


BMJ Open Perceptions of the impact of COVID-19 on healthcare communication in a nationally representative cross-sectional survey of family caregivers

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ABSTRACT

Objective To understand the perceptions of the impact of the COVID-19 pandemic on healthcare communication with family caregivers.

Design Nationally representative survey.

Setting USA (national).

Participants 340 family caregivers, demographically representative of the US population by race/ethnicity.

Primary outcome measures Communication outcomes (feeling involved by the provider, feeling involved by the care recipient, feeling more encouraged to be involved in care, feeling contributory to discussions, feeling questions are being answered), behavioural/wellness outcomes (feeling anxious, feeling isolated, feeling it is easier to attend the clinic visit), and desire to continue using telemedicine.

Results Having less than a college degree was associated with decreased odds of feeling involved by the provider (OR 0.46; 95% CI 0.26 to 0.83; $p=0.01$), feeling involved by the care recipient (OR 0.44; 95% CI 0.24 to 0.79; $p=0.01$), feeling more encouraged to be involved in care (OR 0.49; 95% CI 0.27 to 0.86; $p=0.01$), feeling like they contribute to discussions (OR 0.45; 95% CI 0.25 to 0.82; $p=0.01$) and feeling like their questions are being answered (OR 0.33; 95% CI 0.18 to 0.60; $p<0.001$).

Conclusion In our sample, the shift to telemedicine during COVID-19 was well received but caregivers of low educational attainment reported poorer health communication, and a greater proportion of black/African American and Hispanic caregivers reported a desire to return to in-person visits. There is an opportunity to improve health systems and increase equity as telemedicine becomes more widespread.

BACKGROUND AND OBJECTIVES

Since the coronavirus (COVID-19) pandemic emerged in early 2020, the US healthcare system has undergone drastic changes in care delivery that have impacted how the nation's 53 million family caregivers provide home-based care to adults with chronic illness and disability.¹ While caregiving is commonly reported to be a positive experience, it is also associated with anxiety and depression,

Strengths and limitations of this study

- We conducted a national, demographically representative survey that occurred following the first surge of the COVID-19 pandemic.
- We used a hybrid sampling method of social media and internet-based recruiting that may have excluded those who do not use or do not have access to the internet.
- There is a risk of recall bias as caregivers were asked to reflect on behaviour and wellness experiences prior to the COVID-19 pandemic.

financial distress, poorer health and social isolation.²⁻³ Caregiver burden is significant: it is estimated that the financial costs of informal caregiving exceed \$500 billion, and caregiver burden is connected with negative health outcomes for patients and caregivers.⁴ High burden is connected with an increased risk of institutionalisation.⁵⁻⁶ These stresses have been further compounded by the emergence of the COVID-19 pandemic,⁷⁻⁹ where in one Center for Disease Control report, one in three caregivers had endorsed thoughts of suicide.¹⁰ Caregivers have also reported higher levels of burden and anxiety relative to pre-pandemic times, particularly among caregivers of high-burden conditions.¹¹⁻¹³

Caregivers play a central role in communicating and acting as a patient advocate during medical visits through the provision of logistical assistance, informational support and emotional support for patients.¹⁴ Quality communication with caregivers is critical to better health-related outcomes for the care recipient, through greater caregiver preparedness, and it is also associated with reduced caregiver burden and stress.^{3 14 15} Prior studies have shown that higher caregiver preparedness can lower caregiver burden: one study of 78 patient-caregiver dyads found



that when caregiver preparedness was low, caregivers experienced higher burden than when preparedness was high.^{16 17} Communication between caregivers, patients and providers is important for caregivers to effectively prepare and provide care. The Organizing Framework for Caregiver Interventions identifies four main caregiver activities that can affect caregiver and patient outcomes: clinical knowledge, psychological skills, support seeking and quantity of caregiving.¹⁸ Communication during the clinic visit is important to clinical knowledge and psychological well-being.^{19 20}

