


Needs, concerns and self-management experiences of people with type 2 diabetes during the COVID-19 pandemic: A qualitative study

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Abstract

Background: Type 2 diabetes is associated with increased COVID-19 severity. Little is understood about the needs, concerns and self-management experiences of people with type 2 diabetes during the COVID-19 pandemic.

Aim: To examine the lived experiences of people with type 2 diabetes during the COVID-19 pandemic.

Method: This qualitative study recruited people with type 2 diabetes from the SOUth-London Diabetes (SOUL-D) cohort. Semi-structured interviews via telephone were conducted between September 2020 and January 2021. Deductive thematic analysis derived themes from the data to explore needs, concerns and self-management experiences of people with type 2 diabetes.

Results: Twenty-nine people with type 2 diabetes were interviewed. Three themes with subthemes were outlined: (1) information needs of people with type 2 diabetes during the Covid-19 pandemic, (2) concerns about Covid-19 from people with type 2 diabetes and (3) diabetes self management and well-being during the Covid-19 pandemic.

Conclusion: During a pandemic, there is a need for consistent, diabetes-specific, messaging from healthcare professionals for people with type 2 diabetes. People with type 2 diabetes need support to access digital resources to aid remote communication. Future research could help develop recourses to prevent social isolation and loneliness for people with type 2 diabetes during a pandemic.

KEYWORDS

Covid-19, patient perspectives, qualitative research, type 2 diabetes

1 | INTRODUCTION

In the early stages of the COVID-19 outbreak, people with type 2 diabetes accounted for nearly one-third of COVID-related

deaths.¹ Type 2 diabetes is associated with increased severity of COVID-19 as the SARS-CoV-2 virus induces hyperglycaemia, which in turn leads to immune dysfunction, increased vulnerability to infections, and development of long-term

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diabetes complications.² Consequently, people with diabetes are classed as a 'high-risk group' by the UK government during the COVID-19 pandemic. This may have led to heightened anxiety about diabetes self management and attention towards national recommendations on social distancing and hygiene behaviours.

The COVID-19 pandemic also disrupted access to routine type 2 diabetes services, with healthcare professionals redeployed to other roles, and face-to-face appointments being drastically reduced and partially replaced by virtual communications.³ In the United Kingdom, tests for HbA_{1c}, an important proxy marker to guide clinical decisions to normalise glycaemic levels, fell by up to 77% between March and December 2020.⁴ Reduction in objective monitoring of glycaemic levels has made it more pivotal to have effective diabetes self care to minimise the risk of COVID-19 infection and its consequences. Two cross-sectional survey studies found contradictory findings regarding whether the COVID-19 pandemic has improved or hindered lifestyle behaviours for people with type 2 diabetes. Grabia et al.(2020) found improvements in healthy eating⁵; however, Ruiz-Roso et al. (2020) found people with type 2 diabetes increased snacking behaviours with high levels of physical inactivity.⁶ A qualitative study found mixed self reports from people with type 2 diabetes including maladaptive versus health-promoting diet and physical activity practices.⁷ These cross-sectional and qualitative studies were conducted in Poland,⁵ Spain⁶ and Denmark.⁷ However, the self-management experiences of people with type 2 diabetes living in the United Kingdom during the COVID-19 pandemic has not been studied.

Another impact of COVID-19 lockdown was social distancing resulting in increased social isolation and worsening mental health.⁸ Before the pandemic people with type 2 diabetes were found to have a higher prevalence rate of depressive and anxiety symptoms compared with the general population and are associated with reduced diabetes self care, suboptimal glycaemic levels, increased risk of diabetes complications, and premature mortality.⁹ In a Europe-wide survey, diabetes nurses ($n = 1829$) stated that they had observed an increase in reduced self care and worsening of glycaemic levels and psychological problems such as depression, distress, anxiety during the pandemic. Understanding the perspective of people with type 2 diabetes and the impact of COVID-19 lockdown on social isolation and reduced access to routine diabetes care is important to improve services for people with type 2 diabetes during and after the pandemic. A qualitative interview study of a type 2 diabetes Danish sample¹⁰ found a negative change in self-observation (participants labelling themselves as 'vulnerable'), unclear COVID-19 risk perception, and negative changes in social relationships (e.g.

What's new?

- People with type 2 diabetes were deemed 'high-risk' during the COVID-19 pandemic. However, their experiences of self management during this time are largely unexplored in a UK context.
- This qualitative study found that, during a pandemic, people with type 2 diabetes trust their GPs to give them information on preventative measures, health-promoting behaviours, and address their health concerns.
- The knowledge obtained from this study can be used as a guide for GPs to better support people with type 2 diabetes during the ongoing COVID-19 pandemic and to prepare for future pandemics.

difficulty in creating meaningful relationships) during this time. Our current study explores the views of ethnic minorities and people with depressive symptoms regarding self management during the COVID-19 pandemic that are under-represented in existing qualitative research.

