve had more time to focus on my blood sugars,” while another 16-year-old gender non-binary teen described, “It’s [COVID-19] also been hard emotionally and diabetes management is much harder when it’s difficult to find the energy to care about blood sugars.” If participants indicated a positive or negative valence to their response, results were plotted in **Figure 5**. Overall, for those whose T1D management was affected by the COVID-19

pandemic, participants described more negative impacts than positive impacts.

## DISCUSSION

The purpose of this study was to explore the effects of the COVID-19 pandemic, to understand what coping strategies were utilized, and to describe the impact of the pandemic on diabetes management for a diverse sample of teens with T1D and

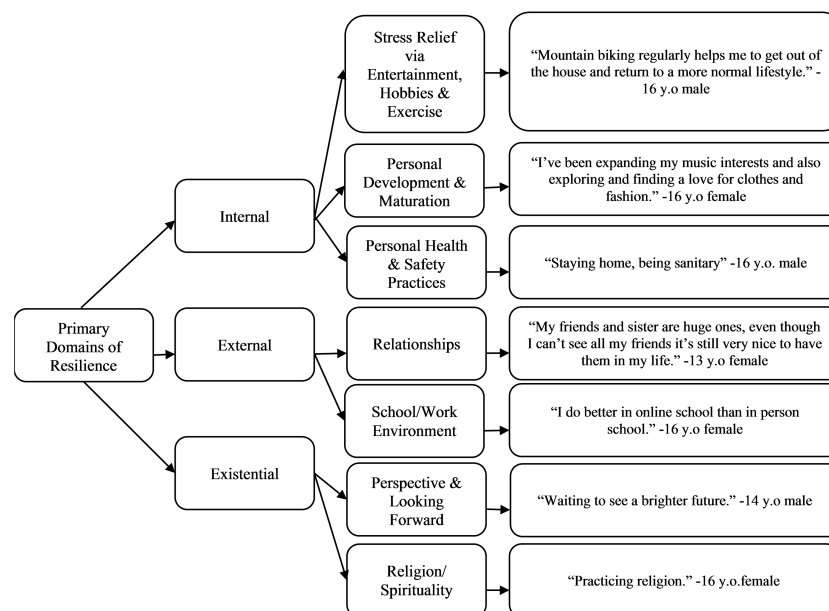




**FIGURE 1** | Most frequently observed code categories of teen-reported COVID-19 effects with example quotes.

elevated diabetes distress participating in a clinical trial. There were pervasive impacts of the COVID-19 pandemic in our sample—the majority of teens reported moderate to high anxiety about the pandemic and had direct knowledge of an important person in their lives having COVID-19. More than 1 in 10 teens in our study were diagnosed themselves or had a family member or other important person die due to COVID-19. Teens also highlighted stressors in a wide range of areas due to the COVID-19 pandemic, including most commonly with family, engaging in personal health and safety practices (e.g., social distancing), in their social relationships, school, and in

their own mental health—all of which are life domains that contain social and relational elements. This finding is in line with other emergent research that suggests that teens have experienced more family conflict and difficulty navigating peer relationships during the COVID-19 pandemic (25, 26). COVID-19 and associated safety measures (e.g., quarantine) have had a crushing social impact globally (27), which may be especially concerning for adolescents who are at a key time of social and emotional development (28). This may be a driving cause as to why teens are at risk of developing mental health symptoms during the COVID-19 pandemic (29).



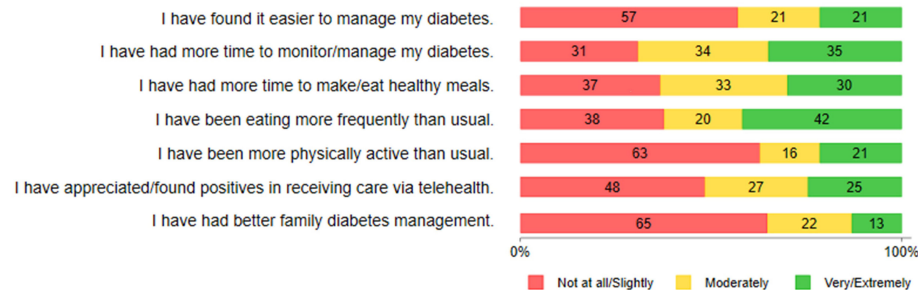
**FIGURE 2** | Themes and code categories of teen-reported resilience with example quotes.

### Since the COVID-19 pandemic...

#### Negative Impacts



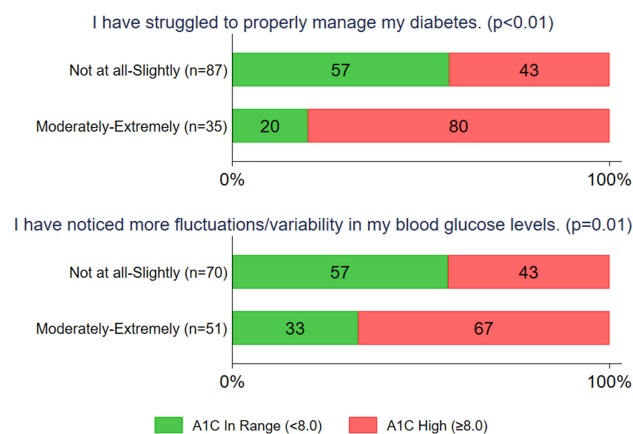
#### Positive Impacts



**FIGURE 3** | Negative and positive impacts of COVID-19 on diabetes management. Numbers shown are percentages.

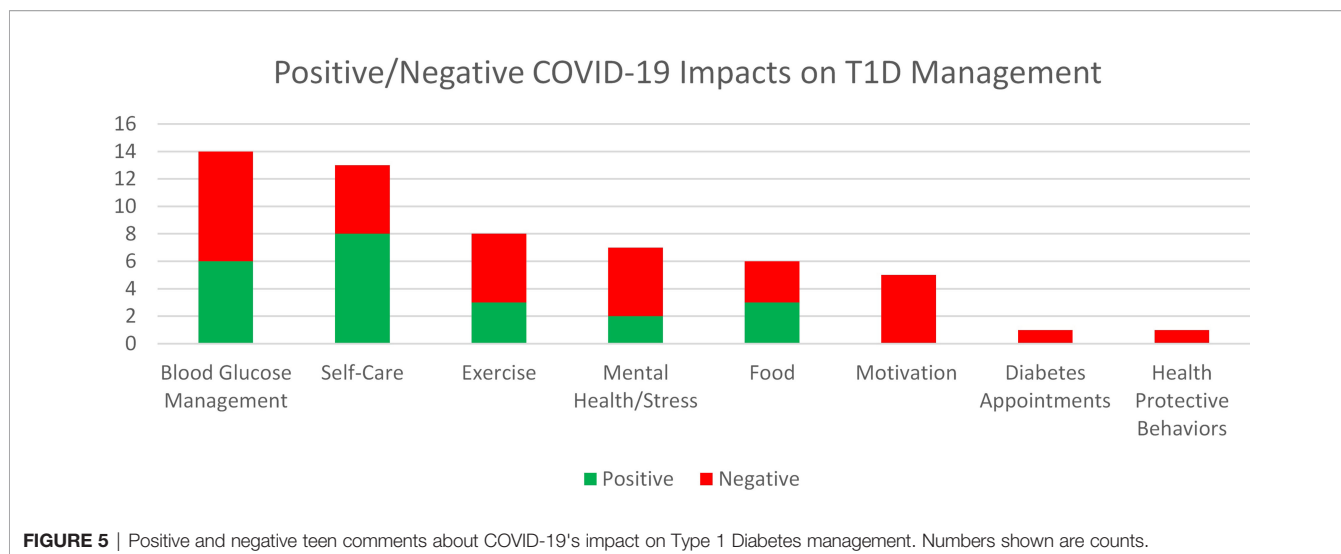
Despite the widespread impact of the COVID-19 pandemic on many parts of life, most teens generated specific strategies, skills, and resources that were helping them to navigate the COVID-19 pandemic. Thematically, many of these resilience strategies were consistent with existent theories of stress, coping, and resilience literature, which suggest that teens, especially in the context of chronic disease, will accumulate and apply resources to navigate challenges as they arise (22–24).

Some theories of resilience further suggest categories of resilience resources, which fall into individual, community, and existential domains (23, 30). Teens reported strategies across all these domains, demonstrating pervasive use of internal, external, and existential resilience resources; this provides support that employing resilience resources is both attainable and a “universal” response to stress (23). This pattern is particularly notable and supportive of resilience, given that these were teens



**FIGURE 4** | Percentages with <8% and ≥8% A1C among subgroups of respondents who did or did not report problems with diabetes management since the COVID-19 pandemic. P values are from Chi square tests.





with elevated diabetes distress. Teens in our sample predominantly reported engaging in personal behavioral strategies, such as using technology or pursuing hobbies, and/or relying on existing social support structures. This finding provides continued rationale for stress management and resilience interventions that bolster personal and existential resources for high-risk groups. These intrapersonal skills can be utilized in multiple settings and life domains, which aligns with teens' reports that they felt stress in multiple arenas of their lives throughout the COVID-19 pandemic.

Contrary to the literature describing adults with diabetes (11), for many teens with T1D, diabetes management was *not* one of the major sources of stress and was not significantly impacted by the pandemic. This suggests that teens' perceived diabetes resilience was high during the pandemic, even higher than what has been reported in adult populations with diabetes (11). Although conclusions cannot be drawn from this study about why this is the case, it is plausible that aspects of the COVID-19 pandemic response in the United States may have facilitated resilience in diabetes management for some. For example, teens may have had more hands-on parental involvement and support for daily diabetes management tasks while at home and may have spent less time in environments that introduce barriers to consistent diabetes self-management (e.g., school, sports, social gatherings, etc.). Together, changes in daily routines may have reduced vulnerability to blood glucose variability and made it easier for teens and families to manage diabetes. This finding is consistent with positive psychology and diabetes literature that suggests that people with diabetes draw on strengths and exhibit resilience during times of stress (24, 31).

Although not the predominant experience of the teens in this study, it was notable that over a quarter of participants reported serious impacts of the COVID-19 pandemic on diabetes management. Further, many of these participants were already struggling with diabetes management given our finding that adolescents in this subgroup were more likely to have higher A1c levels. This aligns with data demonstrating associations

between stress, diabetes distress, and A1c generally (2) and extends the results to stress specifically related to the COVID-19 pandemic (11). Our results suggest that teens may be more likely to feel the effects in the following areas: blood glucose management, self-care, exercise, and mental health. With this knowledge, diabetes teams can identify target areas for intervention and collaborate with patients and families to find workable solutions in light of the specific stressors the teen may be facing.

## Limitations

The nature of this study is descriptive and limits the extent to which we may be able to make any causal inference about this population. Additionally, patients completed the COVID-19 survey as early as August 2020 and as late as June 2021. Major shifts in the COVID-19 pandemic had occurred prior to the start of the study period and occurred during the study period, such as the availability of the COVID-19 vaccine, which may have differentially impacted participant responses on the COVID-19 questionnaire. In addition, throughout our data collection period, there were several notable co-occurring stressors, such as racial tensions in summer 2020, political unrest related to the 2020 election, and multiple climate disasters in our respective regions, any of which could have impacted stress and coping but were not assessed in this study.

Further, due to the free response nature of the qualitative questions, responses were often brief, and we were unable to seek clarification about their responses or follow up with probing questions. This limited our ability to deeply explore the impact of COVID-19 and contributes only a basic understanding of what teens with T1D were experiencing. It is also possible that some patients felt uncomfortable sharing about sensitive topics in this format, which may have restricted the range of responses.

This study was conducted at two large academic pediatric diabetes centers in urban centers of two different areas of the United States (Pacific Northwest and Gulf Coast). While this

allowed for a culturally, racially, ethnically, and socio-economically diverse sample, the results may not be generalizable to adolescents who live in other areas or whose care is delivered in other settings.

## Future Research and Clinical Directions

To more fully understand the phenomena observed here, future studies should include qualitative interviews about stress and resilience both generally and related to specific adverse circumstances, such as future public health crises. Interviews may provide more detailed data about which types of stressors tend to derail T1D management and how teens cope with those stressors.

This study may help to inform stress management and resilience interventions for teens with T1D. Such interventions may benefit from building on teens' existing coping skills (e.g., behavioral and social support strategies) and introducing intrapersonal and existential/meaning-making skills, which were less common in our sample. Given the social nature of many of the teens' stressors, they may benefit from additional support and resources when re-integrating into contexts that were paused during the COVID-19 pandemic. From a strengths-based perspective, it may be valuable to help teens recognize the ways they *already* successfully manage stress, both in general and specific to their diabetes management, and to promote recognition of which resilience resources benefit them most and when.

Finally, results from this study highlight the possible care needs for teens with T1D who are both stressed about their diabetes and experience difficulty managing their disease. Future studies may systematically explore this sub-group's experience of the COVID-19 pandemic. Clinical diabetes teams may consider specifically including questions about the COVID-19 pandemic or other life stressors in clinic surveys, including if and how the COVID-19 pandemic has affected their care routines. Teens in this group may benefit from increased access to services and tailored health interventions to address stress and diabetes management. Existent strengths-based intervention for teens with diabetes (32, 33), which both explore strengths and identify areas for growth, may be particularly beneficial for this higher risk group.

## CONCLUSIONS

The COVID-19 pandemic has undoubtedly made an impact on teens with T1D, and our quantitative and qualitative findings reveal that teens with T1D felt the effects of COVID-19 predominantly in social aspects of their lives. Despite significant changes to major domains of their lives, many teens reported that their T1D management was protected and they described using coping strategies that were helping them through

this stressful time, demonstrating diabetes resilience. However, for those whose T1D management was negatively impacted by COVID-19, higher A1c was more common, suggesting a need for focused follow-up by diabetes care teams.

## DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

## ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Seattle Children's Institutional Review Board (IRB of Record); Baylor College of Medicine Institutional Review Board (Relying Site). Written informed consent to participate in this study was provided by the participants' legal guardian/next of kin or self (if participant had reached the age of majority).

## AUTHOR CONTRIBUTIONS

All authors contributed to either data collection and/or interpretation. JY-F is principal investigator of this study and oversaw all aspects of the research. MO'D was involved in data collection, analysis, and crafted an initial draft of this paper. MH, FM, DD, and AR are co-investigators of the study and have contributed to study design, oversight, and editing. MB and CZ are biostatisticians and contributed to quantitative analysis. KB is a qualitative expert and contributed to oversight of qualitative analyses. All authors have reviewed this manuscript and approved the submitted version.

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## SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: <https://www.frontiersin.org/articles/10.3389/fcdhc.2022.835739/full#supplementary-material>

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The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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# The Impact of the Covid-19 Pandemic on the Well-Being and Diabetes Management of Adolescents With Type 1 Diabetes and Their Caregivers: A Scoping Review

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The Covid-19 pandemic and its related restriction measures might negatively impact diabetes management and well-being of adolescents with Type 1 Diabetes Mellitus (T1DM) and their caregivers. Accordingly, the present scoping review is aimed at mapping the literature in line with the question “How has the Covid-19 influenced diabetes management and well-being of adolescents with T1DM and their caregivers?”. A systematic search has been conducted through three academic databases. Studies carried out during the Covid-19 pandemic focused on adolescents aged between 10 and 19 years with T1DM and/or their caregivers were included. A total of 9 studies, performed between 2020 and 2021, have been identified. In particular, N = 305 adolescents with T1DM and N = 574 caregivers were considered. Overall, studies were not specific in reporting adolescents' age, and only 2 studies were primarily focused on the adolescent population with T1DM. In addition, studies were mainly focused on evaluating adolescents' glycemic control, which remained stable or has improved throughout the pandemic. Contrarily, psychosocial variables have been marginally considered. Indeed, only one study investigated adolescents' diabetes distress, which remained stable from pre-to during post-lockdown, albeit improving among girls, specifically. As regards caregivers of adolescents with T1DM, studies showed mixed results concerning their psychological state during the Covid-19 pandemic. Prevention measures, which are aimed at supporting adolescents with T1DM during the lockdown, were considered by one study only, showing the favorable role of telemedicine during lockdown for adolescents' glycemic control. Altogether, the current scoping review has identified many shortcomings of the available literature, which are given by the limited specificity of the age group considered and by the limited consideration of psychosocial variables, particularly their interplay with the medical ones.

**Keywords:** covid-19, type 1 diabetes, adolescents, caregivers, well-being, scoping review



## INTRODUCTION

Covid-19, the respiratory illness caused by the SARS-CoV-2 virus, was declared a global pandemic in March 2020 by the World Health Organization (1) due to its extremely contagious nature and associated high mortality rates. Although pediatric patients with Type 1 Diabetes Mellitus (T1DM) seem not to be at an increased risk of morbidity and mortality for Covid-19 compared to adults (2), they still are deemed as a particularly vulnerable population, especially considering that DM was found to be one of the most frequent comorbidities among people who got infected with Covid-19 (3). When it comes to diabetes management, which consists of the day-to-day actions required from patients with DM to consistently keep their disease under control, such as undertaking daily insulin shots, regularly monitoring their blood glucose, and maintaining a healthy lifestyle by being physically active and following a balanced dietary regimen (4, 5), adolescents already represent an at-risk group. Indeed, on top of having to deal with the multiple biopsychosocial changes (6) typical of this developmental phase, they are also required to take on a greater sense of responsibility for their daily diabetes management (7).

Before the Covid-19 pandemic, plenty of evidence had already been gathered on how T1DM is a challenging condition for adolescents to live with: its management is often regarded as tedious, complex and time-consuming, and may potentially lead to the development of mental health issues (8, 9). More specifically, Rechenberg and colleagues (8) highlighted how adolescents with T1DM experience heightened levels of anxiety symptoms regarding both the disease itself and diabetes-management specific tasks; other recent studies also confirmed the high prevalence of depression and anxiety symptoms in youth with T1DM and pointed out how these can lead to poorer diabetes management and glycemic control (10, 11).

Within this context, the recent outbreak of the Covid-19 pandemic may become an additional risk factor for adolescents with T1DM. Indeed, restrictions put in place to contain the spread of Covid-19 have implied major repercussions in terms of access to the healthcare system and its resources (12, 13), hindering the possibility for patients to keep up with their follow-up visits with the healthcare professionals. In addition, the lockdown measures imposed to contain the spread of the virus have led to drastic and abrupt changes in adolescents' lifestyles, which could be a further risk factor considering that a consistent daily routine, physical activity, and a healthy diet are pivotal in enabling more efficacious diabetes management among adolescents (14). Nonetheless, the greater closeness between adolescents and their families imposed by the lockdown might be regarded as a favorable aspect for diabetes management, since previous studies have shown that increased and constant family involvement within adolescents' diabetes management was predictive of better blood glucose monitoring and glycemic control (15). However, existing literature highlighted how parents of a child with chronic disease are themselves at increased risk for mental health issues: the burden of partaking in their offspring's everyday disease management can determine high levels of stress, anxiety, and depression symptoms (16–18). Recent literature (19) also shows how parents' and their child's well-being

are strictly intertwined: as mentioned above, adolescents' DM often has a detrimental effect on their parents' well-being; this, on its part, can reflect in low parental self-efficacy, which in turn was shown to have negative effects on their child's self-management and metabolic control (19). On the other hand, there is evidence that adolescents with strong family support display better adherence and glycemic control (20). This, overall, illustrates how both parents and their child with T1DM are involved in maintaining positive diabetes management, which is therefore deemed as a "family disease" (21, 22).

The aforementioned evidence highlights the need to investigate how the ongoing pandemic has affected and still affects adolescents with T1DM, verifying how this topic has been explored within the literature in order to collect evidence and suggestions on which to base and tailor future research and interventions. Therefore, the current scoping review was conducted to map the relevant literature related to the impact of the Covid-19 pandemic on adolescents with T1DM and their caregivers. The broader question guiding this scoping review is "How has the Covid-19 influenced diabetes management and well-being of adolescents with T1DM and their caregivers?". In this regard, it should be noted that the present study followed the definition of adolescence proposed by WHO, according to which it is a period that covers the age from 10 to 19 years (23). Three different and more specific questions were further outlined under this umbrella:

1. What are the protective and risk factors among adolescents with T1DM in the context of Covid-19?
2. How did Covid-19 influence the role of caregivers in supporting their adolescents with T1DM?
3. Which prevention measures have been implemented so far to support adolescents with T1DM in the context of Covid-19?

## MATERIALS AND METHODS

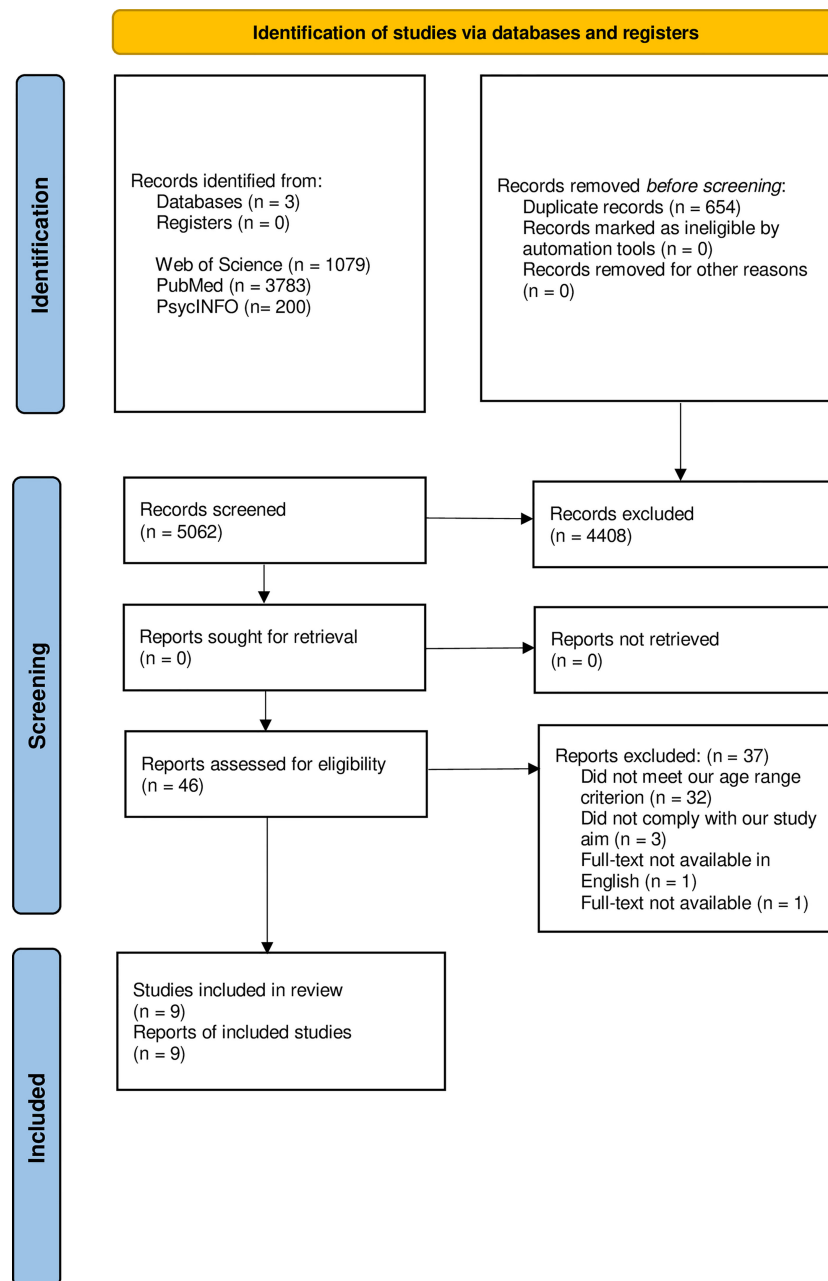
### Scoping Review

Scoping reviews are aimed at mapping the core concepts that underlie a precise research topic by analyzing its nature, features as well as the amount of investigation conducted (24), while providing a global overview of the content and/or findings of it. Indeed, scoping reviews are commonly applied "for reconnaissance" (22, p. 141), that is, to allow for clarification when a body of literature has not yet been reviewed or when there may be inconsistencies and/or heterogeneity on a topic (25).

### Search Strategy

The current scoping review was conducted in compliance with the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) extension for Scoping Reviews (PRISMA-ScR) guidelines (26), as shown in **Figure 1**.

Three electronic bibliographic databases, specifically Web of Science, PubMed and PsycINFO, were screened to identify studies published during the years 2020 and 2021, to ensure they were conducted during the Covid-19 pandemic. Studies were identified using the following MeSH terms: *type 1 diabetes mellitus, adolescent\* OR adolescence, caregiver\* OR parent\*, well-*



**FIGURE 1** | The PRISMA-ScR 2020 flow diagram of the literature search and the selection process (26).

*being, anxiety, stress, depression, health-related quality of life, quality of life, COVID-19, diabetes management.*

## Study Screening

The titles and abstracts retrieved from the above-mentioned electronic databases were independently screened by one author (GDA) and any doubt has been solved by consulting two other authors (GB and EM). This initial screening has been conducted by a single author because of its preliminary nature. The more thorough full-text screening needed to assess studies eligibility, in

line with inclusion and exclusion criteria, has been performed independently by two authors (GB and EM) through a double-blind process; any doubt or conflict has been solved by consulting a third author (SS).

## Inclusion Criteria

Studies were included in the present study if they fulfilled the following inclusion criteria: (I) focused on adolescents with T1DM aged 10 to 19 years [according to the WHO's definition of adolescence (23)]; (II) focused on the caregivers of adolescents



with T1DM aged 10 to 19 years; (III) being published in academic journals during the Covid-19 pandemic and (IV) having undergone peer-reviewing; being written in English; (V) investigated the impact of the Covid-19 pandemic upon adolescents and/or caregivers' regarding diabetes management, well-being, depression, anxiety, stress, diabetes distress, quality of life and adolescents' health-related quality of life, and/or (VI) evaluated prevention measures deployed during the Covid-19 pandemic to support adolescents with T1DM both medically and psychologically.

## Exclusion Criteria

Studies were excluded if they met the following criteria: (I) being a review, dissertation, conference abstract, editorial, or commentary; (II) focused solely on children, young adults, adults, or adolescents with Diabetes Ketoacidosis (DKA); (III) provided only aggregated data for children and adolescents or adults; (IV) focused on any other medical disease different from T1DM.

## Data Extraction and Management

Data extraction was independently performed by two authors (GB and GDA) and any disagreement was resolved by consulting a third author (EM). The data extracted were the studies' DOI, first author's surname, year of publication, country of origin, study design, period (date and month) of the Covid-19 pandemic in which the study was conducted, adolescents and/or caregivers' characteristics (e.g., sample size, age, gender), diabetes duration, assessment instruments used to investigate the mentioned variables and, lastly, outcomes of interest (i.e., adolescents and/or caregivers diabetes management, well-being, depression, anxiety, stress, diabetes distress, quality of life, adolescents' health-related quality of life and prevention measures divulged to adolescents with T1DM).

## RESULTS

### Search Process Results

The search process results are shown in **Figure 1**. A total of 5062 studies were identified following the initial database search. After duplicate removal, the preliminary screening of titles and abstracts was performed on a total of 4408 studies, resulting in 46 studies, which were further evaluated for eligibility through full-text screening. In line with the inclusion and exclusion criteria, 9 studies were included, and 37 studies were excluded; the full list of reasons for exclusion is reported within the supplementary material (**Supplementary Material Table S1**).

### Studies' Characteristics

Characteristics of the included studies are summarized in **Tables 1A, B**. Studies were published between 2020 and 2021 and were all conducted in 2020, thus during the first wave of the Covid-19 pandemic, including the lockdown period. A total of  $N = 305$  adolescents (50.07% female) and  $N = 574$  caregivers (95.45% female) were identified.

Among the included studies,  $N = 2$  (30, 35) were specifically focused on adolescents,  $N = 4$  (29, 32–34) compared children and adolescents,  $N = 1$  (31) compared children, adolescents, and adults, and  $N = 2$  (27, 28) compared caregivers of children with T1DM vs. caregivers of adolescents with T1DM. In this regard, it should be noted that high heterogeneity has emerged within studies' reporting of adolescents' age: only one study (35) provided mean, standard deviation (SD) and specific age range of participants, one study (30) provided mean age and SD, yet not the age range, and one (29), albeit providing this information for the aggregated sample comprising both children and adolescents, did not mention the specific demographic characteristics of the adolescent subsample. About the remaining included studies, only  $N = 2$  reported the sample's age range (32, 34), while  $N = 2$  (31, 33) reported the sample's median age, IQR and age range. Furthermore, the two studies, which focused on caregivers (27, 28), did not report information regarding their child's age. Lastly, information on the household's socio-economic status was reported by  $N = 2$  studies only (29, 35).

Overall,  $N = 5$  studies focused solely on the medical components of adolescents' T1DM, thereby analyzing their glycemic control as assessed through the glycemic indices shown in **Figure 2**. More specifically,  $N = 4$  studies (29–31, 34) reported the Time in Range (TIR), comprising also the Time Above Range (TAR) and the Time Below Range (TBR) which were reported by  $N = 3$  (30, 31, 34) studies. Hemoglobin A1c (HbA1c) was instead reported by  $N = 6$  studies (29, 31–35), with  $N = 2$  studies also reporting information about the Glucose Management Indicator (GMI) (30, 31) representing the estimates A1c (eA1c). The Low and High Blood Glucose Indices (LBGI and HBGI, respectively) were reported by  $N = 2$  studies (29, 31), while the Mean Glucose by  $N = 3$  studies (29, 31, 34); of these,  $N = 2$  (29, 31) also provided the sample's glucose SD. The coefficient of variation expressed in percentage (CV%) was reported by  $N = 3$  studies (29, 30, 34). Furthermore, among these studies,  $N = 3$  (29, 30, 34) only evaluated and provided information on medical measures, while  $N = 2$  (31, 35) provided both medical measures and physical activity-related aspects. Remarkably, only one study (33) (see **Figure 2**) took into account adolescents' psychological variables by investigating their diabetes distress (DD).

Both studies, which focused on caregivers (27, 28), evaluated their emotional burden and worries referred to their child's diabetes management. One also evaluated caregivers' likelihood of developing mental health issues during lockdown (28). It is noteworthy that one study (32) evaluated perceived stress, but unclearly reported if it was assessed referring to adolescents with T1DM or to their caregivers.

### Results of Individual Evidence and Overall Synthesis

The results of the included studies are charted in tabular form (**Tables 2A–C**) in line with the research questions posed by the current scoping review.

Many inconsistencies and overall heterogeneity in information reporting have emerged, in particular regarding adolescents' age.

**TABLE 1A |** Studies Characteristics–Population.

Author, year	Country	Study Design	Population [N, Gender, Age ( <i>M</i> ± <i>SD</i> , <i>Range</i> )]		Socio-demographic characteristics [Ethnicity, SES]	Diabetes dura- tion (years)
			Caregivers	Adolescents		
Alessi et al. (27)	Brazil	Web-based qualitative research	■ N = 144	■ N = N.R. ■ Age = 11.7 ± 4.3	N.R.	N.R.
Alessi et al. (28)	Brazil	Cross-sectional study	■ N = 381 ■ (95.3% female 89.8% mothers) ■ Age = 40.3 ± 8.0	■ N = 146	■ 68.8% white ■ 54.1% lower-middle income	N.R.
Brener et al. (29)	Israel	Longitudinal study	N.A.	N.R.	N.R.	N.R.
Ceconi et al. (30)	Italy	Longitudinal study	N.A.	■ N = 13 (62% female) ■ Age = 14.2 ± 3 ■ N = 24 (37.5% female) ■ Age = 13-17 ■ Median age: 15.6 [IQR: 14.2-16.8]	N.R.	N.R.
Di Dalmazi et al. (31)	Italy	Longitudinal study	N.A.	■ N = 61 (57.4 female) ■ Age: 10-18 years	N.R.	■ Median age = 7.2 ■ [IQR = 5.1-9.5]
Elhenawy et al. (32)	Egypt	Cross-sectional study	N.A.	■ N = 61 (57.4 female) ■ Age: 10-18 years	N.R.	■ 6.6% (6 months-1 year) ■ 32.8% (1-5 years) ■ 60.7% (>5 years)
Mianowska et al. (33)	Poland	Longitudinal study	■ N = 56 (81.8% mothers) ■ Age = N.R.	■ N = 55 (63.6% male) ■ Age = 12-18 ■ Median age: 14.4 ■ [IQR = 13.6-16.1]	N.R.	■ Median age = 4.5 ■ [IQR = 1.8-8.8]
Minuto et al. (34)	Italy	Longitudinal study	N.A.	■ N = 58 ■ Age = 14-18	N.R.	N.R.
Telford et al. (35)	New Zealand	Cross-sectional study	N.R.	■ N = 33 (58% female) ■ Age = 14.1 ± 1.6 (11-18)	■ N = 26 European ■ N = 3 Māori ■ N = 3 Pacific ■ N = 1 Other ■ NZDep18 = 4.7 ± 3.1 ■ School decile = 6.2 ± 3.2	6.2 ± 3.3

NZDep18, New Zealand Deprivation Index 2018; IQR, Interquartile Range; School decile, "School decile is calculated by the Ministry of Education and reflects the proportion of students within the school roll who come from low socioeconomic neighborhoods. Deciles are denoted on a scale from 1–10, where lower decile represents lower income communities." (9, p. 3). N. R., not reported; N. A., not available.