There are known differences in how caregivers of various demographic groups experience communication during caregiving: higher educational attainment has been associated with asking more questions, taking more notes and being more actively engaged in the exchange of healthcare information during clinic visits, while cultural and linguistic differences can result in miscommunication.^{21–23} Race and ethnicity are also important factors for the caregiving experience: lower healthcare communication quality has been reported by caregivers from black/African American and Hispanic/Latinx communities.^{14 24 25} Black/African American and Hispanic/Latinx caregivers have benefited from culturally appropriate interventions like the inclusion of language translators during visits and cultural sensitivity training for providers, which improves communication quality.^{26 27} Caregiver-reported burden also differs significantly among racial and ethnic groups when caring for similar conditions; relative to white caregivers, black/African American caregivers have reported lower burden, while Hispanic/Latinx caregivers have reported higher burden.^{27–31} These differences occur due to disparate service utilisation, cultural context around the expectations of the caregiving role, and styles of communication and coping.^{32 33}

Prior to the COVID-19 pandemic, most communication of healthcare information from providers was conducted in person rather than via telemedicine.³⁴ Racial and ethnic communities, as well as rural caregivers, have historically used telemedicine at lower rates than non-minority or urban caregivers.³⁵ There is also some evidence that these communities prefer in-person care: one study of 10 focus groups including 77 African American and Hispanic/Latinx patients found that 36% of inner-city African American and Latinx patients were uncomfortable using telemedicine technology, and 17% did not want facial pictures taken.^{35–37} The COVID-19 pandemic and related restrictions led to a rapid shift towards telehealth-focused and telemedicine-focused solutions in the early months of the pandemic.³⁸ However, during the COVID-19 pandemic, a probability-based panel survey study of 10 624 US adults found that patients who identify as black were more likely to use telehealth than white patients, particularly when they perceived the pandemic to be a minor threat to their health.³⁹ Rurality is also important to service utilisation during COVID-19: an analysis of telehealth utilisation of 7742 patients from a single academic medical centre in the USA found that patients in rural areas were

less likely to use telehealth.⁴⁰ Early reports suggest that the shift to telemedicine has been especially difficult for family caregivers. Normal caregiving routines have been disrupted, caregivers are more isolated and caregivers have found difficulty using telemedicine technology.⁸ Literature focusing on family caregiver experience has also found that caregivers of minority backgrounds and those with lower educational attainment could be experiencing greater negative pandemic-related outcomes due to increased isolation and increased pandemic-related stress.^{8 35 36}

The preponderance of research on healthcare communication with caregivers and its impact on caregiver behaviour, defined as the actions that caregivers take during their caregiving role, and well-being, defined as the wellness outcomes of caregivers, that is, anxiety and sense of isolation is based on traditional in-person visits.⁴¹ Anxiety and sense of isolation are important metrics of caregiver wellness that have been recognised in national surveys including Caregiving in the US 2020 and the Family and Caregiver Experiences Survey.^{1 42} Little is known about the experience or effect of caregivers communicating with providers during the COVID-19 pandemic with the shift to telemedicine, or their desire to continue to use telemedicine after COVID-19 pandemic restrictions have eased.^{43–47} The aim of this project was to explore how caregivers are interacting with clinic visit communication through the research question ‘How do caregivers perceive the COVID-19 pandemic has impacted (1) their experience of communication during clinic visits, (2) caregiving activities and (3) caregiver wellness?’ We hypothesised that caregivers would experience differences in communication and wellness during the pandemic, and that those differences would vary based on race and ethnicity.

RESEARCH DESIGN AND METHODS

Study design

We conducted a cross-sectional online survey of adult family caregivers in the USA, caring for patients with any condition. We recruited caregivers from June to August 2020. After viewing and acknowledging an information and consent page, English-speaking adults (18 years or older) who lived in the USA and who self-identified as being ‘the individual most responsible for caring for the health of another adult (18 years or older)’ were eligible for the study. This study followed the Checklist for Reporting the Results of Internet E-Surveys (online supplemental file A).

Survey development and design

The survey was developed in consultation with the Open Recordings group, an established stakeholder group of researchers, physicians, patients and caregivers at Dartmouth College, and the National Alliance for Caregiving (NAC). The survey was pilot-tested and refined based on feedback from a six-member NAC caregiver panel.

