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The early impact of the COVID-19 pandemic on adults with type 1 or type 2 diabetes: A national cohort study☆

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ABSTRACT

Aims: To describe the effects of the COVID-19 pandemic on adults with T1D or T2D in the U.S.
Methods: Participants, recruited from the Taking Control of Your Diabetes Research Registry, were ≥19 years old and diagnosed with either T1D or T2D for ≥12 months. Participants completed an online survey on a HIPAA-protected platform.
Results: Completed surveys were received from 763 T1Ds and 619 T2Ds. Average T1D age was 53.3 (SD = 15.3); average T2D age was 64.9 (SD = 10.3). Both samples were predominantly female, non-Hispanic white and well-educated. Average self-reported HbA1c was 6.9 (SD = 1.0; 52 mmol/mol) for T1Ds and 7.1 (SD = 1.1; 54 mmol/mol) for T2Ds. About 40% of respondents reported that all of their diabetes healthcare appointments at the time were cancelled or postponed, 40% reported a switch to telehealth appointments and almost half reported lower overall satisfaction with these visits (compared to pre-pandemic). There were widespread increases in general and diabetes-related stress and social isolation, and negative effects on disease management. About 25% reported increases in highs, lows, and glucose variability in both groups.
Conclusion: There has been a substantive increase in level of diabetes-related and general life stress and social isolation due to the pandemic, with a significant impact on disease management.

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1. Introduction

The coronavirus pandemic has generated widespread concern throughout the world and has forced major changes in lifestyle because of quarantines and other social restrictions and their economic consequences. Individuals with diabetes have an increased risk of infection and if SARS-COV-2 is contracted, those with diabetes have been shown to display greater risks of admission to intensive care units and mortality.1,2 Those with hypertension and obesity, especially common among many of those with diabetes, display a further increased risk of mortality.3

The COVID-19 crisis has had a unique effect on individuals with chronic disease, especially those with demanding management burdens like diabetes.4 These negative effects can include changes in diet and exercise, difficulty obtaining insulin, oral medications, and related monitoring and insulin delivery supplies, disruptions to health care delivery and access, and heightened fears of contracting the virus. These, in turn, can have substantial downstream effects by influencing emotional status and altering disease management behaviors, which can disrupt glycem control, worsen obesity and exacerbate related comorbidities.1,3,5,6 For example, several studies have documented the negative psychosocial effects of quarantine and reduced social mobility.7,8 These changes can substantively influence a variety of diabetes management behaviors.9

Although there has been a growing number of reports documenting the epidemiology and treatment of individuals with both diabetes and SARS-COV-2, far less is known about how the pandemic is affecting adults with diabetes in the community, as they deal with day-to-day life under a variety of social and, for many, economic restrictions. To provide a broad picture of the effects of the pandemic on adults with diabetes, we collected community-based data in four areas: access to care; concerns about obtaining medications and diabetes supplies; changes experienced in diabetes-related and general life stress and social isolation; and alterations in specific aspects of diabetes management. Herein we report the results of a large, national, U.S. sample of adults with either type 1 (T1D) or type 2 (T2D) diabetes. Data were collected in early April, 2020 when the initial quarantine and other social
restrictions were taking place across the United States, and little was known about the spread, timing and impact of the disease over time.

2. Subjects, materials and methods

2.1. Study population

Using an invitational email, participants were recruited from the Taking Control of Your Diabetes (TCOYD) Research Registry, an online platform for individuals recruited primarily from TCOYD’s one-day diabetes education events in the United States who had previously agreed to be contacted for participation in diabetes-related research. For the current study, participants were required to be ≥19 years old and diagnosed with either T1D or T2D for at least 12 months. Those responding to the invitational email were then asked to complete a brief eligibility questionnaire, an informed consent and an anonymous survey battery using a HIPAA-protected online platform. Because the study was unfunded, participants did not receive payment for their time. The research protocol was approved by the Institutional Review Board at the University of California, San Francisco.