Notwithstanding this, for what concerns diabetes management, included studies showed a stable and even improved glycemic control among adolescents with T1DM throughout the pandemic. Notably, a study has reported stable TIR and HbA1c values from pre-lockdown (31), while others have shown improved TIR between the two periods (29, 30) as well as improved TIR (30, 34) and HbA1c (34) from pre-and post-lockdown. However, one study (32) reported a worsening in glycemic control as indexed by increased HbA1c from pre-to post-lockdown. None of the included studies has investigated differences in metabolic control based either on the type of insulin therapy regimen or the type of glucose monitoring.

The protective or risk factors for adolescents' adjustment throughout the pandemic have not been specifically evaluated by the included studies, as they have mainly focused on providing a descriptive "overview" of the situation by mostly referring to the medical aspect of T1DM. Nonetheless, the need to take action as regards the much-reduced physical activity during the lockdown period was reported (34, 35), particularly in light of a foreseen continuation of pandemic-related restrictions. Despite this, some authors (30, 31, 34) have developed a "positive lockdown effect" hypothesis, whereby more stable and constant life routines and

reduced everyday life stress might have accounted for the above-reported stable or improved glycemic control shown by adolescents with T1DM. It is noteworthy that the psychological impact of both the pandemic and lockdown has been investigated by one study only (33), which has compared adolescents' DD levels pre-and during the lockdown, showing a decrease between these two periods, especially in girls. In this regard, the authors (33) pointed out that before the Covid-19 pandemic neither adolescents' nor their parents' DD was influenced by their mode of insulin therapy (i.e., multiple daily injections vs. continuous subcutaneous insulin infusion) nor by the type of glucose monitoring [continuous glucose monitoring (CGM) vs. self-monitoring of blood glucose (SMBG)]. Comparably, during the lockdown period, they observed no changes in DD levels neither among adolescents who had changed the type of glucose monitoring (from SMBG to CGM) nor among those continuing with SMBG.

In line with the scarce investigation of adolescents' psychological adjustment, no specific prevention measures seem to have been deployed and evaluated during the pandemic to specifically support the overall adjustment of adolescents with T1DM. However, Ceconi and colleagues (30), stressed the potentiality of telemedicine to support adherence and self-efficacy during the lockdown.

**TABLE 1B |** Studies Characteristics–Outcome(s) of interest.

Author, year	Assessment period	Outcome	Assessment tool
Alessi et al. (27)	May 18 <sup>th</sup> –June 9 <sup>th</sup> , 2020	<ul style="list-style-type: none"> <li>■ Burden of care</li> <li>■ Personal emotional impact</li> </ul>	Qualitative interview
Alessi et al. (28)	May 18 <sup>th</sup> –June 9 <sup>th</sup> , 2020	<ul style="list-style-type: none"> <li>■ Pandemic-related emotional burden</li> <li>■ Mental disorders</li> <li>■ Diabetes-specific emotional burden</li> </ul>	<ul style="list-style-type: none"> <li>■ <i>Ad hoc</i> 5-points Likert scale questionnaire.</li> <li>■ Self-Report Questionnaire (SRQ-20).</li> <li>■ <i>Ad hoc</i> 5-points Likert scale self-report.</li> </ul>
Brener et al. (29)	<ul style="list-style-type: none"> <li>■ Pre-lockdown = February 23<sup>rd</sup>–March 7<sup>th</sup>, 2020</li> <li>■ During lockdown = March 25<sup>th</sup>–April 7<sup>th</sup>, 2020</li> </ul>	Glycemic control	CGM metrics (TIR, HbA1c, mean glucose, glucose SD) assessed through ambulatory glucose profile report.
Ceconi et al. (30)	<ul style="list-style-type: none"> <li>■ Pre-lockdown = February 10<sup>th</sup>–23<sup>rd</sup>, 2020</li> <li>■ During lockdown = March 9<sup>th</sup>–22<sup>nd</sup>, 2020</li> <li>■ Semi-lockdown = May 4<sup>th</sup>–17<sup>th</sup>, 2020</li> <li>■ Post-lockdown = May 18<sup>th</sup>–31<sup>st</sup>, 2020</li> </ul>	Glycemic control	CGM metric (TIR, TAR, TBR) and GMI, assessed through tele-visit reports.
Di Dalmazi et al. (31)	<ul style="list-style-type: none"> <li>■ Pre-pandemic = January 30<sup>th</sup>–February 19<sup>th</sup>, 2020</li> <li>■ Pre-lockdown = February 20<sup>th</sup>–March 10<sup>th</sup>, 2020</li> <li>■ During lockdown = March 11<sup>th</sup>–20<sup>th</sup>, 2020</li> </ul>	<ul style="list-style-type: none"> <li>■ Glycemic control</li> <li>■ Physical activity</li> </ul>	<ul style="list-style-type: none"> <li>■ CGM metrics (TIR, TAR, TBR, Mean glucose, glucose SD, LBGI, HBGI), GMI, HbA1c.</li> <li>■ International Physical Activity Questionnaire-Short Form (IPAQ-SF).</li> </ul>
Elhenawy et al. (32)	<ul style="list-style-type: none"> <li>■ Pre-lockdown</li> <li>■ Post-lockdown</li> </ul>	<ul style="list-style-type: none"> <li>■ Diabetes management</li> <li>■ Glycemic control</li> </ul>	<ul style="list-style-type: none"> <li>■ Questionnaire administered online, through phone calls.</li> <li>■ HbA1c.</li> </ul>
Mianowska et al. (33)	<ul style="list-style-type: none"> <li>■ Pre-pandemic = November 2019–February 2020</li> <li>■ During lockdown = April 2020</li> </ul>	<ul style="list-style-type: none"> <li>■ Diabetes distress adolescents</li> <li>■ Diabetes distress caregivers</li> <li>■ Glycemic control</li> </ul>	<ul style="list-style-type: none"> <li>■ Problems Areas in Diabetes-Teen (PAID-T).</li> <li>■ Problem Areas in Diabetes-Parents of Teens (P-PAID-T).</li> <li>■ HbA1c (CGM, SMBG)</li> </ul>
Minuto et al. (34)	<ul style="list-style-type: none"> <li>■ Pre-pandemic = February 10<sup>th</sup>–23<sup>rd</sup>, 2020</li> <li>■ During lockdown = April 17<sup>th</sup>–30<sup>th</sup>, 2020</li> </ul>	<ul style="list-style-type: none"> <li>■ Glycemic control</li> <li>■ Physical activity</li> </ul>	<ul style="list-style-type: none"> <li>■ TIR, TAR, TBR, HbA1c.</li> <li>■ Sport in hours/week.</li> </ul>
Telford et al. (35)	During lockdown = May 2020	<ul style="list-style-type: none"> <li>■ Glycemic control</li> <li>■ Physical activity</li> </ul>	<ul style="list-style-type: none"> <li>■ HbA1c</li> <li>■ Physical Activity Questionnaire for Older Children (PAQ-C) aged 11–12 years; Physical Activity Questionnaire for Adolescents (PAQ-A) aged 12–18 years; Children's Physical Activity Questionnaire (CPAQ; parent-proxy measure)</li> </ul>

CGM, Continuous Glucose Monitoring; GMI, Glucose monitoring Index; LBGI, Low Blood Glucose Index; HBGI, High Blood Glucose Index; SMBG, Self-monitoring of blood glucose; TIR, Time in Range; TAR, Time Above Range; TBR, Time Below Range.

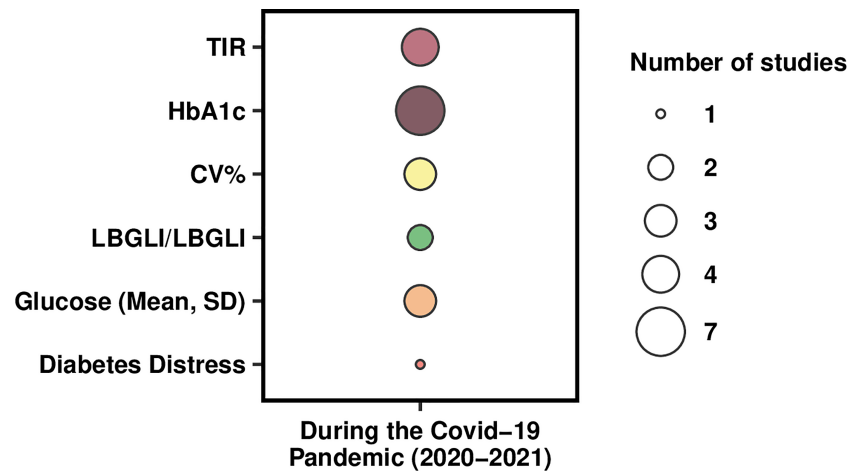
The impact of the pandemic upon caregivers was mainly reflected in increased perceived burden in both diabetes management and child-related worry and burden (27, 28). Still, results also showed that caregivers of adolescents with T1DM did not significantly differ from parents in general in the likelihood of presenting mental health issues during a lockdown.

## DISCUSSION

The present scoping review is aimed at evaluating evidence useful to answer the previously reported three questions that fall within the broader question “How has Covid-19 influenced diabetes management and well-being among adolescents with T1DM and their caregivers?”. To reach this goal, five thousand sixty-two titles were initially identified; yet only nine studies were eligible to be included. Notably, during the full-text screening, several studies were removed since their attention was directed towards children with T1DM under or equal to 9 years of age. Indeed, the

adolescent group with T1DM was scarcely taken into consideration within the literature, and the studies who did often showed results aggregated with those of children under the age of 9 (see **Supplementary Material**): among the included studies, only 23% (two studies) were specifically oriented towards the effect of Covid-19 on adolescents with T1DM (30, 35).

Overall, the included studies have depicted the general *scenario* of the effect of Covid-19 among adolescents with T1DM and their caregivers: this lays the basis for the development of future research, which, beyond the reported choice of age group to investigate, should also be more careful and comprehensive in defining the outcomes to investigate. On this matter, the majority of the included studies focused on evaluating the impact of Covid-19 on medical indices among adolescents with T1DM. In general, they underlined a stable and even improved TIR and HbA1c pre-, during and post-lockdown (29–31, 34), except for one study that showed a downward trend of glycemic control pre- and post-lockdown (32). Another relevant result that emerged was the reduction in physical



**FIGURE 2** | Bubble plot showing the distribution of identified outcomes.

activity, which reflects the fact that the lockdown period has led to a more sedentary lifestyle (34, 35). In this scenario, only one study evaluated the effect of Covid-19 on DD among adolescents with T1DM, thereby taking into account the psychosocial side. Authors pointed out that adolescents experienced moderate DD levels, which although decreased only among girls from pre-to-during lockdown (33). Nonetheless, before the Covid-19 pandemic, girls showed significantly higher DD than boys (33), which suggests that the more stable life routine allowed by lockdown, as reported by other authors (27, 30, 34) referring to its effect upon glycemic control, was much needed and useful for female adolescents as regards their DD. Referring, instead, to diabetes management and glycemic control, evidence suggested that being older adolescents favored improved TIR and reduced glucose variability expressed both as the glucose SD and the CV% throughout the Covid-19 pandemic. In addition to their greater maturity, the increased detachment from the family unit and the increased sense of responsibility that can be observed during late adolescence might further push adolescents toward a greater and more autonomous diabetes management, which in turn leads to improved glycemic control. Contrarily, lower socio-economic status and higher BMI might represent risk factors leading to worsened glycemic levels. Altogether, this evidence provides some preliminary evidence to answer the first specific question of the current scoping review (i.e., *What are the protective and risk factors among adolescents with T1DM in the context of Covid-19?*).

It is also worth noting that the complexity of diabetes management also necessitates continuous caregivers' involvement in adolescents' care in order to establish adaptive family *teamwork*, that sees the joint effort of both the adolescent and the caregiver and thereby prevent the worsening of glycemic control and the maintenance of adherence (14). Indeed, the family provides key support for the optimal management of a child's diabetes, whereby if family conflicts occur, the adolescent's psychophysical health might be affected as well. In this regard, the second specific question to be answered in the

present scoping review is "*How did Covid-19 influence the role of caregivers in supporting their adolescents with T1DM?*". Three studies assessed the emotional impact of Covid-19 (27, 28, 33) upon the caregivers of adolescents with T1DM, also investigating their incidence of mental health disorders as compared to parents from the general population (28). These authors showed mixed results: on the one hand, caregivers have experienced symptoms of anxiety, uncertainty and worries related to the suspension of medical appointments, along with an augmented need to provide care to their child (27, 28); on the other hand, caregivers did not show any worries specifically related to Covid-19 and their DD levels have even decreased (33). As regards this latter result, and as previously pointed out, some studies have speculated a "*positive lockdown effect*" (28, 30, 34), suggesting that a more stable routine in adolescents and caregivers resulting from the limitations imposed by the pandemic may underline the positive and favorable evidence identified regarding glycemic control and DD. Notwithstanding, given the little research identified and evaluated, the need for prevention interventions and support programs directed to all adolescents with T1DM and their caregivers should still be considered, particularly taking into account the current continuous changes in the pandemic-related restrictions, which strongly limits the possibility for stable lifestyle routines. Therefore, following this line, intervention measures represent the next step to be taken into consideration and subsequently implemented, as a mean of support and/or prevention for adolescents with T1DM and their caregiver(s).

In the context of the Covid-19 pandemic, it is even more necessary to encourage and increase, pediatric access to CGM devices, in order to favor glycemic monitoring and data sharing with healthcare professionals and the caregivers that assist the adolescent with T1DM. In this regard, it is worth mentioning that mental health professionals should be intended as active components of the multidisciplinary team, equally involved in providing psychosocial support to all caregivers and adolescents with T1DM (14). Accordingly, digital health solutions directed to

**TABLE 2A |** RQ1: What are the protective and risk factors among adolescents with T1DM in the context of Covid-19?

Author	Protective Factors	Risk Factors	Overall results	Relevant study limits
Brener et al. (29)	■ Being an older adolescent was associated with improved TIR, lower glucose SD, and reduced CV.	■ A lower socioeconomic position was associated with increased delta-mean glucose.	■ Glucose variability was more stable among adolescents compared to children, both before and during lockdown. ■ Adolescents, compared to children, showed improved variability markers during lockdown.	■ Only considered patients that used CGM*.
Di Dalmazi et al. (31)	—	—	■ Mean daily time spent sitting was higher among adolescents compared to children. ■ Among adolescents, all CGM measures remained unchanged from before the lockdown period, while they showed improvement among children. ■ Glucose SD among adolescents decreased from before to during the lockdown period.	■ Protective factors were solely evaluated among adults. ■ Only considered patients that used CGM*. ■ Compared to the broader literature, the adolescent group had better mean HbA1c levels*.
Elhenawy et al. (32)	—	—	■ Adolescents (and children aged 5-10 years) showed increased HbA1c levels from pre-lockdown to after lockdown, compared to children aged 0-5 years. ■ Adolescents (and children aged 5-10 years) showed worse diabetes control during lockdown compared to children aged 0-5 years.	■ Protective/risk factors were solely considered referring to the aggregated sample (i.e., youth aged 0-18). ■ Unclear if perceived stress was assessed on youth or their caregivers.
Mianowska et al. (33)	■ During lockdown, being female was associated with significantly decreased DD.	■ High adolescents' DD before the pandemic was associated with reduced changes in DD scores during the lockdown.	■ Before the pandemic, adolescents' and their caregivers' DD positively associated with adolescents' BMI. ■ Adolescents showed reduced DD during lockdown, especially girls. ■ Females presented significantly greater DD than boys before the pandemic. ■ DD remained unchanged among male adolescents from before to during lockdown.	■ DD assessment during lockdown was performed by phone*.
Minuto et al. (34)	—	—	■ Adolescents showed improved glycemic control from pre- to post-lockdown. ■ Significant reduction of physical activity from pre- to post-lockdown among all age groups (i.e., children, adolescents, adults).	■ The protective role played by physical activity that emerged was solely evaluated considering the aggregated sample.
Telford et al. (35)	—	■ Having T1DM predicted increased BMI during lockdown. ■ Belonging to a lower socio-economic position and higher BMI is associated with poorer glycemic control.	■ Adolescents with T1DM showed significantly higher BMI compared to the control group. ■ Physical activity level showed no association with adolescents' socioeconomic position, HbA1c levels, or the method of insulin delivery. ■ BMI was negatively associated with physical activity during lockdown. ■ All participants showed reduced physical activity during lockdown; rates did not differ between the T1DM and control group, nor between males and females.	■ No information about pre-lockdown physical activity levels*.

BMI, Body Mass Index; CGM: Continuous Glucose Monitoring; CV, Coefficient of Variation; DD, Diabetes distress; glucose SD, glucose standard deviation; TIR, Time in range; \*Authors' reported study limit relevant to the current scoping review.

both psychosocial and medical aspects should also be developed and promulgated. Indeed, the third and last specific question to be answered in the current scoping review is “Which prevention measures have been implemented so far to support adolescents with T1DM in the context of Covid-19?”. Only one of the included studies has investigated the role of telemedicine in monitoring adolescents' glycemic control. The authors found an improvement in the glycemic control among adolescents *via* the continuous assistance deployed through telemedicine during and even post-lockdown, speculating a “dragging effect” (5, p. 5). Nonetheless, the authors themselves stated that there is no

evidence to prove the efficacy of this digital intervention on adolescents' improved glycemic levels (30). Still, the literature shows that most eHealth interventions are predominantly oriented towards adults with diabetes, and they are mainly pilot or proof-of-concept studies (36–38).

## LIMITATIONS

The present scoping review allowed for the delineation of a comprehensive picture of the available literature on the impact of



**TABLE 2B |** RQ2: How did Covid-19 influence the role of caregivers in supporting their adolescents with T1DM?

Author	Constructs	Psychological consequences	Diabetes-management related consequences	Relevant study limits
Alessi et al. (27)	<ul style="list-style-type: none"> <li>■ Burden of care</li> <li>■ Personal emotional impact</li> </ul>	<ul style="list-style-type: none"> <li>■ The burden of care in terms of lack of information on the association between COVID infection and T1DM.</li> <li>■ Reported exhaustion and weariness toward the economic situation and health institutions' sanitary conditions.</li> <li>■ 1/3 reported exhaustion and overload consequent to assume the double role of full-time caregiver and family provider.</li> <li>■ Distress referred to the perceived ineptitude resulting from difficulties in balancing work and caregiving demands.</li> <li>■ Reported feelings of overwhelm and lack of privacy.</li> </ul>	<ul style="list-style-type: none"> <li>■ Anxiety, uncertainty, and feelings of hopelessness resulting from suspension of medical appointments.</li> <li>■ Frustration has given by difficulties linked to glycemic control.</li> <li>■ Guilt and uncertainty about ensuring proper nutritional food because of financial difficulties due to the COVID-19 situation.</li> </ul>	<ul style="list-style-type: none"> <li>■ Interviews did not allow discussion*.</li> <li>■ The majority of the sample (95.6%) was female*.</li> </ul>
Alessi et al. (28)	<ul style="list-style-type: none"> <li>■ Pandemic-related emotional burden</li> <li>■ Mental health linked to social distancing</li> <li>■ Diabetes-specific emotional burden</li> </ul>	<ul style="list-style-type: none"> <li>■ No difference between caregivers of youth with T1DM and caregivers in the control group in terms of overall relationships satisfaction and family perceived welcomeness</li> <li>■ No difference between caregivers of youth over 12 with T1DM and caregivers in the control group in the likelihood of developing mental health issues.</li> <li>■ Increased likelihood of showing child-related concern, personal emotional burden, and child-related emotional burden among caregivers of youth over 12 and with T1DM.</li> </ul>	<ul style="list-style-type: none"> <li>■ Increased difficulty in accessing medical assistance and purchasing medical supplies among parents of youth with T1DM aged both below and above 12 during the pandemic.</li> </ul>	<ul style="list-style-type: none"> <li>■ The majority of the sample (95.3%) was female*.</li> <li>■ The control group was recruited through "medical student leagues"</li> </ul>
Mianowska et al. (33)	<ul style="list-style-type: none"> <li>■ Diabetes distress</li> </ul>	<ul style="list-style-type: none"> <li>■ Caregivers of adolescents with T1DM showing high DD levels before lockdown reported a reduced change in DD scores during lockdown.</li> <li>■ Overall, caregivers showed no difference in DD levels from pre- to during lockdown.</li> </ul>	<ul style="list-style-type: none"> <li>■ Type of glucose monitoring and changing the monitoring tool did not influence the DD levels of caregivers of adolescents with T1DM.</li> </ul>	<ul style="list-style-type: none"> <li>■ DD assessment during lockdown was performed by phone*.</li> <li>■ No socio-demographic information of caregivers.</li> <li>■ Caregivers were for the majority (81.8%) mothers.</li> </ul>

DD, Diabetes distress; \*Authors' reported study limit relevant to the current systematic review.

Covid-19 upon adolescents with T1DM and their caregivers; however, this review did not provide a quantitative synthesis of effect sizes. Moreover, diabetic ketoacidosis (DKA), a complication of T1DM, was not included as an outcome in the present study for its specific characteristics, thus, being DKA a rather common and relevant complication in adolescents with T1DM. Future research is needed to consider DKA weight in diabetes management among adolescents. Lastly, only one author (GDA) independently screened the titles and abstracts. However, this phase of the search process was a preliminary step based only on the evaluation of title and abstract, while the more specific and thorough full-text screening has been conducted following a double-blind process.

## CONCLUSIONS

The main and broader question of the present scoping review was: "How has Covid-19 influenced diabetes management and well-being among adolescents with T1DM and their caregivers?". It is interesting to note that during the lockdown period a stable

routine seems to have played a protective role towards glycemic control and DD among adolescents with T1DM, to the point that the term "positive lockdown effect" was employed. Furthermore, being an older adolescent has also emerged as a possible protective factor for glycemic control, which might be given by the greater psycho-neurological maturity of older adolescents compared to younger ones. On the contrary, a higher BMI was associated with worsened glycemic levels, which stresses the need to carefully monitor eating habits as well as physical activity with prompt attention and intervention. Referring to caregivers, studies showed limited and mixed results regarding their psychological state during the Covid-19 pandemic. Altogether, preliminary findings from the included studies do not allow to draw sound conclusions regarding risk and protective measures, and thus on the actual impact of the Covid-19 upon adolescents with T1DM and their caregiver. Thereby, future research should endeavor to answer the three questions posed by this review in order to gain an in-depth understanding of the underlying risks and protective factors that Covid-19 may have raised among adolescents with T1DM and their caregivers. Moreover, interventions supporting the medical and psychological well-



**TABLE 2C |** RQ3: Which prevention measures have been implemented so far to support adolescents with T1DM in the context of Covid-19?

Author	Prevention Measure	Characteristics	Results	Relevant study limits
Ceconi et al. (30)	Health care continuous assistance through telemedicine	N/R	<ul style="list-style-type: none"> <li>• Telemedicine conducted during the lockdown period and the month following the relaxation of restrictions favored stable and improved glycemic control among adolescents with T1DM.</li> <li>• Hypothesized “dragging effect” of improved glycemic control following lockdown as consequent to constant telemedicine interactions with the physician.</li> </ul>	<ul style="list-style-type: none"> <li>• Not possible to assess telemedicine efficacy on glycemic control (e.g., no control group)*.</li> <li>• Insufficient information on the procedure and overall unclear methodology.</li> <li>• Did not evaluate contextual variables (e.g., socio-demographic information).</li> <li>• No information on the analysis was performed.</li> </ul>

\*Authors' reported study limit relevant to the current scoping review.  
N. R., not reported.

being of both adolescents and caregivers during the Covid-19 pandemic should be strengthened, and new and effective interventions, both in digital and in traditional settings, should be developed. A further important aspect that has emerged from the current scoping review is the need to conduct studies that more carefully distinguish between children and adolescents with T1DM, as their developmental challenges are distinct and have different implications, even more so if a chronic disease is involved. Lastly, this scoping review permitted to highlight the need to also consider psychosocial variables relevant to T1DM when investigating the impact of Covid-19, as the psychosocial components of the disease are influenced by the medical ones and vice versa. Indeed, both psychosocial and medical variables are bidirectionally associated (39) and they are comparably relevant for the investigation, prevention, and promotion of the broader well-being of adolescents with T1DM. In addition, the joint consideration of the two may be of practical benefit in better comprehending the whole functioning of adolescents with T1DM. This would allow to further tailor interventions upon the

specific characteristics of this age group, which would be of great value particularly during the pandemic period.

## AUTHOR CONTRIBUTIONS

GB and EM defined the search strategy. GD'A did the first article screening. GB and EM did the full-text screening and their selection. GB and GD'A did the data extraction. EM conducted the synthesis and GB wrote the narrative summary. SS critically revised the summary and manuscript for important intellectual content. All authors contributed to the article and approved the submitted version.

## SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: <https://www.frontiersin.org/articles/10.3389/fcdhc.2022.835598/full#supplementary-material>

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# Clinical Team Response to the Impact of COVID-19 on Diabetes Self-Management: Findings From a Qualitative Study

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The aims of this study were to explore providers' perceptions of how COVID-19 affected patients' psychological wellbeing and diabetes self-care and discover how providers responded to sustain and improve patients' psychological health and diabetes management during the pandemic. Twenty-four semi-structured interviews were completed with primary care providers (n=14) and endocrine specialty clinicians (n=10) across sixteen clinics in North Carolina. Interview topics included: (1) current glucose monitoring approaches and diabetes management strategies for people with diabetes (2) barriers and unintended consequences encountered with respect to diabetes self-management, and (3) innovative strategies developed to overcome barriers. Interview transcripts were coded using qualitative analysis software and analyzed to identify cross-cutting themes and differences between participants. Primary care providers and endocrine specialty clinicians reported that people with diabetes experienced increased mental health symptoms, increased financial challenges and positive and negative changes in self-care routines due to COVID-19. To offer support, primary care providers and endocrine specialty providers focused discussions on lifestyle management and utilized telemedicine to connect with patients. Additionally, endocrine specialty clinicians helped patients access financial assistance programs. Findings indicate that people with diabetes experienced unique challenges to self-management during the pandemic and providers responded with targeted support strategies. Future research should explore the effectiveness of these provider interventions as the pandemic continues to evolve.

**Keywords:** diabetes, self-management, self-care, COVID-19, qualitative research, mental health

## INTRODUCTION

COVID-19 restrictions challenged patient-centered care for diabetes. Early in the pandemic, many ambulatory practices halted their in-person visits in favor of virtual appointments (1–3). This posed a problem for the management of diabetes, which typically requires routine in-office monitoring, lab testing, and medication management. In the first two months of the pandemic, rates of HbA1c tests fell by as much as 66% (4). There was concern among the diabetes healthcare community that the pandemic would result in poor diabetes outcomes, as interruptions in appointments and HbA1c testing have previously been associated with worsened glycemic control (5, 6).

In addition, people with diabetes have struggled with self-management practices in the face of COVID-19. People with diabetes report eating more and exercising less compared with prior to the pandemic (7–9). Members of the diabetes community also report concerns over finances and employment, which may have impacted insurance status and access to care (8). Additionally, disruptions in diabetes supplies have affected individuals' ability to adhere to medication and self-monitoring recommendations. A U.S. survey of people with diabetes found that one in six people needing insulin experienced a problem. A similar proportion of people had issues obtaining test strips, and 25% had difficulties obtaining pumps or continuous glucose monitoring supplies (10).

In the face of these significant challenges, it is unsurprising that people with diabetes report higher levels of stress and depression than prior to the pandemic (10–12). Restrictions on gatherings limit individuals' access to social support systems and may exacerbate these mental health effects (13). Stress and depression affect glycemic control directly and through their impact on diabetes self-care (14). Therefore, it is imperative for providers to recognize the diverse array of challenges COVID-19 presents to their patients with diabetes and develop targeted strategies for support. In this study, we (1) explore providers' perceptions of how COVID-19 affected patients' psychological wellbeing and diabetes self-care and (2) identify how providers responded to sustain and improve patients' psychological health and diabetes management during the pandemic, with a focus on self-monitoring of blood glucose, A1c testing, dietary intake, and physical activity.

## METHODS

### Study Design

The study used a qualitative design to collect data through in-person and telephone interviews. These in-depth, semi-structured interviews provided rich and detailed descriptions regarding provider impressions of challenges facing patients with diabetes during COVID-19. This study was conducted in the context of a larger study, Re-Think the Strip (RTS), which aims to promote the de-adoption of daily self-monitoring of blood glucose (SMBG) among non-insulin treated patients with controlled type 2 diabetes given the lower utility of this

practice (15–18). Rethink the Strip involves 20 primary care clinics in the North Carolina. We were concerned that decreases in access to A1c test results would lead patients and providers to question the wisdom of de-adopting SMBG during the pandemic. To address this concern, we conducted interviews with staff members within the existing RTS clinics and expanded the interviews to endocrinologists in North Carolina to obtain a more complete picture of diabetes care during COVID-19. Primary care providers focused their discussion on patients with type 2 diabetes, while endocrinologists commented on their experience treating patients with type 1 and type 2 diabetes.

### Study Population

Our study population comprised of 24 diabetes clinicians and staff. This included 9 primary care clinicians and 5 primary care ancillary staff members from the existing RTS practices, and 10 endocrine specialty clinicians. Participants are summarized in **Table 1**. Participants were identified and recruited using purposive sampling based on their ability to provide in-depth, detailed information about diabetes care during COVID-19.

### Data Collection

Semi-structured, in-depth telephone and in-person interviews were conducted from September 2020–August 2021. Before each interview, the researcher explained the goals of the study, reviewed confidentiality measures, and obtained verbal consent. All interviews were recorded using a field recorder with participant consent. The interviews were conducted in English. An interview guide (**Table 2**) was developed prior to participant interviews, based on literature review and previous work completed by the RTS team. Participants were asked a series of pre-determined open-ended questions and follow-up probes were generated based on participant responses. Each interview lasted approximately 35 minutes.

### Data Analysis

Interviews were professionally transcribed and reviewed by a team member for accuracy. Interview transcripts were independently analyzed by two investigators using content analysis. A codebook was developed by the research team, consisting of *a priori* codes derived from discussion questions and additional concepts that emerged from analysis. ATLAS.ti 9, a qualitative software program, was used to facilitate the analysis (19). Differences and discrepancies were discussed and

**TABLE 1** | Interview participants.

Participant Role, Title	Number
Medical Director	1
Primary Care Physician (MD)	2
Nurse Practitioner (NP)	1
Practice Manager	1
Physician Assistant (PA)	5
Registered Dietician (RD)	3
Registered Nurse (RN)	1
Endocrinologist (MD)	10
Total	24



**TABLE 2 |** Key interview questions.

Dimensions	Open Ended Questions
<b>Glucose Monitoring Approaches</b>	As a health care provider, what have been the biggest changes in terms of patient care? How is your practice currently addressing A1c monitoring?
<b>Changes and Barriers in Patients Self-Management Practices</b>	How has your recommendation on glucose monitoring changes, if at all, since COVID-19? What concerns have your patients shared about their diabetes care during COVID-19? How has COVID-19 impacted your patients' ability to adhere to your self-management recommendations? What are challenges your patients have shared about their new glucose monitoring approach or self-management?
<b>COVID-19 Health and Outcomes</b>	To get an overall sense of diabetes control, how often do other indicators like diet, weight, or blood pressure enter the discussions? During this time of COVID-19, for your patients with diabetes, what additional health issues or conditions have come to your attention? Since COVID-19, what changes, if any, have you noticed with your patients' glycemic control?

reconciled. Cross-cutting themes and differences between participants were identified.

## RESULTS

Participant impressions of the impact of COVID-19 on patient self-management were categorized into five key themes, summarized in **Table 3**. Illustrative quotations from primary care providers and endocrine specialty clinicians are presented to highlight study findings.

### Theme 1: Providers Observed an Increase in Mental Health Symptoms Which Made Patient Self-Care More Difficult

Primary care and endocrine providers reported patients had increased mental health symptoms, mainly depression, anxiety, and general stress. These symptoms presented challenges to diabetes self-management.