The South London Diabetes (SOUL-D) cohort is a population-based prospective study of individuals with newly diagnosed type 2 diabetes ($N = 1735$) recruited within 6 months of diagnosis between 2009 and 2012 from 96 general practice (GP) surgeries in south London.¹¹ SOUL-D is unique as it represents a multi-ethnic and socio-economically diverse population of type 2 diabetes residents in an inner-city, which had some of the highest rates of COVID-19 infections during the first three lockdowns: <https://coronavirus.data.gov.uk/details/interactive-map/cases>. Pre-COVID-19 pandemic, a proportion of SOUL-D participants (345 out of 1735) were followed up (8–10 years post-baseline), which allowed for an exploration of lived experiences of diabetes self care during the COVID-19 pandemic. The current study aimed to explore the needs, concerns and self-management experiences of a sample of people with type 2 diabetes from the SOUL-D cohort during the COVID-19 pandemic.

2 | METHODS

This study was a semi-structured qualitative design of one-to-one telephone interviews of people with type 2 diabetes from the SOUL-D cohort. A narrative research approach was adopted whereby participants accounts of diabetes self-management experiences acted as data for analysis.¹² Ethical approval was obtained by King's College Hospital

(ref. 17/LO/0363). This report adhered to the Consolidated Criteria for Reporting Qualitative Research guidelines.¹³

2.1 | Participants

SOUL-D participants who had previously consented to be contacted for future studies were eligible to take part in the current study. Only participants who had been seen for the SOUL-D study at both baseline (2009–2012) and 8 to 10-year follow-up (2017–2020) were eligible so current depressive symptom caseness (participants with or without depressive symptoms) could be recruited. There were 345 eligible participants under this criterion. All participants resided in South London, no participants lived in a medium-long term facility.

Participants were purposively sampled by sex, age (≤ 45 , 46–59, 60+ years), ethnicity (White, Black African or Caribbean, South Asian/other), presence of SOUL-D study baseline depressive symptoms (yes or no; ≥ 10 Patient Health Questionnaire¹⁴ score was the cut-off indicating the presence of depressive symptoms) and 8 to 10-year SOUL-D study follow-up depressive symptoms, see Table S1. Demographic data (age, sex, ethnicity) was obtained via self report in the baseline SOUL-D study.¹¹ Test statistics (chi-square tests) were conducted to compare the baseline socio-demographic factors in the purposive sample with the rest of the SOUL-D cohort.

Participants were recruited and interviewed between 8 September 2020- and 25 January 2021. The interviews were conducted during a period of various changes in the government response to the COVID-19 pandemic as summarised in Table S2.

2.2 | Data collection

The topic guide was developed by authors (RU, LK, IV) by adapting Caress et al.'s (2010) topic guide exploring information needs, concerns and health-related behaviours in patients with respiratory conditions during H1N1 swine-flu pandemic,¹⁵ Appendix S1, Box 1. To optimise timely data collection, the topic guide was piloted on two people with type 2 diabetes, who were not SOUL-D participants and were not included in the study sample. Following these pilot interviews and discussion with the authorship team (KI, KW), revisions to the topic guide included adding diabetes-specific and COVID-19-specific questions.

Participants were invited by the research team (LK, IV, YN) via telephone. In advance of the interview, participants were emailed an online information and consent form (via Qualtrics), or a paper version in the post. The information sheet informed participants of the research aim

to examine experiences of self-managing type 2 diabetes during COVID-19 lockdown.

To optimise data collection, the telephone interviews were conducted by three female interviewers; LK (MSc, research assistant), IV (MSc, clinical psychologist) and YN (medical student). All interviewers had prior qualitative training in their respective degrees with further support from the research team (RU, KW, KI). Each interviewer conducted interviews with the participants they had recruited, all interviews were conducted in English. IV and YN had no prior relationships with the participants, but LK had met $n = 10$ of the participants they had interviewed pre-lockdown in the SOUL-D 8- to 10-year follow-up study. Interviewers disclosed to interviewees their name, job title and role in the research before conducting the interview. Interviewee household members could be present, if desired, but could not respond on behalf of the participants at any time. The interviews were audio-recorded.