The survey began by asking about caregiver demographics (age, gender, self-identified race/ethnicity), caregiving experience (hours caregiving per week, length of time as a caregiver, patient comorbidity) and caregiver experiences with clinic visit communication (what methods they use and with what frequency). Respondents were asked to reflect on their 'usual caregiving experience' and then completed three validated scales: the Preparedness for Caregiving Scale (an 8-item scale measuring perceived preparedness for physical and emotional aspects of caregiving, with scores ranging from 0 to 32, higher scores indicating higher preparedness),⁴⁸ the Burden Scale for Family Caregivers–Short-Form (a 10-item scale measuring level of perceived caregiver burden, with scores ranging from 0 to 30, higher scores indicating higher levels of burden),⁴⁹ and the Positive Aspects of Caregiving Scale (a 9-item scale measuring how positive a caregiver feels about their caregiving, with scores ranging from 9 to 45, higher scores indicating higher positivity).⁵⁰ We wanted to accurately measure caregiver preparedness, burden and positivity, and these scales have been psychometrically validated in caregiving populations.^{51–53} These three dimensions make up a large part of the caregiver experience: how they feel about their caregiving, how prepared they feel to be a caregiver, and how the effect that their caregiving has on their health and well-being. In addition to being clinically relevant, these scales capture constructs in the survey. The Burden Scale for Family Caregivers measures the overall stress of the caregiving situation and has been connected to greater isolation⁵¹; the Preparedness for Caregiving Scale has been linked with health outcomes such as anxiety⁵²; and caregivers with higher Positive Aspects of Caregiving scores report higher relationship quality through improved communication with the person receiving care.⁵⁴

Prior to survey launch, COVID-19 emerged as a pandemic. In order to use this opportunity to identify caregiver experiences, we developed an additional survey section on how caregivers feel the COVID-19 pandemic has impacted their experience of caregiving. Items were developed by considering relevant domains around caregiver health communication, caregiver behaviour and caregiver wellness, which were informed by our research team's work in understanding how information is communicated to caregiving populations, including a systematic review of communication interventions,⁵⁵ as well as seminal caregiving surveys including the Caregiving in the US 2020 Study and the Family and Caregiver Experiences Study.^{1 42}

We asked 10 Likert-style questions with answers including: strongly disagree, disagree, neither agree nor disagree, agree and strongly agree. Questions covered two domains: caregiver communication and caregiver behaviour/wellness. The section with COVID-19 questions asked caregivers to consider how the COVID-19 pandemic has impacted their visit communication (regardless of whether the visit was in person or telehealth), their

behaviour and their wellness, and the questions on caregiver wellness were explicit in their comparison with pre-pandemic caregiving. Participants were asked whether they had attended a telemedicine visit as a caregiver, and all participants were asked whether they would like to continue using telemedicine after pandemic restrictions are eased, regardless of whether they had a telemedicine visit as a caregiver. The intent was to understand if caregivers, regardless of telemedicine status, would consider this strategy in the future (see [figure 1](#) for more information).

To ensure completeness, all questions were forced response, though respondents were reminded they could opt out of the survey at any time by closing their webpage. Participants viewed 31–36 questions, depending on their answer selections; if respondents did not have a telemedicine visit, they received no questions on telemedicine visits. There was no 'back' button. We excluded 'speeders', respondents who completed the survey under half the piloted median time to completion.⁵⁶ Surveys were analysed if they completed more than 97% of questions, which indicated they reached the final page of the survey. Finally, we used the 'Ballot Box Stuffing' feature in Qualtrics to ensure an individual only took the survey once, though we allowed respondents to resume responses up to 1 week after starting the survey.

The full survey can be found in online supplemental file B.

Patient and public involvement

The development of the research question and outcome measures were developed in consultation with patients, caregivers and advocacy organisations. Patients and caregivers were involved in the survey design and actively contributed in development meetings and during the survey pilot. While patient and caregiver partners will be sent a copy of the published survey, respondents were anonymous, and will thus not receive direct dissemination of survey results.