2.2. Methods

Participant demographics and diabetes status included: age, gender, ethnicity, education (years), years with diabetes, T1D or T2D, current diabetes medications (oral only, non-insulin injectables, insulin), use of an insulin pump (yes/no), and use of a continuous glucose monitor (CGM) (yes/no).

Access to health care and diabetes supplies were assessed by the following questions (yes/no): “Have you had any lab tests or procedures canceled or postponed as a result of the coronavirus situation?” Cancellation and change in diabetes healthcare appointments was assessed by “Have you had diabetes-related medical appointments cancelled or postponed as a result of the coronavirus situation? Changes in the medium of health care delivery was assessed by “Since the pandemic began, were any of your diabetes appointments switched to telephone (audio only)?” and “Since the pandemic began, were one or more appointments switched video telemedicine calls?” For those who had telemedicine appointments, we also assessed satisfaction with audio or video appointments: “ Compared to in-person appointments please rate your level of satisfaction with telephone/video encounters.” Responses were recorded on a 7-point scale from least satisfied to more satisfied. We also assessed participants’ difficulty obtaining food to maintain their usual diet, diabetes supplies, access to contact with their healthcare team, and diabetes medications (yes/no).

General and diabetes-related stress/distress was assessed by two items. “Compared to before the coronavirus pandemic, how would you describe your current overall level of stress or worry?” It was rated on a 7-point scale from much lower to much higher, with a rating of 4 indicating no change. A similar item asked about changes in current level of stress or worry about “your diabetes.” Feelings of social isolation was assessed by: “Compared to before the coronavirus pandemic, how alone or isolated from others do you feel?” It was rated on a 4-point scale from “not at all” to “a lot.” Stress regarding finances and employment was assessed with the item, “With regard to the coronavirus, how worried or concerned are you about employment/finances?” (not, somewhat, very concerned).

Changes to diabetes management was assessed by seven items. Impact of the coronavirus “on current ability to effectively manage your diabetes” was rated by a 7-point scale from “significantly harder” to “significantly easier.” Impact on managing diet was assessed by, “Compared to before the coronavirus pandemic, how has the amount of food you are eating now changed?” It was assessed by a 7-point scale from “eating a lot more” to “eating a lot less,” with the middle option indicating no change. A similar item asked about how the coronavirus pandemic affected changes in the amount of exercise, using a 7-point scale from “much less” to “much more.” Changes in medication taking was assessed by, “Compared to before the coronavirus pandemic, how would you describe your diabetes medication taking now?” It was assessed by a 5-point scale from “taking medications a lot more regularly” to “a lot less regularly.” Perceived impact of the coronavirus pandemic on blood glucose levels asked the respondent to check separate boxes to indicate if they experienced major changes regarding: more frequent highs, more frequent lows and greater glucose variability (yes/no). Changes in the frequency of checking glucose levels, either with a finger stick monitor or CGM, was rated on a 3-point scale from “less often,” “about the same,” and “more often.” A similarly phrased item asked about change in frequency in reviewing glucose test results.

2.3. Statistical analysis

Descriptive statistics were computed to review item and scale distributions and report frequencies and measures of central tendency. All items on 7-point scales as described above were collapsed into three levels (1–3 vs. 4 neutral mid-point vs. 5–7) based on distributions and for ease in interpretation and presentation. To examine whether the perceived impact of the COVID-19 pandemic differed on the basis of participant characteristics, associations between participant demographic factors or key characteristics and perceived pandemic impact on access, emotional status and self-management were examined by Pearson or Spearman correlations or chi-square analyses as appropriate.

3. Results

Invitations to participate were sent to all current TCOYD Research Registry members (T1D n = 2582 T1D; T2D n = 3388), with 763 adults with T1D (29%) and 619 adults with T2D (18%) responding with completed surveys (Table 1). Overall, the responding sample was similar to overall registry participant characteristics, e.g., age, gender, time with diabetes. However, the participant sample was significantly less
diverse racially, had a higher level of education, and the T2D sample reported more use of CGM and insulin pumps than the general T2D registry membership (data not shown).

