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Health and healthcare for people with disabilities in the UK during the COVID-19 pandemic

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Abstract

Background

While emerging evidence shows increased mortality from COVID-19 among people with disability, evidence regarding whether there are disability-related inequalities in health during the pandemic is lacking.

Objective

This study compares access to COVID-19 and non-COVID-19 related health care and mental health of people with and without disability.

Methods

Longitudinal analysis of 12,703 adults (16–64 years) who participated in W9 (2017–2019) and the April and/or May COVID-19 special surveys of the UK Understanding Society study. Descriptive analyses and Poisson regression (adjusted for age, gender, ethnicity and financial stress) were conducted to estimate associations between disability (measured at Wave 9) and a number of different COVID-19-related health and health care outcomes (COVID-19 symptoms, testing and hospitalisation), mental health and loneliness, and non-COVID-19 related health care (e.g. outpatient and inpatient hospital care, prescription medications).

Results

Results from the fully-adjusted regression models found that people with disability were more likely: to be hospitalised if symptomatic (adjusted PRR 3.0 95% 1.07–8.43); to experience current symptoms of psychological distress (PRR 1.15, 95% CI 1.05–1.26) and to report being lonely (PRR 1.75, 95% CI 1.46–2.09) compared to non-disabled people. People with disability reported much higher levels of comorbidities than people without disability. However, inability to access health care and treatment were similar.

Conclusions

As the UK opens up, it is important that health care services and social policy address the poor mental health and social isolation of people with disability so that the inequalities occurring early in the pandemic do not become further entrenched.

Keywords: COVID-19, Pandemic, Health care, Mental health

Despite the fact that 15% of the world's population have a disability, the needs of people with disability have been absent in many government pandemic responses. International agencies called for consideration of people with disabilities in COVID-19 pandemic responses, recognising their diverse and varied needs, and the fact that due to these needs, they are more likely to be exposed to SARS-CoV-2 and die if they become infected.[1], [2], [3] Some people with disability rely on paid workers to assist them with intimate tasks such as washing and feeding and therefore have close contact with many people. People with intellectual and developmental disabilities may not understand information regarding personal hygiene and physical distancing, especially if information is not available in Easy Read. Many people with disability also have chronic health problems such as heart and respiratory conditions[4, 5, 6, 7] that place them at higher risk of adverse health outcomes, including death, if they become infected with SARS-CoV-2. The WHO and UN recommend that information, testing, and health services, including life-saving treatments such as ventilators, are accessible to people with disability.[2, 3] When access to testing was constrained, some countries prioritised access to testing for people with disability and their paid workers to prevent spread of infection.[8]

Reports from the UK, particularly England, suggest that governments failed people with disability with high rates of deaths reported. People self-identified as needing a little or a lot of support in the English 2011 census represented 59.5% of all COVID-19 related deaths in England up to November 20, 2020 (compared to 17.2% of people in the population included in the analysis). Age-standardised death rates were 3.5 times higher for more disabled women and 2.0 times higher for less disabled women, and 3.1 times higher for more disabled men and 1.9 times higher for more disabled men.[9] Similar figures have been found for Scotland. [10] Also in England, estimates of the number of COVID-19 related deaths among people with intellectual disabilities vary from 1560 deaths up to June 4, 2021, to 2955 deaths up to November 20, 2020, with a much younger peak age of COVID-19 related death (55–64 years) than the general population.[9, 11, 12, 13, 14]

To date, there have been no UK studies, and few, if any, world-wide that compare people with and without disability in terms of the prevalence of symptoms associated with COVID-19 such as fever and cough; testing for SARS-CoV-2; and hospitalisation with COVID-19-like symptoms. It is important to note that we would not necessarily expect these rates to be equal among people with and without disability. For people with disability, who continued to rely on personal care attendants, rates of symptoms may be similar to non-disabled people if public health directives such as physical distancing and personal hygiene were followed and access to, and safe use of, personal protective equipment for personal care attendants occurred along with restrictions in the number of people with disability they support. However, if any one or more of these health protection measures were not optimally implemented, then we would anticipate higher rates among people with disability than people without disability because of their increased likelihood of exposure to SARS-CoV-2 and similar respiratory viruses.

In situations where people with disability stopped or reduced their use of personal care assistants, instead relying on family members for support, their risk of infection may have been reduced relative to the rest of the population. Further, if people with disability were given priority access to testing because of their increased risks, we would anticipate higher rates of testing among people with disability with symptoms than non-disabled people with symptoms. Finally, given many people with disability have chronic health conditions, we would expect a greater proportion of people with disability to be hospitalised, providing they were not deprioritised for tertiary care.