Survey administration

We distributed the survey with the NAC, a national organisation involved in conducting policy analysis and tracking legislation relating to family caregiving issues. The survey was distributed as a voluntary link through the NAC's newsletter and social media accounts on 1 June 2020. After analysing the demographic characteristics of our initial sample, on 27 July 2020, we added an additional group of caregivers based on caregiver race/ethnicity to mimic the demographic profile of known racial and ethnic demographics of US caregivers as described in the 2020 Caregiving in the US Report, which is distinct from the NAC membership and was collected by the NAC and AARP using KnowledgePanel's probabilistic sampling to estimate the prevalence of caregiving for US populations and households. The additional sample was collected through Qualtrics Panels, an online survey platform which draws a broad demographic of participants.⁵⁷

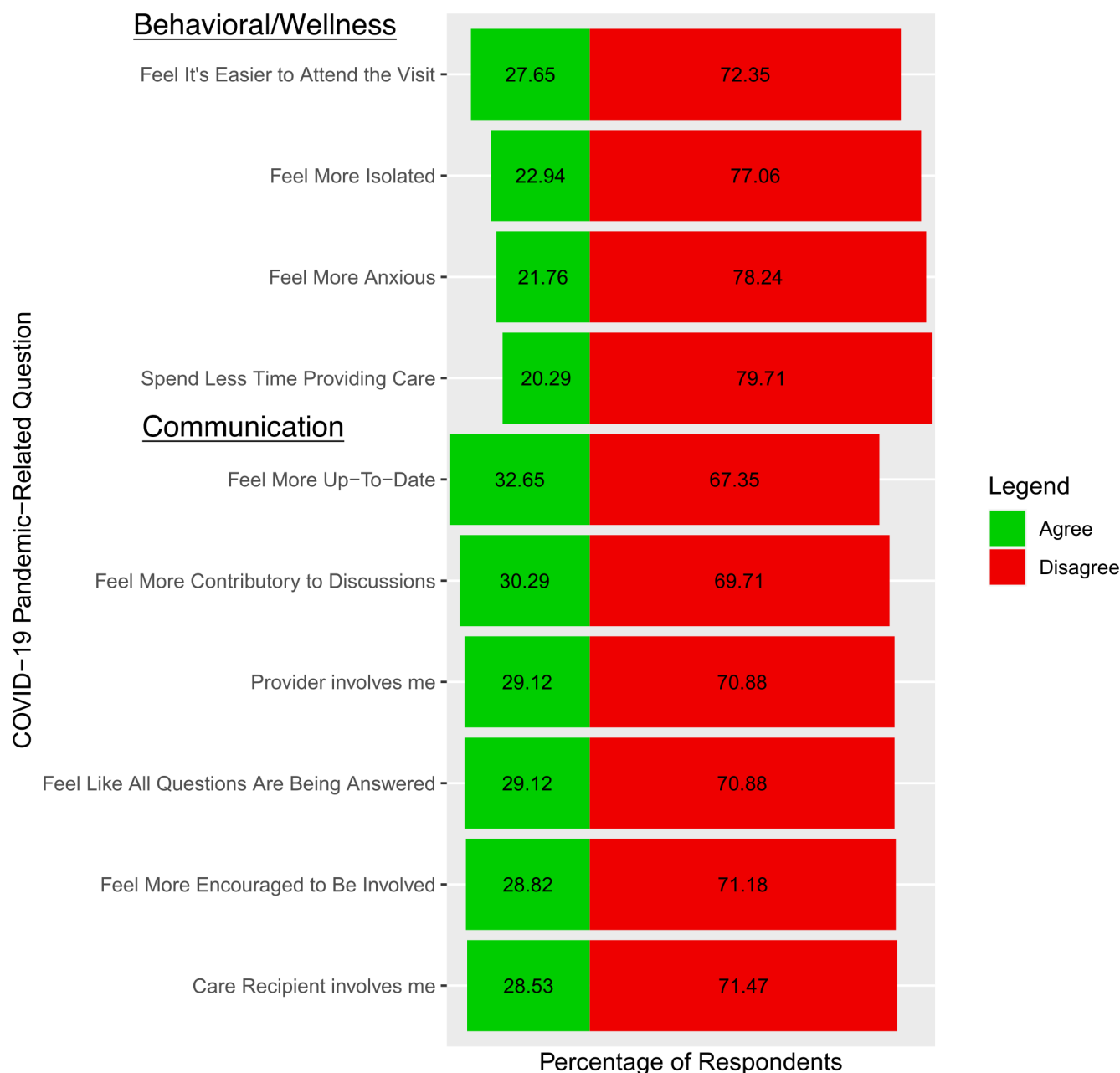


Figure 1 Caregiver communication outcomes, including percentage who agreed/disagreed with the statement on the y-axis for their experience during the COVID-19 pandemic.