Average T1D age was 53.3 (SD = 15.3) years and average T2D age was 64.9 (SD = 10.3). Both samples were predominantly female, non-Hispanic white and well-educated. Average self-reported HbA1c was 6.96 (SD = 1.00; mmol/mol = 52) for T1Ds and 7.15 (SD = 1.16; mmol/mol = 54) for T2Ds. Average duration of diabetes was 30.05 years (SD = 16.50) for T1Ds and 17.07 (SD = 10.30) for T2Ds. CGM use was 84.7% in the T1D sample and 24.6% in the T2D sample. Of note, 46.3% of T2Ds reported using insulin.

3.1. Access to care and diabetes supplies

Of the participants who had diabetes medical appointments scheduled since the start of the pandemic (n = 499, 65.4% T1D; n = 417, 67.4% T2D), around 40% reported that all of their diabetes-related appointments had been cancelled or postponed (T1D n = 196–39.3%; T2D n = 178–42.7%), while a large minority of remaining participants reported that one or more of their diabetes appointments had been switched to a virtual telehealth appointment (T1D = 43.1%; T2D = 37.6%) (Table 2). Of those who switched to telephone or video meetings, in both samples about 45% reported lower satisfaction, only 10–15% reported higher satisfaction, and about 40% reported equal satisfaction, compared to in-person appointments. About a third of both samples reported that laboratory tests had been cancelled or postponed (T1D n = 232–30.9%; T2D n = 190–31.3%).

Compared to before the pandemic, about a third of both samples reported concerns about obtaining food to maintain their usual diet; but only 9–15% expressed concerns about obtaining diabetes supplies, and only 10% or fewer reported concerns about obtaining diabetes medications or gaining contact with their health care team.

3.2. Perceived stress

A substantial number of respondents reported an increase in general life stress, compared to before the pandemic: T1D n = 661–86.6%; T2D n = 486–78.4% (Table 3). Likewise, a majority of respondents from both

| Table 2 | Perceived impact of COVID-19 pandemic on access to care and experience of telehealth. |
|---------|----------------------------------------------------------------------------------|
| Diabetes appointment status: of those with appointments scheduled since pandemic | Type 1 diabetes | Type 2 diabetes |
| All appts cancelled or postponed | 39.3% (196) | 42.7% (178) |
| ≥ 1 appts switch to telehealth | 43.1% (215) | 37.6% (157) |
| ≥ 1 appts switched to telephone | 24.4% (124) | 24.0% (101) |
| ≥ 1 appts switched to video | 23.0% (117) | 16.1% (67) |
| Telephone appointment experience | Lower satisfaction | Type 1 diabetes | Type 2 diabetes |
| | 41.9% (54) | 45.0% (45) |
| | No change in satisfaction | 45.5% (56) | 39.0% (39) |
| | Higher satisfaction | 10.6% (12) | 16.0% (16) |
| Video appointment experience | Lower satisfaction | Type 1 diabetes | Type 2 diabetes |
| | 38.4% (45) | 40.4% (27) |
| | No change in satisfaction | 47.9% (56) | 43.3% (29) |
| | Higher satisfaction | 13.7% (16) | 16.5% (11) |

| Table 3 | Perceived impact of COVID-19 pandemic on general and diabetes-related stress. |
|---------|--------------------------------------------------------------------------------|
| General stress compared to pre-pandemic | Type 1 diabetes | Type 2 diabetes |
| Lower | 4.5% (34) | 7.0% (43) |
| No change | 8.9% (68) | 14.6% (90) |
| Higher | 86.6% (661) | 78.4% (486) |
| Diabetes related stress compared to pre-pandemic | Type 1 diabetes | Type 2 diabetes |
| Lower | 4.1% (31) | 4.5% (28) |
| No change | 34.1% (260) | 44.3% (274) |
| Higher | 61.8% (472) | 51.2% (317) |