The COVID-19 pandemic is also likely to have impacted on the mental and physical health of people with disability. There are widespread reports of disruptions in access to prescription medicine, primary and hospital care which may have differential impacts on people with disability because they are more likely to rely on medicine and health care due to co-morbid health conditions. There is strong evidence emerging about the negative mental health consequences of COVID-19[15, 16, 17, 18] and some suggestion that these effects are more likely to affect disadvantaged groups[16] and people with pre-existing mental health problems.[19] There have also been reports of high levels of loneliness in the general population[20] which may be particularly deleterious for people with disabilities who were already more socially isolated pre-pandemic.[21, 22, 23] People with disability are more likely to be identified as at high risk of complications from COVID-19 due to respiratory and heart conditions and to be on the ‘NHS shielded patient list’[24] which recommends greater restrictions on social contact and movement, and may exacerbate loneliness and so lead to poorer mental health.[25] As noted recently in this journal, there is a lack of empirical research on the experiences of people with disability in COVID-19 with most publications being commentaries, opinion pieces or case reports. [26] However there is some research, mostly qualitative, that has shown that people with disability have experienced difficulties accessing COVID-19 tests, non-COVID medical care and direct support and report poor mental health during the COVID-19 pandemic.27, 28, 29

The overarching aim of this paper is to understand the health and health care experiences of people with disability during the early stages of the COVID-19 pandemic in the UK and to compare these experiences to people without disability. To do this, we draw on data from over 12,000 adults aged 16–64 years who participated in the special April and/or May 2020 COVID-19 waves of Understanding Society – the UK's primary national panel survey. To address our aim we compared the health and health care experiences of people with and without disability to answer three related research questions: 1) What was the prevalence of: COVID-19 outcomes (symptoms, testing and hospitalisations) among people with and without disability?; 2) Did access to non-COVID-19 related health care (e.g. difficulties accessing prescription medicine and general practitioners) vary between people with and without disability?; and 3) Did the frequency of mental health problems and loneliness differ between people with and without disability?

Methods

We conducted secondary analysis of data collected in Wave 9 and the April and May special COVID-19 surveys of *Understanding Society* (https://www.understandingsociety.ac.uk/). *Understanding Society* is an initiative funded by the Economic and Social Research Council (ESRC) and various Government Departments, with scientific leadership by the Institute for Social and Economic Research, University of Essex, and survey delivery by NatCen Social Research and Kantar Public. The research data are distributed by the UK Data Service. [30] Full details of the survey's development and methodology are available in a series of publications,31, 32, 33, 34 key aspects of which are summarised below.

Sampling and procedure

In the first wave of data collection (2009–2011), random sampling from the Postcode Address File in Great Britain and from the Land and Property Services Agency list of domestic properties in Northern Ireland identified 55,684 eligible UK households. At Wave 1, full face-to-face interviews were completed with 41,975 individuals aged 16–64 (individual response rate within participating households, 80%). At Wave 9 (W9: 2017–19), full interviews were completed with 27,359 individuals aged 16–64 (overall response rate 68%).[31, 32] New individuals enter *Understanding Society* if they: (a) are living in a participating household and attain the age of 16; or (b) become resident in a participating household. Individuals leave the survey if they: (a) no longer give consent to participate; (b) cannot be traced; or (c) move abroad.

In response to the outbreak of the global COVID-19 pandemic in early 2020, the ESRC and the Health Foundation funded *Understanding Society* to undertake a monthly online survey (backed up in some months with a telephone survey for households with no internet access) on the experiences and reactions of *Understanding Society* participants to the COVID-19 pandemic.[33] The first wave of the COVID-19 survey was undertaken in April 2020 and the second in May 2020, with field work undertaken by Ipsos MORI and Kantar.[33] All participants who engaged at least once in waves 8 to 10 were invited to participate in the COVID-19 survey. Among those who had given a full adult interview in W9 (the latest wave of data that are currently available), the response rate (including partial completion) for completion of either survey was 49%. Online questionnaires were completed by 12,703 adults aged 16–64 at the time of completion for whom valid disability data were available from Wave 9. Of these respondents, 9052 (71%) participated in April and May, 2817 (22%) participated only in April and 834 (7%) participated only in May.

Data collection for variables used in the present paper (W9 and the April and May COVID-19 surveys) was undertaken using a combination of computer-assisted personal interviewing, computer-assisted self-completion and online surveys.[31], [33], [34]

Measures

Disability

Disability was ascertained in W9 by an affirmative response to two questions.

- 1.

'*Do you have any long-standing physical or mental impairment, illness or disability? By 'long-standing' I mean anything that has troubled you over a period of at least* 12 months *or that is likely to trouble you over a period of at least* 12 months.'

- 2.