Exploratory analysis

Descriptive statistics including means (SDs) and percentages (ranges) were used to describe demographic characteristics of the respondents. Only two participants selected multiple racial categories: these participants were grouped with those who selected 'Other' for analytical purposes. While we included race in the model as a factor to explore differences in hopes of highlighting disparities, we ultimately view race as a construct and find it reasonable that differences may appear due to formal and informal policies that stem from inequality, discrimination, oppression and exclusion.⁵⁸ Caregiver burden, caregiver preparedness, and caregiver positivity were dichotomised as high or low based on previously established cut-offs: a score greater than or equal

to 15 on the Burden Scale for Family Caregivers–Short-Form indicating high burden, a score of 20 or higher on the Preparedness for Caregiving Scale indicating high preparedness, and a score of 35 or higher on the Positive Aspects of Caregiving Scale indicating high positivity.^{17 59 60} Rurality was determined by converting participant zip codes into Rural Urban Commuting Area codes according to the US Department of Agriculture and further dichotomised based on guidelines developed by the University of Washington's Rural Health Research Center.⁶¹ COVID-19-related outcomes were dichotomised according to the top box scoring method used by Press Ganey.^{62 63}

Ten logistic regression models (see figure 2) were used to examine the association between sociodemographic

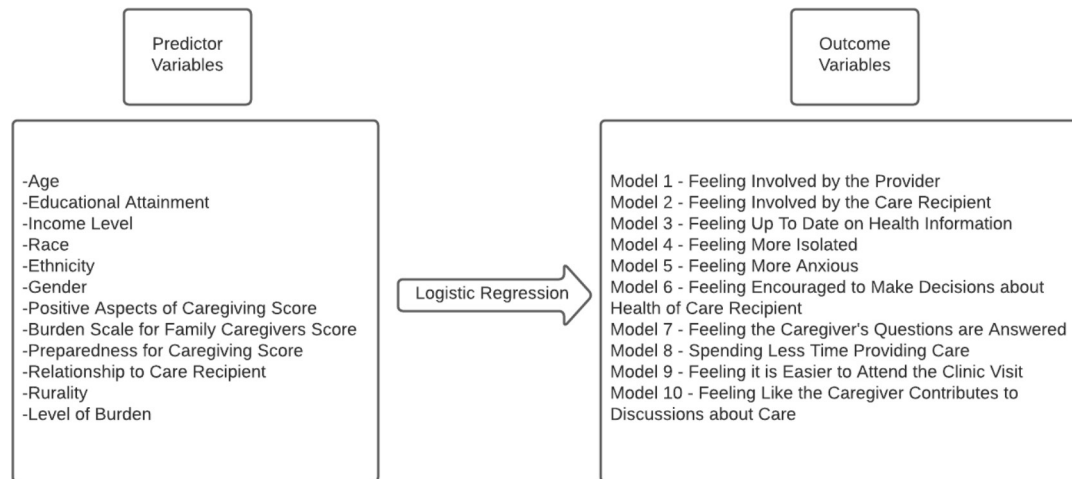


Figure 2 Visual representation of the regression modelling.

data, relationship to the caregiver, comorbidity, rurality and caregiver burden, with COVID-19 pandemic-related outcomes. Referent categories were white race, non-Hispanic ethnicity, male gender, income of >\$100 000 and college educated. Regression modelling included participants who had not participated in a telemedicine visit as a caregiver, as the COVID-19 pandemic restrictions may have affected their caregiving in different ways; we found no statistically significant differences between caregivers who had attended a telemedicine visit as a caregiver, and those who did not.

Resulting ORs were then converted to predictive probabilities using marginal standardisation, where the predicted probabilities (PPs) of each covariate are weighted by their relative frequencies.⁶⁴ All models were tested for potential collinearity between variables at a variance inflation factor of 5.0.^{65 66} Statistical analyses were conducted in R V.4.0.3 (Boston, Massachusetts, USA). While our purpose was to describe our quantitative results, rather than report generalisable or confirmatory findings, a predefined alpha level of 0.05 or less was chosen for statistical significance.