| Table 4 | Perceived impact of COVID-19 pandemic on diabetes management. |
|---------|--------------------------------------------------------------------------------|
| Perceived impact on ability to manage diabetes | Type 1 diabetes | Type 2 diabetes |
| Harder to manage | 45.7% (349) | 48.9% (303) |
| No impact | 43.0% (328) | 44.1% (273) |
| Easier to manage | 11.2% (86) | 7.0% (43) |
| Perceived impact on diet | Type 1 diabetes | Type 2 diabetes |
| Eating more | 36.3% (277) | 38.1% (236) |
| Eating the same amount | 40.8% (311) | 35.7% (221) |
| Eating less | 22.9% (175) | 26.2% (162) |
| Perceived impact on exercise | Type 1 diabetes | Type 2 diabetes |
| Exercising less | 51.6% (394) | 57.2% (354) |
| Exercising the same amount | 24.9% (190) | 24.1% (149) |
| Exercising more | 23.5% (179) | 18.7% (116) |
| Perceived impact on medication taking | Type 1 diabetes | Type 2 diabetes |
| Taking medications less regularly | 4.1% (31) | 7.3% (45) |
| No change in medication taking | 87.8% (670) | 83.2% (514) |
| Taking medications more regularly | 8.1% (62) | 9.5% (59) |
| Perceived impact on glucose levels | Type 1 diabetes | Type 2 diabetes |
| More frequent highs (hyperglycemia) | 24.8% (189) | 24.7% (153) |
| More frequent lows (hypoglycemia) | 9.4% (72) | 7.9% (49) |
| More blood glucose variability | 22.5% (172) | 12.6% (78) |
| Glucose check frequency compared to pre-pandemic | Type 1 diabetes | Type 2 diabetes |
| Less often | 3.6% (27) | 10.4% (62) |
| About the same | 85.0% (631) | 77.3% (463) |
| More often | 11.3% (84) | 12.4% (74) |
| Frequency of reviewing glucose results/trends compared to pre-pandemic | Type 1 diabetes | Type 2 diabetes |
| Less often | 8.0% (59) | 14.9% (89) |
| About the same | 79.9% (593) | 76.0% (455) |
| More often | 12.1% (742) | 9.2% (55) |
samples reported increases in diabetes-related distress (T1D n = 472–
61.8%; T2D n = 317–51.2%). Over half of respondents reported feeling
somewhat or very concerned about employment or finances (T1D n =
454–61.2%; T2D n = 311–51.9%). Strikingly, 654 (85.3%) of T1Ds
and 495 (79.3%) of T2Ds (Table 1) reported greater social isolation,
compared to before the pandemic.

3.3. Diabetes management

Compared to before the pandemic, participants from both samples
reported changes to their diabetes management, some positive and
some negative (Table 4). Almost half of both samples (T1D n = 349–
45.7%; T2D n = 303–48.9%) reported that the pandemic made diabetes
management more difficult, whereas about 10% of both samples indi-
cated that the pandemic made it easier (T1D n = 86–11.3%; T2D n =
43–7.0%). Over a third of participants from both samples reported that
they were eating more (T1D n = 277–36.3%; T2D n = 236–38.1%),
whereas 175 (22.9%) of T1Ds and 162 (26.2%) reported that they were
eating less. The pandemic appears to have had a large impact on exer-
cise, with 394 (51.6%) of T1Ds and 354 (57.2%) of T2Ds reporting that
they were exercising less than before the pandemic. There was little
change in medication taking (T1D n = 670–87.8%; T2D n = 514–
83.2% reported no change).

About a quarter of both samples reported more frequent high glucose
levels than before the pandemic (T1D n = 189–24.8%; T2D n = 153–
24.7%) and less than 10% reported more frequent lows (T1D n = 72–
9.4%; T2D n = 49–7.9%). But twice as many T1Ds than T2Ds reported an
increase in glucose variability (T1D n = 172–22.5%; T2D n = 78–12.6%) compared to before the pandemic. About three quarters of both samples
reported no change in the frequency of their glucose testing (T1D n =
631–82.7%; T2D n = 463–74.8%) or change in the frequency of reviewing
glucose results (T1D n = 593–77.7%; T2D n = 455–73.5%).