If respondents gave an affirmative response to the first question, they were asked '*Does this/Do these health problem(s) or disability(ies) mean that you have substantial difficulties with any of the following areas of your life?*' (12 response options; e.g., 'mobility', 'memory or ability to concentrate, learn or understand' and 'other').

Respondents who reported difficulties in one or more of these life areas were classified as having disability. Disability data were missing for 0.2% of respondents in W9.

Health and healthcare

Full details of the coding of all health variables are presented in Supplementary Table 1.

COVID-19 symptoms, testing and treatment

Survey items included four specific self-reported questions related to COVID-19 infection:

- 1.

Have you experienced symptoms that could be caused by coronavirus (COVID-19)?

- 2.

Are you currently experiencing symptoms that could be caused by coronavirus?

- 3.

Have you been tested for coronavirus?

- 4.

Have you been in hospital because of coronavirus symptoms?

Co-morbidities

Information was collected on the presence/absence of 21 specific long-term health conditions (e.g., asthma, obesity) and four types of existing treatments (medication following an organ transplant, medicines that weaken the immune system, targeted/chemotherapy for cancer treatment, radiotherapy for cancer treatment). In addition, information was collected on whether respondents had '*received a letter from the NHS or Chief Medical Officer saying that you have been identified as someone at risk of severe illness if you catch coronavirus, because you have an underlying disease or health condition'.* These are referred to as *NHS Shielded* patients.

Mental health and loneliness

The GHQ-12 is a widely used screening measure for current symptoms of psychological distress. The 12 items are rated on a four-point scale relating to the frequency or severity of the symptoms over the past few weeks in comparison with what is 'usual' for the respondent.[35], [36] We used the most common form of GHQ-12 scoring ('caseness') which recodes item scores of 1 and 2 to 0, and 3 and 4 to 1, and then sums scores across items to generate a scale with a range of 0 (low probability of current distress) to 12 (high probability of current distress). We used the most stringent of the commonly used cut-off points (4+) to create a binary measure of current distress (referred to as current psychological distress).

The online COVID-19 survey contained a single-item measure of loneliness: *How often do you feel lonely*? Response options were: *hardly ever or never, some of the time, often* which was recoded as a binary variable never/some of the time vs often. This item has recently been included in UK surveys as a headline indicator for the measurement of loneliness.[37]

Access to healthcare

Information was collected on whether 's*ince* January 1, *2020, have you had or been waiting for NHS treatment?'* (yes, tests/consultations planned or in progress; yes, operation or procedure planned; yes, targeted therapy, chemotherapy or radiotherapy planned or in progress; yes, other treatment; and no to all options). Each question was recoded as yes/no and those that answered yes to any of the above options, they were then asked whether *'your treatment plan(s) been changed in any way?'* (yes, consultations/treatment cancelled or postponed by NHS; yes, alternative treatment provided; yes, I cancelled or postponed treatment; no, treatment continued as planned; not required).

In addition, for respondents with one or more long-term health condition (listed above), information was collected on the extent to which respondents had *'been able to access the NHS services you need to help manage your* [health] *condition(s) over the last 4 weeks?'* with regard to: 1. GP or primary care practice staff; 2. prescription medicine; 3. hospital or clinic outpatient care; 4. hospital or clinic inpatient care; 5. NHS 111 in England, Wales and Northern Ireland or NHS 24 in Scotland; 6. local pharmacists for advice; 7. over the counter medications; 8. someone visiting you at home regularly to help with personal care/medications/shopping/cooking/cleaning/wound dressing/injections; 9. counselling or talking therapy. Response options were 'yes/no/not required' for all items with some items having additional options such as 'decided not to seek help/yes with reduced service'. These were recoded into binary variables: yes vs. no/decided not to seek help/yes with reduced service. Those who selected 'not required' were excluded from analyses of that outcome.

Covariates

Demographics

Information was collected on age, gender (male/female) and ethnicity (White UK/White other/Asian/Black/Mixed/Other).

Financial stress

Financial stress was included as a measure of socio-economic circumstances at Wave 9 and in the April COVID survey. Respondents were asked *'How well would you say you yourself are managing financially these days? Would you say you are... Living comfortably, Doing alright, Just about getting by, Finding it quite difficult, Finding it very difficult.'*

Ethics approval

Understanding Society is designed and conducted in accordance with the ESRC Research Ethics Framework. Ethics approval for Waves 9–11 was given via a letter dated October 4, 2016 from the University of Essex Ethics Committee. At that time a system of ethics approval numbers was not in place.

