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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. Those with hypertension and obesity, especially common among many of those with diabetes, display a further increased risk of mortality.

The COVID-19 crisis has had a unique effect on individuals with chronic disease, especially those with demanding management burdens like diabetes. 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

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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 glycemic 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

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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 less 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

Table 1 Participant characteristics.

	Type 1 diabetes $(n = 763)$ Mean (SD) or % (n)	Type 2 diabetes $(n = 619)$ Mean (SD) or % (n)
Age	53.37 (15.35)	64.90 (10.37)
Gender		
Male	27.5% (207)	33.0% (201)
Female	72.5% (546)	67.0% (408)
Latinx	5.7% (42)	7.7% (46)
Race		
Non-Hispanic white	93.4% (678)	77.1% (460)
Black/African American	1.2% (9)	6.0% (36)
Asian	2.2% (16)	9.5% (57)
Other or multiracial	3.2% (23)	7.4% (44)
Education		
High school or less	4.3% (33)	5.9% (36)
Some college	18.2% (138)	21.2% (131)
College degree	42.7% (323)	39.0% (241)
Graduate degree	34.9% (264)	34.0% (210)
Live with a spouse/partner	69.9% (517)	61.8% (369)
Healthcare worker/first responder	13.5% (102)	9.4% (57)
Time since diagnosis (years)	30.05 (16.50)	17.07 (10.30)
HbA1c (%)	6.96 (1.00)(52	7.15 (1.16)(54
	mmol/mol)	mmol/mol)
Diabetes medication		
Orals only	-	37.4% (229)
Non-insulin injectable (no insulin)	-	16.2% (99)
Insulin (with or w/out other meds)	100% (763)	46.3% (283)
Insulin pump use	77.6% (592)	6.8% (42)
CGM use	84.7% (646)	24.6% (152)

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,

Table 2Perceived impact of COVID-19 pandemic on access to care and experience of telehealth.

	Type 1 diabetes (n = 763) % (n)	Type 2 diabetes $(n = 619)$ % (n)
Diabetes appointment status: of those with	. ,	
appointments scheduled since pandemic		
All appts cancelled or postponed	39.3%	42.7%
	(196)	(178)
≥ 1 appts switch to telehealth	43.1%	37.6%
	(215)	(157)
≥ 1 appts switched to telephone	24.4%	24.0%
	(124)	(101)
≥ 1 appts switched to video	23.0%	16.1%
	(117)	(67)
Telephone appointment experience		
Lower satisfaction	43.9%	45.0%
	(54)	(45)
No change in satisfaction	45.5%	39.0%
	(56)	(39)
Higher satisfaction	10.6%	16.0%
	(13)	(16)
Video appointment experience		
Lower satisfaction	38.4%	40.4%
	(45)	(27)
No change in satisfaction	47.9%	43.3%
	(56)	(29)
Higher satisfaction	13.7%	16.5%
N. I	(16)	(11)
Number reporting access concerns Food to maintain usual diet	20.00/	25.50/
Food to maintain usual diet	30.9%	35.5%
P: 1	(236)	(220)
Diabetes supplies	15.2%	8.9% (55)
Contract with househouse to an	(116)	0.0% (5.0)
Contact with health care team	11.1%	9.0% (56)
Diabetes medications	(85)	0 C% (E3)
	6.6% (50) 30.9%	8.6% (53) 31.3%
Labs/tests cancelled or postponed		
	(232)	(190)

Table 3Perceived impact of COVID-19 pandemic on general and diabetes-related stress.

	Type 1 diabetes (n = 763) % (n)	Type 2 diabetes (n = 619) % (n)
General stress compared to pre-pandemic		
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		
Lower	4.1% (31)	4.5% (28)
No change	34.1% (260)	44.3% (274)
Higher	61.8% (472)	51.2% (317)
Concern related employment/finances regarding SARS-COV-2		
Not concerned	38.8% (288)	48.1% (288)
Somewhat concerned	41.5% (308)	35.4% (212)
Very concerned	19.7% (146)	16.5% (99)
Social isolation compared to pre-SARS-COV-2		
Not at all	14.7% (109)	20.7% (124)
A little	31.9% (237)	31.6% (189)
Somewhat	29.0% (215)	27.9% (167)
A lot	24.4% (181)	19.9% (119)

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 4Perceived impact of COVID-19 pandemic on diabetes management.

	Type 1 diabetes (n = 763) % (n)	Type 2 diabetes $(n = 619)$ % (n)
Perceived impact on ability to manage		
diabetes		
Harder to manage	45.7% (349)	48.9% (303)
No impact	43.0% (328)	44.1% (273)
Easier to manage	11.3% (86)	7.0% (43)
Perceived impact on diet	1113/0 (00)	71070 (13)
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		
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	,	
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		
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		
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		
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 indicated 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 (T1Dn 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 exercise, 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 samples 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 significant 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 hypoglycemia (T1D r=0.12, p=.001; T2D r=0.21, p=.001) and greater overall difficulty managing diabetes, but only for T2Ds (r=-0.18, p=.001).

Compared to T2Ds not using insulin, T2Ds using insulin tended to display significantly more frequent concerns about accessing diabetes medication (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 positively, concerns about access to health care teams and to diabetes supplies 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 before the pandemic, and over half report that they were exercising less. Likewise about a quarter of respondents report that their glucose numbers were running higher than before the pandemic, with about a quarter of T1D adults 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 pandemic 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 isolation, and restrictions due to the quarantine. A recent study from Denmark⁸ 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.⁷ Increases in anxiety and depression as a result of being guarantined also have been documented, 4,9,10 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, undereating, off-schedule eating), reduced physical activity, greater alcohol consumption, more frequent hypoglycemia, and more erratic glucose 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 associated 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 emphasized 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 virus¹³ (ndss.com.au). 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". ¹⁶ 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. population¹⁷ 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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