There were opportunities to listen to each interviewer's recordings, in order.

to develop and learn from styles of interviewing and prompts to reduce interviewer bias. Field notes were made after each interview and shared with the research team. No repeat interviews were carried out, or transcripts were returned to participants for clarity due to the time-sensitive nature of the topic. The aim was to recruit 25–30 participants to allow a thorough examination of the research question, so there is enough data to compare conceptual groups (e.g. age, sex, ethnicity differences), maximise exploration of negative cases in the data.¹⁶

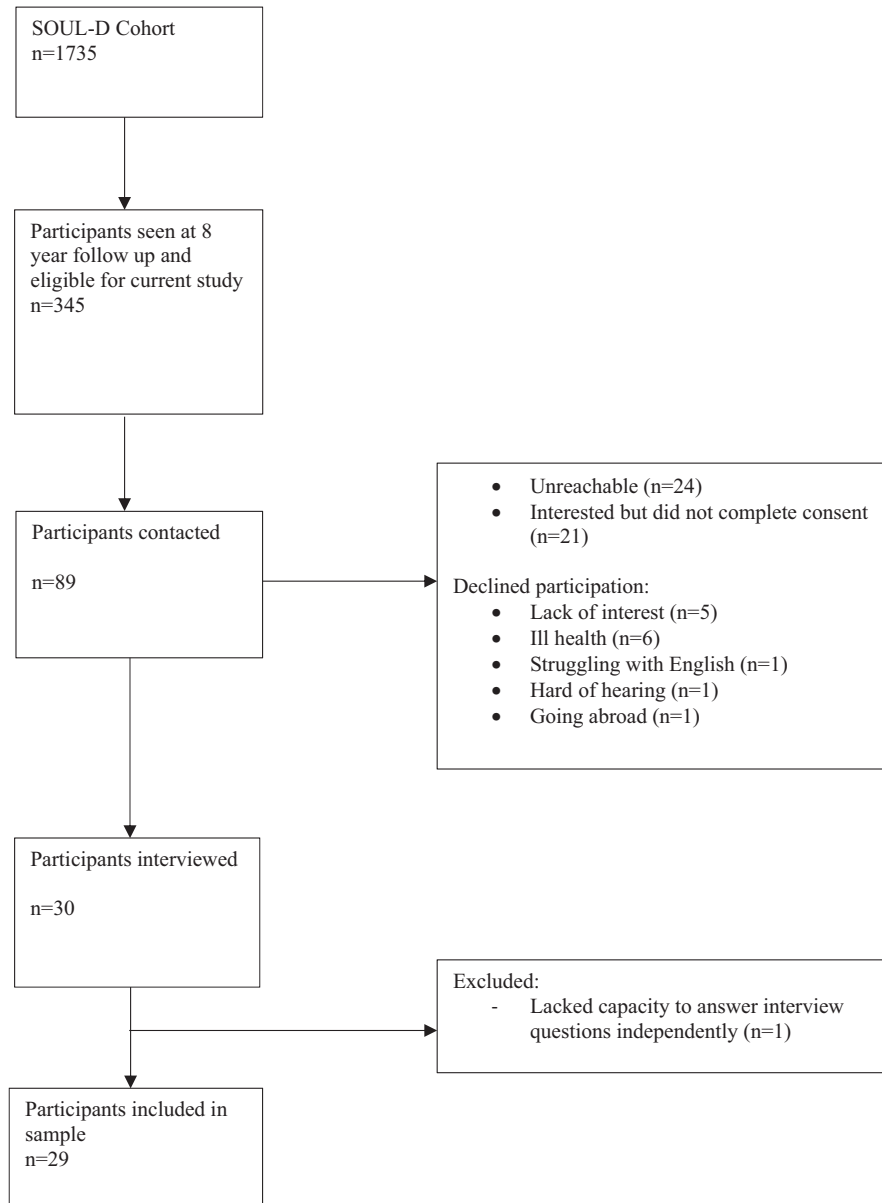
2.3 | Data analysis

Interviews were transcribed verbatim with identifiable information redacted. Data was managed in NVivo12.¹⁷ Deductive thematic analysis was used to match themes to sections outlined in the topic guide, that is, needs, concerns and diabetes self-management behaviours. Inductive subthemes were generated under these deductive main themes to allow a more flexible method in interpreting the experiences of the participants.¹⁸ The following steps were undertaken by three coders (LK, IV, YN and reviewed by RU, KW, KI): familiarisation of transcripts, field notes and audio files; generation of initial codes; generation of subthemes under deductive themes; defining and naming themes and subthemes and producing the manuscript.

3 | RESULTS

Eighty-nine participants from the SOUL-D cohort were contacted, $n = 24$ were uncontactable, $n = 21$ were

FIGURE 1 Summary of recruitment.



interested but did not complete the consent form, $n = 14$ declined participation, and $n = 30$ people with type 2 diabetes were interviewed (Figure 1). One participant was excluded after they signed consent to be contacted as they lacked the capacity to understand the patient information sheet. Most participants completed an online consent form (86%) compared with postal (14%). The majority of participants were over 65 years of age (79%), of white ethnicity (62%), did not have depressive symptoms at the SOUL-D study baseline (72%) or at 8-year follow-up (79%), and were not currently prescribed insulin treatment (65%), Table 1. Due to the demand on health services, there was difficulty obtaining HbA_{1c} values of participants from GP surgeries (response of 59%).