#### Depression

Both primary care providers and endocrine specialty clinicians noticed that more patients were struggling with depression compared with time prior to the pandemic. Some patients' depression stemmed from isolation and lack of social support due to COVID-19 restrictions. One endocrine provider stated:

*I would say definitely mental health has suffered in all my patients including diabetes patients, lots of just social isolation and general isolation. I'm definitely seeing more depressive symptoms in that regard...*

A primary care provider echoed these sentiments:

*Then there's been quite a bit of depression too. Not necessarily depression that needs medication, but definitely some decreased moods just with patients not being able to see their loved ones, or see their friends, or get out and do anything.*

Isolation seemed to be especially difficult for patients with diabetes who had incorporated social support groups into their self-care routines.

*I think there was a component of maybe even like loneliness or what is it called, like the diabetes distress ... I had an older population that did group classes and things like that. They didn't have the gym to go out and socialize with, which caused them to be depressed, which would cause them to not take as good a care of themselves as they could. Patients that did walking groups, things like that, again, they didn't have that support. (Endocrine Specialty Clinician)*

Patients also experienced depression following the loss of family and friends during the pandemic.

*Depression is very common, stress and they have lost a lot of loved ones and their family which led to stress and stress eating which led to everything like the weight gain and poor control. (Endocrine Specialty Clinician)*

#### Anxiety

Both endocrine specialty clinicians and primary care providers endorsed that patients experienced increased rates of anxiety during the pandemic. One source of anxiety was the risk of contracting COVID-19, especially given the high-risk status of people with diabetes.

*I'm definitely seeing more depressive symptoms in that regard, more anxiety as there was worry about contracting the virus and worry about going out in public, so I've definitely seen that. (Endocrine Specialty Clinician)*

Another significant source of anxiety was financial concerns, as patients lost their job and were forced to juggle competing priorities.

*People are suddenly having to feel the financial losses and that sort of thing with COVID. I think people are definitely stress eating more or just distracted from their own health issues because they suddenly have – trying to figure out how to find another job or how they're going to pay their rent. Dealing with their diabetes is sort of a lower thing on their priority list. (Primary Care Provider)*

Finally, participants reported that caretakers experienced increased anxiety over the desire to protect their loved ones during the pandemic.

**TABLE 3 |** COVID-19 impacts on self-management.

Theme	Subtheme and Illustrative Quotation
<b>Increase in mental health symptoms made self-care difficult.</b>	<p><b>Depression</b>  <i>Then there's been quite a bit of depression too. Not necessarily depression that needs medication, but definitely some decreased moods just with patients not being able to see their loved ones, or see their friends, or get out and do anything. (Primary Care Provider)</i></p> <p><b>Anxiety</b>  <i>We've seen more anxiety, a lot more anxiety, a lot more anxiety and depression as well. But I think it's been, I would say, maybe 75/25 anxiety/depression for me because I only see women. I think women, especially women with young children or families, they're taking this very seriously some of them. It's really affecting them mentally because they're the protectors of the children, and they can't protect their children, and it's really working their nerves very badly. (Primary Care Provider)</i></p> <p><b>General stress and wellbeing</b>  <i>In general I think more folks were just feeling down. In general you could feel that they were stressed. A lot of their normal routine was disrupted, and they were not able to keep up with their families just because everyone was somewhat staying at home. So, I think it was definitely a time where people were just not feeling well. (Endocrine Specialty Clinician)</i></p>
<b>Financial challenges impacted self-care.</b>	<p><b>Job or insurance loss</b>  <i>I think they had more challenges because a lot of people did lose jobs and it was a big challenge to go to doctors and paying copays and everything. They lost insurances too. That way I think they're also having issues paying bills for their medical health. (Endocrine Specialty Clinician)</i></p> <p><b>New Expenses</b>  <i>People who are not working their full hours, people who were having to pay for childcare that didn't usually because the kids were in school ... I think a lot of people were having to pinch a penny here or there, and if they weren't really vested in doing [self-management] before, it was certainly one of the easier things to cut loose. (Primary Care Provider)</i></p>
<b>Restrictions disrupted self-care routines.</b>	<p><b>New family responsibilities</b>  <i>The people who suffer the most are the same people who always suffer the most, women for sure, childcare. There was always kids in the background. They're the ones for the most part stuck with childcare, and elder care, and everything else. (Endocrine Specialty Clinician)</i></p> <p><b>Reduced safe exercise space</b>  <i>They're not able to go to the gym for a long time ... Some of them are even afraid to go out and walk which I kind of told them that hey, you can go outdoors without a mask if you're not around other people it's okay but some were not willing to do that initially so many patients have gained weight. (Endocrine Specialty Clinician)</i></p> <p><b>Reduced access to healthy food</b>  <i>Of course, a lot of people are stress eating or tending to eat food because they really don't want to go to the grocery store as often, so they're not buying as many fresh fruits and vegetables. They're tending to eat more processed, non-perishable foods. (Primary Care Provider)</i></p> <p><b>Increased availability of unhealthy food</b>  <i>Their access to food ended up being worse because they were doing drive-thru rather than going to the grocery store. (Endocrine Specialty Clinician)</i></p>
<b>Restrictions allowed patients to prioritize self-care.</b>	<p><b>Improved diet</b>  <i>They would say, "Yeah, it was great to be home with the kids, and I also cooked all the time, so I did well with my blood sugar monitoring and carb intake," (Endocrine Specialty Clinician)</i></p> <p><b>Increased exercise</b>  <i>I have occasional patients who now find themselves with more free time because of COVID. Maybe their work hours have been cut back or whatever, so they're actually exercising more. (Primary Care Provider)</i></p> <p><b>More time for self-management</b>  <i>A lot of my patients cut down on one to two hours of commuting a day into their office ... they were able to check for the first time three times a day before they ate their meals and could decide how much insulin to give which, in an office environment, sometimes, they wouldn't check before lunch because they didn't want to do it or didn't have time. (Primary Care Provider)</i></p> <p><b>Improved participation in care</b>  <i>And that actually made my patients a little bit more participatory in their diabetes care because there was all these other setbacks meaning they couldn't come in for routine bloodwork and evaluation in a clinic type setting. (Endocrine Specialty Clinician)</i></p>
<b>Clinical team utilized patient-centered strategies.</b>	<p><b>Prioritized lifestyle discussions</b>  <i>With the gyms closing and now that they're back open some people do feel comfortable to go back but some people are still saying "yeah, I'm still not feeling great about it" but then kind of having the discussion of "alright, I get it, I'm not going back to the gym either right now but it is still nice outside and you can walk" and then they're like "oh yeah, I guess I could do that" ... so having to make more of a conscious effort to go for a walk, to get up and move every hour or so to get some more steps in. (Primary Care Provider)</i></p> <p><b>Utilized telemedicine</b>  <i>I would say in the patient who is pretty tech savvy and can upload their CGM or their pump, the virtual visits actually work quite well because we have all of the data in front of us so especially if they're on a CGM, we can estimate their A1C just from that. In that population, I think it actually went pretty well. (Endocrine Specialty Clinician)</i></p> <p><b>Offered financial assistance</b>  <i>We encouraged patients to apply for drug assistance, and sometimes helping them out with doing that. We directed them to clinics, pharmacies, clinics that have pharmacies for indigent patients that offer a drug program that they can access. All of that, and then we do have an active sampling system (Endocrine Specialty Clinician)</i></p>

*We've seen more anxiety, a lot more anxiety, a lot more anxiety and depression as well. But I think it's been, I would say, maybe 75/25 anxiety/depression for me because I only see women. I think women, especially*

*women with young children or families, they're taking this very seriously some of them. It's really affecting them mentally because they're the protectors of the children, and they can't protect their children, and it's*



*really working their nerves very badly. (Primary Care Provider)*

## General Stress and Well-Being

Primary care providers and endocrine participants noted that patients were also facing more general mental health challenges, such as “just feeling down”, or experiencing “high levels of stress”. These mood changes resulted in patients becoming increasingly isolated and, for many patients, translated to more difficulty with diabetes-self management practices.

*I see that the stress is impacting their eating, emotional eating. It's impacting their blood pressure. It's impacting their food choices which is ending up sometimes causing their cholesterol to go up or their blood sugars to be higher so emotional eating, stress eating and things like that. (Primary Care Provider)*

## Theme 2: Patients Encountered Financial Challenges Which Impacted Self-Care

Participants noted patients had trouble affording diabetes supplies, medications, or healthy food due to job or insurance loss or new expenses.

### Job or Insurance Loss

Both primary care providers and endocrine specialty clinicians explained that patients had trouble following self-management strategies due to “financial hardships with some people losing their job”. As one primary care provider explained, “patients who have lost their job often times also have lost their health insurance”. Financial pressures forced patients to choose what expenses to prioritize. Diabetes self-management practices “seem to be easier things to let go of because it's not life-threatening to not test your blood sugar”. One endocrine specialty clinician summarized:

*We have several patients that had to start working two jobs because of COVID and a lot of them were laid off. So a lot of patients lost insurance during COVID. So then they stopped their medications and didn't check their blood sugar because test strips are expensive.*

### New Expenses

In addition to loss of income, primary care and endocrine participants noted that patients had new expenses, such as childcare.

*People who are not working their full hours, people who were having to pay for childcare that didn't usually because the kids were in school ... I think a lot of people were having to pinch a penny here or there, and if they weren't really invested in doing [self-management] before, it was certainly one of the easier things to cut loose. (Primary Care Provider)*

*The cost of the medication in diabetes care has been an issue even as I said pre-pandemic and then the*

*pandemic put more stress on it. People lost their jobs and things like that or they had some other expenses. Let's say child care for example and things like that so the cost of diabetes medication I would say is probably ... challenging. (Endocrine Specialty Provider)*

## Theme 3: Restrictions Created Disruptions to Patient Self-Care Routines

Participants discussed the ways that COVID-19 restrictions disrupted patient self-care routines, including new family responsibilities and changes to diet and exercise habits.

### New Family Responsibilities

Endocrine specialty clinicians noted that new “childcare” or “eldercare” responsibilities impacted patients’ ability to practice self-care. One clinician noted that for many patients, especially women, there were “always kids in the background” during virtual appointments.

*People with diabetes that were having distress related to care that had children at home and then were doing the homeschooling and things like that, their control definitely deteriorated because they were struggling to manage just day-to-day activities... (Endocrine Specialty Clinician)*

Another endocrine clinician wondered if family responsibilities may have played a role in the differences he observed between type 1 and type 2 diabetes patients:

*Actually, come to think of it, the majority of my type 1's would be in their 30's or maybe 40's ... And with the pandemic, schools were shut so everything was virtual. So now I can imagine if they had to help with their kids as well as thinking of themselves, that would have been a lot more challenging. With my type 2's, a little bit older in general, and so their kids are already grown and that's not a concern. So, maybe they had more me time. (Endocrine Specialty Clinician)*

### Reduced Safe Exercise Space

Endocrine and primary care providers discussed barriers to safe exercise during COVID-19. Gym closures disrupted patients’ exercise routine, and it was difficult to find a safe alternative.

*We have to talk a lot about weight and exercise even when the gym is closed or even when they don't feel comfortable going to the gym even when it's re-opened and when they're trying to really socially distance, and so they don't want to walk in the mall anymore, and that sort of thing. Of course, they all, by definition, are high risk if they got COVID, so it's even trickier with that population to find ways that they can safely exercise. (Primary Care Provider)*

For people with diabetes, their high-risk status created significant distress about leaving the house to exercise.

One endocrine provider noted that some patients were “*afraid to go out and walk*”. A primary care provider with a similar experience said, “*they feel like they have to wear a mask outside because somebody might walk too close to them and they can’t breathe with the mask outside because it was too hot*”.

Additionally, working from home reduced patients’ level of activity.

*I’ve said multiple times to people, “You’re not working. You’re working from home. You’re sitting in front of a computer eight hours a day”. I have a teacher who she just absolutely couldn’t understand why she had gained weight, and I said, “You’re not chasing around a five-year-old anymore for eight hours a day”, and so we’ve seen a lot of that. (Primary Care Provider)*

*People did not walk. People didn’t go out to play or to exercise as much as they would. People didn’t go to the gym as much as they did. The lifestyle management aspect of diabetes management went out the window. (Endocrine Specialty Clinician)*

### Reduced Access to Healthy Food

Primary care and endocrine providers noted that concerns over COVID-19 impacted patients’ access to healthy food, because “*These patients don’t want to get out and go to the grocery store, go to the farmers market or whatever*”. Because patients were hesitant to make frequent trips to the grocery store, “*they’re not buying as many fresh fruits and vegetables*”. If patients did make it to the grocery store, healthy options were not always available.

*I also heard patients saying that they were eating what was available in the supermarkets and that they couldn’t always find what it is that they felt they should be eating, and they had to just take what was there at one point. (Primary Care Provider)*

### Increased Availability of Unhealthy Food

Primary care and endocrine providers discussed the increased accessibility of unhealthy food during the pandemic. An endocrine provider described that for some patients, “*their access to food ended up being worse because they were doing drive-thru rather than going to the grocery store*”. One primary care provider explained that if patients went to the grocery store, they tended to buy “*more processed, non-perishable foods*” to reduce the frequency of grocery trips. Additionally, a primary care provider explained that lockdowns and work from home placed many patients “*within twenty feet of their refrigerator*”, with constant access to less healthy foods.

Primary care and endocrine providers noted that this increased availability coupled with emotional eating led to an increase in unhealthy food consumption. Patients turned to food to deal with “*stress*”, “*boredom*” or to find “*comfort*”. As one primary care provider summarized, “*People working at home and having easy access to snacks and being stressed and stress eating*” often resulted in weight gain.

## Theme 4: COVID-19 Restrictions Allowed Patients to Prioritize Self-Care

More endocrine providers than primary care providers noted that for some patients, lockdowns allowed more time for self-management, encouraged healthier routines, and improved patient participation in care.

### Improved Diet

Endocrine and primary care providers noticed that lockdowns and working from home allowed patients to cook meals at home and pay more attention to their diet. One primary care provider stated that for many patients, eating out at restaurants “*wasn’t an option, many more people were cooking more so I have noticed a change over time where a lot of people I was talking to were cooking more often, eating out less*”. An endocrine provider with a similar experience recalled patients saying, “*Yeah, it was great to be home with the kids, and I also cooked all the time, so I did well with my blood sugar monitoring and carb intake*”.

One endocrine provider noticed an improvement in patients with type 2 diabetes:

*I think it has gotten better for my type 2 because they were able to appreciate their caloric intake, and they were actually prepping the meals themselves. They no longer had access to eating at restaurants, which was the majority, 70 percent of their situation prior to Covid. And so I think it helps with betterment of glycemic control during the pandemic in the shutdown.*

### Increased Exercise

Endocrine and primary care providers felt that for some patients, working from home led to increased opportunism for exercise. One endocrine provider stated, “*a lot of my patients cut down on one to two hours of commuting time a day*” which allowed them to “*walk more*” for exercise. A primary care provider observed how job loss allowed more time for exercise:

*I have occasional patients who now find themselves with more free time because of COVID. Maybe their work hours have been cut back or whatever, so they’re actually exercising more. I have a couple of patients who have actually lost a lot of weight during COVID.*

### More Time for Self-Management

Endocrine and primary care providers discussed that some patients’ self-management improved because of “*more free time*”. An endocrine provider noted that patients “*weren’t obligated to go somewhere to partake in or help out in other scenarios*” so they “*had more time to themselves*”. One endocrine provider described how working from home made monitoring blood sugar more convenient:

*They were able to check for the first time three times a day before they ate their meals and could decide how much insulin to give which, in an office environment,*

*sometimes, they wouldn't check before lunch because they didn't want to do it or didn't have time, and they got home after dinner, and they were eating on the road, so they didn't have time to check their sugar or give their insulin. For a small subset, maybe not small, but for a subset, I would say they increased their blood sugar monitoring because they had more time, and they were able to take better care of themselves.*

### Improved Participation in Care

Endocrine providers discussed how aspects of the pandemic made patients “more participatory in their diabetes care”. One endocrine provider noted that because patients “couldn't come in for routine bloodwork and evaluation in a clinic type setting”, they were more motivated to care for their diabetes. Another endocrine provider explained that the risk of COVID-19 encouraged more participation in care:

*In general, COVID was a very scary event for them. And so they tried really hard to get their sugars under control because they were very afraid of winding up in the hospital and getting very ill. And because there were fewer no-shows ... because we did telemedicine they were more engaged. And our CDEs were excellent in having visits between the physician visits. And so overall, I think, after we all got through the craziness of COVID, we felt more connected. And patients felt more engaged, more a sense of responsibility over caring for themselves ... And it's not just a theoretical risk of harm if you don't take your medications, but it was a very real risk. So I would say that there's a lot of education that was achieved during COVID and then more ownership of their care.*

## Theme 5: Clinical Team Members Utilized Patient-Centered Management Strategies

Primary care and endocrine providers discussed the strategies used to help patients maintain optimal self-care during the pandemic, including prioritizing lifestyle discussions, utilizing telemedicine, and helping with financial assistance.

### Prioritizing Lifestyle Discussions

Primary care and endocrine providers made lifestyle discussions a priority during COVID-19. Discussions with patients focused on creative ways to stay active despite pandemic restrictions.

*With the gyms closing and now that they're back open some people do feel comfortable to go back but some people are still saying “yeah, I'm still not feeling great about it” but then kind of having the discussion of “alright, I get it, I'm not going back to the gym either right now but it is still nice outside and you can walk” and then they're like “oh yeah, I guess I could do that” ... so having to make more of a conscious effort to go for a walk, to get up and move every hour or so to get some more steps in. (Primary Care Provider)*

*When it came to weight, I tried to coach as much as possible because a lot of the gyms were shut down during COVID. What I would do is encourage them to go for short walks after the biggest meal of the day to help keep blood sugars under control as well as cholesterol. I encouraged them to start out at like just five minutes at a time and then build up to 30 minutes. That was probably the most common instructions I gave for weight management and weight control. (Endocrine Specialty Clinician)*

### Utilizing Telemedicine

Primary care and endocrine providers noted that the use of telemedicine had allowed them to stay connected to their patients during COVID-19. Although the physical exam was limited and accessing blood glucose data was challenging, providers felt that it was largely successful.

*I don't think I've had anybody where we've kind of not been able to accomplish what we kind of want to get done [with a virtual visit]. Obviously we can't do like foot exams and things like that. Obviously there are some cases where we want to know what the A1C is or we want to know what the blood sugar is and we can't check it but I think in those cases where we're kind of saying alright well let's see how things are looking in another couple of months and we can do it then. But I think overall it's been pretty good. I've been able to accomplish all I want to accomplish pretty much. (Primary Care Provider)*

Endocrine participants noted that telemedicine visits were especially successful when patients were able to share glucose data through CGM devices or pumps.

*Yeah, my hope is that there will be a continued option for virtual because I do think it was helpful and worked well in certain circumstances. Yeah, I would hope that we would still have that as an option. Diabetes specifically, I would say in the patient who is pretty tech savvy and can upload their CGM or their pump, the virtual visits actually work quite well because we have all of the data in front of us so especially if they're on a CGM, we can estimate their A1C just from that. In that population, I think it actually went pretty well. (Endocrine Specialty Clinician)*

Endocrine providers felt telemedicine offered patients a convenient way to access their healthcare team. This seemed especially beneficial for patients in rural areas, or who were busy with work or family obligations.

*Now, it's been great for patients that live very far away because I'm the only endocrinologist in this part or in this county that takes Medicare/Medicaid, so I have a lot of patients that travel greater than an hour to see me. They don't necessarily have reliable transportation*



unfortunately, so being available by telehealth has allowed them to have their diabetes monitored more routinely. (Endocrine Specialty Clinician)

We have several patients that had to start working two jobs because of COVID and a lot of them were laid off. So they were doing you know a lot of temp jobs. And so they had no time to come into clinic. So when I called them for a tele-visit, it was almost always at work. And they were in their car or driving an Uber, for example, they would pull over and will conduct the visit. So we had extremely high satisfaction rates because we were able to offer tele medicines, you know, even up till now. And so actually our no-show rate was the lowest it's been because people didn't have to take public transportation in and they didn't have to take out like a whole half day from work. (Endocrine Specialty Clinician)

Endocrine participants did note that the benefits of telemedicine were limited for older patients who had difficulty interfacing with the technology and for patients without reliable access to a computer or internet.

So there's definitely barriers when a patient doesn't have access to technology, so if they don't have a smartphone, or a computer, then you're severely limited. And so it doesn't work as well ... But so I would say, you know, and that's sad, because the patients that are economically disadvantaged, still have barriers to care, because this is mostly technology based. (Endocrine Specialty Clinician)

There just seems to be kind of an age barrier to the virtual as far as especially over 65 for a diabetes visit where they have to figure out how to upload [CGM] or something. I think that just becomes a significant burden. And sometimes even just trying to figure out how to get my microphone on or my camera on in that age group is just a big source of stress on their part. And they will be begging to come in even if we advise them not to. (Endocrine Specialty Clinician)

### Offering Financial Assistance

Endocrine providers aimed to help patients afford diabetes supplies and medications by suggesting inexpensive options, offering product samples or helping patients apply for drug assistance programs.

So I tell them to go to Walmart and buy a Walmart meter which I find that out of all the generic, cheap meters out there out there it's probably more reliable than some of them and are more affordable and they can get it at a much cheaper price and the test strips are also a lot cheaper so I'm trying to encourage them to not worry about the insurance and get more testing supplies from Walmart. (Endocrine Specialty Clinician)

We encouraged patients to apply for drug assistance, and sometimes helping them out with doing that. We directed them to clinics, pharmacies, clinics that have pharmacies for indigent patients that offer a drug

program that they can access. All of that, and then we do have an active sampling system (Endocrine Specialty Clinician)

## DISCUSSION

The COVID-19 pandemic caused significant impacts on the lives of people with diabetes. Based on this qualitative study, primary care and endocrine providers noted that people with diabetes had increases in mental health symptoms, increased financial challenges and positive and negative changes in self-care routines. Primary care and endocrine providers discussed prioritizing lifestyle discussions and noted more use of telemedicine, specifically in blood glucose review. Results from this study can help guide management of people with diabetes as the pandemic evolves.

Our study found that most primary care and endocrine providers noted an increase in mental health concerns in their patients with diabetes. This included a subjective increase in the number of patients complaining of depression, anxiety and stress. These symptoms stemmed in part from social isolation and concern over the high risk of severe infection in the diabetes population. Diabetes was already associated with an increase in mental health conditions prior to the pandemic, and early in the pandemic concerns existed regarding worsening mental health during the pandemic in patients with diabetes (20). A recent study found that 93% of patients with diabetes showed signs of mental suffering and 43% had signs of severe distress (12). Additionally, one in 10 patients with diabetes had suicidal thoughts during the pandemic (21).

Primary care and endocrine providers noted disruptions in self-care in patients with diabetes during the pandemic. A significant theme was a decrease in physical activity and an increase in unhealthy eating patterns. People with diabetes struggled to find safe ways to exercise and obtain healthy foods while protecting themselves from the virus. However, a minority of providers reported patients had improved diets, exercise and time for self-management with a new change in routine. A recent qualitative study investigating the impact of the pandemic on Chinese patients with diabetes found decreases in physical activity, increased anxiety and feeling of lack of support from healthcare professionals (22). However, distinct differences in this study included complaints of lack of access to blood glucose monitoring and lack of space to perform physical activity related to strict quarantine/isolation procedures. An additional study looking at the effect of COVID-19 on self-management in patients with type 2 diabetes using a DMSQ assessment found decreases in physical activity and decreased use of health services (23). Therefore, the literature seems to support the negative changes in self-care routines most of our providers described.

An important question is how these changes in self-care ultimately effect glycemic control. Despite early concerns regarding glycemic control, numerous studies during the pandemic have shown no change in diabetes control in patients with diabetes (24, 25). Additionally, a recent meta-analysis noted a modest improvement in many glucose control parameters in patients with type 1 diabetes during the pandemic (26). The

ability of some patients to improve their control may be due to improved diets and exercise regimen that a minority of providers noted in our study.

A finding in our study that may be unique to the US healthcare system is providers noting significant financial stress in patients with diabetes due to job loss and subsequent insurance loss. Early in the pandemic, a report estimated 7.3 million workers in the United States would lose health insurance coverage due to job loss (27). A cross sectional survey conducted April 15-20, 2020 found 28% of respondents had coronavirus related employment or earnings loss. Additionally, 45% of respondents who had COVID job loss are not confident that they could pay for medical care or insurance premiums (28). Though the number of total job losses is less than predicted, it is likely numerous people with diabetes have lost insurance and this has been noted by our participants. There is lack of ongoing research into insurance loss during the COVID-19 pandemic in people with diabetes.

Both primary care and endocrine providers in our study noted the widespread use of telemedicine early in the pandemic with a focus on CGM data review (endocrine specific providers) and increase in lifestyle-based discussions (all clinical team members). Providers did note difficulties with virtual visits in select elderly patients who did not have access to, or knowledge of, specific technologies. The beneficial effects of telemedicine during the COVID-19 pandemic have been noted in studies (29). The perceived and actual benefit to clinicians and patients will need to be an area of further study and development.

Our study included primary care and endocrine providers. Providers reported similar experiences treating patients with diabetes during the early COVID-19 pandemic with a few notable differences. Endocrine providers discussed improvements in self-care in some patients with diabetes and emphasized the benefit of virtual care on CGM and insulin pump monitoring. These differences are likely due to the increased population of patients with type 1 diabetes and use of technology in endocrine specific clinics.

## Strengths/Limitations

To our knowledge, this is the first study to examine clinical team member impressions of challenges facing people with diabetes during the COVID-19 pandemic. Other studies have directly studied patients' experiences and outcomes with various methods. It is important to study this issue from the clinical team perspective to gain insight into what challenges clinicians perceive to be impacting their patients with diabetes. Additionally, because each clinical team member interacts with multiple patients, they offer a more comprehensive overview of the topic than would be provided by individual patients. Using qualitative methods, we have been able to focus on overarching themes clinical team members have observed during this time.

That said, this study has several limitations. Because we did not directly interview patients with diabetes, our findings are representative of what care team members understood about their patients' experiences during the pandemic. The comments from providers may not be completely accurate or comprehensive of their patients' lived experiences. Although our

principal interest was to investigate what providers perceived during this time, our overall understanding of the challenges facing people with diabetes during COVID-19 would have been enriched by directly interviewing patients with diabetes. A potential future direction of this work would include interviewing patients to obtain a more complete picture of living with diabetes during COVID-19.

Additionally, our method of purposive sampling has the potential to induce selection bias, as we selected participants based on their ability to provide robust information rather than collecting a random sample. To increase the external validity, we recruited participants from a diverse range of roles and practice settings. However, our study population was limited by high staff turnover and changes in staff roles in clinics due to COVID-19. Though clinical providers were solicited, only a select number responded and participated in the interview process. We were unable to engage every clinical team member, including social workers and mental health workers in clinics who could have added a unique perspective to our findings.

## CONCLUSION

Clinical team members of patients with diabetes described increases in mental health symptoms, financial stress and disrupted routines leading to self-care challenges during COVID-19. Participants additionally noted the increased use of telemedicine in the care of patients with diabetes during the pandemic. Our study of this clinical team cohort provides information regarding stressors facing patients with diabetes during the pandemic. It is important that these are noted as clinical team members continue to care for patients with diabetes as the pandemic evolves. Mental health support and lifestyle encouragement are critically important. Continued use of telemedicine may help many patients access these services.

## DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

## ETHICS STATEMENT

The studies involving human participants were reviewed and approved by UNC Chapel Hill Office of Human Research Ethics. Written informed consent for participation was not required for this study in accordance with the national legislation and the institutional requirements.

## AUTHOR CONTRIBUTIONS

LH: Recruited participants, conducted interviews, coded data, conducted analyses, wrote/edited manuscript. TC: Conducted

interviews, coded data, wrote/edited manuscript. MV: Conducted interviews, coded data, conducted analyses, reviewed/edited the manuscript. JL: Developed interview guide, tested codebook, review/edited the manuscript. AJ: Coded data, reviewed/edited the manuscript. KD: Contributed to writing, reviewed/edited the manuscript. ER: Reviewed/edited the manuscript. JR: Study recruitment, reviewed/edited the manuscript. LY: Reviewed, edited manuscript. All authors contributed to the article and approved the submitted version.

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# Lifestyles Under Lockdown: A Scoping Review of International Studies on Type 2 Diabetes Self-Management Behaviors During COVID-19

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**Background:** The effect of the COVID-19 pandemic on diabetes self-management behaviors is unclear.

**Objectives:** This paper is a scoping review of studies examining health behaviors among people with type 2 diabetes during the COVID-19 pandemic.

**Eligibility Criteria:** We searched articles available in English using the Search terms “COVID” and “diabetes”, and, separately, each of the following terms: “lifestyle”, “health behavior”, “self-care”, “self-management”, “adherence”, “compliance”, “eating”, “diet”, “physical activity”, “exercise”, “sleep”, “self-monitoring of blood glucose”, or “continuous glucose monitoring”.

**Sources of Evidence:** We searched PubMed, PsychInfo, and Google Scholar databases from December 2019 through August 2021.

**Charting Methods:** Data were extracted by 4 calibrated reviewers and study elements were charted.

**Results:** The search identified 1,710 articles. After screening for relevance and eligibility, 24 articles were included in this review. Findings show the strongest evidence for reduced physical activity and stable glucose monitoring and substance use. There was equivocal evidence for deleterious changes in sleep, diet, and medication intake. With one minor exception, there was no evidence for favorable changes in health behaviors. Limitations of the literature include small samples, predominantly cross-sectional study designs, reliance on retrospective self-reports, sampling through social media, and few standardized measures.

**Conclusions:** Early studies of health behaviors among people with type 2 diabetes during the COVID-19 pandemic suggest a need for novel interventions to support diabetes self-management, especially targeting physical activity. Future studies should go beyond documenting changes in health behaviors and examine predictors of change over time.

**Keywords:** type 2 diabetes, COVID-19, self-management, physical activity, diet, adherence

## INTRODUCTION

Over 460 million individuals, which equates to over six percent of the global population, have type 2 diabetes mellitus (T2DM) (1). Prevalence rates continue to rapidly incline across age groups and all regions of the world (1). The diabetes epidemic is alarming, as a diagnosis of T2DM is associated with a greater risk of mortality (2) and chronic (e.g., heart disease; renal disease) (3) and terminal (e.g., cancer) illnesses (4). To effectively manage T2DM, patients are prescribed a comprehensive self-management plan (5). Diabetes self-management plans typically encourage regular engagement in various health behaviors, including but not limited to self-monitoring blood glucose levels (SMBG), medication intake, conducting foot examinations, eating a balanced diet, and engaging in physical activity (5). However, due to various factors (e.g., financial constraints, difficulties with planning, low self-efficacy), patients with T2DM often struggle with regularly completing their diabetes self-management behaviors (6).

In response to increased stressors and social distancing requirements, the Coronavirus Disease of 2019 (COVID-19) pandemic has affected individuals' engagement in daily health behaviors (7–9). It can be hypothesized that health behavior engagement in the T2DM community has been impacted as well. For example, in a pre-pandemic study, adults with T2DM reported financial strain as a reason for below-target medication intake (6). The pandemic has affected the financial security of many individuals globally, causing downstream effects on financial stress and psychopathology (10), such that it can be anticipated that patients with T2DM have encountered additional barriers that further reduced their medication intake in the context of the COVID-19 pandemic. Accordingly, researchers have examined changes in metabolic outcomes in patients with T2DM during the COVID-19 pandemic (11–15). Data are equivocal and suggest metabolic control has either decreased or remained stable in patients with T2DM during the pandemic (11–15). Yet, less attention has been paid to examining changes in the diabetes self-management behaviors that are important in contextualizing metabolic outcomes in this population. The pandemic is expected to persist (16) and pandemics will continue to present in the future (17). It is imperative to explore diabetes self-management behavior engagement during the COVID-19 pandemic to identify ways to support patients with T2DM, both during the pandemic and beyond.

The purpose of the current review was two-fold: 1) to characterize diabetes self-management behavior engagement in individuals with T2DM during the COVID-19 pandemic, and 2) where available, to characterize changes in diabetes self-

management behavior engagement in individuals with T2DM from the pre-pandemic period to the pandemic period. Given the dearth of studies in the area, we conducted a scoping review. Scoping reviews are uniquely indicated to identify and map types of available evidence, to examine how research has been conducted, and to identify knowledge gaps. Based on the extant literature reviewed, we provide recommendations for future research and preliminary suggestions for practice with individuals with T2DM during and after the pandemic.

## METHODS

### Search

We followed methodological guidance (18) for Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) (19). We systematically searched PubMed, PsychInfo, and Google Scholar databases from December 2019 through August 2021. We restricted the search to articles available in English and used the Search terms “COVID” and “diabetes”, and, in separate searches, each of the following terms: “lifestyle”, “health behavior”, “self-care”, “self-management”, “adherence”, “compliance”, “eating”, “diet”, “physical activity”, “exercise”, “sleep”, “self-monitoring of blood glucose”, “SMBG”, “continuous glucose monitoring”, or “CGM”.