Prior to running our regression models, we determined that the data were adequately structured to accurately capture regression coefficients by confirming that there were at least five subjects per variable.⁶⁷ In determining whether this study is adequately powered to detect statistical significance, we based our calculation on the validated measures: caregiver burden, caregiver preparedness and caregiver positivity. In order to reach 95% power to estimate the true population mean of caregiver burden within ± 0.9 points (scale 0–30), caregiver preparedness within 0.8 points (scale 0–32) and caregiver positivity within ± 0.7 points (scale 9–45), we would need a sample size of 290.

Qualitative analysis

The survey included a single open response item: ‘Will you use telemedicine after the COVID-19 pandemic restrictions are eased?’ A content analysis was conducted

where two researchers coded the first 30 responses independently, then met to confirm concordance and discuss the codebook.⁶⁸ Once the codebook was determined, each reviewer coded the remaining responses. Upon completion, the researchers met to discuss any discrepancies.

RESULTS

The NAC newsletter survey section was seen by 449 individuals, while the social media post received 676 unique views. There were 113 respondents who completed the survey after having seen the survey link. Through Qualtrics, we received 227 respondents, but data on ‘views’ of the survey advertisement were unavailable. This resulted in a total of 340 respondents (see [table 1](#) for more information on participant characteristics, and online supplemental file C for participant flow).

Descriptive results

Demographics

The 340 respondents were primarily male (58.3%, n=198) and white (59.7%, n=202), and most performed between 1 and 3 hours of caregiving-related tasks per day (40.6%, n=138). Mean age of respondents was 40.3 years old (SD 13.9), and most caregivers cared for a parent/grandparent (57.4%, n=195) or a spouse/partner (30.5%, n=103). Most caregivers had been providing care to an individual for more than 1 year (60.7%, n=206), and most were urban residents (88.1% n=299) rather than rural. Rural and urban caregivers had a similar breakdown of race/ethnicity. Most caregivers (62.4%, n=212) cared for people with single condition, while 38.5% (n=131) cared for people with two or more comorbid conditions: diabetes (26.2%, n=89) and dementia (20.3%, n=69) were most common. A greater portion of Hispanic/Latinx (41.2%, n=140) and black/African American caregivers (40.7%, n=138) cared for patients with comorbidities than white caregivers (31.4%, n=107). The mean Preparedness for Caregiving Scale score was 23.34 (SD 6.22), while the mean Caregiver Burden Scale score was 17.48 (SD 7.65)

Table 1 Participant characteristics

	Total (N=340)
Age	
Mean (SD)	40.3 (13.9)
Range	18–85
Gender	
Male	199 (58%)
Female	141 (42%)
Race/ethnicity	
White	203 (59.7%)
Asian	42 (12.4%)
Black or African American	42 (12.4%)
Other	12 (3.5%)
Hispanic	41 (12.1%)
Education	
College degree	129 (37.9%)
Less than college	69 (20.3%)
More than college	142 (41.8%)
Income	
\$100 000 or more	127 (37.4%)
<\$50 000	91 (26.8%)
\$50 000–\$99 999	122 (35.9%)
Rurality	
Rural	54 (15.9%)
Urban	286 (84.1%)
Attended a telemedicine visit with Care Recipient during COVID-19	
No	117 (34.4%)
Yes	223 (65.6%)
Would like to use telemedicine post-COVID-19	
No	101 (29.7%)
Yes	239 (70.3%)
Care for >1 condition	
No	210 (61.7%)
Yes	130 (38.2%)
Preparedness for Caregiving Scale score (32 high)	
Mean (SD)	23.341 (6.221)
Range	0.000–32.000
Caregiver Burden Scale score (30 high)	
Mean (SD)	17.482 (7.651)
Range	0.000–30.000
Positive Aspects of Caregiving Scale score (45 high)	
Mean (SD)	35.671 (7.586)
Range	9.000–45.000

CR, care recipient.

and the mean Positive Aspects of Caregiving Scale score was 35.67 (SD 7.59).

Respondents' racial and ethnic demographics approximated those of the Caregiving in the US 2020 Report. Each racial and ethnic demographic group in our sample

was within 1 percentage point of the demographics of Caregiving in the US 2020; for instance, the Caregiving in the US Report had a sample that was 12.6% black/African American, while our sample was 12.4% black/African American. Full racial and ethnic demographic information can be found in [table 1](#).