Baseline demographics of this sample were similar to the remainder of the SOUL-D cohort, Table 1. Two participants had microvascular complications, and one

participant had macrovascular complications at 8–10 year SOUL-D follow-up.

Three key themes are presented: (1) Information needs of people with type 2 diabetes during the Covid-19 pandemic; (2) Concerns about Covid-19 from people with type 2 diabetes; (3) Diabetes self management and well-being during the Covid-19 pandemic. There were.

subthemes within each theme, see Figure 2.

3.1 | Information needs of people with type 2 diabetes during the COVID-19 pandemic

There were contrasting experiences of accessing healthcare for participants. Some were generally unaffected and able

TABLE 1 Overall demographics of interviewees

Characteristics	Number	Percentage	p-value: purposive sampling versus rest of SOUL-D cohort
Sex			0.712
Women	12	41	
Men	17	59	
Age (years)			0.694
<65	23	79	
65+	6	21	
Ethnicity			0.386
Black African/Caribbean	8	28	
White	18	62	
Asian/other	3	10	
Baseline depressive symptoms			0.063
No	21	72	
Yes	8	28	
8-Year follow-up depressive symptoms ^a			—
No	23	79	
Yes	5	17	
Missing information	3	4	
Insulin use ^a			-
No	19	66	
Yes	10	34	
HbA _{1c} levels (mmol/mol) Pre-COVID-19 pandemic ^a			—
Optimal HbA _{1c} (<58 mmol/mol)	12	41	
Sub-optimal HbA _{1c} (≥58 mmol/mol)	5	18	
Cannot obtain	12	41	

^aFollow-up data only.

to contact relevant healthcare professionals when needed. However, others found contacting healthcare professionals extremely difficult for support with their type 2 diabetes or obtaining information regarding COVID-19. There were also concerns about the digital evolution of healthcare and the lack of information concerning the link between diabetes and COVID-19 from healthcare professionals.

3.1.1 | Ability to contact healthcare professionals

A minority of participants found it challenging to get in touch with healthcare professionals when they needed help with their diabetes during the COVID-19 pandemic:

Normally I would get an appointment to see a doctor, but uh you know I said to them before it's easier to see God than to see you lot. (Male, White, <65 years)

In contrast, other participants were able to access routine diabetes care with minimal disruption or postponement. Most recounted that they did not need to contact healthcare professionals during the pandemic but had the confidence of being able to do so if needed.

I haven't had any anything specific about COVID from them (healthcare professionals), but I haven't needed or wanted anything specific about COVID. I've been pleased. But you know, those are sort of routine care I get has been able to continue. (Female, White, <65 years)

3.1.2 | Perceptions of using remote healthcare communication

Participants recalled their experiences of accessing online healthcare services, for example, the ease of accessing online services versus the difficulty of calling their GP surgery:

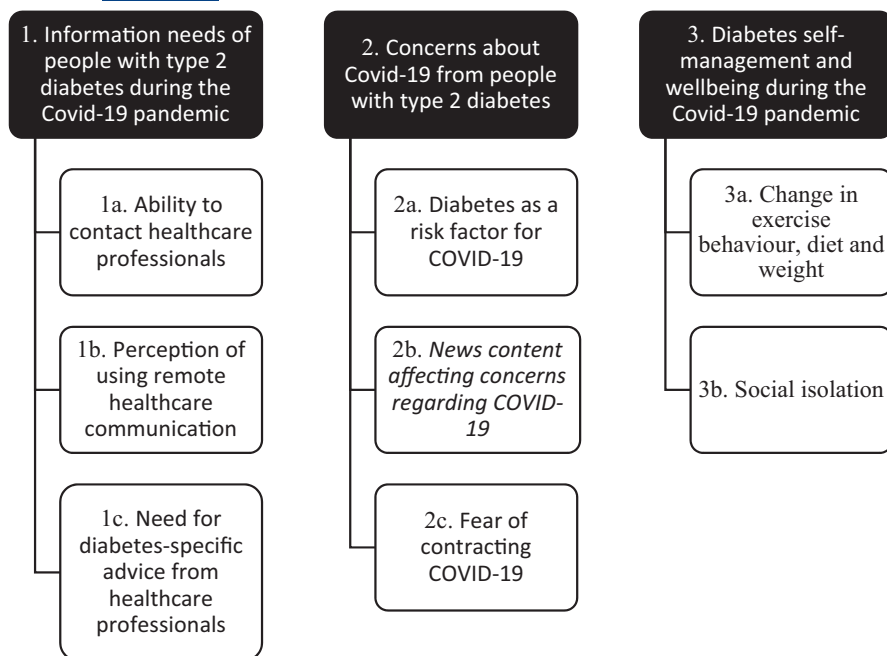


FIGURE 2 Summary of themes and sub-themes.