### Charting

One author (JW) drafted a data extraction chart based on PRISMA scoping guidelines which was beta tested by all four authors and modified to include directional arrows for results. Data were charted for author, publication year, country and time period of data collection, sample size and characteristics, sampling method, health behavior(s) studied, specific measures, results, and unique or ancillary findings.

### Reviewer Calibration

One author (KS) conducted the electronic database searches and screened all titles and abstracts to remove irrelevant papers. Two screeners (KS and JW) reviewed remaining abstracts to remove ineligible papers. All four authors (CC, RT, KS, JW) read the remaining full articles, and further removed ineligible papers. To address consistency across the reviewers and to decrease bias, five articles were reviewed independently by all four reviewers and extracted data were compared. Differences in responses were noted and discussed until consensus was reached. An additional five articles were reviewed independently by two reviewers (CC and RT) using the same process until the first author (CC)

judged that data extraction was sufficiently consistent. The first author reviewed the final tables for accuracy and consistency.

## Data Synthesis

We followed guidelines for conducting (18) and reporting (19) a scoping review. A scoping review is a particular type of review that is indicated for topics in which the body of literature is nascent. A scoping review should be differentiated from, for example, a systematic review or a meta-analysis, which are indicated when a body of literature is well developed and are designed to produce statements to guide clinical decision making (20). Scoping reviews do not report indicators of assessments of bias. Also, scoping reviews are, by definition, not designed to produce clear practice guidelines, but instead to update readers regarding needed future research. To describe the role of COVID-19 on health behaviors, attempts were made to characterize results in terms of increase, decrease, or no change in the health behavior compared to pre-COVID-19 levels.

## RESULTS

See **Figure 1** for PRISMA-ScR flow diagram. Search results identified 1,710 articles. Of them, 1,428 articles were removed because they were not relevant. Many of the articles that were removed at this stage reported, for example, incidence and prevalence of COVID-19 among people with diabetes, hyperglycemia as a risk factor for COVID-19 morbidity and mortality, or experimental treatments for COVID-19 in people with diabetes.

The remaining 282 abstracts were reviewed and of them,  $n=25$  were removed because they reported only biological (not behavioral) outcomes (to be included, articles were not required to report health behaviors as the primary outcome but were required to report health behaviors). Additional articles were removed because they were case studies or did not include a diabetes sample ( $n=86$ ), reported results of an intervention ( $n=16$ ), were reviews that did not report any primary data ( $n=42$ ), included qualitative data ( $n=1$ ), or reported that there had been changes in health behaviors but did not report the direction of the changes ( $n=2$ ). Of the remaining articles, an additional  $n=45$  were removed because they were duplicates across searches. The remaining full articles were read and an additional  $n=41$  articles were removed because they reported data only for type 1 diabetes mellitus ( $n=26$ ) or gestational diabetes ( $n=1$ ), or they included mixed diabetes types but did not report results separately by type of diabetes ( $n=10$ ). One article was a published abstract only and three reported mixed chronic diseases and did not report results for diabetes separately.

Articles were divided into two categories based on study design. One category of studies asked participants about their current level of health behaviors; those articles only reported frequencies or means of health behaviors during COVID-19 ( $n=5$ ). The other category attempted to characterize changes in self-management from pre-COVID-19 levels to COVID-19

levels ( $n=19$ ). See **Figure 2** for a map of health behaviors measured by number of studies.

In the first category, articles reported data from Brazil, China, Ethiopia, and Turkey. Sample sizes ranged from  $n=101$  in Turkey (21) to  $n=1,253$  in China (22). All participants were recruited from clinics. Shimels et al. (23) studied people with diabetes and comorbid hypertension. For the articles that reported a time period of data collection, dates ranged from March 2020 to August 2020. See **Table 1**. Note that where articles reported only frequencies—even if there was considerable variability—for parsimony we present only the modal response.

Three studies assessed physical activity. Onmez et al. (21) found that the modal response was that physical activity rarely or never occurred. Kaplan Serin and Bulbuloglu (27) found that physical activity was irregular. Tao et al. (22) found moderate levels of physical activity.

Four studies assessed diet. Onmez et al. (21) found that the modal response was that following dietary recommendations rarely occurred. Alessi et al. (24) found that 74% screened positive for an eating disorder. However, Kaplan Serin and Bulbuloglu (27) found high dietary compliance and Tao et al. (22) found regular meal intake.

One study (24) assessed sleep and found that 78% screened positive for a sleep disorder.

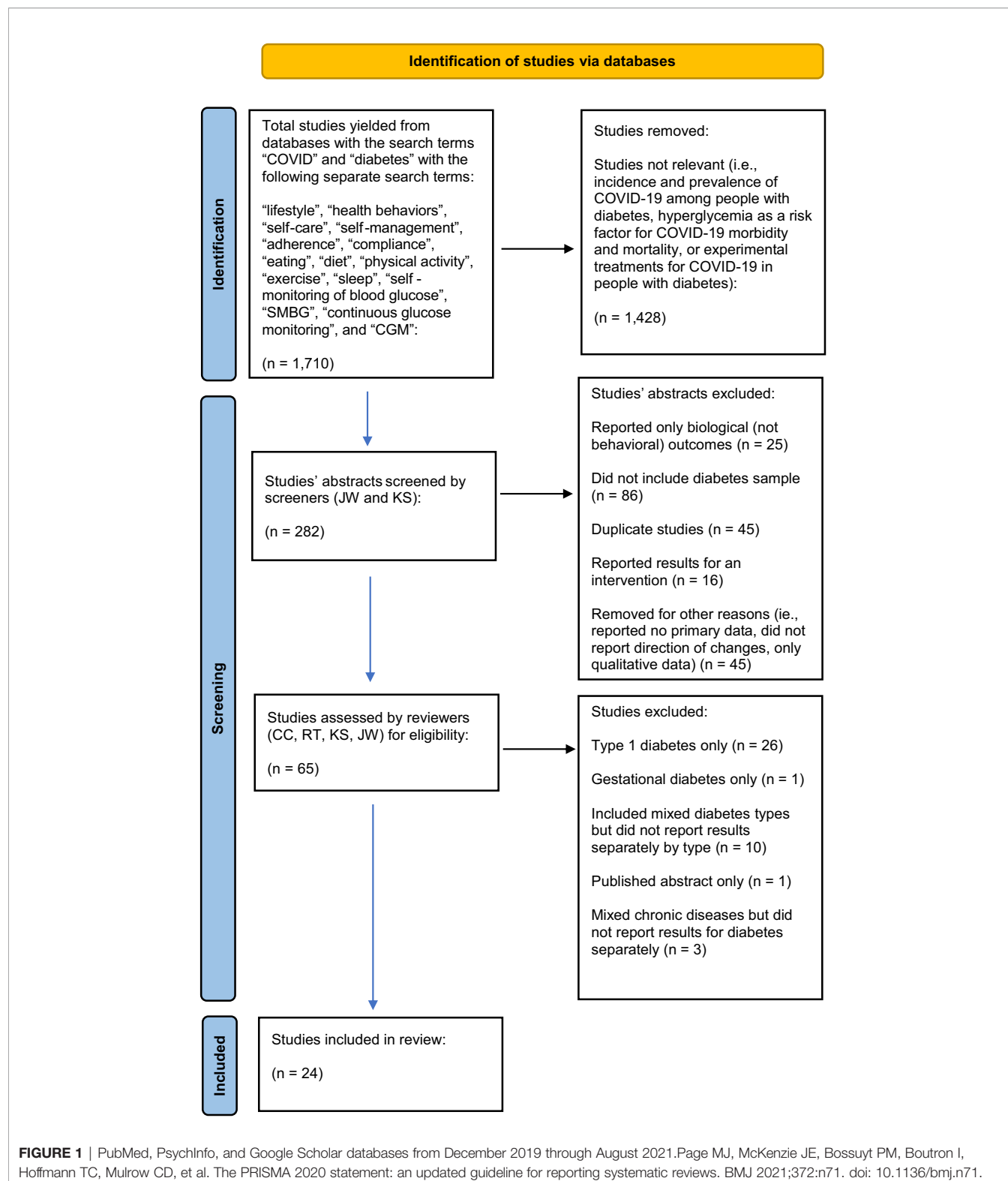
Two studies assessed medication intake. Shimels et al. (23) found low levels of medication intake and Tao et al. (22) found high levels of medication intake.

Two studies assessed SMBG. Onmez et al. (21) found that the modal response was that SMBG rarely occurred. Tao et al. (22) found that the modal response was  $\geq 2$  times per week for SMBG.

No studies in this category assessed substance use.

In the second category (i.e., papers that described change in health behaviors from pre-COVID-19 to COVID-19), articles reported data from Australia, Brazil, France, India, Japan, Malaysia, Mexico, the Netherlands, Poland, Saudi Arabia, Spain, Turkey, United Kingdom, and USA. Notably, one study examined bariatric surgery patients (32) and another studied children and adolescents (33). Only  $n=3$  implemented longitudinal methodology, i.e., followed the same cohort over time; they were based in India (34), the United Kingdom (35), and Australia (36). For the articles that reported a time period of data collection, dates ranged from March 2020 to April 2021, though Rowlands et al. (35) had baseline data dating back to 2017. One study in Brazil compared data from a sample of people with diabetes during COVID-19 to data from an age-matched sample of people with diabetes in 2016 (37). The remainder ( $n=15$ ) of studies asked participants to report their current health behaviors and also to recall their pre-COVID-19 health behaviors. Sample sizes ranged from  $n=56$  in Japan (38) to  $n=1,633$  in Brazil (39).  $N=4$  were recruited using social media,  $n=3$  reported data from people with diabetes in registries or who were already enrolled in research studies, and the remainder ( $n=12$ ) recruited clinic samples. See **Table 2**.

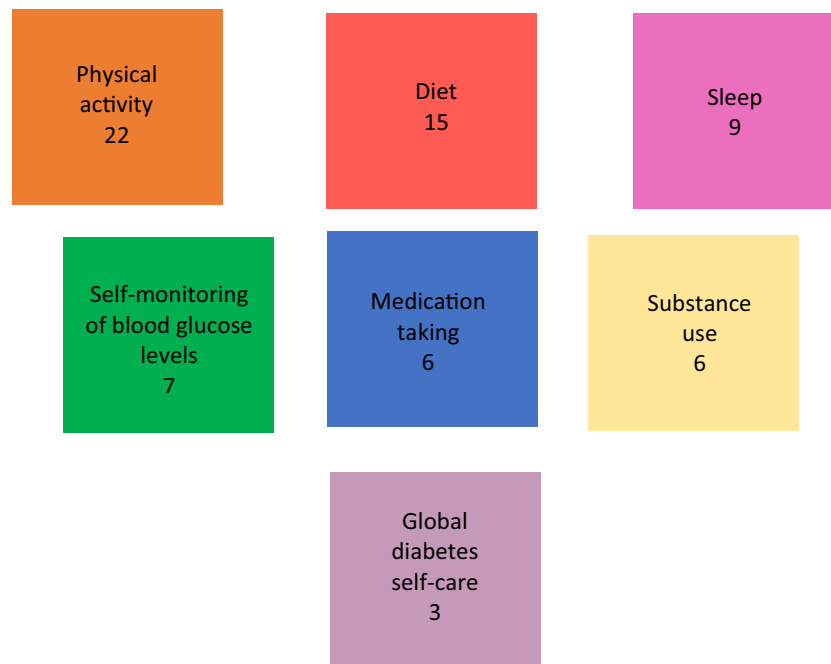
Sixteen of the 19 articles assessed physical activity. The majority ( $n=15$ ) of studies reported decreased physical activity (32, 33, 35, 38, 40, 43, 45–48, 53, 60) or low physical activity (39). Three studies reported no change (36, 51, 58) and one reported



increased physical activity (34). Regeer et al. (51) found that changes in physical activity were related to stress and emotional wellbeing; participants with higher emotional wellbeing were more likely to report no change than to report decreased

physical activity. Rowlands et al. (35) found that being a woman or having a higher body mass index predicted lower physical activity and higher inactive time. Being older or an ethnic minority predicted higher inactive time.





**FIGURE 2** | Map of health behaviors measured by number of studies.

Eleven studies assessed diet. Several studies reported an increase in unfavorable dietary habits, including decreased dietary adherence (40), high consumption of fatty foods and sweets (39), and increased food intake (43, 53). One study reported favorable changes in diet, i.e., increased fruit and vegetables and decreased snacks, fried, or processed foods (58). Four studies reported no change in dietary habits, including no change in appetite, quantity or quality of diet, or consumption of fruits (45), no change in overall dietary intake, snacking, fruit and vegetable consumption (47), and no change in total dietary intake or snack intake (48). One study reported various detailed favorable and unfavorable changes in diet (46).

Eight studies reported on sleep. Cheng et al. (33) reported increased sleep and Hasegawa et al. (38) reported increased sleep duration. One study reported decreased sleep quality (60). Four studies reported that the modal response was no changes in sleep (35, 45, 48, 58).

Four studies reported medication intake. Two studies reported decreased medication intake (40), and two studies reported no change (36, 43).

All five studies that assessed SMBG reported no change (36, 40, 43, 45, 58).

Six studies reported substance use. For alcohol, Binhardi et al. (39) and Ghosh et al. (45) reported that modal responses were no alcohol consumption or no change in alcohol consumption, respectively. Hansel et al. (47) and Sacre et al. (36) reported no change in alcohol consumption. For smoking, Utli et al. (60) and Ghosh et al. (45) reported no smoking as the modal response.

Three studies examined global diabetes self-care scores. One study reported no change (37) and two studies (59, 60) reported decreased total diabetes self-care scores. Silva-Tinoco et al. (59) found that higher pre-pandemic self-care was related to fewer problems with self-care during the pandemic. Utli et al. (60) found that being a man, smoker, and older in age, and having more anxiety and stress and decreased support from healthcare providers, predicted lower global self-care.

## DISCUSSION

This scoping review examined the extant literature regarding health behavior engagement among individuals with T2DM during the COVID-19 pandemic. Across studies, the strongest evidence was for a reduction in physical activity and there was small but consistent evidence for no change in SMBG and substance use. Global diabetes self-care decreased in two of three studies. Overall, dietary habits appear to have remained stable or worsened and in one study a high percentage of participants screened positive for a possible eating disorder. There were equivocal findings regarding medication intake and sleep. Older age, lower pre-pandemic self-care, and decreased emotional wellbeing and support from healthcare providers predicted greater deterioration in diabetes self-care behaviors. Unfortunately, many studies included the administration of unstandardized measures and descriptive statistics as an analytic plan; thus, a comparison of findings across studies and evaluation of effect sizes could not be conducted. This review

**TABLE 1 |** Frequency of health behaviors among people with type 2 diabetes during COVID only.

Author, year +	Sample size, age range, diabetes type, and place	Health behaviors studied	Specific measures++ and mode of data collection (internet, phone call, mail-in survey)	Sampling (community; clinic; registry; social media)	Data collection cross-sectional or longitudinal	Month and year of data collection	Main findings	Notes
1 (24) Alessi et al., 2020	N=120; Adults; mixed (T2DM n=68 type 2); Brazil	Diet; sleep	26-item Eating Attitudes Test (EAT; 25) and 10-item Mini Sleep Questionnaire (26); phone survey	Outpatient endocrine clinic of a public hospital	Cross-sectional	8-day period; dates not reported	Modal responses: 74% screened positive for an eating disorder; 78% screened positive for sleep disorder	Diabetes distress and screens for other psychiatric disorders also reported
2 (27) Kaplan Serin & Bulbuloglu, 2021	N=103; Adults; T2DM; Turkey	Diet; PA	Diabetes Self-Management Questionnaire (DSMQ; 28); in person survey	University internal medicine clinic	Cross-sectional	Unknown	Modal responses: Irregular PA; high dietary compliance	Working more days outside the home predicted higher self-care. Fear of COVID and death reported.
3 (21) Onmez et al., 2020	N=101; Adults; T2DM; Turkey	SMBG; PA; diet	Clinical forms and Short Form 36-item survey (29, 30); in person survey	University diabetology clinic	Cross-sectional	July-August 2020	Modal response: SMBG rarely occurred; PA rarely or never occurred; diet rarely occurred.	Comparisons of A1c, glucose, and BMI from pre-lockdown to lockdown reported.
4 (23) Shimels et al., 2021	N=409; Adults; T2DM and comorbid hypertension; Ethiopia	Medication adherence	Morisky Medication Adherence Scale (MMAS; 31), in-person survey	7 public health facilities in the capital city	Cross-sectional	August 2020	Modal response: low adherence to anti-diabetes and anti-hypertension medications	Higher income, comorbidities and substance use predicted non-adherence. Data provided about sleep and access to medications
5 (22) Tao et al., 2020	N=1253; Adults; mixed (T2DM n=1159); China	Diet; PA; medication adherence; SMBG; foot self-examination	Health behavior questionnaire; phone survey	Patients with past-year hospital discharge	Cross-sectional	March-April 2020	Modal response: SMBG >2x/week, no foot self-examination, no smoking; high medication adherence, regular meal intake, and moderate PA.	T1DM data reported separately; factors linked to glycemic outcomes included

points to multiple recommendations for future research and clinical practice with the T2DM population.

Most studies demonstrated a reduction in physical activity during the pandemic, highlighting the need for novel interventions to support individuals with T2DM in engaging in this essential diabetes management behavior. A few studies (35) pointed out that when activity occurred, planned fitness activities (e.g., a workout session) may have replaced incidental physical activity (e.g., walking to the store). It has been hypothesized that reductions in physical activity by the general public in the context of the pandemic might be a function of stress and fear associated with potential contraction of COVID-19 (7), which may in turn motivate individuals to reduce or avoid physical activity in groups and in public areas. This may be especially true for the T2DM population, who have received public health messaging that they are at a higher risk of contracting COVID-19 and experiencing severe symptoms due to their altered immune and metabolic system functioning (61). Given the key role of physical activity in supporting optimal glycemic

control in this population (62), it is imperative to further investigate patterns of physical activity during the pandemic and as societies shift towards “normalcy” and a post-pandemic period.

A lack of change in SMBG levels was observed in the studies that reviewed glucose monitoring, which suggests that, despite an increase in stress and disruption in individuals’ daily routine (63), SMBG remained relatively stable in this population. Given that SMBG is strongly correlated with glycemic control (64), and some studies show an increase in blood glucose levels and glycated hemoglobin during the pandemic (11), this finding is surprising and suggests that other key diabetes management behaviors might be impacted during the pandemic that are causing downstream unfavorable effects on individuals’ glycemic control. Moreover, the lack of change in SMBG should be of concern when considering that those individuals who demonstrated low SMBG pre-pandemic were also likely to demonstrate continued difficulties with SMBG (65); thus, there remains a subpopulation of individuals with T2DM (i.e., those

**TABLE 2 |** Change in health behaviors from pre-COVID period to COVID among people with type 2 diabetes.

	Author, year +	Sample size, age range, diabetes type, and place	Health behaviors studied	Specific measures++ and mode of data collection (internet, phone call, mail-in survey)	Sampling (community; clinic; registry; social media)	Data collection cross-sectional or longitudinal	Month and year of data collection	Main findings	Notes
1.	(40) Alshareef et al., 2020	N=394; Adults; T2DM; Saudi Arabia	Medication taking; SMBG; PA; diet	8-item health behavior questionnaire; phone survey	National guard primary care clinics	Cross-sectional	Not reported	Modal responses: *↓ medication taking compliance; ↓ PA and diet ; → SMBG	Psychological distress also reported
2.	(39) Binhardi et al., 2021	N=1633; Adults; mixed (T2DM n=628); Brazil	Alcohol consumption	Alcohol consumption questionnaire; internet survey	Social media; traditional media (e.g., radio, television)	Cross-sectional	September-October 2020	Modal responses: No alcohol consumption or → alcohol consumption; high consumption of fatty food and sweets, and low PA all >40%.	Participants also reported changes in glucose control and COVID status; data from T1DM patients also reported
3.	(33) Cheng et al., 2021	N=123; Children and adolescents; mixed (T2DM n=30); Malaysia	PA; diet; sleep; screen time	Physical Activity Questionnaire (PAQ; 41, 42); health behavior questionnaire; in-person paper-and-pencil survey	Hospital pediatric diabetes clinic	Cross-sectional	June-December 2020	*↑ sleep and screen time; ↓ PA and meal frequency	Results for boys and girls reported separately; body mass index and glycemia also reported
4.	(43) Fisher et al., 2020	N=1382; Adults; mixed (T2DM n=619); USA	Diet; PA; medication taking; SMBG; reviewing BG trends	7-item health behavior questionnaire; internet survey	Diabetes research registry	Cross-sectional	April 2020	Modal responses: ↑food intake; ↓ PA; → medication taking, SMBG, and reviewing BG trends	Data about stress, isolation, and impact on access to care and supplies reported
5.	(37) Franco et al., 2021	N=260; Adults; mixed (T2DM n=150); Brazil	Overall diabetes self-care	Portuguese version of Self-Care Inventory Revised (SCI-R; 44); phone survey	Endocrinology outpatient clinic	Cross-sectional with comparison group from 2016	1 month after start of social distancing guidelines; dates not reported	→ SCI score	Data from T1DM patients also reported
6.	(45) Ghosh et al., 2020	N=150; Adults; T2DM; India	Diet; PA; SMBG; sleep; substance use	40-item health behavior questionnaire; phone survey	Clinic	Cross-sectional	May 2020	Modal responses: → SMBG, sleep, appetite, quantity or quality of diet; ↓ PA; no alcohol or tobacco	87% reported "mental stress"
7.	(46) Grabia, et al., 2020	N=124; adults and children; mixed (T2DM n=34); Poland	PA; diet; sleep; screen time	Health behavior questionnaire; internet survey	Social media diabetes groups	Cross-sectional	July 2020	Various favorable and unfavorable changes in diet and PA	Most health behavior changes not reported by diabetes type. Detailed food and exercise items.
8.	(47) Hansel et al., 2021	N=5280, Adults, mixed (T2DM and BMI ≥ 25 n=2632); France	Diet; snacking; PA; substance use	Health behavior questionnaire; web application survey	Social media/ web application	Cross-sectional	March-April 2020	Modal responses: → overall dietary intake, snacking, smoking, vegetable, fruit consumption, and alcohol consumption; ↓ PA	Data about diabetes located in supplemental data files. Higher BMI predicted healthier behavior changes
9.	(38) Hasegawa et al., 2021	N=56; Adults; T2DM; Japan	Sleep; exercise	Health behavior questionnaire; mode of data collection not reported	Clinic	Retrospective cohort study	April-May 2020	Modal responses: ↓ PA; either → or ↑sleep duration	n=22 reported health behaviors; data extracted from larger study of skeletal muscle mass; reduced sleep and exercise predicted loss of muscle mass

(Continued)

TABLE 2 | Continued

Author, year +	Sample size, age range, diabetes type, and place	Health behaviors studied	Specific measures++ and mode of data collection (internet, phone call, mail-in survey)	Sampling (community; clinic; registry; social media)	Data collection cross-sectional or longitudinal	Month and year of data collection	Main findings	Notes
10. (48) Munekawa et al., 2021	N=183; Adults; T2DM; Japan	Sleep; PA; diet	6-item health behavior questionnaire; in-person survey	University endocrinology clinic	Cross-sectional	April-May 2020	Modal responses: ↓ PA; → sleep, total diet intake, snack intake	Higher stress was associated with higher consumption of prepared food and lower exercise
11. (34) Rastogi et al., 2020	N=422; Adults; T2DM; India	PA	Global Physical Activity Questionnaire (49, 50); pre-lockdown: in-person survey, during lockdown: phone survey	Diabetes clinic	Longitudinal	Not reported	*↑ PA	Increased self-reported PA was not associated with changes in weight or glycemia
12. (51) Regeer et al., 2021	N=536; Adults; T2DM; Netherlands	PA	Physical activity questionnaire; Short Questionnaire to Assess Health Enhancing PA (SQUASH; 52); internet survey	Registry of participants of previous PA research in past 5 years	Cross-sectional	May 2020	Modal response: → PA	Higher emotional wellbeing was associated with decreased likelihood of becoming less active
13. (35) Rowlands et al., 2021	N=165; Adults; T2DM; United Kingdom	PA; sleep	Wrist accelerometer	Registry of participants of previous chronotype and glycemia study	Longitudinal	Baseline: 2017-2020; COVID: May to June 2020	*↓ overall PA, days per week with 30 and 60 minutes of MVPA; *↑ inactive minutes; → sleep duration, MVPA minutes, continuous MVPA for 10 mins and 30 mins	Being a woman, older, or an ethnic minority was associated with lower PA
14. (53) Ruiz-Roso et al., 2020	N=72; Adults; T2DM; Spain	Diet; PA; food craving	Food Frequency Questionnaire (54), International Physical Activity Questionnaire (55), Food Craving Questionnaire (56); phone survey	Clinic	Cross-sectional	April-May 2020	↑* dairy, vegetable, snack, and sugary food intake; ↓* PA	HbA1c noted
15. (36) Sacre et al., 2021	N=489; Adults; T2DM; Australia	PA; sedentary time; alcohol intake; medical visits; SMBG; medication adherence	Confidence in Diabetes Self-Care (57) and other health behavior questionnaires; phone/internet survey	Clinic and registry	Longitudinal population-based cohort	April-May 2020	Trend for ↓ PA; → alcohol intake, SMBG, and medication adherence; ↑* medical visits	Planned walking replaced incidental walking. Symptoms of anxiety, depression, and diabetes distress also reported.
16. (58) Sankar et al., 2020	N=110; Adults; T2DM; India	SMBG; PA; dietary adherence; food intake; and sleep	7-10min questionnaire; verbal, in-person survey	Hospital outpatient diabetes clinic	Cross-sectional	May-June 2020	Modal response: ↑ vegetable and fruit intake; ↓ snacks, fried, or processed foods intake; → PA, sleep, SMBG, and dietary adherence	Higher stress and anxiety related to worsened sleep and diet habits. Decreased access to medications; A1c noted.
17. (59) Silva Tinoco, et al., 2021	N=212; Adults; T2DM; Mexico	Global self-care	Summary of Diabetes Self-Care Activities; unknown mode of data collection	Patients of a quality improvement program at a diabetes pharmacy	Cross-sectional	April-May, 2020 with comparison group from February-March 2020	*↓ global self-care behavior (diet, PA, SMBG)	Higher pre-pandemic self-care scores predicted fewer self-care problems during pandemic

(Continued)

TABLE 2 | Continued

	Author, year +	Sample size, age range, diabetes type, and place	Health behaviors studied	Specific measures++ and mode of data collection (internet, phone call, mail-in survey)	Sampling (community; clinic; registry; social media)	Data collection cros- sectional or longitudinal	Month and year of data collection	Main findings	Notes
18.	(60) Utli et al., 2021	N=378; Adults; T2DM; Turkey	PA; substance use; sleep	Diabetes Self- Management Questionnaire (DMSQ; 28); paper-and-pencil, in- person survey	Outpatient endocrine clinic in a government hospital	Cross sectional	December 2020 to April 2021	Modal responses: COVID negatively impacted diabetes self-management; ↓ sleep quality and PA; no smoking	Data on demographic and psychosocial factors impacting diabetes self- management reported
19.	(32) Wysocki et al., 2020	N=885; Adults; Pre- and post-operative bariatric surgery patients with and without T2DM (T2DM=356); Poland	Diet; PA	Health behavior questionnaire; internet survey	Social media	Cross- sectional	Not reported	Modal responses: ↓ PA in both pre-operative and post- operative patients with T2DM	Bariatric care under COVID reported

For studies in which frequencies are reported, for parsimony, we report only the modal response though there may have been considerable variability in responses.

T1DM, type 1 diabetes mellitus; T2DM; type 2 diabetes mellitus; PA; Physical activity; SMBG, self-monitoring of blood glucose; CGM, continuous glucose monitor.

→ = no change.

↓ = decrease.

↑ = increase.

\* = change reported as significant.

Social media includes, for example, Facebook, Instagram, Twitter.

Conversation Apps includes, for example, WhatsApp, Telegram.

Traditional media are, for example, radio, television, newspaper.



who demonstrate low SMBG and, in turn, above-target glycemic control) who are highly susceptible to experiencing adverse reactions when acquiring COVID-19. Continued study of SMBG and its relation to glycemic control, and possibly COVID-19 infection severity, across the pandemic is warranted.

Most individuals with T2DM reported little to no substance use during the pandemic and no change from the pre-pandemic period. This is inconsistent with data highlighting the widespread increase in substance use by the general population during the pandemic (66). It is possible that participants may have underreported substance use due to demand characteristics and social desirability, especially when questionnaires were administered by healthcare providers (e.g., studies with samples of patients that were being seen in clinic at the time of questionnaire completion). Nonetheless, findings suggest that substance use may be a relatively lower priority for researchers and clinicians to address in their work with people with diabetes, compared to other health behaviors that were more clearly impacted by the pandemic, such as physical activity.

Studies examining changes in and frequency of engagement in the remaining health behaviors yielded equivocal results. Specifically, there was a near-even split of studies that reported a lack of change or decrease in medication intake, sleep, and diet. Only two studies suggested a favorable increase in any of these health behaviors, finding an increase in participants' consumption of dairy, vegetables, and/or fruits (53, 58), but this was an exception. For the T2DM population as a whole, the reviewed studies suggest that there are no consistent or compelling data to suggest that diabetes self-management behaviors improved during the pandemic.

There are several possible explanations for differing results across studies, including the time frame of data collection, region in which the study was conducted, measure/questionnaire employed, and sampling strategy. First, it is possible that contradictory findings may be a result of differences in COVID-19 guidelines and lockdown regulations across time and regions. For example, medication intake and SMBG may have been influenced by an individual's inability to pick up prescriptions in regions that had more restrictive lockdowns, or when medical supply chains were disrupted. Second, inconsistent findings may have emerged due to use of varying measures. Most studies reviewed designed their own questionnaires which varied by content, item stem, and response options. Most were retrospective self-reports that required participants to recall temporally distal health behaviors from 6-months to 1-year ago or more. Self-report measures are subject to numerous sources of bias and retrospective measures are subject to poor recall. Depending on the research question at hand, objective measures may be preferable when feasible. Objective sleep and physical activity characteristics may be best captured by actigraphy data, which was only used in one study that indicated decreased overall physical activity and stable sleep duration from the pre-pandemic period to the pandemic period (35). Diet is extremely challenging to measure without intensive methods, such as photographic food records (67), which were not used in any studies. Measuring the frequency

of glucose monitoring is made easier with uploadable meters and continuous glucose monitors, but these data were not reported in most studies. Also, substance use is best measured *via* daily reports (68) or, in some cases, biospecimen testing. Finally, sampling strategies may have yielded differing results. Several studies recruited participants through social media. Data from those studies may have limited generalizability, as reviews have shown that participants recruited through social media differ from those recruited through traditional methods (69).

Perhaps the greatest missed opportunity in the literature to date is that, with a few exceptions (35, 51, 59, 60), the majority of studies simply reported change in behavior as frequencies of 'increase', 'decrease', or 'no change', but did not examine predictors of direction or degree of change. In order to efficiently direct resources to the patients most in need of self-management support, it is helpful to know the individual characteristics that predict diabetes self-management during the pandemic. For example, perhaps individuals who experienced financial downturn, who live alone, or whose pre-pandemic glycemic control was suboptimal are in the greatest need of self-management support during the pandemic. On the other hand, perhaps those who were allowed to work from home, with greater access to outdoor space for physical activity, or with home prescription delivery were able to maintain or even improve their diabetes self-management. Elucidating the factors related to behavioral vulnerability and resilience can help tailor intervention development and delivery.

It should be acknowledged that researchers had to move quickly to document changes in diabetes self-management during the COVID-19 pandemic. Planning the study, procuring funding, obtaining ethics approval, and collecting data are all time intensive. Moreover, this research was being conducted in the midst of social distancing measures that made best-practices for behavioral diabetes research difficult or impossible. Efforts to conduct research under these conditions are to be lauded. Notwithstanding these commendations, as researchers continue to collect data on pandemic-specific health behavior engagement in this population, it will be important going forward to use standardized, objective measures where possible, as well as recruit participants who are well characterized, follow them over time across different phases of the pandemic, and examine predictors of behavior change.

## Limitations

Our conclusions are qualified by several limitations of this review. First, database review concluded in August of 2021, and it is likely that additional articles have been published since then but were not included in the current review. Second, studies reviewed were limited to data from individuals with T2DM. Findings may not be representative of changes in health behavior in individuals with type 1 diabetes, gestational diabetes, or pre-diabetes. This is an area for future research. Third, most studies were conducted with adult samples, thus findings may not generalize to health behavior of children and adolescents with diabetes. Fourth, due to the extreme

heterogeneity in samples, sampling, and measures across studies, a meta-analysis could not be conducted, thus the interpretability of findings is limited. Fifth, in those studies that reported frequencies only, we reported modal responses. Across every study, there were subsamples of participants who reported favorable changes, unfavorable changes, and stable health behaviors. Therefore, it should not be concluded that all individuals with T2DM demonstrated self-management decrements in response to the pandemic. Finally, scoping reviews do not report indicators of assessment of bias and do not produce clear practice guidelines.