3.4. Associations between participant characteristics and perceived impact
of the COVID-19 pandemic

Compared to older participants, younger participants from both sam-
pies reported significantly greater concerns about finances (T1D r =
−0.17, T2D r = −0.29, p < .001). Age had a more impactful effect,
however, on T2D adults than on T1D adults. For T2D adults only, younger
respondents reported greater feelings of social isolation (r = −0.10, p =
.02), greater difficulty managing their diabetes (r = 0.15, p < .001), more
frequent hyperglycemia (r = −0.15, p < .001), higher general stress (r =
−0.13, p = .002), and higher diabetes-related distress (r = −0.14, p <
.001) when considering the impact of the COVID-19 pandemic. No signif-
icant relationships between these variables occurred among T1Ds.

There was a significant correlation between higher reported HbA1C
and larger increases in diabetes-related stress, compared to before the
pandemic (T1D r = 0.08, p = .03; T2D r = 0.13, p = .002), but not
with general life stress (T1D and T2D ns.). Higher reported HbA1C
was also significantly associated with more frequent hyperglycemia
(T1D r = 0.12, p = .001; T2D r = 0.21, p = .001) and greater overall dif-
ficulty managing diabetes, but only for T2Ds (r = −0.18, p = .001).

Compared to T2Ds not using insulin, T2Ds using insulin tended to dis-
play significantly more frequent concerns about accessing diabetes medica-
tion (12% vs. 5%, p = .003) and larger changes in glucose values,
including more frequent hyperglycemia (29% vs. 21%, p = .02), hypoglycemia
(11% vs. 5%, p = .005), and glucose variability (18% vs. 8%, p = .001).

There was no systematic pattern of associations between perceived
impact of the COVID-19 pandemic and race, education level, identifying
as a healthcare worker or first responder, or having a spouse or partner.

4. Discussion

The onset of the COVID-19 pandemic in the U.S. in March, 2020 had a
significant impact on adults with diabetes, even as early as mid-April. In
general, adults with diabetes in the community report significant
changes in their healthcare. Approximately four in ten adults with
type 1 or 2 diabetes report all of their diabetes healthcare appointments
at the time were cancelled or postponed. Another 40% report one or
more appointments were retained but switched to audio or video
telehealth appointments from in-person encounters, and, of those,
almost half (45%) reported lower overall satisfaction with these visits,
compared to in-person visits. There were substantial increases in
general and diabetes-related stress and social isolation among both
T1D and T2D adults, compared to before the pandemic. Although
some of these changes can be attributed to both the emergence of the
pandemic and to the uncertainty about what might lie ahead, changes
in healthcare and the dramatic increases in distress and feelings of social
isolation, in contrast to before the pandemic, are striking. More posi-
tively, concerns about access to health care teams and to diabetes sup-
plies and medications at this early stage in the pandemic are minimal.

Even with the availability of healthcare, albeit through a different
medium for many, and with the availability of diabetes supplies and
medications, almost half of adults with either T1D or T2D report that
the pandemic made their diabetes management more difficult. About
60% report a change in the amount of food consumed, compared to be-
fore the pandemic, and over half report that they were exercising less.
Likewise about a quarter of respondents report that their glucose num-
bers were running higher than before the pandemic, with about a quar-
ter of T1Ds reporting greater glucose variability than before. Thus,
a significant number of those with diabetes report significant changes
in their diabetes management, even during the early stages of the pan-
demic in the US.

Given that access to healthcare, medications and diabetes supplies
are reported to be relatively the same as they were before the pandemic,
changes to diabetes management most likely are related to higher levels
of both diabetes-related and general life stress, increases in social iso-
lation, and restrictions due to the quarantine. A recent study from
Denmark reported high levels of worry and concern about both
contracting the virus and becoming quite ill if the virus was contracted.
Increases in worry and concern were significantly linked with changes
in diet, with downstream effects on glucose management. Likewise,
several studies have outlined the negative impact of quarantine on
both psychosocial functioning and disease management. For example,
the negative effects of social restrictions and isolation include confusion,
anger, PTSD-like symptoms, insomnia, frustration, boredom, and
increased fearfulness. Increases in anxiety and depression as a result
of being quarantined also have been documented, with similar
increases in general mental health concerns as a result of the pandemic.11
These emotional reactions most likely have direct effects on disease
management: they affect changes in eating (i.e., overeating,
dereating, off-schedule eating), reduced physical activity, greater
alcohol consumption, more frequent hypoglycemia, and more erratic glu-
cose levels.12,13