...the phone just rings and rings...it's not always uh successful. But online, I do a lot of online now, um e-consultations and uh...they always call you back the next day to say...what to do or whatever. (Male, White, <65 years)

Many participants were comfortable using digital platforms when accessing care, although nearly all highlighted their preference for face-to-face consultations.

I miss the idea that I can go and see my doctor physically. But I'm quite prepared to do um telephone or Zoom or WhatsApp, that sort of thing. I don't mind doing virtually if necessary. (Female, White, <65 years)

Due to increased reliance on digital communication during the COVID-19 pandemic, participants described becoming more digitally literate and comfortable using technology than before the pandemic:

I'm very comfortable with it...it's kind of I guess a benefit of remote working is that I'm used to various platforms now so, um because it's a lot of video remote working as I say. (Male, White, <65 years)

3.1.3 | Need for diabetes-specific advice from healthcare professionals

Many participants demonstrated high levels of trust in information from healthcare professionals. However, they

seemed concerned by the lack of diabetes-specific advice from healthcare professionals regarding COVID-19.

I think it [diabetes-specific information] would be helpful and so because we can take extra precautions you know... [information] from the GP would be advisable because they are the closest contact with us... (Female, Asian/Other, <65 years)

Many people with type 2 diabetes were not advised to shield during the COVID-19 pandemic as shielding was limited to those who are 'extremely clinically vulnerable'. However, many participants were surprised by the lack of shielding and diabetes-specific advice from the healthcare professionals involved in their care.

...no I haven't received a shielding letter. Umm but my workplace did a risk assessment, ... and I think because the guidance mentioned those with diabetes type 2, um they recommended that I shielded as much as I could. (Female, Black, <65 years)

3.2 | Concerns about Covid-19 from people with type 2 diabetes

There were various discrepancies between participants' concern about COVID-19, for example, their perception of type 2 diabetes as a risk factor for COVID-19. Media and other people's attitudes and behaviour also had an influence on participants' concern about COVID-19.

3.2.1 | Diabetes as a risk factor for COVID-19

There was a perception that type 2 diabetes was not a risk factor for Covid-19:

No, you're a person first, and you know a diabetic second.....I don't think I'm any more susceptible or the consequences will be any greater to it than any other person of my age. (Female, White, <65 years)

Managing diabetes through medication or lifestyle measures and keeping generally well seemed to negate any concern about diabetes being a risk factor during the pandemic:

But to be honest, I've never really worried too much about my diabetes because it's always been under control...um, with diet and my parents both had diabetes. (Female, White, 65+ years)

A minority of participants felt more concerned about COVID-19 due to their diabetes, and while they may not have understood the reasons behind it, they were aware that diabetes and its complications can place them at increased risk.

...maybe to be extra careful because, um, type 2 diabetes, and obviously, there are underlying health conditions that might affect outcomes. (Male, White, <65 years)

3.2.2 | News content affecting concerns regarding COVID-19

The media coverage of the COVID-19 pandemic appeared to have a significant negative impact on the participants' mental health and resulted in decreased news consumption.

I don't really use the news because the news makes me more depressed. (Female, Black, <65 years)

Participants acknowledged that the news caused increased anxiety and distress because of reports on diabetes being one of the conditions causing higher deaths in patients with COVID-19:

...when you see on the News it's you know, X number of people have died because they had

underlying problems and quite often, they seem to reference diabetes as one of those problems. But that tends to just ramp up the... the discomfort levels around it you know? (Male, White, >65 years)

Others mentioned that the lack of clarity from news outlets has impacted their anxiety about diabetes risk and COVID-19 vulnerability.

...they should enable us to become more secure about what it is (COVID-19) without putting too much stress and making people nervous. (Female, Asian/Other, <65 years)

3.2.3 | Fear of contracting COVID-19

Other people's attitudes such as lack of fear of developing COVID-19 and risk-taking behaviours such as not following government advice on protective measures was a cause of worry for interviewees:

Other people they just walk about without anything on their face, on the buses they don't put any masks on or anything so, I don't know what is going on...It frustrates me really because why should somebody wear a mask when others aren't. (Female, Black, <65 years)

Public transport was a common concern among participants and resulted in participants avoiding it:

I'm worried...Even to go inside the buses I'm scared, or a train or anything I'm very scared... to go shopping, I'm scared of the coronavirus. Because you don't want to get too close, you don't know anybody, you don't know. (Female, Black, <65 years)

Participants noted that the COVID-19 virus is indiscriminate and invisible in nature, and unknowingly passing the virus on to others was particularly difficult to deal with:

I think the biggest concern is, it doesn't matter who you are, as far as I know, I don't think anybody's eyesight is good enough to actually see this virus [laughs] um, which is the essence of the problem. It's an invisible threat. (Male, White, >65 years)

3.3 | Diabetes self management and well-being during the Covid-19 pandemic

Social distancing restrictions have meant that many participants have adopted.

more sedentary lifestyles, with minimal social activities. On the other hand, the restrictions.

have offered a unique opportunity to focus on diabetes management and improve general.

well-being.