## Conclusions and Future Directions

Findings from this brief review indicate that individuals with T2DM demonstrated reduced engagement in physical activity during the pandemic and no change in SMBG or substance use. The frequency of and potential change in medication intake, sleep, and diet during the pandemic was less clear, but there is virtually no evidence that the population as a whole improved their diabetes self-management during the COVID-19 pandemic.

Moving forward, researchers should aim to use standardized health behavior measures to allow for a comparison of findings across samples. In addition, where available, researchers should attempt to access pre-existing data, such as data located within patients' medical records, to allow for more precision in their comparisons of health behavior prior to and during the pandemic. These data are especially important in identifying ways to support this population in returning to "normalcy" and re-establishing their diabetes self-management routines as the pandemic progresses and eventually ends. Even if the pandemic does eventually conclude, there may be other pandemics, natural disasters, climate disruptions, warfare, or civil unrest that have the potential to drastically impact the self-management of people with diabetes. In addition, researchers should prioritize conducting research with children and adolescents with T2DM. Moreover, future data should help identify those individuals with T2DM who demonstrated limited engagement in diabetes self-management behaviors pre-pandemic and continued to struggle, or deteriorate, throughout the pandemic. This subpopulation is important to study and may require more assistance in developing an individualized, specific diabetes self-management plan. Upon publication of further reports, a systematic review and meta-analysis should be conducted to further characterize the frequency of and changes in diabetes self-management health behaviors during the COVID-19 pandemic.

Clinically, providers are encouraged to closely monitor diabetes self-management in their patients, especially their

older patients, as the pandemic continues to unfold globally with additional waves and new variants. Specifically, we recommend patient-provider problem-solving of specific steps to increase physical activity within the confines of COVID-19 guidelines and restrictions, such as scheduling daily 30-minute virtual physical activity exercises with friends or family. Patients should be encouraged to explore outdoor venues, such as parks, trails, and other open space, if available, in their neighborhood. Next, with the current increases in access to digital health technologies, healthcare providers should consider "prescribing" patients to download and complete digital health programs. This could include informal tracking of diet and physical activity with applications that allow users to share these data with friends and/or family, thereby providing external motivation and social support to improve the corresponding diabetes self-management behaviors. More structured digital health programs exist and should be considered. For example, see Fu et al. (70) for a review of existing diabetes/lifestyle applications. Last, and importantly, for those individuals with T2DM who demonstrate disruptions in diabetes self-management as a result of impaired psychological functioning in the context of the pandemic, providers should connect patients to psychological care where it is accessible. This might include "prescribing" patients mindfulness/meditation, relaxation, or other evidence-based digital mental health applications. In addition, provision of either in-person or telemedicine mental health services is recommended for patients experiencing significant mental health concerns and may elicit downstream improvements in diabetes self-management.

## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author, JW, upon reasonable request.

## AUTHOR CONTRIBUTIONS

JW conceived of the study and wrote methods and results. KS screened articles. CC, JW, KS, and RT reviewed articles and populated tables. CC and JW wrote the manuscript. RT formatted tables. CC and KS designed figures. KS and RT edited the manuscript. All authors contributed to the article and approved the submitted version.

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# Impact of COVID on Professionals Addressing Psychosocial Needs of People With Diabetes: An International Survey

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We investigated how COVID-19 has disrupted the work of health professionals who address behavioral and psychosocial needs of people with diabetes (PWD). English language emails were sent to members of five organizations that address psychosocial aspects of diabetes, inviting them to complete a one-time, anonymous, online survey. On a scale from 1=no problem, to 5=serious problem, respondents reported problems with the healthcare system, their workplaces, technology, and concerns about the PWD with whom they work. Respondents (n=123) were from 27 countries, primarily in Europe and North America. The typical respondent was a woman, aged 31-40 years, who worked in an urban hospital in medicine or psychology/psychotherapy. Most judged that the COVID lockdown in their region was moderate or severe. Over half felt moderate to serious levels of stress/burnout or mental health issues. Most participants reported moderate to severe problems due to the lack of clear public health guidelines, concerns with COVID safety of themselves, PWD, and staff, and a lack of access or knowledge on the part of PWD to use diabetes technology and telemedicine. In addition, most participants reported concerns with the psychosocial functioning of PWD during the pandemic. Overall, the pattern of findings reveals a high level of detrimental impact, some of which may be ameliorated with changes in policy and additional services for both health professionals and the PWD with whom they work. Concerns about PWD during the pandemic must go beyond their medical management and also consider the health professionals who provide them with behavioral and psychosocial support.

**Keywords:** diabetes, telemedicine, technology, COVID, social distancing, health professional, psychosocial, workforce

## INTRODUCTION

COVID-19 has disrupted the work of health professionals who work with people with diabetes (PWD) (1–3). The most common reasons for the disruption of health services are cancellations of scheduled treatments, implementation of lockdowns, community quarantines or movement control (4), and a lack of staff due to reassignment of a number of health professionals to COVID-19 activities (5). Risk of travel by public transportation and reluctance on the part of PWD to venture out for appointments is also a factor. Routine care is important not only for medical management, but also for providing diabetes self-management support and detection and treatment of diabetes distress and other psychosocial problems (6). Behavioral diabetes research has also been disrupted by COVID-19, causing delay and cancellations of study assessments and delivery of experimental behavioral interventions. Health professionals working with PWD have had to quickly adapt to these changes and learn ways to address behavioral and psychosocial needs of PWD and conduct behavioral diabetes research in the midst of the pandemic.

The toll of COVID-19 on frontline healthcare workers delivering lifesaving care to COVID-19 positive patients is well documented (7). Yet, the impact of COVID on the work of health professionals addressing the behavioral and psychosocial needs of PWD has not been investigated. This study was conducted to explore the nature and severity of those impacts. In an international group of health professionals who address behavioral and psychosocial needs of PWD, we explored problems that they have experienced with the healthcare system, their workplaces, technology, and concerns about the behavioral and psychosocial functioning of the PWD with whom they work.

## METHODS

### Procedures

All procedures were approved by the UConn Health institutional review board (4/15/2021 IRB# 21X-219-1) which determined the research to be exempt. Data were collected over 6 months between April 2021 and October 2021. Participants provided online consent. Anonymous survey data were collected *via* Remote Electronic Data Capture [REDCap (8)].

### Sampling

English language emails were sent to invite participation in a one-time, anonymous, online survey. Invitations and a link to the survey were sent to five organizations whose members address psychosocial aspects of diabetes: 1) the psychosocial study group of the European Association for the Study of Diabetes (Psychosocial Aspects of Diabetes [PSAD, ~110 members]); 2) a behavioral diabetes research society (Behavioral Research in Diabetes Group Exchange [BRIDGE, ~125 members]); 3) the mental health interest group of the International Society for Pediatric and Adolescent Diabetes (ISPAD ~125 members); 4) the American Diabetes Association mental health care provider directory (~75 emails); 5) the diabetes special interest group of the

Society of Behavioral Medicine (~200 members), and, 6) attendees at the 2021 Slovenia-based DiaMind online conference (~100 attendees), for a total of approximately 735 invitations. After providing online informed consent, participants responded to 50 questions. There were no incentives for participation.

### Measures

All survey questions were in English. Participants reported demographics, the characteristics of their workplace, the region in which they work, and the population of PWD with whom they work. Participants reported the country in which they work and these were coded according to World Bank gross national income (GNI) per capita categories as 1=low income (\$1,045 or less), 2=lower middle income (\$1,046 and \$4,095), 3=upper middle income (\$4,096 and \$12,695), and 4=high income (\$12,696 or more) (9).

For reporting problems, the instructions were as follows. “You may work with people with various medical conditions. We are interested in your work with people with diabetes. The people with diabetes that you work with may be your patients, clients, research participants, or some combination. Think about your own experience of working during the pandemic. Things may have changed over time with different surges, lockdowns, and re-openings. In general, over the past year, which of the following COVID-related issues has been a problem in your work with people with diabetes?” Response options were on the following scale: 1=no problem, 2=minor problem, 3=moderate problem, 4=somewhat serious problem, to 5=serious problem, “not applicable” and “prefer not to say”. We used this response option because it was applicable to our research question, and also because it is familiar to many behavioral diabetes health professionals from the Problem Area in Diabetes scale [PAID (10)].

Questions pertained to problems with the healthcare system, in their workplace, with technology, and concerns they had regarding the PWD with whom they worked. One question asked about the respondent’s level of stress/burnout/mental health issues. Items were generated by two of the authors (KK and JW) with qualitative input from colleagues based on a review of the literature and clinical experience.

### Data Analysis

Descriptive statistics included means with standard deviations for quantitative variables and frequencies with percentages for categorical variables. Data were analyzed using SPSS v27.

## RESULTS

### Sample Characteristics

Of the 735 invitations, 149 people (20%) accessed the online consent. Of them, one recruit declined informed consent, 25 provided consent but did not complete the survey, while 123 consented and completed the survey, for a 17% completion rate. The majority of respondents were from Europe (45.5%), particularly Slovenia (19.5%), and North America (32.8%), predominantly the US (29.3%). Other countries included

Australia, Austria, Belgium, Cambodia, Canada, Chile, Croatia, Ecuador, Egypt, Germany, India, Indonesia, Ireland, Italy, Jamaica, Mauritius, Mexico, the Netherlands, New Zealand, Romania, Russia, Saudi Arabia, Serbia, Slovakia, Turkey, and the United Kingdom. Most were from high (81.4%) and upper middle (11.5%) income countries. The typical respondent was a woman (74.8%), aged 31-40 years (38.2%), worked in an urban (77.2%) hospital (35.2%) and was from the discipline of medicine (47.5%) or psychology/psychotherapy (32.8%). About 1/3 (34.1%) used telemedicine prior to COVID and of those who did not, 80.5% adopted telemedicine due to COVID.

Most respondents (75.4%) worked with more than three others in their same profession and 46% saw between 51-500 PWD annually. About half saw only adult PWD and one-third worked exclusively with children. Most (90.2%) judged that the COVID lockdown in their region was moderate or severe. In response to a single question, over half (56.4%) reported moderate to serious levels of stress/burnout/mental health issues. Only 1% reported that COVID has not been a problem with their work with PWD. See **Table 1** for descriptives.

## Problems With the Healthcare System

Below we provide the percentage of respondents reporting a problem as moderate to serious. As seen in **Table 2**, with respect to the healthcare system the greatest problem reported was lack of clear public health guidelines, where 56.4% reported it was a moderate to serious problem. Other common problems were delay or lack of access to COVID testing (32.0%) and COVID-related issues with reimbursement for their work (30.7%). Over 1/5 of respondents reported disagreement about COVID-related work issues with government bodies (28.3%), their organization's administration (23.8%), and research funders (22.6%).

## Problems in the Workplace

Workplace problems were abundant (**Table 3**). Over half the respondents reported moderate to severe problems regarding COVID safety at work, including COVID safety for PWD (69.0%), changing the flow of people in the workspace (69.3%), safety of self and staff (62.4%), making decisions to close or reopen (59.3%), and possibly exposing family members to COVID from a work-related exposure (50.9%). Nearly half (48.5%) reported isolation from colleagues as a moderate to serious problem.

Working with PWD was impacted; 44.3% reported that disruption to the relationship with PWD was a moderate to serious problem and over 1/3 (34.7%) reported lack of time with PWD. Skepticism about COVID among PWD was reported by 40%, and uncertainty how to explain COVID risks by 1/3 (32.6%).

## Problems With Technology

One set of technology questions pertained to diabetes technology (CGMs, uploadable pumps, data sharing platforms). The majority of respondents reported that "PWD not having access or knowledge to use diabetes technology" was a moderate to serious problem (54.5%; mean = 2.7, SD = 1.1) but that their own use of diabetes technology was less problematic (22.1%; mean = 1.8, SD = 0.9).

**TABLE 1 |** Demographic characteristics of respondents (n=123).

Characteristic	Frequency	Percentage
<b>Gender</b>		
Female	92	74.8%
Male	31	25.2
<b>Age Group</b>		
<30	6	4.9%
31-40	47	38.2
41-50	27	22.0
51-60	18	14.6
61-70	14	11.4
>70	11	8.9
<b>Country Region</b>		
Africa/Middle East	6	5.2%
Asia/Oceania	9	7.8
Europe	56	45.5
United Kingdom	3	2.4
North America	38	32.8
South America/Caribbean	4	3.3
<b>Country Income Level</b>		
Low	0	0.0%
Low Middle	8	7.0
High Middle	13	11.5
High	92	81.4
<b>Urbanicity</b>		
Urban	95	77.2%
Suburban	19	15.4
Rural	9	7.3
<b>Severity of COVID Lockdown</b>		
Mild	11	8.9%
Moderate	57	46.3
Severe	54	43.9
<b>Personal COVID-Related Stress/Burnout/ Mental Health</b>		
Not a Problem	11	10.7%
Minor Problem	34	33.0
Moderate Problem	35	34.0
Somewhat Serious Problem	15	14.6
Serious Problem	8	7.8
<b>Work Setting</b>		
Primary Care	2	1.6%
Community Health Center	5	4.1
Specialty Care	22	18.0
Academic	28	23.0
Hospital	43	35.2
Private Practice	17	13.9
Other	5	4.1
<b>Discipline</b>		
Medicine	58	47.5%
Nursing	10	8.2
Psychology/Psychotherapy	40	32.8
Social Work	2	1.6
Nutrition	4	3.3
Other	8	6.6
<b>Primary Professional Activity</b>		
Medical Care	56	45.5%
Mental Health Care	27	22.0
Diabetes Education	13	10.6
Clinical Research	23	18.7
Other	4	3.3
<b>Number of Employees in Your Profession in your Workplace</b>		
I'm the only one	10	8.2%
2-3	20	16.4
>3	92	75.4

(Continued)

**TABLE 1 |** Continued

Characteristic	Frequency	Percentage
<b>PWD Seen in a Year</b>		
<50	24	19.5%
51-500	57	46.3
510-1000	21	17.1
>1000	21	17.1
<b>Type of Diabetes of PWD</b>		
Type 1	47	38.5%
Type 2	28	23.0
Mixed	47	38.5
<b>Age of PWD</b>		
Pediatric	41	33.3%
Adult	61	49.6
Mixed	21	17.1
<b>Socioeconomic Status of PWD</b>		
Low	11	8.9%
Medium	30	24.4
High	1	0.8
Mixed	81	65.9
<b>How Much COVID affected Your Work with PWD</b>		
Not a Problem	1	1.0%
Minor Problem	28	28.0
Moderate Problem	40	40.0
Somewhat Serious Problem	21	21.0
Serious Problem	10	10.0

PWD, People with diabetes, i.e., people with whom the respondent works.

Another set of technology questions pertained to telemedicine. The most frequently reported moderate to serious technology problems included “PWD not having access or knowledge of telemedicine” (59.1%; mean = 2.9, SD = 1.0), “too much screen time from telemedicine” (46.7%; mean = 2.6, SD = 1.2), and “legal, licensure, reimbursement issues with telemedicine” (35.3%; mean = 2.2, SD = 1.3). Other issues included “Needing to learn to use telemedicine” (17.3%; mean = 1.8, SD = 1.0) and “not having access to telemedicine” (21.5%; mean = 1.74, SD = 1.1).

## Concerns About PWD

**Figure 1** shows the mean scale scores to questions regarding respondent concerns about the impact of COVID on the behavioral and psychosocial wellbeing of PWD; most means are above three (moderate problem). Behaviorally, the top

concerns were physical activity (90%), weight gain (89%), eating problems (79%), diet (75%), and sleep (72%). Regarding psychosocial wellbeing, top concerns were anxiety (90%), loneliness (87%), depression and diabetes distress (both 83%), and family conflict (74%). Suicidality among PWD was reported as a moderate to serious problem by 52% of respondents.

## DISCUSSION

The current manuscript describes the impact of the COVID-19 pandemic as reported by professionals working to address the psychosocial needs of PWD. Most participants reported that they were experiencing moderate to serious levels of stress, burnout or mental health issues. They also reported problems due to the lack of clear public health guidelines, concerns with COVID safety for themselves, PWD, and staff. Another clear problem was PWD lacking access to, or not knowing how to use, diabetes technology and telemedicine. In addition, most participants reported concerns with the behavioral and psychosocial functioning of PWD during the pandemic and a disruption to the PWD relationship. Overall, the pattern of findings reveals a high level of detrimental impact, some of which may be ameliorated with changes in policy and additional services for both health professionals and the PWD with whom they work, at the levels of the healthcare system, institution, and workplace. Concerns about the health and wellbeing of the PWD during the pandemic must go beyond their medical management and also consider their need for behavioral and psychosocial support and the impact of COVID-19 on the health professionals who provide it.

First, our findings point to the risk of a potential decline in the already under-resourced workforce of professionals who address the behavioral and psychosocial needs of PWD. Both pediatric and adult treatment guidelines recommend psychosocial screening, intervention, or referral to mental health care when warranted (11). Yet, most settings do not offer this type or level of service. Whereas reimbursement continues to be a challenge, a shortage of professionals to meet the practice and research needs for PWD diabetes is a crucial factor. Over half of respondents reported that their own level of stress, burnout, and mental health was a moderate to serious problem. Healthcare

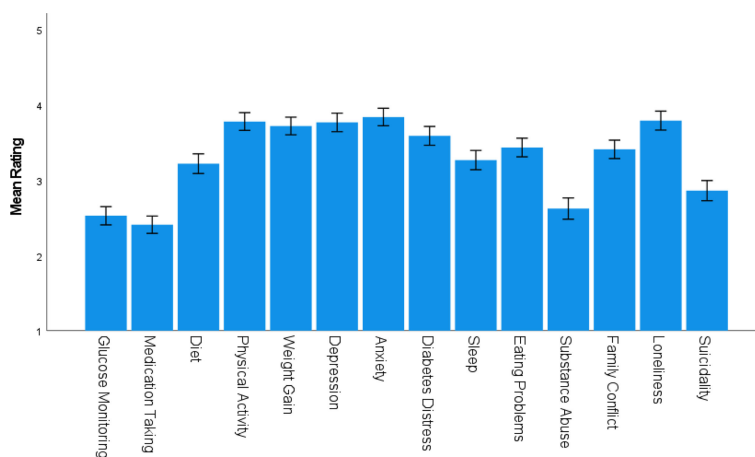
**TABLE 2 |** Problems with the healthcare system (Scale Range 1 = not a problem to 5 = serious problem).

Problem	Mean	SD	Percentage Moderate to Serious
Lack of public health guidelines for COVID	2.77	1.30	56.4%
Delay/lack of access to COVID testing for peoples with diabetes	2.11	1.12	32.0%
COVID related issues regarding reimbursement	1.93	1.08	30.7%
COVID related issues regarding documentation	1.88	0.99	26.3%
Delay/lack of access to COVID testing for you and staff	1.69	1.13	18.4%
Disagreement about work-related COVID issues with:			
Government bodies	1.96	1.27	28.3%
Organization administration	1.84	1.02	23.8%
Research funders	1.80	1.28	22.6%
Licensure organizations	1.59	1.16	16.0%
Human subjects protection and regulatory bodies	1.59	1.02	18.6%
Colleagues	1.59	0.91	14.7%

**TABLE 3** | Problems in the workplace (Scale Range 1= not a problem to 5 = serious problem).

Problem	Mean	SD	Percentage Moderate to Serious
COVID safety for PWD	3.12	1.18	69.0%
Changing flow of people through workspace	3.06	1.16	69.3%
Your own and your staff COVID safety	2.85	1.16	62.4%
Making decision to close/reopen workplace	2.81	1.32	59.3%
Possibly exposing family to COVID	2.68	1.24	50.9%
Isolation from colleagues	2.50	1.14	48.5%
Disruption to relationship between you and PWD	2.42	1.15	44.3%
Skepticism about COVID among PWD	2.34	1.10	40.0%
Financial consequences of COVID to work	2.27	1.30	42.1%
Lack of time with PWD	2.20	1.19	34.7%
Uncertainty how to explain COVID risks to PWD	2.09	1.11	32.6%
Wearing personal protection equipment	2.06	1.08	30.7%
Disruption of supply chains	2.06	1.09	29.5%
Keeping up with COVID research	1.97	1.04	32.7%
Needing to quarantine from family due to possible exposure at work	1.93	1.17	28.3%
Staff vaccine hesitancy	1.88	1.09	25.0%
Skepticism about COVID among your staff	1.72	0.94	17.9%
Your own vaccine hesitancy	1.11	0.50	2.1%

PWD, People with diabetes, i.e., people with whom the respondent works.

**FIGURE 1** | Mean (± SEM) Concerns Regarding PWD. PWD, People with diabetes, i.e., people with whom the respondent works.

professionals who are more psychologically impacted by the COVID-19 pandemic report greater intentions to quit or retire (12). Ignoring the needs of professionals who address psychosocial issues in PWD may result in a loss of workforce that is already seriously underpowered (13). This may be especially true for women health professionals, who report barriers to remaining in their career field, including work-family conflicts and workplace harassment (14). Indeed, in the context of the current pandemic, female health professionals report greater professional and family-related stress than their male counterparts (15). If the workforce declines, combined with limited support for workers—especially women—there will be downstream negative consequences for PWD, including a net loss in evidence-based intervention development and the delivery of clinical services to PWD exactly when these are needed most.

Second, many respondents reported significant problems with the healthcare system, their workplace, and access to technologies that would allow them to work safely and efficiently during COVID, providing specific areas for improvement of workplace functioning. Respondents were concerned about potential COVID exposure of themselves and in turn their families as well as exposure of their staff and PWD. Safety concerns were compounded by the limited patient access to telemedicine, precluding professionals from shifting to remote delivery of services which could have reduced exposure to workplace hazards. There are data suggesting that greater perceptions of exposure to workplace hazards may reduce the quality of life of healthcare professionals (16) and reduced quality of life of professionals is associated with reduced quality of care (17). Therefore, the continued stress associated with the pandemic may not only impact workplace functions, but also the



well-being of professionals and the care PWD receive. It is imperative to identify ways to better support professionals working with PWD, which should prioritize elevating staff voices in the implementation of protocols.

Third, respondents reported significant concerns with both access to care and behavioral and psychosocial functioning of PWD, which highlights the importance of overcoming the aforementioned workplace hazards and obstacles to providing quality care to PWD. For example, respondents reported a perceived disruption to their relationship with PWD. There are extensive data highlighting the importance of the patient-provider relationship in predicting diabetes self-management in patients (18, 19). The disruption to this key relationship may in part explain the perceived reduction of patients' engagement in key health behaviors (i.e., physical activity, diet, sleep) required for effective diabetes management. Respondent concerns are consistent with recent studies which indicate COVID-related disruptions in physical activity (20, 21), diet (20–23), sleep (20, 24) and diabetes self-care (25), among PWD. Disruption of the professional-provider relationship may also in part explain perceptions of the overall decrease in emotional wellbeing of patients (i.e., increased depression, anxiety, suicidality, diabetes distress, loneliness, and family conflict). Here, too, respondent concerns are consistent with the literature showing reduced psychosocial wellbeing (26) in PWD during the COVID-19 pandemic. Non-pharmacological interventions exist for many of the behavioral (27, 28) and psychosocial (29–31) problems faced by PWD. Unfortunately, respondents within our study are also the professionals specifically trained to screen, assess, and intervene on problems with diabetes self-management and wellbeing of PWD. Yet, due to the workplace hazards and other obstacles previously mentioned, these professionals are limited in the quality and quantity of services that can be provided. The pandemic is likely to continue (32) and climate disruption will likely bring natural disasters and associated social unrest that could also interrupt routine medical care for many. Initiating modified in-person diabetes services, and/or telemedicine-delivered services, including and especially psychological services to improve psychosocial wellbeing of PWD, is crucial to face these future challenges.

A lack of clear public guidelines was a top problem among participants. Lack of clear guidelines may be related to the disagreement that participants reported with various institutions such as government bodies, research funders, licensure organizations and human subjects protections committees. This is consistent with data highlighting inconsistencies in guidelines across various global and national organizations (33). It is likely also related to participants' relatively low confidence in explaining COVID risk to PWD. Uncertainty about COVID-19 guidelines and vaccination has been studied across various health professions (34, 35) and is problematic because professionals may inadvertently transfer their uncertainty onto patients, thereby reinforcing distrust of the medical system. Moreover, data supports that knowledge about the COVID-19 vaccine, including its benefits, strongly

predicts intention to accept the vaccine (36). Thus healthcare professionals play a key role in countries achieving herd immunity primarily by vaccination.

## Limitations

There are limitations to consider in the context of study findings. First, the response rate was low (20%) and the sample was small which limits the analyses that can be conducted and the generalizability of findings. Larger samples would allow comparison across respondents by discipline (e.g., medicine vs nursing vs. psychology), primary professional activity (e.g., clinical care vs research) and patient population (e.g., adults vs pediatrics). Of those who responded, most were middle-aged women from European countries and the United States; thus, self-selection bias may have impacted results. Of note, the majority of the sample was from Europe where women outnumber men in the health professions (37) thus, our preponderance of women may not be unrepresentative. Future research should include more respondents from low- and low-middle income countries where experiences of the pandemic may be very different from those reported here. Respondents were limited to English speakers and findings may not generalize to professionals who do not speak English. Second, study methodology required respondents to retrospectively report problems which can be influenced by forgetting and/or recall bias. The role of threat perception on responding should also be considered, as those who are more distressed may report more problems. Future research should also clearly define terms such as stress/burnout/mental health issues. Finally, data collection occurred during middle to late 2021, after the initial nationwide closures and re-openings occurred. Findings may not be representative of changes at other periods of the pandemic.

## Conclusion and Future Directions

The current study highlights professional perspectives of the effect of the COVID-19 pandemic on the healthcare system, workplace, technology, and behavioral and psychosocial functioning of PWD. Many of the reported concerns could be addressed through increasing public and professional knowledge about COVID-19 in a clear and timely manner. Organizations should attempt to provide trainings about how professionals can disseminate evidence-based knowledge about COVID-19 to PWD. This might include reference to emerging studies about the impact of COVID-19 social distancing measures on lifestyle and mental health of PWD. It could also include reference to studies about the impact of COVID-19 infection (38) and vaccine administration (39) on diabetes. More broadly, professional organizations should develop and disseminate trainings on providing care in the context of a global crisis.

In addition, given participants' notable concerns with COVID-19 exposure, it will be important to ensure organizations are equipped with the technology needed to deliver services remotely. Organizations might consider reallocating funds to make telemedicine accessible for PWD and professionals, and providing trainings about how PWD

and professionals can use telemedicine and troubleshoot any technology problems (e.g., camera angle). Data show that telemedicine, when properly introduced, is well received by PWD (40, 41) and providers (42). Importantly, consideration of a hybrid model of service delivery (i.e., remote and in-person) should be considered, even after the pandemic resolves. From a policy standpoint, it will also be important for insurance companies and licensing boards to allow for flexible provision of services across regions (e.g., across state lines in the United States) and across modalities (i.e., in-person and *via* telemedicine) over time and waves of the pandemic. Moreover, governments should prioritize providing equitable access to: 1) internet for all citizens to reduce barriers to telemedicine, 2) diabetes technologies to reduce the burden of daily diabetes management, 3) diabetes management supplies across all regions of the world, including building better infrastructure to protect supply chains, and, 4) personal protective equipment for all private and public healthcare settings to reduce exposure to workplace hazards.

Also, with the specter of a declining workforce, there is a need to increase the pipeline of professionals trained to address the biopsychosocial needs of PWD. This might include training bachelor's or master's level clinicians to provide supportive services or increasing the workforce of peer counselors and community health workers who can provide diabetes self-management education and support. Prior clinical trials support the efficacy and acceptability of interventions led by peer counselors (43, 44) and community health workers (45, 46). Therefore, such interventions should be delivered more broadly, especially in the context of the COVID-19 pandemic during which health and wellbeing of PWD are found to be impacted. Also, there are pilot data supporting the implementation of the Look AHEAD and Diabetes Prevention Program Group Lifestyle Balance program in providing support during the pandemic (47), thus the program should be implemented more widely. There may also be a role for mobile mental health applications to equip patients with readily accessible psychological support.

Professionals should also seek psychological care for themselves, as needed, to improve their own wellbeing, which

is likely to have downstream effects on the care they provide (17). For example, mindfulness-based stress reduction interventions have been demonstrated to yield significant improvements in quality of life (48), anxiety, depression and stress (49) in healthcare professionals.

Last, and importantly, as hospitals, clinics and other diabetes service organizations continue to re-instate services, professionals might consider ways to re-establish the PWD-professional relationship. In a recent study, patients who were reached by phone were more than twice as likely to book and keep an appointment compared to those who were not reached or who had a voicemail message left (50). Therefore, providers might consider making direct contact with patients to increase the likelihood that patients will re-initiate access to care, as well as to provide an opportunity for a positive, brief interaction between the patient and their provider, thereby taking the first step towards rebuilding this important relationship.

## DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

## ETHICS STATEMENT

The studies involving human participants were reviewed and approved by UConn Health IRB. The participants electronically provided their signed informed consent to participate in this study.

## AUTHOR CONTRIBUTIONS

JW, KK, and MK conceived and implemented the study. RF conducted data analysis. CC contributed to writing the manuscript. All authors read and edited the manuscript. All authors contributed to the article and approved the submitted version.

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# Diabetes Distress and Self-Reported Health in a Sample of Alabama Medicaid-Covered Adults Before and During the COVID-19 Pandemic

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Temporary closures of outpatient health facilities and transitions to virtual care during the COVID-19 pandemic interrupted the care of millions of patients with diabetes contributing to worsening psychosocial factors and enhanced difficulty in managing type 2 diabetes mellitus. We explored associations between COVID time period and self-reported diabetes distress on self-reported health among a sample of Alabama Medicaid-covered adults with diabetes pre-COVID (2017-2019) and during-COVID (2020-2021).

**Method:** In this cross-sectional study, we surveyed a population-based sample of adults with type 2 diabetes covered by the Alabama Medicaid Agency. Participants were dichotomized into pre-COVID (March 2017 to October 2019) vs during-COVID (October 2020 to May 2021) groups. Participants with missing data were removed from analyses. We assessed diabetes related stress by the Diabetes Distress Scale. We measured self-reported health using a single item with a 5-point Likert scale. We ran logistic regressions modeling COVID time period on self-reported poor health controlling for demographics, severity of diabetes, and diabetes distress.

**Results:** In this sample of 1822 individuals, median age was 54, 74.5% were female and 59.4% were Black. Compared to pre-COVID participants, participants surveyed during COVID were younger, more likely to be Black (64.1% VS 58.2%,  $p=0.01$ ) and female (81.8% VS 72.5%,  $p<0.001$ ). This group also had fewer individuals from rural areas (29.2% VS 38.4%,  $p<0.001$ ), and shorter diabetes duration (7 years VS 9 years,  $p<0.001$ ). During COVID individuals reported modestly lower levels of diabetes distress (1.2 VS 1.4,  $p<0.001$ ) when compared to the pre-COVID group. After adjusting for demographic differences, diabetes severity, and diabetes distress, participants responding during COVID had increased odds of reporting poor health (Odds ratio [OR] 1.41, 95% Confidence Interval [CI] 1.11-1.80).



**Discussion:** We found respondents were more likely to report poorer health during COVID compared to pre-COVID. These results suggest that increased outreach may be needed to address diabetes management for vulnerable groups, many of whom were already at high risk for poor outcomes prior to the pandemic.

**Keywords:** diabetes, self-reported health, medicaid, COVID, survey

## INTRODUCTION

The coronavirus disease of 2019 (COVID-19) pandemic had extensive impact in the United States causing over 700,000 deaths and sparked new fears of economic turmoil and social isolation (1). The US underwent several protective measures including temporary closure of public facilities, suspending external travel, and nightly curfews to prevent the spread of coronavirus (2).

These changes posed new barriers to care for patients with chronic disease including closing of outpatient clinics, decreased inpatient capacity, staff shortage, and medicine shortage. During COVID, many patients were unable to afford medicines or access transportation resulting in delay in seeking care (3, 4). For patients with Diabetes Mellitus (DM), these experiences could contribute to worse disease management and elevated diabetes distress, defined as an emotional state where people experience feelings such as stress, guilt, or denial that arise from living with diabetes and the burden of self-management (5, 6). Increased diabetes distress is closely linked to poor glycemic control in adults with DM (7).