Analytic approach

The analytical sample comprised 12,703 respondents aged 16–64 at the time of the COVID-19 survey for whom valid disability data was available in the W9 sweep of *Understanding Society* and who participated in either the April or May COVID-19 surveys. Data were missing for <0.1% of the analytical sample for all variables related to COVID-19 symptoms and treatment, comorbidities and demographics. Data on healthcare access was missing for 1.4%, loneliness was missing for 3.1%, financial stress was missing for 6.8% and GHQ-12 data was missing for 10.5% of the analytical sample. Complete case analyses were undertaken in Stata 16 using the 'svy' routines to take account of the clustered sample design and sample weights released with the COVID-19 data to account for known biases in recruitment and retention. We first conducted descriptive analyses of the association between disability and covariates. Second, we compared the diagnoses of chronic conditions and use of treatments that might suppress immune function between people with and without disability to ascertain the extent to which people with disability have co-morbidities that make them more vulnerable if infected with SARS-CoV-2.

Third, we estimated the association between disability and health and health care outcomes using Poisson regression yielding prevalence rate ratios with 95% confidence intervals.[38] In Model 1, we adjusted for personal demographics (age, gender, ethnicity). In Model 2 we also adjusted for current socio-economic disadvantage using self-reported financial stress. In analyses of current psychological distress we adjusted for Wave 9 GHQ score and in analyses of loneliness we adjusted for loneliness reported at Wave 9.

For those participants who took part in both the April and May COVID-19 surveys we created variables for each outcome of interest (e.g., difficulty in accessing healthcare, often feeling lonely) based on the occurrence of the outcome in either April or May or both (versus the occurrence of the outcome in neither April nor May). For those that participated in only one wave – their response for only one wave was used. As a sensitivity analysis, we repeated all analyses for data collected in April only.

Given that 49% of participants in the Wave 9 survey did not respond to the April COVID-19 survey, we investigated whether disability status was associated with non-response. After controlling for key demographics (age, gender, ethnicity), living arrangements (single/couple/other) and indicators of socio-economic position (income poverty, self-assessed financial stress, household ownership of domestic assets, employment status, housing tenure), respondents with disability at W9 were slightly less likely to respond to the April COVID-19 survey (PRR = 0.95, 95%CI 0.91–1.00).

Results

Participant characteristics (Table 1)

Table 1

Characteristics of participants of COVID-19 surveys.

	With disability		**Without disability**	
	N	**% (95% CI)**	**N**	**% (95% CI)**
Gender				
Male	971	41.6% (38.1–45.2)	5062	48.8% (47.4–50.2)
Female	1363	58.4% (54.8–61.9)	5308	51.2% (49.8–52.6)
Age				
17–19	34	1.5% (0.9–2.5)	415	4.0% (3.4–4.8)
20–29	268	11.5% (9.2–14.2)	2385	23.0% (21.4–24.7)
30–39	408	17.5% (14.7–20.7)	1964	18.9% (17.7–20.3)
40–49	461	19.7% (17.1–22.7)	2157	20.8% (19.6–22.0)
50–59	713	30.6% (27.3–34.1)	2433	23.5% (22.3–24.7)
60–64	451	19.3% (16.5–22.5)	1017	9.8% (9.0–10.7)
Ethnicity				
White UK	2002	85.8% (82.6–88.4)	8692	83.9% (82.3–85.3)
White other	67	2.9% (2.0–4.2)	452	4.4% (3.7–5.1)
Asian	122	5.2% (3.7–7.4)	729	7.0% (5.9–8.4)
Black	74	3.2% (1.7–5.9)	232	2.2% (1.8–2.8)
Mixed	49	2.1% (1.4–3.1)	209	2.0% (1.5–2.7)
Other	21	0.9% (0.5–1.7)	50	0.5% (0.3–0.7)

	With disability		**Without disability**	
	N	**% (95% CI)**	**N**	**% (95% CI)**
Financial stress				
Living comfortably	255	11.6% (9.8–13.7)	2317	23.9% (22.5–25.3)
Doing alright	892	40.6% (36.4–44.7)	4505	46.4% (44.8–48.0)
Just about getting by	656	29.8% (26.4–33.5)	2072	21.3% (19.9–22.8)
Finding it quite difficult	216	9.8% (7.6–12.6)	630	6.5% (5.5–7.7)
Finding it very difficult	180	8.2% (6.2–10.8)	186	1.9% (1.5–2.4)

Notes.

N = weighted sample size.

% = weighted percentage.

17.4% (95% CI 16.4–18.4) of the sample were identified as having a disability at W9. Compared to people without disability, people with disability were more likely to be older, women, experiencing financial difficulty and classified as ‘White UK’.

Supplementary Table 2 shows the demographics for the Wave 9 and COVID-19 surveys in April and and May 2020. The proportion reporting disability, gender breakdown, age (accounting for the fact that Wave 9 was in 2017–2019) and ethnicity were almost identical across the surveys.