3.3.1 | Change in exercise behaviour, diet and weight

The majority of interviewees noted a decrease in their level of physical activity and increased weight gain. Decreased physical activity during lockdown was a consequence of disrupted day-to-day routine, for example, working from home, shopping online for groceries instead of visiting the supermarket in person:

I haven't exercised, I need to, I need to sort of, um, break a lot of bad habits. I've eaten a lot more, as it were. I put, all the weight I lost I've put back on. (Male, White, <65 years)

However, a few participants increased physical activity during the pandemic. Although some of these individuals had been active pre-pandemic, some discovered new methods of exercise during the lockdown restrictions:

I brought a machine for exercise [during lockdown] and I do a lot of exercise, walking in and out in my place. So...yeah, I do a lot of exercise (Male, Black, <65 years)

3.3.2 | Social isolation

Social restrictions were reported as a salient factor that affected participants mental well-being.

'I think lockdown is a very bad idea actually. Uh because it leads to social isolation on the grand scale and I don't think that's healthy, certainly not good for me. I'm an outgoing, gregarious person, and sitting in this house on my own...um is not really...a very healthy thing to do.' (Male, White, >65 years)

Social isolation was worse during the autumn/winter months when the United Kingdom was in its third lockdown and travel restrictions were in place:

... September to December I was- I let things go and you know, when I let things go physically, I think mental and physical all connected... you gotta see that in the context of the life we have had to lead last year and the fact that, you know, a lot of the plans that we've made couldn't happen. You know I had several holidays that didn't happen. (Female, White, <65 years)

One participant made a direct link between fatigue (as a result of high blood glucose), lockdown measures restrictions, and feelings of loneliness:

I [suffer] a lot of mental health because you don't know if you can go out [during lockdown], my diabetes is high...Anything I do I'm tired, even I eat- when I eat something I will feel too sleepy...I'm eating every day so I do sleep...[it makes me feel] lonely, very lonely, very lonely. (Female, Black, <65 years)

4 | DISCUSSION

4.1 | Summary

This qualitative study aimed to describe the experiences of diabetes self care during the COVID-19 pandemic, in a purposively diverse group of people with type 2 diabetes from South London, UK. Three major themes were outlined: information needs of people with type 2 diabetes during the Covid-19 pandemic; concerns about Covid-19 from people with type 2 diabetes; and diabetes self management and well-being during the Covid-19 pandemic.

Participants' access to healthcare varied, from ease to extreme difficulty in contacting their GP during the pandemic. In our sample, most people with type 2 diabetes preferred face-to-face appointments but understood the need for telephone or online communication during the COVID-19 pandemic. For some, this was an opportunity to increase their digital literacy skills. UK-based¹⁹ and worldwide organisations (e.g. World Health Organization²⁰) are working towards improving digital literacy and reducing digital inequalities. During the pandemic, 'Healthwatch' conducted an analysis investigating the barriers to

accessing digital and remote care of people who were unable to access remote services.²¹ They outline suggestions for improving digital access in healthcare including respect for individual preferences, support programs to improve digital literacy, increasing access to digital resources (i.e. digital inclusion), and recording of digital literacy level on health records to enable appropriate communication and support. These suggestions and developments would be helpful for people with type 2 diabetes during a pandemic to ensure they have the support needed for optimal diabetes self management, especially in south London, which is socio-and-economically diverse, thus impacting access and skills using digital resources.

Many participants were concerned about the lack of diabetes-specific COVID-19 information and would have expected it to come from their healthcare professional. Interviewees displayed a trust in healthcare professionals. Although conducted pre-pandemic on a sample within the United States, this view is supported by Jackson et al. (2019)'s study that found the general public have high levels of trust for their healthcare professionals including accuracy of information.²² Therefore, during a pandemic, there would be an opportunity for healthcare professionals to provide information to people with type 2 diabetes to negate pandemic-related risk-perception, anxiety, and worry. Especially, as participants expressed distrust, negative mental health, and avoidance of information from the media. This was also observed in the 2003 SARS pandemic.²³ In the general population, Taha et al. (2014) found that negative mental health leads to increased threat appraisals and avoidant behaviours.²⁴ In our study, threat appraisals were communicated as concerns about other people not following government COVID-19 regulations, and avoidant behaviours such as avoiding public transport. During a pandemic, obtaining accurate information from official sources, e.g. from healthcare professionals, can increase an individual's awareness of preventative measures in the face of a novel virus. This consequently increases adoption of adaptive behaviours, such as social distancing, general hygiene and wearing face coverings.²⁵

There was a broad range of perceptions and concerns regarding COVID-19 risk. While many participants were aware of diabetes being an 'underlying health condition' that could place them at increased COVID-19 severity, many did not understand the reasons behind this. Other qualitative¹⁰ and cross-sectional survey data²⁶ report a similar discord between type 2 diabetes and COVID-19 severity risk perception. This ties in with the need for healthcare professionals providing diabetes-specific information and support during the pandemic.