The "Diabetes Belt," a term coined by the Centers for Disease Control (CDC), refers to the southeastern region of the United States where prevalence of DM is disproportionately high (> 11%) as are rates of diabetes-related complications and mortality (8). Notably, this region has a greater percentage of African Americans (23.8% compared to 8.6%) and higher rates of poverty compared to the rest of the country (9). Centrally located within the Diabetes Belt, Alabama is the 6th poorest state in the US with over 37% of the population living at or below 200% federal poverty level (7). Limited studies have reviewed the effects of the COVID pandemic on this population. The compounding high burden of disease with limited financial resources may further complicate diabetes management and may worsen diabetes distress.

Evidence also suggests that COVID protective measures may have had significant impact on individuals physical and mental health, with some populations experiencing higher rates of anxiety, depression, and perceived stress during the pandemic (10). Moreover, individuals who were directly impacted by COVID reported declines in self-rated health (11). Lower self-rated health and higher levels of mental distress are associated with poor health management, increased hospitalizations, and increased mortality in patients managing chronic disease (12).

In this study, we examined the relationship between diabetes distress, depressive symptoms, diabetes management self-efficacy, and perceived stress with self-reported health in Alabama Medicaid-covered adults with diabetes between COVID time periods (prior to vs during).

## METHODS

### Study Design and Population

We conducted a cross-sectional survey within the Alabama Care Plan study. Briefly, the Alabama Care Plan (ACP) was an observational study of the quality of care of adults with diabetes covered by Alabama Medicaid. The Alabama Care Plan study enrolled a population-based sample of adults with type 1 or 2 diabetes who were covered by Alabama Medicaid between March 2017 and May 2021. Medicaid eligibility for adults in Alabama includes parents of minor children with incomes at or below 18% of Federal Poverty Level (FPL) and adults with disability eligible for the Supplemental Security Income (SSI) program (13). As part of the ACP study, a survey was conducted among a sample of Medicaid-covered adults with diabetes to assess patient-reported outcomes and satisfaction with care.

The current study examines survey responses before and during the COVID pandemic. Adults were eligible if they met the following criteria: age 19 to 64 years old, covered by Medicaid for the prior 12 months, and were diagnosed with diabetes, defined by the presence of at least one inpatient or two outpatient International Classification of Diseases (ICD-9 or ICD-10) diagnosis codes used by the CMS Chronic Conditions Warehouse project (14), in the preceding two years (15). Potential participants were excluded if they were non-English speaking, were mentally or physically incapable of completing the survey per caregiver report. All procedures performed in studies involving human participants were in accordance with the ethical standards of the Institutional Review Board and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. All study data were HIPAA-compliant and secured with additional password protection.

### Data Collection

Survey methods have been described previously (7). Briefly, using Alabama Medicaid enrollment and claims data files, the survey unit generated a list of potential participants who met the age, Medicaid enrollment and diabetes diagnosis inclusion criteria. We contacted potential participants by letter, which provided information about the study and an option to decline participation by contacting a toll-free number or by mail. Subsequently, study interviewers contacted potential participants who did not decline by phone to invite them to participate and schedule a time to complete the survey. Study interviewers called participants multiple times at different times and days, including evenings and weekends, with a maximum of 15 call attempts. For eligible participants who agreed to participate, informed consent was obtained by phone. Study interviewers used

a computer-assisted telephone interview system to complete a 125-item survey which included measures detailed below. The study was reviewed and approved by the UAB Institutional Review Board.

## Measures

Measures (described below) included those that assessed self-reported health, depressive symptoms, perceived stress, diabetes management, and stress relating to diabetes with additional questions on socio-demographics. Participants during COVID completed additional questions relating to COVID experiences and access to care.

### Self-Reported Health Survey

The self-reported health survey is a single-item ordinal measure with 5 levels varying from excellent, very good, good, fair, or poor. This survey is a widely used indicator of general health status in epidemiologic and population health research and is often categorized into excellent, very good, or good versus fair or poor (16).

### Patient Health Questionnaire-8 (PHQ-8)

The PHQ-8 is an 8-item survey used for assessing depression that incorporates DSM-IV depression criteria with other leading major depressive symptoms into a numerical score graded as mild (5-9), moderate (10-14), moderately severe (15-19), and severe depression ( $>20$ ) (17).

### Perceived Stress Scale (PSS-4)

The PSS-4 is a 4-item survey used to measure perceived psychological stress relating to general stress in the previous month. Scores range from 0 to 16 with higher scores indicating greater perceived stress (18, 19).

### Perceived Diabetes Self-Management Scale (PDSMS)

The PDSMS is an 8-item survey measuring diabetes self-efficacy, adapted from the Perceived Medical-Condition Self-Management Scale. Scores range from 8 to 40, with higher scores indicating more confidence in self-managing one's diabetes. Higher scores are associated with higher reported self-care activities and better glycemic control (20).

### Diabetes Distress Scale

The DDS is a 17-item scale that evaluates distress relating to the emotional burden, physician-related distress, regimen-related distress, and interpersonal distress of managing type 2 diabetes over the past month. The mean score is graded on a possible score range of 1–6 with a score of less than 2 indicating low diabetes distress, 2 to greater than 3 moderate diabetes distress and  $\geq 3$  severe diabetes distress (7).

### Questions on the Impact of COVID

To assess the impact of COVID in the past 6-months, questions ( $n=20$ ) were pulled from two sources and modified based on feedback from a community advisory board and/or to simplify administration over the phone (21, 22). Participants reported if they experienced any cancelled or rescheduled medical appointments, completed any telemedicine appointments, or faced any delay in

diabetes medications or supplies. Participants were also asked if they experienced any income change *via* loss of employment or employment loss of spouse related to COVID.

## Analysis

For analysis, participants were dichotomized into pre-COVID (March 2017 to October 2019) vs during-COVID (October 2020 to May 2021) groups (see **Figure 1**). These dates were defined based on availability of data. Survey implementation was paused after October of 2019 due to a Medicaid policy change whereby primary care providers were no longer designated as gatekeepers for care. Surveys were scheduled to resume in early Spring however this was delayed due to the impact of COVID on University operations; as such, survey implementation resumed in October 2020. All respondents were unique: no individuals were surveyed twice (pre and during COVID). First, we examined the distribution of continuous variables and the number of observations per cell. Descriptive statistics were used to characterize the study population overall and by COVID time period. Wilcoxon's tests, t-tests, and chi-square tests were used to determine differences between demographics, depressive symptoms, perceived stress, diabetes distress and self-reported health between groups. Wilcoxon's and t-test results were similar; results from Wilcoxon's tests are presented here. Logistic regression was used to model the effect of COVID time period on self-rated health controlling for demographics, severity of diabetes, and diabetes distress. The self-reported health survey scores were dichotomized into poor health (poor, fair) and better health (good, very good, excellent) for analysis. Covariates selected were either: 1. Specified *a priori* based on established or potential relationship of the covariate with our outcome variable; or 2. Found to differ between the pre- vs. during-COVID groups. Model 1 adjusted for demographics, model 2 added disease severity factors to model 1 and model 3 added diabetes distress to model 2. We present results for model 3. We then compared experiences of individuals reporting poor and better health during COVID.

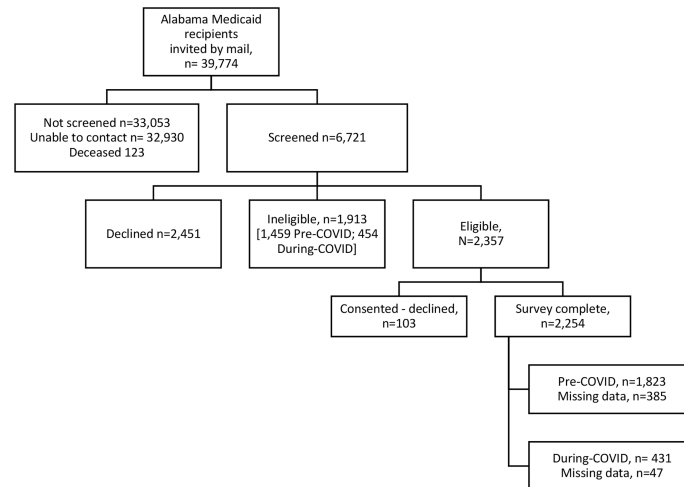
## RESULTS

### Population

In this sample of 1,822 individuals (**Table 1**), median age was 54, 74.5% were female and 59.4% were Black. Most participants had a high school level education and were unable to work. Median time with DM was 9 years and 44.2% were on insulin. Only 43.3% of participants reported having received diabetes education. Of the sample, 1,438 participants were dichotomized into pre-COVID (March 2017 to October 2019) group and 384 during-COVID (October 2020 to May 2021) group.

### Bivariate Associations by COVID Time Group

Participants during COVID were younger with higher proportion of Black individuals (64.1% VS 58.2%,  $p=0.01$ ) and more females (81.8% VS 72.5%,  $p<0.001$ ). The during COVID group had fewer individuals reporting inability to work (72.1% VS 87.2%,  $p<0.001$ ); fewer individuals from rural areas (29.2% VS 38.4%,  $p<0.001$ ); and



**FIGURE 1** | Survey population flow diagram of Alabama Medicaid-covered adults with type 2 diabetes mellitus (March 2017 to May 2021).

**TABLE 1** | Characteristics of survey participants with type 2 diabetes covered by Alabama Medicaid prior to the COVID-19 pandemic and during the COVID-19 pandemic.

Characteristic	ALL N = 1822	Pre-COVID N = 1438	During-COVID N = 384	P-value
Age in years, median [IQR]	54 [45, 60]	55 [46, 60]	51 [42, 59]	<0.001
Sex, N (%)				<0.001
Male	465 (25.5%)	395 (27.5%)	70 (18.2%)	
Female	1357 (74.5%)	1043 (72.5%)	314 (81.8%)	
Race, N (%)				<0.01
White	703 (38.6%)	577 (40.1%)	126 (32.8%)	
Black	1083 (59.4%)	837 (58.2%)	246 (64.1%)	
Other	36 (2.0%)	24 (1.7%)	12 (3.1%)	
NonWhite, N (%)	1119 (61.4%)	861 (59.9%)	258 (67.2%)	<0.01
Hispanic, N (%)	54 (3.0%)	50 (3.5%)	4 (1.0%)	0.01
Education, N (%)				0.06
Less than HS	612 (33.6%)	499 (34.7%)	113 (29.4%)	
High School	735 (40.4%)	561 (39.1%)	174 (45.3%)	
More than HS	473 (26.0%)	376 (26.2%)	97 (25.3%)	
Income less than 10K, N (%)	1003 (67.4%)	783 (67.6%)	220 (66.9%)	0.81
Employment, N (%)				<0.001
Working/Studying	107 (5.9%)	73 (5.1%)	34 (8.9%)	
Not working	184 (10.1%)	111 (7.8%)	73 (19.1%)	
Cannot work	1524 (84.0%)	1248 (87.2%)	276 (72.1%)	
Marital Status, N (%)				0.38
Single	1448 (79.5%)	1149 (79.9%)	299 (77.9%)	
Married	374 (20.5%)	289 (20.1%)	85 (22.1%)	
Rural, N (%)	664 (36.4%)	552 (38.4%)	112 (29.2%)	<0.001
Diabetes Duration in years, median [IQR]	9[3,18]	9[4,18]	7[2,16]	<0.001
Insulin Use, N (%)	806 (44.2%)	643 (44.7%)	163 (42.4%)	0.43
Diabetes Education, N (%)	788 (43.4%)	612 (42.7%)	176 (46.0%)	0.25
<b>Psychosocial Measures</b>				
Self-Reported Health				0.12
Better	919 (50.4%)	739 (51.4%)	180 (46.9%)	
Poor	903 (49.6%)	699 (48.6%)	204 (53.1%)	
PHQ-8 Scale, median [IQR] <sup>a</sup>	6 [3, 10]	6 [3, 11]	5 [2, 10]	0.14
PDSMS Scale, median [IQR] <sup>b</sup>	28 [25, 32]	28 [25, 31]	30 [26, 32]	<0.001
PSS4, median [IQR] <sup>c</sup>	5 [2, 8]	6 [2, 8]	5 [2, 7]	<0.01
DDS, median [IQR]	1.3 [1.1, 1.8]	1.4 [1.1, 1.9]	1.2 [1.1, 1.6]	<0.01

Patient Health Questionnaire-8 (PHQ-8), Perceived Diabetes Self-Management Scale (PDSMS), Perceived Stress Scale (PSS4), Diabetes Distress Scale (DDS).

<sup>a</sup> N=14 were missing from the Pre-COVID group, <sup>b</sup> N=16 were missing (12 from Pre-COVID and 4 from During-COVID); <sup>c</sup> N=62 were missing (61 from Pre-COVID and 1 from During-COVID).

a shorter diabetes duration (10.6 years VS 12.5 years,  $p < 0.001$ ). The during COVID group reported slightly higher perceived self-management (PDSMS Score 30 VS 28,  $p < 0.001$ ); moderately better stress ratings (PSS-4 Score 5 VS 6,  $p < 0.01$ ); and modestly lower levels of diabetes distress (1.4 VS 1.2,  $p < 0.01$ ) when compared to the pre-COVID group.

## Multivariable Analysis

After adjusting for demographic differences, diabetes severity, and diabetes distress, participants responding during COVID had increased odds of reporting poor or fair health (Odds ratio [OR] 1.41, 95% Confidence Interval [CI] 1.11-1.80) as seen in **Table 2**.

## Bivariate Differences Between Poor Health vs Better Health During COVID

Participants during COVID who reported poor health were less likely to be working (5.9% VS 12.3%,  $p = 0.0352$ ) compared to those with better health. This group was also less likely to be married (81.9% VS 73.3%,  $p = 0.0445$ ). This group had higher PHQ-8 scores (8 VS 3,  $p < 0.001$ ), lower PDSMS scores (28 VS 30,  $p < 0.001$ ), higher PSS-4 scores (5 VS 4,  $p < 0.001$ ), and higher DSS scores (1.2 VS 1.4,  $p < 0.001$ ) as seen in **Table 3**.

## Impact of COVID Between Poor Health vs Better Health During COVID

Among participants surveyed during COVID, 34.8% of participants experienced an appointment cancellation or rescheduled appointment with majority due to doctor's office canceling or moving appointment. Over half of participants were offered a virtual visit *via* telehealth or phone visit with majority of this group completing a telephone visit. Within this group, 19.8% of participants reported a video visit. Participants who reported poor health were significantly more likely to believe they have had COVID-19 regardless of testing.

## DISCUSSION

We found significant differences between the pre-COVID and during-COVID groups participants (**Table 1**). Notably, the during-COVID group is a younger and more urban group with less diabetes severity. This likely contributes to the higher levels of diabetes self-management (PDSMS), reduced perceived stress (PSS-

4), and lower levels of diabetes distress (DDS) observed in this analysis. However, there was a modest decrease in self-reported health in the during-COVID group. Multivariate analysis allowed a deeper look into the association of the COVID time period and poor self-reported health (**Table 2**). After controlling for demographics, severity of diabetes, and diabetes distress, the participants surveyed during COVID were significantly more likely to report poor self-reported health compared to those pre-COVID. Within the during-COVID group, individuals reporting poor health were more likely to report worse depressive symptoms, worse perceived stress, less competency in managing their diabetes, and higher levels of diabetes distress compared to those with better health as seen in **Table 3**. These factors likely contribute to an overall decreased sense of health and could contribute to worse health outcomes in this group.

Our survey questions related to healthcare experiences during COVID (**Table 4**) shed additional light on possible barriers experienced by participants. Over a third of respondents experienced cancellation or rescheduled appointment and more than half experienced a virtual health appointment. However, few participants reported delays of care or experienced changes to household income during COVID. Moreover, there was no significant difference in experience between individuals reporting better health or poor health. We predicted that this transition may have been challenging to populations with significant financial barriers and limited access to or unfamiliarity with technology (10, 11, 23). However, this population tolerated this transition well and seems to have minimal changes to their care and household income. This could be related to a limited baseline utilization of healthcare resources within this population prior to COVID and the increased use of virtual medicine during COVID. Recent studies describing the many benefits of virtual care suggest that virtual care is effective in managing patients with diabetes, especially in low socioeconomic groups. With proper access, virtual care can motivate patients, facilitate better medical competency, and provide better decision support for patients. These studies also support the effectiveness of virtual care shown by A1C management similar to or superior to usual care (24).

Interestingly, participants who reported poor health were significantly more likely to believe they have had COVID regardless of testing. Additional studies may be needed to identify other contributors to poor self-reported health during COVID within this Alabama Medicaid population.

**TABLE 2 |** Association of COVID time period on self-reported poor health among survey participants with type 2 diabetes covered by Alabama Medicaid (N = 1,822).

Characteristic	Comparison	Odds Ratio (95% Confidence Limits)	P-value
COVID time period	Pre-COVID vs During-COVID	1.41 (1.11-1.8)	<0.01
Age (years)	Per one-year increase	1.00 (0.99-1.01)	0.87
Gender	Male vs Female	0.78 (0.62-0.98)	0.03
Race	Nonwhite vs White	0.66 (0.53-0.81)	<.0001
Education	Less than High School vs More than High School	1.23 (1-1.52)	0.05
Marital Status	Married vs Not Married	0.85 (0.67-1.09)	0.21
Rurality	Rural vs Non-rural	1.04 (0.84-1.27)	0.74
Diabetes Duration (years)	Per one-year increase	1.00 (0.99-1.01)	0.67
Insulin use	Yes vs No	1.17 (0.95-1.43)	0.15
Diabetes Distress Scale (score)	Per one-point increase	2.71 (2.29-3.22)	<.0001

**TABLE 3 |** Comparison of during-COVID survey participants with type 2 diabetes mellitus by self-reported health status.

Characteristic	Total N = 384	Better health N = 180	Poor Health N = 204	P-value
Age in years, median [IQR]	51 [42, 59]	52 [42, 59]	51 [41, 58]	0.28
Sex, N (%)				0.40
Male	70 (18.2%)	36 (20.0%)	34 (16.7%)	
Female	314 (81.8%)	144 (80.0%)	170 (83.3%)	
Race, N (%)				0.67
White	126 (32.8%)	55 (30.6%)	71 (34.8%)	
Black	246 (64.1%)	119 (66.1%)	127 (62.3%)	
Other	12 (3.1%)	6 (3.3%)	6 (2.9%)	
Nonwhite, N (%)	258 (67.2%)	125 (69.4%)	133 (65.2%)	0.38
Hispanic, N (%)	4 (1.0%)	2 (1.1%)	2 (1.0%)	0.90
Education, N (%)				0.19
Less than HS	113 (29.4%)	45 (25.0%)	68 (33.3%)	
High School	174 (45.3%)	88 (48.9%)	86 (42.2%)	
More than HS	97 (25.3%)	47 (26.1%)	50 (24.5%)	
Income less than 10K, N (%)	220 (66.9%)	95 (63.8%)	125 (69.4%)	0.28
Employment, N (%)				0.04
Working/Studying	34 (8.9%)	22 (12.3%)	12 (5.9%)	
Not working	73 (19.1%)	38 (21.2%)	35 (17.2%)	
Cannot work	276 (72.1%)	119 (66.5%)	157 (77.0%)	
Married, N (%)	85 (22.1%)	48 (26.7%)	37 (18.1%)	0.05
Rural, N (%)	112 (29.2%)	53 (29.4%)	59 (28.9%)	0.91
Diabetes Duration, median [IQR]	7[2,16]	9[2,17]	7[2,16]	0.26
Insulin Use, N (%)	74 (41.1%)	89 (43.6%)	163 (42.4%)	0.62
Diabetes Education, N (%)	80 (44.7%)	96 (47.1%)	176 (46.0%)	0.64
<b>Psychosocial Measures</b>				
PHQ-8 Scale, median [IQR] <sup>a</sup>	5 [2, 10]	3 [1, 7]	8 [4, 13]	<0.001
PDSMS Scale, median [IQR] <sup>b</sup>	30 [26, 32]	30 [27, 32]	28 [24, 32]	<0.01
PSS4, median [IQR]	5 [2, 7]	4 [1, 6]	5 [3, 8]	<0.001
DDS, median [IQR] <sup>a</sup>	1.2 [1.1, 1.6]	1.2 [1.0, 1.4]	1.4 [1.1, 1.9]	<0.001

Patient Health Questionnaire-8 (PHQ-8), Perceived Diabetes Self-Management Scale (PDSMS), Perceived Stress Scale (PSS4), Diabetes Distress Scale (DDS).

<sup>a</sup> n=4 missing (1 from Better Health and 3 from Poor Health); <sup>b</sup> n=1 missing (1 from Poor Health).

## Limitations

This is a cross-sectional study; thus, we are unable to infer causation between COVID and poor self-reported health. A longitudinal survey with the same respondents at both time periods would help mitigate this limitation. Further, we cannot be sure that

differences were not due to policy changes occurring within Medicaid itself or other seasonal changes that may have co-occurred temporally. Our study sample includes adults with type 2 diabetes covered by Alabama Medicaid, which limits the generalizability of our findings to other populations. We used

**TABLE 4 |** Responses to COVID specific questions by self-reported health status among survey participants who participated during COVID (October 2020 to May 2021).

Survey item	Total (N=384)	Better health (n=180)	Poor Health (n=204)	P-value
Cancelled health-related appointments or treatments	133 (34.8%)	56 (31.3%)	77 (37.9%)	0.17
Rescheduled or postponed any health-related appointments or treatments	146 (38.2%)	67 (37.2%)	79 (39.1%)	0.71
Provider offered a video visit or phone visit	207 (53.9%)	96 (53.3%)	111 (54.4%)	0.83
Completed a telephone visit	195 (50.8%)	89 (49.4%)	106 (52.0%)	0.62
Completed a video visit	76 (19.8%)	33 (18.3%)	43 (21.1%)	0.50
Delayed in needed diabetes medicines	39 (11.5%)	15 (9.6%)	24 (13.1%)	0.30
Delayed in needed diabetes testing supplies	45 (11.8%)	18 (10.1%)	27 (13.3%)	0.34
Due to the coronavirus pandemic, my household income has:				0.75
Decreased	71 (18.6%)	36 (20.2%)	35 (17.2%)	
Increased	30 (7.9%)	14 (7.9%)	16 (7.9%)	
Not changed	280 (73.5%)	128 (71.9%)	152 (74.9%)	
Lost job or primary source of income due to COVID	19 (5.0%)	12 (6.7%)	7 (3.4%)	0.14
Spouse or partner lost job or primary source of income due to COVID	14 (3.7%)	5 (2.8%)	9 (4.5%)	0.40
Obtained COVID19 testing	227 (59.1%)	106 (58.9%)	121 (59.3%)	0.93
Received Positive COVID test	43 (19.0%)	22 (21.0%)	21 (17.4%)	0.49
Believe you have had COVID-19	92 (24.3%)	35 (19.8%)	57 (28.4%)	0.05

Participants were asked if they experienced the above over the last 6 months.



single item measures to review self-reported health which does not fully reflect the multidimensionality or complexity of a participant's health. Assessments of health were based on self-report, we were unable to include objective measures of diabetes control such as HbA1c. Additional limitations include the limited number of respondents in the during-COVID group and significant demographic differences between respondent groups.

## Conclusions

In this sample of Medicaid-covered adults with type 2 DM living in Alabama, individuals surveyed during-COVID reported poorer health compared to those surveyed pre-COVID. Within the during-COVID group, those reporting poor health were more likely to report worse psychosocial symptoms than those who reported better health. Further findings also suggest that while individuals reporting poor health and better health faced similar delays in care, those reporting poor health during-COVID were more likely to believe they have had COVID regardless of testing. Taken together, these findings suggest that physical and mental health may have worsened among some low-income individuals with type 2 DM. Outreach efforts should include specific screening for stress and depression in order to identify and support those in need.

## DATA AVAILABILITY STATEMENT

The datasets presented in this article are not readily available because of institutional restriction, the generated dataset is not publicly available. Requests to access the datasets should be directed to Andrea Cherrington, MD, MPH, [acherrington@uabmc.edu](mailto:acherrington@uabmc.edu).

## ETHICS STATEMENT

The studies involving human participants were reviewed and approved by University of Alabama at Birmingham, Office of the

Institutional Review Board. Written informed consent for participation was not required for this study in accordance with the national legislation and the institutional requirements.

## AUTHOR CONTRIBUTIONS

ACA contributed to the design of the study, analyzed the data, wrote the manuscript, and revised prior drafts of the manuscript for intellectually important content. CH contributed to the design of the study, wrote the manuscript, and revised prior drafts of the manuscript for intellectually important content. ACA, CH, and CP assisted LJ with the analysis and revised the manuscript for intellectually important content. EL contributed to the conception and design of the study, provided expertise on the analysis plan, and revised the manuscript for intellectually important content. AAA contributed to the design of the study and provided expertise on survey implementation. LJ takes responsibility for the integrity of the data and the accuracy of the data analysis. CP provided input on the analysis plan and revised prior drafts of the manuscript for intellectually important content. ACA and AC conceived and designed the study, assisted in data analysis and interpretation, wrote parts of the introduction and discussion section, and revised prior drafts of the manuscript for intellectually important content. The survey data from reported here were collected from Alabama Medicaid Agency recipients with diabetes mellitus. All authors contributed to the article and approved the submitted version.

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# Psychosocial Impact of the COVID-19 Pandemic on People With Type 1 Diabetes: Results of an Ecological Momentary Assessment Study

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**Aims:** Psychological distress due to living with diabetes, demanding self-management tasks, impacts on life, and risks of complications is common among people living with diabetes. COVID-19 could pose a new additional risk factor for psychological distress in this group. This study aimed to analyze levels of COVID-19-related burdens and fears, variables explaining these levels, and associations with the concurrent 7-day COVID-19 incidence in people with type 1 diabetes (T1D).

**Methods:** A total of 113 people with T1D (58% women; age:  $42.3 \pm 9.9$  years) participated in an ecological momentary assessment (EMA) study between December 2020 and March 2021. The participants reported daily levels of COVID-19-related burdens and fears over 10 consecutive days. Global ratings of COVID-19-related burdens and fears were assessed using questionnaires, as were current and previous levels of diabetes distress (PAID), acceptance (DAS), fear of complications (FCQ), depressive symptoms (CES-D), and diabetes self-management (DSMQ). Current levels of diabetes distress and depressive symptoms were compared with pre-pandemic ratings gained during an earlier study phase. Associations between burdens and fears, psychosocial and somatic aspects, and the concurrent 7-day incidence rate were analyzed using multilevel regression.

**Results:** Diabetes distress and depressive symptoms reported during the pandemic were comparable to pre-pandemic levels (PAID:  $p = .89$ ; CES-D:  $p = .38$ ). Daily EMA ratings reflected relatively low mean COVID-19-related burdens and fears in everyday life. However, there was substantial day-to-day variation per person indicating higher burdens on specific days. Multilevel analyses showed that daily COVID-19-related burdens and fears were significantly predicted by pre-pandemic levels of diabetes distress and diabetes acceptance but were not associated with the concurrent 7-day incidence rate nor with demographic and medical variables.

**Conclusions:** This study observed no increase in diabetes distress and depressive symptoms during the pandemic in people with T1D. The participants reported low to moderate levels of COVID-19-related burdens. COVID-19-related burdens and fears could be explained by pre-pandemic levels of diabetes distress and acceptance but not by demographic and clinical risk variables. The findings suggest that mental factors may constitute stronger predictors of COVID-19-related burdens and fears than objective somatic conditions and risks in middle-aged adults with T1D.

**Keywords:** diabetes distress, depression, COVID-19-related burden, ecological momentary assessment, COVID-19 incidence rate

## INTRODUCTION

The COVID-19 pandemic is a global health threat on a scale not seen in many years. While any person can be severely affected by the virus, people with pre-existing health problems or chronic conditions are at particularly elevated risk (1). One such risk group is people with type 1 diabetes (2). It has been demonstrated that suboptimal glucose control and pre-existing long-term complications of diabetes increase the risk of a severe clinical course of COVID-19. A recent study found that the odds of hospitalization 14 days after a positive test were 3.9 times higher in people with type 1 diabetes than in comparable persons without diabetes (2). Additionally, people with type 1 diabetes may be at higher risk for infectious diseases, including respiratory tract infections, thus the risk of infection with COVID-19 might also be increased (3). Furthermore, meta-analyses showed a nearly twofold increase in mortality risk for COVID-19-infected people with diabetes vs. without (4, 5).

In addition, adverse effects of the COVID-19 pandemic on psychological well-being and mental health have been observed. Systematic reviews and meta-analyses have shown that between 28% and 34% of people reported increased depressive symptoms due to the pandemic (6, 7). In people with chronic diseases, the prevalence of anxiety and depressive symptoms even be increased to 55% (6). Furthermore, several studies reported increases in mental symptoms in people with diabetes during the pandemic. Fisher et al. (8) found that 67% of people with type 1 diabetes reported higher diabetes distress than before the pandemic. A study by Moradian et al. (9) with German people with type 1 and type 2 diabetes suggests increases in depressive symptoms, anxiety, and psychological distress during the pandemic compared to before, however, using a retrospective evaluation. Moreover, Joensen et al. (10) showed that diabetes distress was positively associated with greater worries about COVID-19 and diabetes in people with type 1 and type 2 diabetes. A study by Brailovskaia et al. (11) demonstrated that depressive symptoms were positively associated with psychological distress caused by the pandemic. Finally, Sauchelli et al. (12) found that the confidence in diabetes self-management decreased during the pandemic and people reported that their needs for assistance and support were not sufficiently met by the diabetes healthcare system.

The psychological repercussions of COVID-19 in people with diabetes are particularly concerning considering the potential effects on diabetes outcomes. Depressive disorders as well as elevated diabetes distress have been frequently associated with detrimental effects on self-care behavior, glycemic control, and quality of life (13). Existing evidence suggests that depression and diabetes distress may have increased during the pandemic. Thus, it is important to understand the psychological impacts and risks that the COVID-19 pandemic poses on people with type 1 diabetes including people's subjective daily experiences of the pandemic.

We re-examined a sample of people with type 1 diabetes, who had participated in an observational study regarding psychosocial aspects of living with diabetes before the COVID-19-pandemic, during the pandemic. Experiences of burdens and fears due to COVID-19 were captured using questionnaires. Levels of diabetes distress and depressive symptoms as well as fear of complications, acceptance, and self-management were assessed and compared to the pre-pandemic assessment.

Furthermore, we aimed to analyze the subjective experience of COVID-19-related burdens and fears in everyday life. Therefore, we applied ecological momentary assessment (EMA) to assess the day-to-day COVID-19-related experiences. EMA is a methodology allowing the continued daily sampling of participants' experiences in their everyday life (14).

Finally, we aimed to determine predictors of COVID-19-related burdens and fears, including medical risk factors, psychological aspects, and the concurrent 7-day incidence rate. To our knowledge, this is the first study in people with diabetes that analyzes the associations of the objective risk of infection with COVID-19 (i.e., 7-day incidence rate) with the subjective experience (i.e., burdens and fears) on that day, longitudinally over several days.

## MATERIALS AND METHODS

The present study was a follow-up of participants of the DIA-LINK Study, a prospective observational study on affective conditions in type 1 diabetes, which was conducted before the COVID-19 pandemic started in Germany. The DIA-LINK study is described in detail elsewhere (14). In short, participants were recruited at a large diabetes clinic in Germany. Participants had



to be between 18 and 70 years of age, have type 1 diabetes, and were stratified based on elevated depressive symptoms and diabetes distress levels. Participation in the study went over three months including the baseline assessment, an EMA phase, and a follow-up after three months. This follow-up was used as baseline time point in the current analysis. The study was approved by the Ethics Committee of the German Psychological Society (DGPs) (file number NH082018). The follow-up survey, focusing on participants' burdens and fears due to the COVID-19 pandemic, which constitutes the basis of the present research, was conducted between December 2020 and March 2021, usually about one year after participation in the original DIA-LINK Study.

## Participant Enrollment

Of the 203 participants of the original DIA-LINK Study, those who had consented to be contacted for a follow-up were informed about the present COVID follow-up *via* email, mail, or telephone. Interested persons were then informed about the follow-up survey, both orally and in writing, and written informed consent was obtained prior to inclusion. A total of 113 former study participants took part in this COVID follow-up. Actual assessment then took place *via* online questionnaires and *via* EMA.

## Assessments

All participants had completed a questionnaire package and interview prior to the beginning of the pandemic as part of their original participation in the DIA-LINK Study. HbA1c had been determined at the same time in a central laboratory from venous blood samples.