Long-term health conditions and current treatments (Table 2)

Table 2

Health Conditions and Current Treatments – Frequency among peope with and without disability and Poisson regression comparing people with disability to people without disability.

	Prevalence		
	With disability (n = 2317)	**Without disability (n = 10,281)**	**Adjusted Prevalence Rate Ratio**
Long-term health conditions			
Asthma 1	23.2% (20.1–26.7)	13.8% (12.8–14.9)	1.82 (1.55–2.13)

	Prevalence		
	With disability (n = 2317)	Without disability (n = 10,281)	Adjusted Prevalence Rate Ratio
Arthritis 2	24.4% (21.2–28.0)	3.8% (3.2–4.4)	4.69 (3.83–5.74)
Congestive heart failure 3	0.6% (0.3–1.3)	0.0% (0.0–0.1)	9.32 (3.83–22.71)
Coronary heart disease 4	1.4% (0.9–2.1)	0.7% (0.4–1.3)	2.37 (1.55–3.61)
Angina 5	2.2% (1.1–4.5)	0.2% (0.1–0.4)	4.66 (2.84–7.64)
Heart attack or myocardial infarction 6	1.7% (1.2–2.5)	0.5% (0.3–0.7)	3.20 (2.11–4.84)
Stroke 7	4.7% (2.9–7.5)	0.7% (0.4–1.3)	5.03 (2.24–11.28)
Emphysema 8	1.3% (0.5–3.7)	0.0% (0.0–0.2)	7.25 (2.69–19.53)
Chronic bronchitis 11	1.4% (0.5–4.2)	0.1% (0.0–0.3)	5.99 (2.96–12.16)
COPD (Chronic Obstructive Pulmonary Disease) 21	4.6% (2.9–7.1)	0.5% (0.4–0.7)	5.12 (3.57–7.34)
Hypothyroidism or an under-active thyroid 10	6.4% (5.0–8.2)	2.3% (2.0–2.7)	1.99 (1.64–2.42)
Any kind of liver condition 12	2.7% (1.5–4.9)	0.6% (0.4–0.9)	3.70 (2.55–5.39)
Cancer or malignancy 13	4.0% (3.1–5.2)	1.8% (1.5–2.1)	1.63 (1.20–2.21)
Diabetes 14	15.0% (12.5–17.8)	3.5% (2.9–4.1)	3.54 (2.76–4.54)
Epilepsy 15	3.7% (2.3–6.1)	0.9% (0.6–1.2)	4.24 (2.41–7.46)

	Prevalence		
	With disability (n = 2317)	Without disability (n = 10,281)	Adjusted Prevalence Rate Ratio
High blood pressure/hypertension 16	17.7% (15.0–20.8)	8.4% (7.7–9.2)	1.56 (1.31–1.86)
An emotional, nervous or psychiatric problem 22	17.4% (15.1–20.0)	3.9% (3.3–4.5)	4.44 (3.62–5.44)
Multiple Sclerosis 19	1.5% (1.0–2.3)	0.1% (0.0–0.2)	13.18 (6.95–25.02)
Chronic kidney disease 23	1.1% (0.7–2.0)	0.3% (0.2–0.4)	3.66 (1.77–7.56)
Conditions affecting the brain and nerves 24	2.5% (1.7–3.9)	0.3% (0.1–0.5)	12.25 (7.00–21.45)
Severely obese (having a BMI of 40 or above) 27	12.2% (9.8–15.1)	2.4% (1.9–3.0)	4.33 (3.18–5.89)
One or more long-term health condition	72.7% (69.5–75.7)	33.3% (31.8–34.8)	1.97 (1.85–2.09)
Current treatments			
Medication following an organ transplant	0.3% (0.2–0.7)	0.0% (0.0–0.2)	4.22 (0.94–19.97)
Medicines that weaken the immune system	5.7% (4.1–8.0)	0.5% (0.4–0.7)	10.85*** (6.57–17.93)
Targeted/chemotherapy for cancer treatment	0.5% (0.3–1.1)	0.2% (0.1–0.4)	2.69** (1.29–5.63)
Radiotherapy for cancer treatment	0.1% (0.0–0.9)	0.0% (0.0–0.1)	2.82 (0.34–23.38)
One or more of the above four immunosuppressive treatments	6.3% (4.6–8.5)	0.7% (0.6–1.0)	7.60*** (4.79–12.05)
One or more long-term health condition or one or more immunosuppressive treatments	73.6% (70.4–76.5)	33.4% (31.9–34.9)	1.99*** (1.87–2.11)

Note: Prevalence rate ratios adjusted for age group (as categorical variable), gender and ethnicity.