Similar to the results of the Denmark study,8 we find that younger
adult T2Ds and those with higher reported HbA1C levels are at higher
risk of experiencing these difficulties than the rest of the sample. Several
studies unrelated to the pandemic have reported similar findings.
For example, in general, younger T2D adults report higher distress and life
difficulties, poorer medication taking and higher HbA1C than older
T2D adults.14,15 It appears that the increased stresses and strains associ-
ated with the coronavirus pandemic may have exacerbated the impact
on this high risk subgroup.

Because of increased social isolation, worries about finances and
family, and vulnerability to the virus itself, several reports have empha-
sized the need for active interventions to reduce the negative impact
of the pandemic on adults with diabetes. These include increased online
support and contact from the healthcare community, greater access to
online education, increased home monitoring, introduction of new
technologies, and digital support groups to reduce social isolation (9).
Likewise, the National Diabetes Services Scheme from Diabetes
Australia has assembled a set of pamphlets emphasizing a focus on “keeping up to date with the newest information, learning the symptoms of SARS-COV-2, and knowing what to do if you get sick.” They also identify the importance of: doing your best to stay safe, being kind and compassionate to yourself and not feeling guilty or blaming yourself if you contract the virus. These and related programs emphasize the need to keep perspective, utilize adaptive styles of emotion regulation, and increase contact with health care teams and the diabetes community through, for example, peer support. Undoubtedly, more specific strategies of intervention will need to be developed as more information about the effects of the pandemic become available for targeted adult diabetes populations.

The relatively negative reaction to changes in the medium of clinical encounters from in-person visits to telephone or video encounters is somewhat surprising. Although telehealth can reduce inconvenience and anxiety about exposure to the virus caused by a trip to a healthcare facility, it can also introduce multiple challenges, including participants’ lack of experience with the medium, technological difficulties, lack of access to glucose downloads and lab reports, and a wish for more of a “human touch.” It will be important to document if this initial lack of satisfaction persists over time and the reasons for it; and to identify ways to improve telehealth encounters for this population.

This study has a number of strengths. It included a relatively large, national U.S. sample of both T1D and T2D adults, it assessed many aspects of life with the coronavirus pandemic and it enabled separate analyses of T1D and T2D adult samples. Three limitations should be noted, however. First, the sample was not as diverse as hoped and included mostly white, educated adults with good blood glucose management and high use of diabetes-related technologies. Our findings, however, may have underestimated the negative impact of the pandemic on the broader, more diverse diabetes community. Second, no non-diabetes comparison group was included. The pandemic has led to documented increases in distress and uncertainty within the entire U.S. population and, despite the fact that those with diabetes are more vulnerable to the coronavirus and despite its potential negative impact on disease management, it is unclear what similarities and differences in reactions to the pandemic between those with and without diabetes might be. Third, the data for this report were collected only a few weeks after the pandemic began in earnest and the selective social restrictions were put in place. How these effects will be exacerbated or modified over time are not known. A second survey has been sent to the initial respondents to determine change over time and will be the subject of a future report.

5. Conclusion

This study reports on the reactions of a large sample of U.S. adults with either T1D or T2D to the coronavirus pandemic. It indicates that there is a substantive increase in level of diabetes-related and general life stress and worry about being vulnerable to the virus, and significant social isolation. Furthermore, it suggests that there is a significant impact on disease management. Changes in the medium of healthcare delivery were only modest during the early stages of social restriction, but satisfaction with these changes was generally low. These findings suggest the need for greater attention to the emotional and psychosocial impact of the pandemic on this population and its implications for disease management and diabetes-related healthcare delivery.

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