In support of previous qualitative research of people with type 2 diabetes during the COVID-19 pandemic,⁷ we also found mixed experiences of engagement in lifestyle

behaviours such as physical activity. This demonstrates a need for (a) education from healthcare professionals to outline the association between maladaptive lifestyle behaviours long-term, increased glycaemic levels, and COVID-19 severity and (b) support in improving these lifestyle behaviours during a pandemic.

Within our sample, social isolation because of COVID-19 lockdowns were a challenge that impacted mental health. This corresponds to research conducted outside the United Kingdom, where pandemic-induced social isolation was associated with increased loneliness,²⁷ decreased quality of life²⁷ and worsening glycaemic levels.²⁸ With people with type 2 diabetes being more likely than the general population to experience mental health problems (such as depression),²⁹ social isolation during the pandemic amplifying negative mental health is a cause for concern.³⁰ This indicates a need to identify people with type 2 diabetes who are struggling with mental health to provide additional support during a pandemic lockdown, for example, through online peer support.

4.2 | Strengths and limitations

The present study is the first in the United Kingdom to qualitatively explore the needs, concerns and self-management experiences of people with type 2 diabetes during the COVID-19 pandemic. Even though purposive sampling is open to selection bias, the strength of this method was to promote generalisability i.e. the sample was comparable with the whole SOUL-D cohort in age, sex, ethnicity and depressive symptoms. Compared with the National Diabetes Audit 2021–2022 (<https://digital.nhs.uk/data-and-information/publications/statistical/national-diabetes-audit/core-q2-21-22/content-copy#>), our sample is similar to the type 2 diabetes UK population in regards to sex (Men: 59% versus 56%) and ethnicity (62% versus 70%). However, our sample was younger (<65 years; 79%) than the overall UK population (<65 years; 47%). While we aimed to sample a range of people with type 2 diabetes, that is, from mild to moderate risk of diabetes complications, most of our sample did not have depressive symptoms, existing complications or were not prescribed insulin therapy. Therefore, the majority were mild–moderate risk type 2 diabetes. Further research is required to fully understand the perspective of people with type 2 diabetes at high risk of or current diabetes complications.

It was evident during recruitment that many potential participants were unable to complete an online consent form and we may have missed out on views of those who struggled with digital literacy. We aimed to overcome this by posting consent forms ($n = 4$ completed postal), but

this was burdensome, and many participants did not respond. This limitation may have affected some of the findings as individuals who cannot access resources digitally maybe had restricted health access too. Due to the demand on health services, there was difficulty obtaining HbA_{1c} values of participants from GP surgeries (response of 59%). There may have been potential bias with one of the interviewers (LK) having met interviewees in a prior study, this was overcome by other interviewees listening to audio recordings and providing feedback.

5 | CONCLUSION

The findings in this study have several implications for public health and forthcoming research in the face of future pandemics and a new age of digital consulting. Firstly, there is a need for consistent, clear messages from healthcare professionals that offers diabetes-specific advice to promote preventative measure in the presence of a virus, encourage health-promoting behaviours (to prevent health decline during lockdowns), and mitigate concerns for people with type 2 diabetes regarding the pandemic. Despite our sample describing themselves as digitally literate, in accordance with the NHS long-term plan, better support for people with type 2 diabetes who have poor digital literacy or lack access to digital resources is essential. And finally, there is a need for further development of resources to alleviate experiences of social isolation, in people with type 2 diabetes who are already at increased risk of poor mental health.

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CONFLICT OF INTEREST

N/A.