In the COVID follow-up, participants were surveyed using EMA over a period of 10 consecutive days. The 10-day period was chosen as it was considered long enough for gaining generalizable results and short enough to avoid participation rejection due to overly high effort. Also, the period should include both week and weekend days to reflect daily patterns of variations. For the EMA, a smartphone app ("mEMA"; Ilumivu Software for Humanity, North Carolina) was installed on the participants' personal smartphones. Burdens and fears due to the COVID-19 pandemic were assessed each day as part of the evening assessment. A questionnaire survey including a set of questionnaires and specific COVID-19-related questions was administered online at the end of the 10-day EMA period. The most recent HbA1c value was requested personally as part of a telephone interview referring to the most recent estimation as documented in the participants' diabetes booklets. The following variables were measured before the beginning of the COVID-19 pandemic (baseline):

- Diabetes distress was assessed using the 20-item Problem Areas in Diabetes Scale (PAID) containing diabetes-specific emotional problems and burdens (15). Items are scored on a five-point scale from 0 ("not a problem") to 4 ("serious problem"). A total score is derived and transformed to a scale from 0 to 100. Scores of 40 and above are considered to indicate elevated diabetes distress (16).

- Depressive symptoms were assessed using the Center for Epidemiologic Studies Depression Scale (CES-D) consisting of 20 items assessing the frequencies of depressive symptoms in the past week (17, 18). Each item is scored on a four-point scale from 0 ("never or rarely") to 3 ("most of the time"). A total score is calculated ranging from 0 to 60 with higher values indicating higher depressive symptoms. The CES-D has suitable properties in detecting clinical depression (19).
- Fear of diabetes complications was assessed using a short form of the Fear of Complications Questionnaires (FCQ) (20) containing six items. The items request frequencies of complication-related worries or fear and are scored on a four-point scale from 0 ("never or rarely") to 3 ("most of the time"). A sum score is calculated ranging from 0 to 18 with higher scores indicating higher fear of diabetes complications.
- Diabetes self-management was assessed using the Diabetes Self-Management Questionnaire (DSMQ-R) containing 27 items regarding specific self-management practices (21). Responses are given on a four-point scale from 0 ("does not apply to me") to 3 ("applies to me very much"). The scale values are transformed to a range between 0 and 10. Higher scores indicate better self-management behavior (21, 22).
- Diabetes acceptance was assessed using a short form of the Diabetes Acceptance Scale (DAS) (23). The scale contains 10 items to be answered on a four-point Likert scale from 0 ("never true for me") to 3 ("always true for me"). The sum score ranges from 0 to 30 with higher scores indicating higher acceptance of diabetes.

The following variables were measured as part of the assessment during the pandemic (COVID follow-up):

- Participants reported experiences of the COVID-19 pandemic in a self-report scale. Perceived personal burden due to the pandemic, perceived threat, perceived likelihood of infection, and perceived likelihood of a severe course were rated on an 11-point Likert scale from 0 ("very low"/"very unlikely") to 10 ("very high"/"very likely").
- Using EMA, the following aspects were assessed once daily during the 10-day period: To determine the impact of the COVID-19 pandemic in everyday life, participants were asked to rate (i) the burden due to worries regarding COVID-19 and health, (ii) the burden due to COVID-19-related restrictions, (iii) the fear of getting infected with COVID-19, and (iv) the fear of family members or friends getting infected with COVID-19. Responses were given on an 11-point Likert scale from 0 ("very low") to 10 ("very high").
- Participants also completed the above-mentioned questionnaires (PAID, CES-D, FCQ, DSMQ-R, DAS) again right at the end of the 10-day EMA-period.

## Statistical Analyses

For each of the EMA items, the mean of response scores over the 10 days was calculated for each person (e.g., mean burden level per person). Furthermore, for each item, the mean score across all participants was calculated (e.g., mean burden level in the sample).



In addition, the average course of the EMA item scores over the 10 study days (1–10) was examined. For this purpose, the mean value of each item was calculated for each EMA day (1–10).

To reflect the day-to-day variability of responses of each participant, the coefficient of variation was calculated per person and item. The extent of day-to-day variability across participants is given as mean, median, and 25% and 75% percentiles of the coefficients of variation per item.

To examine possible changes in questionnaire scores, sum scores before and during the pandemic were compared using Student's *t*-test.

To assess the associations between EMA-based ratings of COVID-19-related burden and the concurrent 7-day incidence rate, multilevel modelling with the participant as the nesting factor was used. Analyses were conducted separately with each EMA item as dependent variable and the 7-day incidence rate on that day as within-level predictor. In the first step, the within factor 7-day incidence rate was entered. In the second step, the medical and demographic risk factors for severe course of COVID-19 were added as between-level predictors, that is, age, sex, BMI, smoking, diabetes duration, presence of diabetes complications, presence of other comorbidities (e.g., cancer), and HbA1c. Finally, in the third step, psychosocial/psychobehavioral predictors were added: diabetes distress (PAID), depressive symptoms (CES-D), diabetes acceptance (DAS), diabetes self-management (DSMQ), and fear of complications (FCQ). The questionnaire scores from before the pandemic were used for the analyses. In each analysis, we controlled for study day and first autoregressive parameter. Bayes estimation was used and raw estimates as well as standardized coefficients ( $\beta$ ) are reported.

## RESULTS

### Characteristics of the Study Sample

A total of 113 people with type 1 diabetes participated in the COVID follow-up. The sample characteristics are displayed in **Table 1**. Sixty-six participants (58.4%) were women. The mean age was 43.7 ( $\pm$  12.0) years. The mean duration of diabetes was 21.6 ( $\pm$  12.2) years. Fifty-seven persons (50.4%) were diagnosed with at least one long-term complication of diabetes, mostly diabetic neuropathy and/or retinopathy. The mean HbA1c value was 7.8% ( $\pm$  1.2) or 61.5 ( $\pm$  13.3) mmol/mol, respectively.

Using the COVID-19-specific questionnaire, the perceived burden due to the COVID-19 pandemic was rated 4.99  $\pm$  3.13 on a scale of 0–10. The perceived threat from COVID-19 was rated with 5.04  $\pm$  3.11 on average. Other risks such as the perceived risk of becoming infected during the pandemic (4.29  $\pm$  2.53) and the risk of severe clinical course if infected (5.00  $\pm$  2.97) were rated similarly (also rated on the questionnaire).

DIA-LINK study participants who did not attend the follow-up survey, compared to those who did (present sample), were significantly younger, more likely to live

**TABLE 1 |** Characteristics of the study sample (at the time of the pandemic).

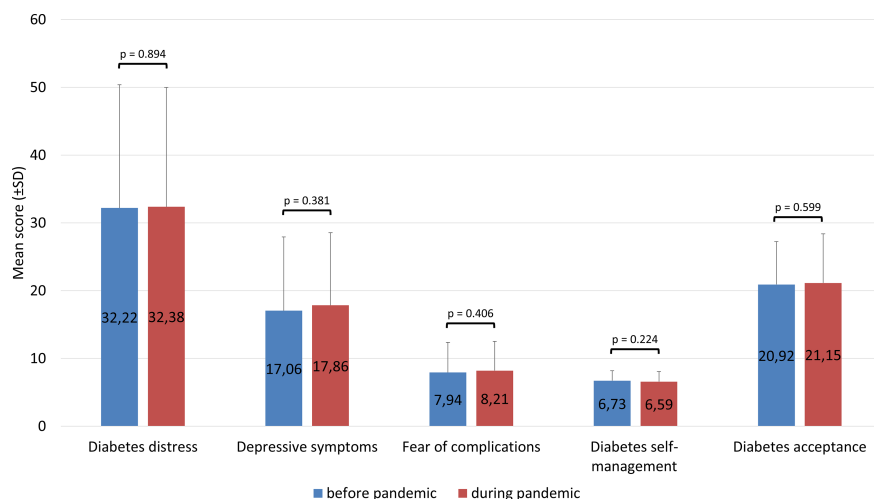
Variable	Participants (N = 113)
Age (years)	43.7 $\pm$ 12.0 (22–70)
Female sex	66 (58.4%)
Smoking	20 (17.7%)
BMI (kg/m <sup>2</sup> )	27.0 $\pm$ 4.9 (18.2–43.9)
Living alone	27 (23.9%)
Persons in household (number)	2.4 $\pm$ 1.1 (1–6)
Years of education	13.3 $\pm$ 2.4 (9–18)
Diabetes duration (years)	21.6 $\pm$ 12.2 (2–50)
With long-term complications	
* Retinopathy	29 (25.7%)
* Neuropathy	40 (35.4%)
* Nephropathy	4 (3.5%)
* Foot syndrome	2 (1.8%)
* Cardiovascular disease	1 (0.9%)
* Arterial vascular disease	4 (3.5%)
With other serious diseases	
* Liver disease	6 (5.3%)
* Cancer (past)	2 (1.7%)
Had severe hypoglycemia requiring assistance in the past year	15 (13.3%)
Had ketoacidosis with medical treatment in the past year	7 (6.2%)
HbA1c in %	7.8 $\pm$ 1.2 (5.5–13.0)
HbA1c in mmol/mol	61.5 $\pm$ 13.3 (36.6–118.6)
PAID score (0–100)	32.4 $\pm$ 17.6 (1–71)
CES-D score (0–60)	17.9 $\pm$ 10.7 (0–44)
DSMQ score (0–10)	6.6 $\pm$ 1.5 (3.1–9.1)
FCQ score (0–18)	8.2 $\pm$ 4.3 (0–18)
DAS score (0–30)	21.1 $\pm$ 7.2 (0–30)
Perceived burden due to the COVID-19 pandemic (questionnaire item)	4.99 $\pm$ 3.13 (0–10)
Perceived threat from the COVID-19 (questionnaire item)	5.04 $\pm$ 3.11 (0–10)
Perceived likelihood of becoming infected later in the pandemic (questionnaire item)	4.29 $\pm$ 2.53 (0–10)
Perceived risk of severe course if infected (questionnaire item)	5.00 $\pm$ 2.97 (0–10)

Data are  $M \pm SD$  (range) or  $n$  (%). BMI, body mass index; HbA1c, glycated hemoglobin; PAID, Problem Areas in Diabetes questionnaire; CES-D, Center for Epidemiological Studies Depression Scale.

alone, had higher HbA1c, higher diabetes distress, and more acute complications (i.e., diabetic ketoacidosis) according to baseline assessments (at the time of enrolment) (all  $p \leq 0.036$ ; data not shown).

### Depression and Diabetes Distress Levels Before and During the Pandemic

**Figure 1** shows the scores of depressive symptoms and diabetes distress before and during the COVID-19 pandemic. Interestingly, neither diabetes distress nor depressive symptoms differed at the time point during the pandemic from the time point before the pandemic (all  $p \geq 0.38$ ). The mean PAID value was 32.2  $\pm$  18.1 before pandemic and 32.4  $\pm$  17.6 during the pandemic ( $p = .89$ ). The average CES-D score remained stable at 17.1  $\pm$  10.9 before the pandemic and 17.9  $\pm$  10.7 during the pandemic ( $p = .38$ ). In addition, no significant changes were observed for the other questionnaires (**Figure 1**).



**FIGURE 1** | Changes in questionnaire scores before vs. during the COVID-19 pandemic.

## EMA Period: Mean Levels of COVID-19-Related Burdens and Fears

In the daily assessment (EMA), participants reported a mean of  $2.3 \pm 2.3$  (scale: 0–10) regarding burden due to worries about COVID-19 and health. The burden due to COVID-19-related restrictions was rated as  $2.9 \pm 2.4$  on average. The fear of getting infected with COVID-19 was rated with a mean of  $1.9 \pm 2.0$ . The fear of family members or friends getting infected with the virus was rated with a mean of  $2.3 \pm 2.3$ . **Figure 2** depicts the course of COVID-19-related burdens (**Figure 2A**) and fears (**Figure 2B**) together with the corresponding incidence rates across the study period. Burdens due to worries and restrictions increased toward January 2021 and declined afterward with the nadir in mid-February (**Figure 2A**). Fears of getting infected also showed a slight increase in December 2020 with a steady decline toward March 2021 (**Figure 2B**). Burdens and fears seemed to increase toward April 2021.

## EMA Period: Variability of Burdens and Fears due to COVID-19

The mean day-to-day variability (coefficient of variation) per person of the burden due to worries about COVID-19 and health was 1.14 and indicates that the score varied by 114% around the mean from day to day. Twenty-five percent of individuals had a coefficient of variation of  $\leq 0.48$  on the question regarding burden due to worries about COVID-19 and health over the 10 days and can be considered relatively stable with respect to their worries. For 25% of all participants, the coefficient of variation was  $\geq 1.58$ , indicating highly fluctuating worry. The coefficient of variation of burden due to COVID-related restrictions was 0.92, indicating that the rating varied by 92% from day to day.

The rating of fear of getting infected with COVID-19 varied from day to day by 114% around the mean. Twenty-five percent

of participants had a coefficient of variation  $\leq 0.53$ . In contrast, 25% had a value  $\geq 1.38$ , indicating highly variable anxiety. The mean coefficient of variation of fear of family members or friends getting infected with COVID-19 was 0.97.

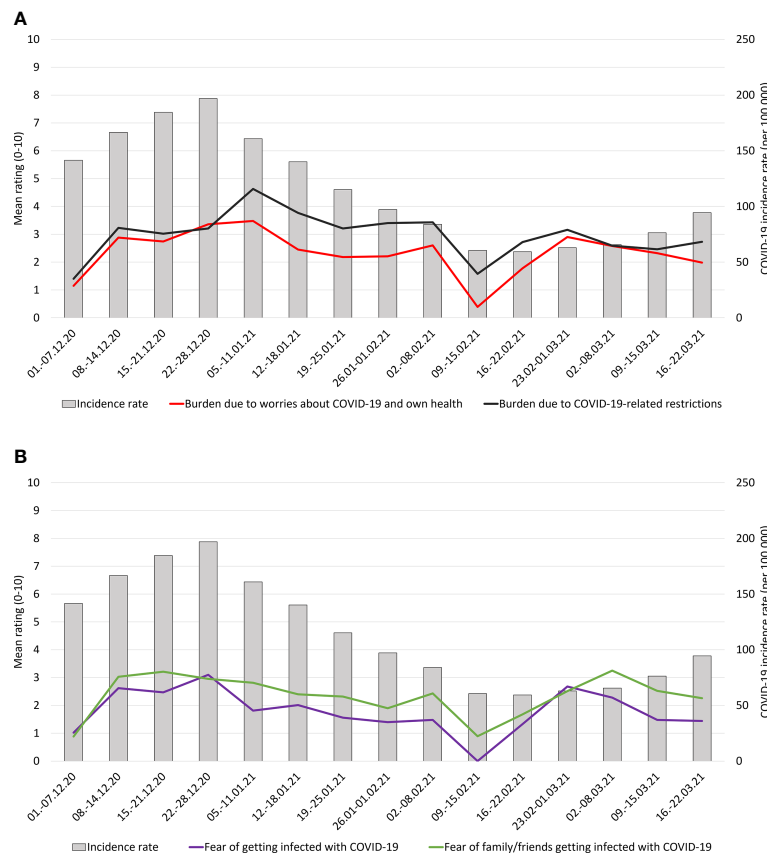
Overall, substantial day-to-day variation per person was observed. The results are displayed in **Figure 3**.

## Associations of COVID-19 Burden and Fear Ratings with Risk Factors and the 7-Day Incidence Rate

**Table 2** shows the associations of COVID-19 burdens and fears and 7-day incidence rate. Neither burden due to COVID-19-related restrictions nor burden due to worries about COVID-19 and health, fear of getting infected or the fear of family members/friends getting infected were significantly associated with the concurrent 7-day incidence rate (all  $\beta < 0.08$ ).

The addition of clinical and demographic risk factors in step 2 yielded a slight improvement of explained variation of burdens and fears (**Table 2**). Simply, fear of getting infected as well as fear of family members/friends getting infected were associated with diabetes duration ( $\beta > 0.21$ ) in this step.

When adding psychosocial risk factors, the explained variation was significantly increased (**Table 2**). Between 48% and 61% of the variation of each aspect could be explained by the models. All COVID-19 items were significantly and positively associated with pre-pandemic levels of diabetes distress (PAID) (all  $\beta > 0.45$ ) and diabetes acceptance (DAS) (all  $\beta > 0.25$ ). Higher daily COVID-19-related burdens and fears were significantly predicted by higher diabetes distress before the pandemic. Furthermore, higher daily COVID-19-related burdens and fears were also predicted by higher diabetes acceptance scores notably. In contrast, no demographic or medical variable, except diabetes duration for the fear of infection of family members, was significantly associated with COVID-19-related burdens and fears in the third step.



**FIGURE 2 |** Course of COVID-19-related burdens (A) and fears (B) displayed against concurrent incidence rates over the study period.

## DISCUSSION

### Main Findings

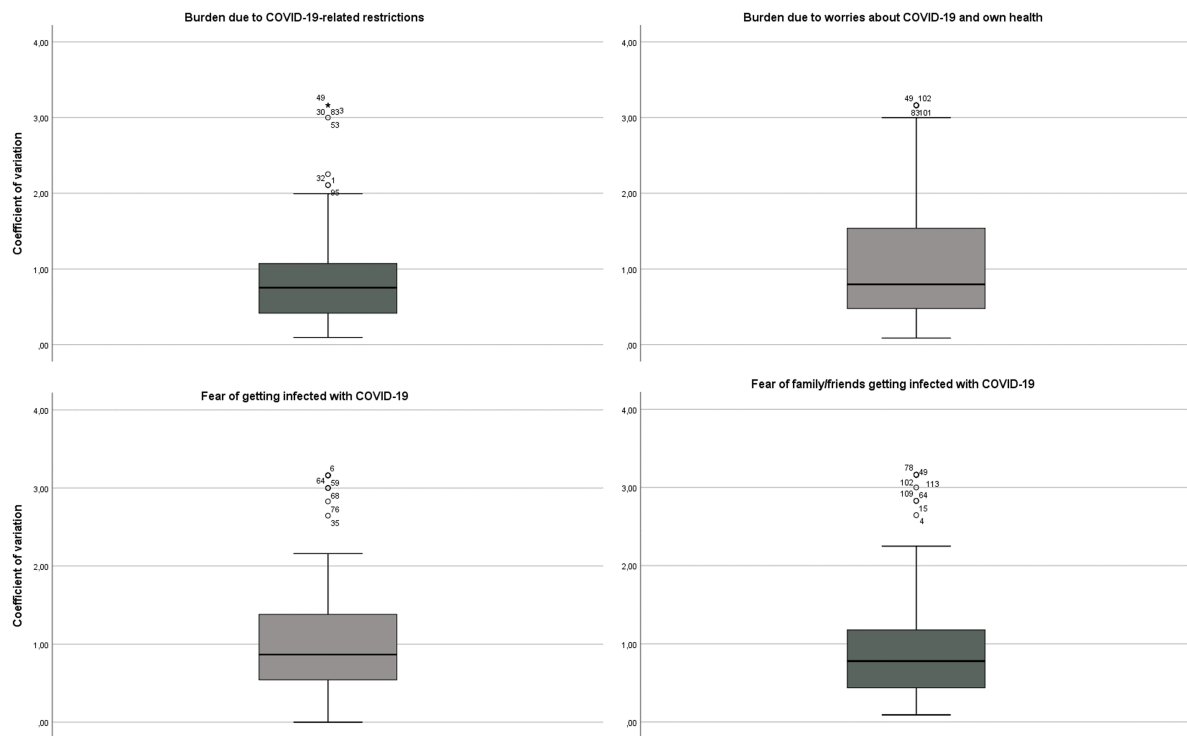
The present study found no evidence of increased levels of depressive symptoms and diabetes distress during the COVID-19 pandemic in people with type 1 diabetes. The mean day-to-day ratings of COVID-19-related burdens ranged at a rather low to moderate level. The intra-individual variability of these burdens and concerns were considerable. Elevated diabetes distress and higher diabetes acceptance significantly and independently predicted higher COVID-19-related burdens, whereas the concurrent 7-day incidence rate was not significantly associated.

On average, there was no indication of an increase of diabetes distress and depressive symptoms during the COVID-19 pandemic compared to before in this group of middle-aged adults with type 1 diabetes. This result differs from previous study findings which suggest higher rates of depressive symptoms in the general population (6, 7) as well as higher diabetes distress and depressive symptoms in people with type 1 and type 2 diabetes (8, 9) during the pandemic. On the other hand, the lack of increase in depressive symptoms and diabetes distress is in line with a study by Sacre et al. (24) that also found no increase in people with type 2 diabetes during the pandemic.

A possible explanation for the different results in this study compared to Fischer et al. (8) could be the higher mean age of their sample, possibly associated with more COVID-19-related burdens and fears. Furthermore, their study was conducted at an earlier stage of the pandemic at which people with diabetes may have been less habituated to the restrictions and burdens due to COVID-19 (25). Differences to the study by Moradian et al. (9) could be explained by the retrospective evaluation of mental health (depressive symptoms, anxiety, and psychological distress before the pandemic) after the pandemic had begun, which could have overestimated the effect. The lack of change in diabetes distress and depressive symptoms in our study was mirrored by the lack of significant changes in diabetes self-management, fear of complications, and diabetes acceptance notably.

The average daily reported COVID-19-related burdens and fears were lower than those assessed *via* questionnaire. This effect is frequently observed in EMA studies, indicating that questionnaire-assessed burden ratings are usually higher than the day-to-day reported ratings due to more global evaluations and generalization (26, 27).

In the daily assessment over 10 days, the mean levels of burdens and fears were relatively low. However, the individual participant's burden and fear ratings varied significantly from day-to-day, suggesting that clinically relevant burdens and fears



**FIGURE 3** | Boxplots displaying variability (CV) of COVID-19-related burdens and fears. Data are bowled line = median; box upper line = 75%; low line = 25%; lower end line = minimum; upper end line = maximum.

may have been experienced on specific, while not all, days. COVID-19-related burdens and fears showed some level of trend that seemed to follow the daily 7-day incidence rates. However, on a within-person level, there was no evidence of an association of subjective burdens and fears due to COVID-19 and the concurrent objective incidence rate. This analysis showed the benefit of the EMA approach, as objective and subjective risk could be analyzed concurrently daily. Since the burdens and fears were not associated with the 7-day incidence rate in this study, it would be of interest for further research to identify the impacts that lead to greater fluctuations of burdens.

Diabetes distress and diabetes acceptance before the pandemic were the strongest predictors of COVID-19-related burdens and fears. They remained significant even when controlling for more traditional risk factors such as HbA1c and long-term complications. Diabetes distress and acceptance also seemed more relevant for explaining COVID-19-related burdens and fears than the 7-day incidence rate on the respective day. This suggests a partial independence of burdens and fears due to COVID-19 from rather objective risk markers. The finding that higher acceptance of diabetes was related to higher COVID-19-related burdens seems surprising at first look because diabetes acceptance is negatively related with diabetes distress (23, 28). However, considering the objectively higher risks of COVID-19 for people with type 1 diabetes (2), this result may suggest that people who accept their diabetes are also more likely to accept the associated health risks. We hypothesize that low diabetes

acceptance, in contrast, might represent rejection and avoidance of dealing with the associated risks for COVID-19. Their perceived personal threat and burden as well as their perceived risk of a severe course if infected might therefore be less pronounced. Further research will be needed to better understand these relations.

The 7-day incidence rate, demographic, and clinical risk factors for COVID-19 infection contributed little to the prediction of COVID-19-specific burdens and fears. It seems that objective risk factors for severe disease progression were less relevant in creating COVID-19-related burdens and fears than psychological aspects such as diabetes-related emotional concerns and integration of diabetes into daily life. Persons reporting higher distress due to their chronic condition also experienced higher burden due to the COVID-19 pandemic. This suggests an overarching way of dealing with stress that can have positive and negative effects, respectively, on both diabetes distress and COVID-19 burden.

## Limitations and Strengths

When interpreting the results, the following limitations must be considered. The conservative findings regarding diabetes distress and depressive symptoms during the pandemic as well as COVID-19-related burdens and fears should be interpreted against the specific characteristics of the study sample, that is, middle-aged adults with type 1 diabetes with relatively good overall health on average. Self-selection may have occurred

**TABLE 2 |** Multilevel analyses of variables to explain COVID-19-related burdens and fears.

Predictor	Burden due to COVID-19-related restrictions		Burden due to worries about COVID-19 and health		Fear of getting infected with COVID-19		Fear of family members or friends getting infected with COVID-19	
	Estimate (95% CI)	$\beta$	Estimate (95% CI)	$\beta$	Estimate (95% CI)	$\beta$	Estimate (95% CI)	$\beta$
<b>Step 1 - only within</b>								
7-day COVID incidence	0.000 (-0.006 - 0.006)	0.01	0.003 (0.000 - 0.006)	0.08	0.002 (-0.002 - 0.008)	0.06	0.002 (-0.004 - 0.009)	0.06
<b>Step 2 - within + demographic &amp; medical risk factors</b>								
7-day COVID incidence	0.003 (-0.002 - 0.009)	0.07	0.001 (-0.004 - 0.006)	0.03	0.001 (-0.003 - 0.006)	0.03	0.003 (-0.004 - 0.007)	0.09
Age	-0.021 (-0.060 - 0.021)	-0.10	0.02 (-0.02 - 0.06)	0.11	0.019 (-0.015 - 0.053)	0.11	0.037 (-0.004 - 0.078)	0.19
Female sex	0.542 (-0.323 - 1.388)	0.11	0.517 (-0.348 - 1.330)	0.11	0.244 (-0.502 - 0.990)	0.06	0.803 (-0.063 - 1.705)	0.17
BMI	0.049 (-0.046 - 0.139)	0.10	0.072 (-0.021 - 0.159)	0.14	0.029 (-0.053 - 0.107)	0.07	0.035 (-0.063 - 0.147)	0.08
Smoking	0.498 (-0.878 - 1.909)	0.08	0.969 (-0.302 - 2.326)	0.16	0.838 (-0.241 - 2.066)	0.16	0.765 (-0.370 - 1.972)	0.12
Diabetes duration	0.043 (-0.001 - 0.081)	0.21	0.031 (-0.012 - 0.070)	0.15	<b>0.040 (0.002 - 0.073)</b>	<b>0.22</b>	<b>0.040 (0.004 - 0.079)</b>	<b>0.21</b>
With long-term complications	-0.464 (-1.190 - 0.076)	-0.15	-0.289 (-1.014 - 0.255)	-0.10	-0.208 (-0.824 - 0.267)	-0.08	-0.215 (-0.875 - 0.332)	-0.08
With other chronic diseases	1.276 (-0.0368 - 3.274)	0.13	0.892 (-0.692 - 2.728)	0.09	0.986 (-0.417 - 2.581)	0.11	1.263 (-0.557 - 2.928)	0.12
HbA <sub>1c</sub>	-0.025 (-0.487 - 0.346)	-0.01	-0.122 (-0.565 - 0.218)	-0.06	-0.135 (-0.508 - 0.173)	-0.08	-0.084 (-0.425 - 0.196)	-0.04
<b>Step 3 - plus psychosocial risk factors</b>								
7-day COVID incidence	0.001 (-0.005 - 0.006)	0.02	-0.001 (-0.005 - 0.004)	-0.02	0.000 (-0.004 - 0.004)	0.001	-0.001 (-0.007 - 0.002)	-0.04
Age	-0.022 (-0.067 - 0.024)	-0.09	0.014 (-0.028 - 0.056)	0.06	0.008 (-0.027 - 0.046)	0.04	0.033 (-0.003 - 0.075)	0.15
Female sex	0.484 (-0.481 - 1.383)	0.09	0.271 (-0.602 - 1.105)	0.05	0.084 (-0.674 - 0.801)	0.02	0.465 (-0.348 - 1.263)	0.09
BMI	0.035 (-0.071 - 0.148)	0.06	0.052 (-0.044 - 0.156)	0.09	0.015 (-0.069 - 0.102)	0.03	0.036 (-0.052 - 0.113)	0.07
Smoking	-0.048 (-1.135 - 1.121)	-0.006	0.175 (-0.839 - 1.275)	0.02	0.066 (-0.840 - 0.993)	0.01	0.244 (-0.967 - 1.492)	0.04
Diabetes duration	0.035 (-0.007 - 0.077)	0.14	0.023 (-0.014 - 0.061)	0.09	0.030 (-0.001 - 0.063)	0.15	<b>0.037 (0.001 - 0.075)</b>	<b>0.17</b>
With long-term complications	-0.432 (-1.083 - 0.152)	-0.13	-0.349 (-0.940 - 0.202)	-0.11	-0.308 (-0.819 - 0.161)	-0.11	-0.276 (-0.771 - 0.268)	-0.09
With other chronic diseases	1.483 (-0.577 - 3.304)	0.12	0.747 (-1.147 - 2.400)	0.06	0.746 (-0.924 - 2.124)	0.08	0.741 (-0.857 - 2.474)	0.07
HbA <sub>1c</sub>	0.066 (-0.317 - 0.416)	0.03	-0.026 (-0.385 - 0.262)	-0.01	-0.029 (-0.352 - 0.233)	-0.01	-0.077 (-0.429 - 0.233)	-0.04
Diabetes distress score (pre-pandemic)	<b>0.074 (0.026 - 0.113)</b>	<b>0.45</b>	<b>0.093 (0.050 - 0.127)</b>	<b>0.58</b>	<b>0.069 (0.032 - 0.099)</b>	<b>0.53</b>	<b>0.068 (0.033 - 0.100)</b>	<b>0.48</b>
Depressive symptoms score (pre-pandemic)	0.001 (-0.044 - 0.047)	0.004	-0.008 (-0.049 - 0.033)	-0.03	-0.007 (-0.041 - 0.027)	-0.03	-0.004 (-0.046 - 0.039)	-0.02
Diabetes acceptance score (pre-pandemic)	<b>0.171 (0.067 - 0.264)</b>	<b>0.36</b>	<b>0.173 (0.080 - 0.255)</b>	<b>0.37</b>	<b>0.146 (0.065 - 0.219)</b>	<b>0.38</b>	<b>0.101 (0.010 - 0.190)</b>	<b>0.25</b>
Diabetes self-management score (pre-pandemic)	-0.135 (-0.462 - 0.229)	-0.07	-0.001 (-0.283 - 0.326)	-0.001	0.027 (-0.223 - 0.308)	0.02	0.097 (-0.175 - 0.382)	0.05
Fear of complications score (pre-pandemic)	-0.093 (-0.237 - 0.047)	-0.14	-0.006 (-0.130 - 0.120)	-0.01	0.071 (-0.032 - 0.183)	0.13	0.061 (-0.066 - 0.168)	0.11
<b>Variation explained by each model (<math>R^2</math> [95% CI])</b>								
<b>Step 1 - only within</b>	0.071 (0.027 - 0.130)		0.092 (0.05 - 0.164)		0.092 (0.045 - 0.155)		0.047 (0.020 - 0.103)	
<b>Step 2 - within + demographic &amp; medical risk factors</b>	within: 0.072 (0.029 - 0.128) between: 0.192 (0.062 - 0.343)		within: 0.093 (0.045 - 0.136) between: 0.187 (0.066 - 0.329)		within: 0.091 (0.038 - 0.138) between: 0.189 (0.070 - 0.345)		within: 0.047 (0.016 - 0.092) between: 0.207 (0.092 - 0.362)	
<b>Step 3 - plus psychosocial risk factors (pre-pandemic)</b>	within: 0.068 (0.028 - 0.108) between: 0.531 (0.281 - 0.677)		within: 0.095 (0.049 - 0.158) between: 0.606 (0.369 - 0.715)		within: 0.087 (0.043 - 0.139) between: 0.580 (0.351 - 0.697)		within: 0.042 (0.014 - 0.084) between: 0.484 (0.296 - 0.633)	

Data are estimates = unstandardized coefficient (b [95%CI]) or standardized coefficient ( $\beta$ ); BMI= body mass Index, HbA<sub>1c</sub> = glycated hemoglobin. Significant findings ( $p < .05$ ) in bold.



during recruitment. Compared to the main study, individuals who participated in the follow-up survey had lower HbA1c levels, less diabetes distress, and were less likely to live alone at the time of the original DIA-LINK Study. These are factors that might contribute to lower COVID-19-related burdens and fears. Furthermore, the DIA-LINK Study sample was mainly recruited at a tertiary diabetes center; thus, the sample may not represent people with diabetes in primary care. Comparisons of the changes in diabetes distress and depressive symptoms over time with a control group without diabetes might support a better understanding of the possible impacts, but due to the design of the DIA-LINK Study, controls were not available. Comparisons of the present data with data from the general population would be of great interest; thus, further research will be needed. Finally, the specific time point of the follow-up survey within the pandemic should be considered: the survey was conducted during a period of higher incidence, mainly during the third wave. At that time, lockdown regulations and contact restrictions were in place for the second time in Germany. In addition, the first vaccine against the virus had been approved, which might have led to hopeful expectations. It is unclear to which extent these results can be generalized to other periods, for instance, with lower incidence rates.

Strengths of this study are the assessment of daily impacts of COVID-19 using EMA, probably yielding higher ecological validity than global questionnaire ratings, as well as the direct comparison of depression and diabetes distress levels during the pandemic with pre-pandemic values of the same individuals. Furthermore, fluctuations in COVID-19-related burdens and fears could be made visible *via* EMA demonstrating the additional information compared to single spot questionnaire assessment.