Respondents with disability were more likely than other respondents to report the presence of all long-term health conditions investigated. Notably, diabetes and respiratory and cardiac conditions were more common among people with disability and 12% of people with disability were severely obese compared with 2.4% of people without disability. Overall 73% of people with disability and 33% of those without a disability had at least one long-term health condition. People with disability were also more likely to be receiving medication following organ transplant, medicines that weaken the immune system, chemotherapy or radiotherapy (6.3% for people with disability compared to 0.7% for people without disability). 15.0% of participants with disability and 2.4% of participants without disability reported having been informed that they were *NHS Shielded* Patients.

COVID-19 symptoms, testing and treatment (Table 3)

Table 3

Health Outcomes by Disability status - Frequency among peope with and without disability and Poisson regression comparing people with disability to people without disability.

	Prevalence		**PRR**	
	With disability	**Without disability**	**Model 1**	**Model 2**
COVID-19	N = 2334	N = 10,368		
Has experienced or is currently experiencing symptoms that could be caused by COVID-19	15.9% (13.4–18.7)	14.3% (13.3–15.4)	1.12 (0.94–1.34)	1.13 (0.94–1.37)
Has been tested for coronavirus	4.5% (3.4–5.8)	4.3% (3.7–5.0)	1.07 (0.80–1.44)	1.13 (0.84–1.53)
If has experienced symptoms that could be caused by COVID-19 … …	N = 370	N = 1491		
has been tested for coronavirus	12.4% (8.1–18.6)	10.9% (8.8–13.3)	1.11 (0.70–1.76)	1.21 (0.76–1.91)
has been in hospital because of coronavirus symptoms	4.2% (2.0–8.7)	1.5% (0.8–2.9)	2.49 (0.90–6.91)	3.00 (1.07–8.43)*
Mental health	N = 2123	N = 9389		
Current psychological distress (GHQ)	53.8% (49.9–57.7)	37.0% (35.5–38.6)	1.27*** (1.17–1.39)	1.15** (1.05–1.26)
Loneliness	N = 2265	N = 10,095		

	Prevalence		PRR	
	With disability	Without disability	Model 1	Model 2
Often Lonely	26.1% (22.6–29.8)	10.7% (9.7–11.9)	1.92∗∗∗ (1.63–2.27)	1.75∗∗∗ (1.46–2.09)

Notes: ∗p < 0.05, ∗∗p < 0.01, ∗∗∗p < 0.001.

N: weighted N.

Model 1: for all outcomes adjusted for age (as categorical variable), gender, ethnicity (6 class summary). For GHQ also adjusted for W9 GHQ-12 score. For loneliness also adjusted for W9 loneliness score.

Model 2 also adjusted for financial stress most recent COVID-19 wave.

There was no statistical evidence to support an association between disability and report of symptoms consistent with COVID-19 (adjusted PRR 1.13, 95% CI 0.94–1.37) or to have been tested (adjusted PRR 1.13, 95% CI 0.84–1.53). However, respondents with disability were more likely than other respondents to have been hospitalised if they had experienced possible symptoms of COVID-19 (adjusted PRR = 3.00; 95% CI 1.07–8.43).

Mental health and loneliness (Table 3)

54% of people with disability reported current psychological distress compared with 37% of people without disability, an association which persisted in adjusted models (adjusted PRR 1.15, 95% CI 1.05–1.26). Loneliness was also more prevalent among people with disability (26%) than people without disability (11%) (adjusted PRR, 1.75%, 95% CI 1.46–2.09).

Difficulties accessing health care (Table 4)

Table 4

Access to healthcare - Frequency among peope with and without disability and Poisson regression comparing people with disability to people without disability.

	Prevalence		PRR	
	With disability	Without disability	Model 1	Model 2
	N = 2313	N = 10,258		
Since January 1, 2020 has been waiting for NHS treatment	41.8% (38.0–45.7)	15.1% (14.0–16.2)	2.54∗∗∗ (2.25–2.87)	2.41∗∗∗ (2.12–2.74)