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REFERENCES

- Holman N, Knighton P, Kar P, et al. Risk factors for COVID-19-related mortality in people with type 1 and type 2 diabetes in England: a population-based cohort study. *Lancet Diabetes Endocrinol.* 2020;8(10):823-833.
- Pal R, Bhadada SK. COVID-19 and diabetes mellitus: an unholy interaction of two pandemics. *Diabetes Metab Syndr Clin Res Rev.* 2020;14(4):513-517.
- NHSEngland. Preparedness letter for general practice: 14 April. Updates and Guidance for General Practice. Accessed July 7, 2021. <https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/C0264-GP-preparedness-letter-14-April-2020.pdf>
- Carr MJ, Wright AK, Leelarathna L, et al. Impact of COVID-19 on diagnoses, monitoring and mortality in people with type 2 diabetes: a UK-wide cohort study involving 14 million people in primary care. *Lancet Diabetes Endocrinol.* 2021;9(7):413-415.
- Grabia M, Markiewicz-Żukowska R, Puścion-Jakubik A, et al. The nutritional and health effects of the COVID-19 pandemic on patients with diabetes mellitus. *Nutrients.* 2020;12(10):3013.
- Ruiz-Roso MB, Knott-Torcal C, Matilla-Escalante DC, et al. COVID-19 lockdown and changes of the dietary pattern and physical activity habits in a cohort of patients with type 2 diabetes mellitus. *Nutrients.* 2020;12(8):2327.
- Grabowski D, Overgaard M, Meldgaard J, Johansen LB, Willaing I. Disrupted self-management and adaption to new diabetes routines: a qualitative study of how people with diabetes managed their illness during the COVID-19 lockdown. *Diabetology.* 2021;2(1):1-15.
- WHO. Mental health and psychosocial considerations during the COVID-19 outbreak. Last accessed 7th June 2021, <https://www.who.int/docs/default-source/coronaviruse/mental-health-considerations.pdf>
- Nouwen A, Winkley K, Twisk J, et al. Type 2 diabetes mellitus as a risk factor for the onset of depression: a systematic review and meta-analysis. *Diabetologia.* 2010;53(12):2480-2486.
- Grabowski D, Meldgaard J, Hulvej RM. Altered self-observations, unclear risk perceptions and changes in relational everyday life: a qualitative study of psychosocial life with diabetes during the COVID-19 lockdown. *Societies.* 2020;10(3):63.
- Winkley K, Thomas S, Sivaprasad S, et al. The clinical characteristics at diagnosis of type 2 diabetes in a multi-ethnic population: the South London diabetes cohort (SOUL-D). *Diabetologia.* 2013;56(6):1272-1281.
- Elkatawneh HH. The five qualitative approaches: problem, purpose, and questions/the role of theory in the five qualitative approaches/comparative case study. *SSRN Electron J.* 2016;1-18.
- Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care.* 2007;19(6):349-357.
- Kroenke K, Spitzer RL, Williams JB. The PHQ-9: validity of a brief depression severity measure. *J Gen Intern Med.* 2001;16(9):606-613.
- Caress A, Duxbury P, Woodcock A, et al. Exploring the needs, concerns and behaviours of people with existing respiratory conditions in relation to the H1N1'swine influenza'pandemic: a multicentre survey and qualitative study. *Health Technol Assess.* 2010;14(34 Article 1):1-108.
- Charmaz K. *Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis.* Sage; 2006.
- Edhlund B, McDougall A. *NVivo 12 Essentials.* Lulu Com; 2019.
- Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol.* 2006;3(2):77-101. doi:10.1191/1478088706qp0630a
- NHS. The NHS Long Term Plan. Accessed July 30, 2021. <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf>
- WHO. WHO guideline: recommendations on digital interventions for health system strengthening: evidence and recommendations. 2019.
- Healthwatch. Five principles for post-COVID-19 digital healthcare. Accessed July 30, 2021. <https://www.healthwatch.co.uk/news/2021-06-16/five-principles-post-covid-19-digital-healthcare>

22. Jackson DN, Peterson EB, Blake KD, Coa K, Chou W-YS. Americans' trust in health information sources: trends and sociodemographic predictors. *Am J Health Promot.* 2019;33(8):1187-1193.
23. Leung GM, Ho L-M, Chan SK, et al. Longitudinal assessment of community psychobehavioral responses during and after the 2003 outbreak of severe acute respiratory syndrome in Hong Kong. *Clin Infect Dis.* 2005;40(12):1713-1720.
24. Taha SA, Matheson K, Anisman H. H1N1 was not all that scary: uncertainty and stressor appraisals predict anxiety related to a coming viral threat. *Stress Health.* 2014;30(2):149-157.
25. Barry M, Al Amri M, Memish ZA. COVID-19 in the shadows of MERS-CoV in the Kingdom of Saudi Arabia. *J Epidemiol Global Health.* 2020;10(1):1.
26. Nachimuthu S, Vijayalakshmi R, Sudha M, Viswanathan V. Coping with diabetes during the COVID-19 lockdown in India: results of an online pilot survey. *Diabetes Metab Syndr Clin Res Rev.* 2020;14(4):579-582.
27. Madsen KP, Willaing I, Rod NH, Varga TV, Joensen LE. Psychosocial health in people with diabetes during the first three months of the COVID-19 pandemic in Denmark. *J Diabetes Complicat.* 2021;35(4):107858.
28. Fisher L, Polonsky W, Asuni A, Jolly Y, Hessler D. The early impact of the COVID-19 pandemic on adults with type 1 or type 2 diabetes: a national cohort study. *J Diabetes Complicat.* 2020;34(12):107748.
29. Ali S, Stone M, Peters J, Davies M, Khunti K. The prevalence of co-morbid depression in adults with type 2 diabetes: a systematic review and meta-analysis. *Diabet Med.* 2006;23(11):1165-1173.
30. Hillson R. COVID-19: psychological issues for people with diabetes and health care staff. *Pract Diabetes.* 2020;37(3):101-104.

SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

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