## Conclusions

In summary, the results show substantial day-to-day variability of COVID-19-related burdens and fears in this sample of people with type 1 diabetes. Although the levels of burdens and fears were rather modest on average, clinically relevant levels were experienced on specific days. The findings regarding predictors of COVID-19 burdens and fears suggest that diabetes-specific psychological factors and subjective experiences may be more relevant in explaining burdens and fears than objective health aspects and risk factors for a severe COVID-19 course. The findings highlight the importance of mental factors in dealing with COVID-19 and suggests the need for a psychosocial approach to reducing burdens and worries due to the pandemic in addition to information/education about a

person's individual risk to foster realistic expectations and corresponding feelings.

## DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation. The dataset analyzed for this study is restricted by the German Federal Data Protection Act (BDSG) and will be made available upon reasonable request to the corresponding author.

## ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Ethics committee of the German Psychological Society. The patients/participants provided their written informed consent to participate in this study.

## AUTHOR CONTRIBUTIONS

FS: collected the data; analyzed and interpreted the data; drafted the manuscript. AS: planned and designed the study; collected the data; discussed the findings; revised the manuscript. NH: planned and designed the study; discussed the findings; revised the manuscript. BK: planned and designed the study; discussed the findings. DE: planned and designed the study; analyzed and interpreted the data; revised the manuscript. All authors contributed to the article and approved the submitted version.

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# How has the COVID-19 Pandemic Affected Diabetes Self-Management in People With Diabetes? - A One-Year Follow-Up Study

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**Background and Aim:** In Denmark, the COVID-19 pandemic resulted in two lockdowns, one from March to May 2020 and another from December 2020 to April 2021, which had severe impact on everyday life. The aim of this study was to explore changes in diabetes self-management behaviors during the pandemic and to examine how specific population characteristics were associated with changes in diabetes management.

**Methods and Participants:** In a cohort study from March 2020 to April 2021, two online questionnaires were collected from a total of 760 people with diabetes. Descriptive statistics were used to assess the proportion of participants experiencing improvements, deterioration, and status quo in diabetes self-management during the pandemic. Using logistic regressions, baseline characteristics were explored as potential predictors of change.

**Results:** Approximately half of the participants reported that they experienced lower physical activity in April 2021 compared to before the pandemic, approximately one fifth reported diabetes self-management to be more difficult than prior to the pandemic, and one fifth reported eating more unhealthily than before the pandemic. Some participants reported higher frequency of high blood glucose levels (28%), low blood glucose levels (13%) and more frequent blood glucose variability (33%) compared to before. Easier diabetes self-management was reported by relatively few participants, however, 15% reported eating more healthily, and 20% reported being more physically active. We were largely unable to identify predictors of change in exercise activities. The few baseline characteristics identified as predictors of difficulties in diabetes self-management and adverse blood glucose levels due to the pandemic were sub-optimal psychological health, including high diabetes distress levels.

**Conclusion:** Findings indicate that many people with diabetes changed diabetes self-management behaviors during the pandemic, mostly in a negative direction. Particularly high diabetes distress levels in the beginning of the pandemic was a predictor of both positive and negative change in diabetes self-management, indicating that people with

high diabetes distress levels could potentially benefit from increased support in diabetes care during a period of crisis.

**Keywords:** diabetes self-management, diabetes distress, psychological distress, lifestyle, corona virus (COVID-19), SARS-CoV-2

## INTRODUCTION

In early 2020, the COVID-19 disease spread worldwide and was declared a global pandemic by the World Health Organization (WHO) on March 11 (1). The consequences of COVID-19 infection were largely unknown at the time, but it was quickly established that the disease could cause severe respiratory infections and potentially be fatal (2). Mass-media coverage reported high mortality levels in some regions of developed countries, and societies across the globe quickly implemented measures to prevent spread of the disease. Among other challenges, it was suggested that the pandemic and its accompanying societal changes could result in significant consequences for access to high quality health care. Moreover, it was reported that people with diabetes were at increased risk of severe disease if infected with COVID-19 (3).

In Denmark, all schools and childcare services were closed on March 12, 2020, employees in the public sector with noncritical functions were ordered to work from home and gatherings of more than ten people were prohibited, resulting in many people not going to work on a daily basis and temporary closure of non-critical public facilities such as cinemas, restaurants, and sport facilities (4). During the following months, restrictions were gradually lifted; however, some restrictions were reintroduced the following winter due to an increased incidence of COVID-19 in the population (4). From December 2020 to April 2021, a second lockdown was enforced due to renewed widespread disease in the population.

For people with diabetes, complex diabetes self-management is necessary to avoid adverse acute and long-term consequences of the illness and is, for many people, an integrated part of daily life (5, 6). A primary goal in the management of diabetes is to always obtain near-normal blood sugar levels for which exercise and a healthy diet are among the integral components (5, 6). A variety of factors influencing diabetes self-management has been identified including age, gender, educational attainment, diabetes type and duration, and psychological health. However, consistency is lacking across studies and most of the variance in diabetes self-management remains unexplained (7). This indicates that factors influencing diabetes self-management are not fully understood and may vary across time and setting.

Research on the impact of the COVID-19 pandemic and diabetes management has suggested that many people experienced difficulties in managing their diabetes due to the pandemic. Thus, deterioration in healthy lifestyle, i.e., less exercise and unhealthier diet have been observed in various populations (8–13), and according to one study particularly in women (9). A single study found improvements in diabetes self-management in a population characterized by young participants with high educational level (14), whereas a recent qualitative

study found improvements in diabetes self-management (15). A recent meta-analysis analyzed the body of literature on COVID-19 and blood glucose levels in people with type 1 and type 2 diabetes and concluded that the studies were heterogenous in their findings with many studies being inconclusive (16). Some studies, however, reported higher blood glucose levels either in combination with weight gain (17, 18) or independent of weight gain (19). While previous studies have suggested that changes in diabetes self-management due to the pandemic have been negative overall, it is largely unknown what characterizes people with diabetes who have experienced either improved or deteriorated diabetes self-management behaviors during the pandemic. Research has established that people with diabetes distress experience difficulties in managing diabetes (20–22). The potential psychosocial burden of the pandemic and disruption in everyday life activities by societal restriction may have constituted a new challenge for people with diabetes in maintaining their diabetes management (20–22). Whilst the restrictions for many may have been perceived as a burden, they could simultaneously offer opportunities for improved diabetes self-management (15). Knowledge about characteristics that facilitated or reduced optimal diabetes care during the pandemic may give the opportunity to move away from “one-size-fits-all solutions” and in times of crisis to focus resources at those with the highest risk of being negatively affected by such disruption.

For these reasons, the aim of this study was to explore changes in self-reported ability to effectively manage diabetes, including changes in diet, exercise, and blood glucose levels from the beginning and one year into the pandemic. Another aim was to examine how selected population characteristics were associated with positive as well as negative changes in diabetes self-management during the pandemic.

## MATERIALS AND METHODS

### Study Design

In March 2020, a cohort was established by inviting 2,430 adults (aged >18 years) with diabetes to participate in an online questionnaire-based survey, hereafter referred to as the ‘baseline questionnaire’. In a follow-up questionnaire one year after the initiation of the survey, responders from the initial survey were invited to complete a new questionnaire, referred to hereafter as the ‘follow-up questionnaire’, providing information about their experienced changes in diabetes management behaviors during the pandemic and their everyday life during the last year of the COVID-19 pandemic. Participants were recruited from two user panels situated at, respectively, Steno Diabetes Center Copenhagen and the Danish Diabetes Association. Together, the panels



represent people with type 1 or type 2 diabetes from across Denmark.

Questionnaires were sent to potential participants' e-mail addresses, and informed consent was obtained digitally from all participants. Upon sign-up to each of the user panels, participants had agreed to be contacted for research purposes. For this analysis, we exclusively utilized data from participants responding to both the baseline and the follow-up questionnaire. Among these participants, characteristics from the baseline questionnaire was compared to behavior changes reported in the follow-up questionnaire, approximately one year after the baseline survey. Moreover, descriptive data from both baseline and follow-up were presented as well. Recruitment strategy and baseline characteristics have been reported in detail elsewhere (23).

## Included Measures

Information about age, gender, education, employment status, cohabitation status, type of diabetes, diabetes duration, diabetes complications, and health status was obtained from the baseline questionnaire (23). Likewise, psychosocial data on diabetes distress (2-item Diabetes Distress Scale (DDS-2)) (24), quality of life (25) and worries related to diabetes and the pandemic (23) were collected from the baseline questionnaire. Diabetes distress and quality of life were measured on continuous scales; worries about diabetes were measured by a set of dichotomous variables. Baseline data and measures have been described in detail elsewhere (23). Variables measuring perceived impact of the COVID-19 pandemic on diabetes self-management in the follow-up questionnaire were developed by Fisher and colleagues (13) and translated into Danish for this study. Wordings and meanings of the adopted questions were tested among people similar to the participants. After minor adjustments, the interviewees did not indicate further problems related to comprehensibility and unambiguity of the questions. Impact of the pandemic on difficulties in diabetes management was assessed by the question, "Compared to before the coronavirus pandemic, how has your diabetes management changed?" It was assessed by a 7-point scale from "significantly easier", "moderately easier", "slightly easier", "no change", "slightly harder", "moderately harder", and "significantly harder," with the opportunity to indicate "no change" using the middle option (13). A similar item asked about changes in the amount of exercise, using a 7-point scale from "much less" to "much more" (13). Furthermore, a new item was developed measuring changes in diet ranging from "much healthier" to "much unhealthier". Perceived impact of the coronavirus pandemic on blood glucose levels was assessed using 7-point scales asking the respondent to indicate if they experienced major changes regarding frequency of: high blood glucose, low blood glucose and larger glucose variability with response options ranging from "a lot more frequent" to "a lot less frequent" (13). Medication taking was measured with a similar item but with only five response options: "a lot more regularly", "a little more regularly", "no change", "a little less regularly", and "a lot less regularly". Exact wording of the outcome variables and their response options is available in **Supplementary Material**.

## Statistical Analysis

Population characteristics and perceived changes in diabetes management behaviors were explored using descriptive statistics. The data were inappropriate for cumulative logit models due to violation of the proportional odds assumption. Instead, baseline predictors of change in diabetes management were analyzed using nominal logistic regressions with independent variables measured at baseline and categorized outcome variables measured at follow up. The 7-point scales used as outcomes were reversed if needed to let low values consistently represent desirable status and collapsed into three levels 1–3 (positive change), 4 (unchanged), 5–7 (negative change). The "unchanged" category was used as reference.

All estimates were adjusted for age, gender, education, employment status, diabetes type, diabetes duration, diabetes-specific complications, and co-morbidities. The models were not adjusted for psychosocial variables, i.e., DDS-2, quality of life and worries due to similarities between the concepts and risk of over-adjustment. Thus, impact of psychosocial factors was estimated in independent models, each with a single psychosocial factor added. All analyses were carried out using SAS Enterprise Guide 7.1. The level of significance was  $p < 0.05$ .

## RESULTS

Out of 1,396 individuals who replied to the baseline questionnaire, 760 (54%) also responded to the follow-up questionnaire.

**Table 1** shows characteristics of the study population at baseline. Most participants were older than 65 years, men (58%), and had completed a higher education (<5 years) (58%). Almost two thirds had type 2 diabetes, had long diabetes duration (50% > 15 years) and almost one out of five had one or more complications to diabetes. More than half (55%) had at least one additional chronic disease, whereas one out of ten reported at least one mental disorder. Most participants (71%) reported high quality of life, whereas (78%) scored less than two on the DDS-2 indicating little or no diabetes distress. Almost two thirds were worried about being overly affected due to their diabetes if infected with COVID-19, and one third was worried about not being able to manage their diabetes properly if infected by COVID-19.

**Table 2** shows the distributions of perceived changes in difficulties in diabetes self-management, medication taking, diet, physical activity, high blood glucose levels, low blood glucose levels and blood glucose variability measured one year after baseline. Approximately three quarters of the participants reported unchanged difficulties in managing diabetes, almost none (3%) reported that diabetes management was easier during the pandemic whereas the remaining participants (21%) reported diabetes management to be harder. Almost all participants (93%) reported unchanged medication taking. Most of the participants experienced unchanged diet (62%) and blood glucose levels (65-, 62-, 79%) whereas a minority (29%) experienced unchanged physical activity. Among people who experienced changes, difficulties in managing diabetes were more frequent in all



**TABLE 1 |** Baseline characteristics of the study population (N = 760).

Characteristic	Frequency (%)
<b>Gender</b>	
Male	439 (57.8)
Female	321 (42.2)
<b>Age (years)</b>	
Years (P25, Median, P75)	(57, 66, 72)
<b>Educational attainment</b>	
Primary	44 (5.8)
Secondary	243 (32.0)
Higher education (<5 years)	441 (58.0)
Higher education (>= 5 years)	32 (4.2)
<b>Employment</b>	
Employed	251 (33.0)
Retired	453 (59.6)
Other	56 (7.4)
<b>Diabetes type</b>	
Type 1	262 (34.5)
Type 2	498 (65.5)
<b>Diabetes duration</b>	
Years (P25, Median, P75)	(8, 15, 26)
<b>Complications to diabetes</b>	
0 complications	611 (80.4)
1+ complications	149 (19.6)
<b>Chronic diseases (other than diabetes)</b>	
0 chronic diseases	341 (44.9)
1+ chronic diseases	419 (55.1)
<b>Mental disorder</b>	
None	673 (88.6)
1+ mental disorder	87 (11.4)
<b>Quality of Life*</b>	
Suboptimal quality of life	224 (29.5)
High quality of life	536 (70.5)
<b>Diabetes distress*</b>	
Little to no DDS (score <2)	589 (77.5)
Moderate to high DDS (score >=2)	171 (22.5)
<b>Overly affected due to diabetes if infected</b>	
Not worried	293 (38.6)
Worried	467 (61.5)
<b>Unable to manage diabetes if infected</b>	
Not worried	521 (68.6)
Worried	239 (31.4)

\*Continuous variable categorized exclusively for this table for the purpose of meaningful presentation.

categories – particularly regarding high and low blood glucose levels and blood glucose variability, where less than 8% experienced improvements in one or more of the measures. In all, 13- to 33% experienced more frequent low and high blood glucose levels and blood glucose variability.

**Tables 3A, 3B** show regression coefficients predicting whether the pandemic had made it, respectively, easier (3A) or harder (3B) to manage diabetes according to participant reporting one year after baseline.

Shown in **Table 3A**, participants with less frequent high blood glucose levels, less frequent blood glucose variability and less frequent low blood glucose levels were characterized by higher levels of diabetes distress compared to participants experiencing no change in blood glucose levels. Participants who reported healthier eating were more likely to have a mental disorder and to have type 2 diabetes. Additionally, participants who experienced less frequent low blood glucose levels had lower quality of life and were more often worried about their diabetes management during

the pandemic compared to participants experiencing no change in blood glucose levels. Due to the low number of participants reporting easier diabetes management (n=34), more regularly medication taking (n = 12) and less regularly medication taking (n =45) medication taking, the study did not offer the opportunity to explore predictors of these kind of changes.

As shown in **Table 3B**, experiences of more frequent high blood glucose levels and more frequent blood glucose variability were associated with lower quality of life, higher diabetes distress and worries about being overly affected by the COVID-19 in case of infection. Experiences of more frequent low blood glucose levels were associated with higher diabetes distress and being worried about management of diabetes during the pandemic. Participants who reported eating more unhealthily were more likely to be female, have type 2 diabetes and have lower quality of life.

## DISCUSSION

The onset of the COVID-19 pandemic from March 2020 had significant impact on everyday life among people with diabetes as well as on their diabetes self-management the following year. In this study of 760 individuals with type 1 or type 2 diabetes, several changes in diabetes self-management were observed. However, most participants reported unchanged diabetes self-management across all investigated aspects, except for physical activity for which many reported less activity. Negative impact of COVID-19 was dominating compared to positive impact in almost all investigated aspects of diabetes self-management, including impact on difficulties in diabetes management, eating unhealthily and doing less physical activity. Negative changes were also reported in terms of more frequent sub-optimal blood glucose levels. Almost one out of four participants reported diabetes management to be harder during the pandemic; very few reported it to be easier. This means that despite home-based working and cancelled social activities with better opportunities for planning and performing diabetes self-management, only very few participants considered the situation advantageous for diabetes management. In line with this, most studies find that diabetes management has been increasingly difficult and less effective due to the pandemic (8–11, 26, 27) whereas a single study on young, highly educated people demonstrated improved diabetes management (14). Likewise most studies report negative impact on specific self-management behaviors, i.e., less exercise and more unhealthy diet during the pandemic across various populations (12, 18, 28–32). Regarding changes in blood glucose levels during the pandemic, previous findings are mixed and improvements have been found particularly in studies of people with type 1 diabetes (15, 33). Our finding that less physical activity was the most frequently reported behavior change is not surprising, as the physical activity level was likely to be affected when organized sports activities were shut down during the pandemic. Furthermore, for people who were working from home, transport to work and physical activity as a part of the workday was not “automatically” happening. The results suggest that the lack of exercise due to COVID-19 restrictions was not compensated for by the participants by introducing new forms of

**TABLE 2 |** Self-reported changes in diabetes self-management behaviors.

Events	Proportion (%) responses in categories						
	Much Easier	Somewhat Easier	Easier	Unchanged	Slightly Harder	Somewhat Harder	Much Harder
<b>Diabetes management</b>							
Type 1 diabetes	0.4	1.2	3.1	71.8	20.2	3.1	0.4
Type 2 diabetes	0.8	0.4	1.0	76.3	15.3	4.6	1.6
All	0.7	0.7	1.7	74.7	17.0	3.1	1.2
<b>Medication taking</b>		Much more regularly	Slightly more regularly	Unchanged	Slightly less regularly	Much less regularly	
Type 1 diabetes			3.1	92.8	3.1	1.2	
Type 2 diabetes		0.2	0.6	92.8	2.1	4.2	
All		0.1	1.5	92.8	2.5	3.2	
<b>Diet</b>	Much Healthier	Somewhat Healthier	Healthier	Unchanged	Slightly Unhealthier	Somewhat Unhealthier	Much Unhealthier
Type 1 diabetes	0.0	2.7	7.3	67.2	18.3	4.2	0.4
Type 2 diabetes	2.2	3.4	11.9	59.8	17.3	5.2	0.2
All	1.5	3.2	10.3	62.4	17.6	4.9	0.3
<b>Physical activity</b>	Much More	Somewhat More	Slightly More	Unchanged	Slightly Less	Somewhat Less	Much Less
Type 1 diabetes	1.2	4.6	13.0	30.5	26.3	16.4	8.0
Type 2 diabetes	1.2	7.6	12.5	28.3	20.3	21.9	8.2
All	1.2	6.6	12.6	29.1	22.4	20.0	8.2
<b>Blood sugar levels</b>	Much Less	Somewhat Less	Slightly Less	Unchanged	Slightly More	Somewhat More	Much More
<b>High blood sugars</b>							
Type 1 diabetes	0.8	2.3	3.8	60.3	23.7	9.2	0.0
Type 2 diabetes	1.4	1.4	4.2	67.3	20.1	4.8	0.8
All	1.2	1.7	4.1	64.9	21.3	6.3	0.5
<b>Blood sugar variability</b>							
Type 1 diabetes	0.4	0.8	3.8	54.6	27.9	10.7	1.9
Type 2 diabetes	1.0	1.2	2.0	66.5	22.9	5.8	0.6
All	0.8	1.1	2.6	62.4	24.6	7.5	1.1
<b>Low blood sugars</b>							
Type 1 diabetes	1.2	1.9	4.6	66.8	22.1	3.1	0.4
Type 2 diabetes	3.4	1.0	3.6	84.7	6.2	1.0	0.0
All	2.6	1.3	4.0	78.6	11.7	1.7	0.1

Now compared to before the pandemic (N = 760).

Bold values indicate statistically significant predictors.

appropriate exercise. This finding is in line with a systematic review of exercise among older adults who, during the lockdown, performed less exercise or presented with more sedentary behavior. Most of the identified studies of behavior change during the lockdown presented the same findings (12, 34). Likewise, maintaining an unhealthier diet was also reported in some studies whereas none reported improved diet because of the lockdown (33). Lower level of physical activity in the study population combined with overall difficulties in managing diabetes is likely to have influenced blood glucose levels (34) which may explain the increased frequency of high and low blood glucose levels as well as variability in blood glucose levels during the pandemic.

Overall, our analyses showed that sub-optimal psychosocial health was associated with negative impact on diabetes self-management behaviors and frequency of adverse blood glucose levels. Particularly diabetes distress at baseline was associated with changes in diabetes self-management behaviors during the pandemic. Importantly, higher diabetes distress was simultaneously associated with lowered and increased frequency of adverse blood glucose levels. Research has shown associations between psychosocial health and diabetes self-management. For example, research before the pandemic had already established strong evidence for associations

between diabetes distress and diabetes self-management (20, 35). Improved diabetes self-management among some participants with high diabetes distress may be a consequence of successful support from health care professionals and/or relatives combined with room for improvements in diabetes self-management behaviors in this sub-population of people with diabetes distress. This suggests that people with diabetes distress constitute a heterogeneous group with different needs for support. We were largely unable to identify characteristics of people with changed level of physical activity indicating that people who changed level of physical activity was a heterogeneous group with no common characteristics. People in jobs, among whom many were sent home, were not significantly more prone to changes in diabetes self-management during the lockdown.

A key strength of the present study is the individual level linkage between survey responses in the early stages of the pandemic and follow up responses one year later. This provided the opportunity to include factors measured at baseline in the first week of the first lockdown – free of influence from future events – to the changes reported at follow up. Another strength of the study is the high number of participants with type 1 and type 2 diabetes included in the study population. The inclusion of validated measures in the questionnaire ensured high internal validity of the self-reported predictors.

**TABLE 3A |** Predictors of reporting improved diabetes self-management behaviors during the pandemic.

	Less frequent high blood sugar	Less frequent blood sugar variability	Less frequent low blood sugar	Healthier diet	More physical activity
Characteristics (measure)	OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)
Female (ref male)	1.19 (0.65; 2.18)	1.18 (0.56; 2.49)	1.35 (0.77; 2.38)	1.39 (0.89; 2.18)	1.34 (0.86; 2.08)
Age (years)	0.99 (0.96; 1.03)	1.00 (0.96; 1.05)	0.98 (0.95; 1.02)	1.01 (0.98; 1.04)	0.98 (0.95; 1.01)
Secondary education (ref primary)	0.71 (0.24; 2.09)	1.20 (0.25; 5.76)	0.57 (0.21; 1.55)	1.84 (0.60; 5.68)	1.02 (0.37; 2.80)
Higher education <5 years (ref: primary)	0.51 (0.18; 1.46)	0.77 (0.17; 3.57)	0.52 (0.20; 1.35)	2.07 (0.69; 6.21)	1.41 (0.53; 3.77)
Higher education ≥ 5 years (ref primary)	1.45 (0.36; 5.92)	3.31 (0.53; 20.71)	0.20 (0.02; 1.84)	3.13 (0.75; 13.10)	1.31 (0.31; 5.50)
Retired (ref working)	0.96 (0.42; 2.20)	1.25 (0.43; 3.65)	1.26 (0.57; 2.77)	0.66 (0.35; 1.23)	0.91 (0.49; 1.68)
Other (ref working)	1.13 (0.38; 3.31)	1.50 (0.38; 5.97)	1.77 (0.68; 4.64)	0.90 (0.37; 2.19)	0.65 (0.26; 1.61)
Type 2 (ref type 1)	0.98 (0.45; 2.16)	0.57 (0.23; 1.42)	1.03 (0.48; 2.18)	<b>1.92 (1.05; 3.51)</b>	1.43 (0.81; 2.52)
Diabetes duration (years)	0.99 (0.97; 1.02)	0.99 (0.96; 1.02)	1.01 (0.99; 1.03)	0.99 (0.97; 1.01)	0.99 (0.98; 1.01)
complications (ref no complications)	1.84 (0.91; 3.71)	0.77 (0.28; 2.16)	1.05 (0.52; 2.14)	1.54 (0.90; 2.64)	1.18 (0.67; 2.07)
1+ chronic illness (ref: none)	0.95 (0.52; 1.74)	1.25 (0.60; 2.62)	1.51 (0.85; 2.68)	1.09 (0.70; 1.70)	0.97 (0.63; 1.50)
1+ mental disorder (ref: none)	1.18 (0.50; 2.75)	0.41 (0.09; 1.85)	0.79 (0.33; 1.88)	<b>2.57 (1.40; 4.71)</b>	0.72 (0.37; 1.41)
Quality of life (1-10)	0.94 (0.81; 1.10)	0.97 (0.79; 1.18)	<b>0.85 (0.74; 0.97)</b>	0.95 (0.84; 1.06)	1.02 (0.90; 1.16)
DDS (1-6)	<b>1.58 (1.17; 2.13)</b>	<b>1.67 (1.15; 2.42)</b>	<b>1.46 (1.12; 1.92)</b>	<b>1.80 (1.42; 2.27)</b>	1.07 (0.84; 1.38)
Worried. overly affected (y/n)	0.86 (0.47; 1.55)	0.78 (0.38; 1.62)	0.84 (0.48; 1.46)	1.45 (0.92; 2.29)	1.06 (0.68; 1.64)
Worried. unable to manage diabetes (y/n)	1.35 (0.72; 2.53)	1.78 (0.83; 3.82)	<b>2.25 (1.27; 4.00)</b>	1.07 (0.66; 1.74)	1.04 (0.65; 1.66)

Adjusted for gender, age, educational attainment, occupational status, diabetes type, diabetes duration, diabetes complications, and comorbidities.

Improved compared to unchanged behavior.

(N = 760).

Bold values indicate statistically significant predictors.

**TABLE 3B |** Predictors of reporting worse diabetes management behaviors during the pandemic.

	More frequent high blood sugar	More frequent blood sugar variability	More frequent low blood sugar	Unhealthier diet	Less physical activity	Harder to manage diabetes
Characteristics (measure)	OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)
Female (ref male)	1.27 (0.90; 1.79)	1.21 (0.87; 1.68)	<b>1.62 (1.02; 2.58)</b>	<b>1.83 (1.25; 2.66)</b>	1.30 (0.91; 1.87)	1.39 (0.96; 2.01)
Age (years)	1.00 (0.98; 1.02)	0.98 (0.96; 1.00)	1.02 (0.99; 1.04)	0.97 (0.95; 0.99)	0.99 (0.97; 1.01)	0.97 (0.95; 0.99)
Secondary education (ref primary)	1.61 (0.72; 3.58)	1.51 (0.74; 3.09)	1.86 (0.53; 6.58)	0.92 (0.43; 1.98)	0.75 (0.35; 1.60)	1.07 (0.47; 2.40)
Higher education <5 years (ref: primary)	1.23 (0.56; 2.68)	0.83 (0.41; 1.69)	1.16 (0.33; 4.04)	0.77 (0.37; 1.62)	0.85 (0.40; 1.77)	1.00 (0.45; 2.20)
Higher education ≥ 5 years (ref primary)	1.17 (0.38; 3.61)	1.26 (0.45; 3.51)	1.07 (0.22; 5.19)	1.14 (0.38; 3.44)	1.02 (0.34; 3.06)	1.81 (0.61; 5.37)
retired (ref working)	0.90 (0.56; 1.44)	1.00 (0.63; 1.58)	0.80 (0.42; 1.52)	0.79 (0.47; 1.32)	0.79 (0.48; 1.31)	0.67 (0.40; 1.10)
other (ref working)	0.97 (0.50; 1.87)	1.09 (0.58; 2.03)	0.89 (0.39; 2.06)	0.96 (0.48; 1.90)	0.89 (0.45; 1.77)	0.66 (0.33; 1.33)
Type 2 (ref type 1)	0.73 (0.47; 1.12)	0.68 (0.45; 1.04)	0.20 (0.11; 0.34)	<b>1.73 (1.05; 2.85)</b>	1.18 (0.75; 1.84)	1.59 (0.97; 2.59)
Diabetes duration (years)	1.00 (0.99; 1.01)	1.00 (0.99; 1.01)	1.00 (0.98; 1.01)	1.00 (0.98; 1.01)	0.99 (0.98; 1.01)	1.01 (1.00; 1.03)
complications (ref: no comp.)	1.23 (0.80; 1.89)	<b>1.55 (1.03; 2.33)</b>	1.31 (0.76; 2.28)	1.49 (0.92; 2.40)	1.28 (0.82; 2.00)	1.42 (0.89; 2.25)
1+ chronic illness (ref: none)	0.99 (0.71; 1.39)	1.08 (0.78; 1.50)	1.04 (0.66; 1.65)	1.45 (0.99; 2.13)	1.24 (0.88; 1.77)	1.22 (0.84; 1.78)
1+ mental disorder (ref: none)	0.92 (0.54; 1.57)	0.84 (0.51; 1.39)	0.92 (0.46; 1.88)	1.23 (0.69; 2.17)	0.63 (0.37; 1.08)	<b>1.97 (1.18; 3.29)</b>
Quality of life (1-10)	<b>0.88 (0.80; 0.96)</b>	<b>0.85 (0.78; 0.93)</b>	0.93 (0.83; 1.05)	<b>0.89 (0.81; 0.98)</b>	<b>0.86 (0.78; 0.95)</b>	<b>0.84 (0.76; 0.92)</b>
DDS (1-6)	<b>1.51 (1.25; 1.82)</b>	<b>1.60 (1.33; 1.92)</b>	<b>1.47 (1.16; 1.85)</b>	<b>1.56 (1.27; 1.91)</b>	1.11 (0.91; 1.35)	<b>1.96 (1.61; 2.39)</b>
Worried. overly affected (y/n)	<b>1.60 (1.12; 2.28)</b>	<b>1.56 (1.11; 2.18)</b>	1.25 (0.77; 2.03)	1.45 (0.98; 2.13)	1.11 (0.78; 1.57)	<b>2.32 (1.54; 3.49)</b>
Worried. manage diabetes (y/n)	1.03 (0.72; 1.49)	1.30 (0.92; 1.85)	<b>1.87 (1.18; 2.98)</b>	1.17 (0.78; 1.75)	0.87 (0.59; 1.27)	<b>1.93 (1.31; 2.85)</b>

Adjusted for gender, age, educational attainment, occupational status, diabetes type, diabetes duration, diabetes complications, and comorbidities.

Worsened compared to unchanged behavior.

(N = 760).

Bold values indicate statistically significant predictors.

Limitations include that due to relatively few participants reporting improvements in diabetes self-management behaviors, the study lacked statistical power to sufficiently explore predictors of improved diabetes management during the pandemic. Mechanisms towards improved diabetes management during pandemics as well as other societal crises should be explored with different study designs. As with any self-report method, recall bias may have influenced the data and findings of the study, particularly when asking to events more than a year back in time in the follow-up questionnaire and accuracy of the responses may be reduced. Therefore, we did not ask participants to give exact measures of changes in their activities, but merely requested participants to report trends, e.g., much less, somewhat less, slightly less, unchanged. The exact proportion of people reporting change should be interpreted with caution. Diabetes self-management behaviors are, however, an integral part of everyday life for people with diabetes, and it is likely that significant behavior changes will be remembered. The beginning of the pandemic and national lockdown was a watershed moment for many Danes, which makes the everyday life and events of the time easier to recall. From our data we are unable to establish to which extent the identified predictors of change in diabetes management are exclusively due to the pandemic or whether they would have occurred regardless of the pandemic.

Due to the study design, certain groups have been highly represented in the study population. In particular people with type 2 diabetes and people who have passed statutory retirement age are highly represented. Thus, the study data does not offer opportunity for in depth analyses of people in specific life-situations, such as being responsible for small children and a full-time job while managing diabetes.

In conclusion, this study confirmed that many people with diabetes experienced difficulties in managing diabetes as usual during the pandemic, although the majority did not experience any difference. An important predictor for both deterioration and improvement in diabetes management was diabetes distress. Thus, diabetes management should be of concern during times of crisis and particular attention should be devoted to people with high levels of diabetes distress, who will be at increased risk of experiencing difficulties in managing diabetes.

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## DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/**Supplementary Material**. Further inquiries can be directed to the corresponding author.

## ETHICS STATEMENT

The study was reviewed and approved by the Danish Data Protection Agency. Participants provided written informed consent prior to participating in the study.

## AUTHOR CONTRIBUTIONS

KO, LJ, KM and IW designed the study. KM prepared data for analysis and KO carried out the statistical analyses. Interpretation of the findings was discussed among all authors. KO drafted the manuscript and all authors contributed to the final version of the manuscript.

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## SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: <https://www.frontiersin.org/articles/10.3389/fcdhc.2022.867025/full#supplementary-material>

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