COVID-19 pandemic-related outcomes

When considering outcomes related to caregiving during the COVID-19 pandemic compared with pre-pandemic, most respondents thought the provider had made an effort to involve them in the care process (68.5%, n=233). Caregivers felt more isolated (58.5%, n=199) and more anxious about providing care (53.7%, n=183) during the COVID-19 pandemic. Less than half of respondents (47.4%, n=161) felt they spent less time providing care, while 60.0% (n=204) felt that it was easier to attend a clinical visit (either telehealth or in person) (see [table 1](#) for more information).

Telemedicine use during the COVID-19 pandemic

When asked if they would continue using telemedicine after pandemic restrictions are eased, 239 (70.3%) participants wanted to continue to use telemedicine. Similar proportions of rural (72%, n=172) and urban (69.3%, n=166) respondents wanted to continue using telemedicine. While the majority of caregivers from any racial or ethnic group preferred telemedicine, a smaller proportion of Hispanic/Latinx caregivers (51.3%, n=22) and black/African American caregivers (64.2%, n=26) expressed a desire to continue using telemedicine, compared with white caregivers (76.1%, n=154). Overall, 101 respondents (29.7%) indicated a desire to return to in-person visits. A majority of respondents reported attending a telemedicine visit with their care recipient during the COVID-19 pandemic (65.6%, n=223). White caregivers had the highest proportion of telehealth visits (69.2%, n=140) compared with Hispanic/Latinx (52.1%, n=23), Asian (61.9%, n=31) and black/African American (66%, n=28) caregivers.

Statistical analysis

Due to the number of models, we have chosen to only report the adjusted regression models in the paper (unadjusted analyses can be found in online supplemental file D). Fully adjusted models can be found in [table 2](#). Caregiver preparedness and caregiver positivity were excluded from the models due to collinearity with caregiver burden; we included burden in the model to see the effect on our outcome variables when controlling for level of caregiver burden, which we believed was more sensitive to change based on restrictions imposed during the pandemic.

Fully adjusted statistical exploratory analysis

Fully adjusted exploratory analysis controlled for age, gender, education, race/ethnicity, relationship to caregiver, comorbidity, rurality and burden.

Table 2 Adjusted regression model (predicted probabilities and 95% CIs)

	Provider involves me		Care recipient involves me		Feel up to date		Feel isolated	
	Predicted probability	95% CI	Predicted probability	95% CI	Predicted probability	95% CI	Predicted probability	95% CI
Age								
<35 (referent)								
35–64	6%	–6% to 17%	5%	–7% to 16%	3%	–8% to 15%	12%*	2% to 23%
65+	14%	–8% to 35%	1%	–18% to 21%	18%	–5% to 41%	–5%	–20% to 1%
Caring for comorbidities	–2%	–12% to 9%	6%	–4% to 17%	3%	–8% to 14%	2%	–8% to 11%
Education								
More than college (referent)								
College degree or less	–15%**	–27% to –4%	–15%**	–27% to –5%	–6%	–18% to 5%	–7%	–17% to 4%
Female gender	–2%	–12% to 9%	7%	–4% to 17%	1%	–11% to 12%	–8%	–18% to 1%
High burden	–1%	–12% to 1%	7%	–4% to 17%	–3%	–15% to 8%	9%*	0% to 19%
Race								
White (referent)								
Asian	2%	–16% to 19%	8%	–9% to 25%	–6%	–23% to 11%	3%	–12% to 19%
Black/African American	–7%	–24% to 1%	–5%	–21% to 11%	–14%	–3% to 1%	2%	–14% to 17%
Ethnicity								
Non-Hispanic (referent)								
Hispanic	–20%***	–33% to –7%	–2%	–17% to 14%	–14%	–3% to 2%	4%	–11% to 19%
Relationship to care recipient								
Parent/grandparent	4%	–12% to 2%	18%***	7% to 30%	13%	–2% to 29%	4%	–1% to 18%
Spouse/partner	12%	–6% to 30%	29%***	15% to 44%	9%	–8% to 27%	11%	–5% to 27%
Urban	–2%	–16% to 12%	–3%	–17% to 11%	1%	–13% to 15%	4%	–8% to 16%
	Feel anxious		Feel encouraged to make decisions		Feel contributory to discussions			
	Predicted probability	95% CI bound	Predicted probability	95% CI	Predicted probability	95% CI	Predicted probability	95% CI
Age								
<35 (referent)								
35–64	4%	–0.06 to 0.15	6%	–5% to 18%	7%	–4% to 19%		
65+	–14%*	–28% to –1%	9%	–12% to 31%	17%	–5% to 39%		
Caring for comorbidities	–1%	–1% to 9%	1%	–9% to 11%	7%	–0.4% to 17%		
Education								
More than college (referent)								
College degree or less	–14%**	–25% to –4%	–14%*	–26% to –3%	–16%**	–28% to –4%		