	Prevalence		PRR	
	With disability	Without disability	Model 1	Model 2
	N = 939	N = 1453		
If waiting, has had treatment cancelled, postponed or altered	80.4% (75.4–84.6)	75.6% (72.2–78.7)	1.06 (0.98–1.13)	1.05 (0.97–1.13)
If waiting, cancelled treatment themselves	11.4% (8.6–15.0)	13.0% (10.6–15.8)	0.89 (0.63–1.26)	0.88 (0.59–1.30)
Cannot access of those with chronic conditions[a] … ….				
GP or primary care practice staff (Needed PWD: n = 1,390, 59.6% Needed others: n = 2,181, 21.0%)	28.8% (25.0–32.8)	29.5% (26.5–32.7)	1.00 (0.85–1.19)	0.98 (0.82–1.16)
Prescription medicine (Needed PWD: 1661 PWD, 71.2%; Needed others: 2,914, 28.1%)	4.6% (2.9–7.1)	5.0% (3.9–6.4)	0.95 (0.63–1.43)	0.86 (0.54–1.36)
Hospital or clinic outpatients (Needed PWD: n = 1,027, 44.0%; Needed others: n = 1,262, 12.2%)	54.7% (49.1–60.2)	52.2% (47.8–56.6)	1.05 (0.93–1.20)	1.05 (0.92–1.19)
Hospital or clinic inpatient (Needed PWD: n = 533, 22.8%; Needed others: n = 512, 4.9%)	66.7% (57.7–74.6)	66.0% (57.9–73.3)	1.00 (0.87–1.16)	0.98 (0.84–1.14)
NHS 111 or NHS 24 in Scotland (Needed PWD: n = 432, 18.5%; Needed others: n = 488, 4.7%)	14.9% (9.6–22.4)	9.4% (6.2–13.9)	1.47 (0.86–2.51)	1.22 (0.72–2.07)
Local pharmacists for advice (Needed PWD: n = 919, 39.4%; Needed others: n = 961, 9.3%)	27.2% (22.2–32.9)	19.7% (16.3–23.5)	1.35* (1.03–1.76)	1.22 (0.93–1.60)
Over the counter medications (Needed PWD: n = 1,167, 50.0%, Needed others: 1,720, 16.6%)	16.3% (11.9–21.9)	6.0% (4.5–8.1)	2.51*** (1.67–3.79)	2.42*** (1.58–3.72)
Home visiting regularly to help with care, medications etc. (Needed PWD: n = 439, 18.8%; Needed others: n = 201, 1.9%)	64.9% (53.7–74.6)	65.0% (49.7–77.7)	1.04 (0.80–1.34)	1.04 (0.78–1.38)

	Prevalence		PRR	
	With disability	Without disability	Model 1	Model 2
Counselling or talking therapy (Needed PWD: n = 498, 21.3%; Needed others: n = 458, 4.4%)	63.9% (56.1–71.0)	56.4% (47.8–64.7)	1.13 (0.94–1.36)	1.04 (0.86–1.26)

Model 1 adjusted for age group (as categorical variable), gender and ethnicity.

Model 2 also adjusted for current self-assessed financial situation.

[a]Excludes respondents who reported that they did not require this service.

42% of people with disability and 15% of people with disability were waiting for planned health interventions (PRR = 2.41, 95% CI 2.12–2.74). However, there was no evidence that people with disability were more or less likely to have planned interventions cancelled or changed following the onset of the COVID-19 lockdown period.

Even among people with and without disability with chronic conditions, those with disability needed access to services at a higher rate than people without disability. For example, 60% of people with disability required access to a GP, 71% needed to access prescription medicine, 39% wanted to access pharmacists for advice, 44% required outpatient visits compared with 21%, 28%, 9% and 12% for people without disability respectively. Of those that needed services, being unable to access services or treatments was common among people with and without disability. Nearly 30% of respondents reported being unable to access GPs; over 50% could not access outpatients; and around two thirds could not access inpatient treatment and home visits for help with care. Counselling was also inaccessible, with 64% of respondents with disability and 56% of respondents without disability reporting difficulties accessing counselling if they needed it. Difficulties accessing over the counter medications was more frequently reported by respondents with disability than those without (16% vs 6%, adjusted PRR 2.42, 95% CI 1.58–3.72).

Sensitivity analyses (Supplementary Tables 3 and 4)

Supplementary Table 2 shows the results of the analyses of symptoms and testing and treatment and mental health and loneliness using data from the April survey only. Unsurprisingly fewer people had been tested for SARS-CoV-2 in April than in April and May combined however the associations between disability and health care and mental health outcomes were consistent across both sets of analyses.

Supplementary Table 3 shows the results of analyses for access to health care services and treatments. Again a greater proportion of respondents reported requiring access to services or treatments using data from April and May combined (Table 4) than in April only however the associations between disability and service treatment access were similar.

Discussion

Summary and interpretation of findings

This paper presents new information about differences in the health and health care experiences of people with and without disability in the early stages of the COVID-19 pandemic in the UK. People with disability reported high-levels of co-morbidity from conditions such as diabetes and respiratory disease and were more likely to be classified as *NHS Shielded* patients. People with disability reported similar levels of COVID-19-like symptoms. Testing was low irrespective of whether or not someone had a disability. If symptomatic, people with disability were three times more likely to be hospitalised potentially due to their risk of complications and/or difficulties accessing care in the home. Worryingly, respondents with disability were more likely to report current psychological distress and were 75% more likely to report being lonely.

The low levels of testing among symptomatic people in this sample during the first wave of the pandemic is worrying, and particularly so for people with disabilities among whom only 12.4% of those with COVID-19 symptoms were tested. People with disabilities are more likely to have comorbidities that put them at greater risk of complications (reflected in the high prevalence of chronic conditions and treatments that suppress immunological function). Therefore, we might have expected to see higher prevalence of testing for people with disabilities.

By identifying the greater impact of COVID-19 on the mental health of disabled people, this paper extends previous research showing poor mental health during the early stages of the COVID-19 pandemic.[15, 16, 17, 18, 39] Our findings also illuminate the difficulties that respondents reported in accessing mental health services and the fact that many were not receiving the mental health support they required. These findings are concerning given the pre-existing mental health inequalities between disabled and non-disabled people (which were controlled for in the analyses),[4] and flag the potential that these mental health inequalities will be exacerbated by the COVID-19 pandemic.

In terms of non-COVID-19 related health care, similar proportions of people with and without disability who were awaiting treatment in the NHS, had their treatment cancelled or cancelled the treatment themselves. However, because of the higher proportion of disabled people waiting for planned health interventions (42% people with disability compared to 15% of people without disability), these issues affected people with disability disproportionately. Concerningly, being unable to access primary care, outpatients, hospital care and counselling were commonly reported, however, with a similar prevalence among respondents with and without disability with the exception of access to over the counter medications which was slightly more common among people with disability. Here too, because of the higher proportion of people with disability requiring these health services, a greater proportion of people with disability were affected by these difficulties.

A review of COVID-19 responses in social care in England in the second wave revealed that there were improvements in access to testing and had compared to the first wave and that people receiving social care were prioritised for vaccination however more information was available for older people living in residential care and less about people with disability in residential care or living in the community. Outcomes on mental health and health care use in the second wave was not reported.[40]

Strengths and limitations

The study has a number of limitations. Unfortunately, only half of the adult respondents in Wave 9 participated in either the April or May COVID-19 survey introducing potential selection bias. While respondents classified as having a disability in Wave 9 were only slightly less likely to participate in the COVID-19 surveys, it is possible that people with severe disabilities were even less likely to respond, and response bias may still occur if the associations between disability and health care and health outcomes were different among respondents and non-respondents. There was negligible missing data on disability and other covariates and for most outcome variables however the GHQ-12 had 10% missing data which may also introduce selection bias in an unknown direction. Only 71% of respondents participated in both waves, so estimates of the prevalence of outcomes will be an underestimate of the outcomes of both April and May, however our sensitivity analyses of the April survey showed estimates of the associations between disability and the health care and mental health outcomes were similar to that of the combined analyses of April and May. Another limitation of *Understanding Society* is that it is limited to people living in private homes and thus excludes those living in congregate settings. People with disability in these settings have already been heavily impacted by COVID-19[9], [10] so it is likely the problems we have identified will be worse in this group. Further, the survey is likely to under-represent people with learning disability and it is possible they experienced more difficulties during COVID-19 than people with other disabilities.

The study also has a number of strengths. Understanding Society is one of the few longitudinal studies worldwide that has data on participants both prior to and subsequent to the onset of the COVID-19 pandemic. Most studies of the impacts of COVID-19 have been cross-sectional raising the possibility of reverse causation and increasing the likelihood of differential and/or dependent misclassification where effect estimates may be biased away from the null in an unknown direction. [31]

Recommendations for policy and future research

In terms of policy and practice, given that people with disability were more likely to experience symptoms of psychological distress and loneliness even after adjusting for prior mental health, it is important that targeted mental health interventions are developed to ensure that these problems do not become further entrenched. Active outreach to reduce the impact of social isolation on the mental health may be required. We also note that people with disability were no more likely to be tested for COVID-19 despite the fact that overall they are more likely to be exposed to COVID-19 and experience more deleterious outcomes if they are infected. As testing for COVID-19 is now more widely available, it is important that testing sites are accessible and in-home testing is offered when people are unable to attend testing sites. Finally, the lack of access to inpatient and outpatient care is troubling particularly given the high levels of co-morbidity people with disability experience. If the trends reported in this early stage of the pandemic have continued, the gap between the health of people with and without disability will widen.

In terms of future research, we suggest ongoing monitoring of health care access and the health care and mental health outcomes of people with disability to ensure that policy and practice is appropriately targeted. In addition to longitudinal studies, qualitative studies are required to provide in-depth insights into the experiences of people with disability. Building solutions to addressing the problems we have identified will require close collaboration between government, people with disability and their supporters, health services and clinicians.

Data availability

The data used in this article were provided by the UK Data Service under licence. Additional derived variables will be shared on request to the corresponding author with permission of the UK Data Service.

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Conflicts of interest

There are no other conflicts of interest.

Footnotes

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