Continued

Table 2 Continued

	Feel anxious		Feel encouraged to make decisions		Feel contributory to discussions	
	Predicted probability	95% CI bound	Predicted probability	95% CI	Predicted probability	95% CI
Female gender	-6%	-16% to 3%	2%	-9% to 12%	-3%	-14% to 8%
High burden	12%**	3% to 22%	-5%	-16% to 6%	-1%	-12% to 1%
Race						
White (referent)						
Asian	-1%	-16% to 15%	-3%	-2% to 14%	-2%	-19% to 14%
Black/African American	13%	-3% to 29%	0%	-17% to 17%	-1%	-18% to 16%
Ethnicity						
Non-Hispanic (referent)						
Hispanic	-4%	-17% to 9%	-13%	-27% to 2%	-14%*	-29% to 0%
Relationship to care recipient						
Parent/grandparent	5%	-9% to 18%	6%	-9% to 21%	6%	-1% to 22%
Spouse/partner	10%	-5% to 25%	14%	-3% to 31%	4%	-14% to 22%
Urban	-2%	-14% to 11%	-2%	-16% to 12%	-9%	-24% to 5%
	Feel questions are answered		Spend less time providing care		Feel it's easier to attend visits	
	Predicted probability	95% CI	Predicted probability	95% CI	Predicted probability	95% CI
Age						
<35 (referent)						
35-64	-1%	-13% to 1%	5%	-5% to 16%	11%	0% to 22%
65+	5%	-16% to 25%	1%	-18% to 19%	8%	-13% to 29%
Caring for comorbidities						
Education						
More than college (referent)						
College degree or less	-21%***	-33% to -1%	-8%	-18% to 3%	-2%	-12% to 9%
Female gender	-1%	-12% to 1%	-3%	-13% to 7%	-13%**	-24% to -3%
High burden	-3%	-14% to 8%	13%	0.04% to 0.21%	13%**	0.04% to 0.24%
Race						
White (referent)						
Asian	10%	-7% to 27%	-3%	-19% to 12%	-10%	-26% to 5%
Black/African American	-8%	-24% to 8%	3%	-13% to 18%	-3%	-19% to 14%
Ethnicity						

Continued

Table 2 Continued

	Feel questions are answered		Spend less time providing care		Feel it's easier to attend visits	
	Predicted probability	95% CI	Predicted probability	95% CI	Predicted probability	95% CI
Non-Hispanic (referent)						
Hispanic	-15%*	-29% to -2%	-11%	-23% to 1%	-8%	-23% to 6%
Relationship to care recipient						
Parent/grandparent	18%**	5% to 32%	5%	-9% to 18%	4%	-12% to 2%
Spouse/partner	17%*	2% to 32%	14%	-2% to 29%	10%	-8% to 27%
Urban	-1%	-15% to 12%	-6%	-19% to 7%	-3%	-17% to 1%

*=<0.05; **=<0.01; ***=<0.001.

Caregiver communication outcomes during the COVID-19 pandemic

Compared with having at least a college degree, having less than a college degree was associated with decreased likelihood of feeling involved by the provider (PP -15%; 95% CI -27% to -4%), feeling involved by the care recipient (PP -16%; 95% CI -27% to -5%), feeling more encouraged to be involved in care (PP -14%; 95% CI -26% to -3%), feeling like they contribute to discussions (PP -16%; 95% CI -28% to -4%) and feeling like their questions are being answered (PP -21%; 95% CI -33% to -10%). Compared with caregivers identifying as non-Hispanic, identifying with Hispanic/Latinx ethnicity was associated with lower likelihood of feeling the provider involves them in care (PP -20%; 95% CI -33% to -7%). Compared with caring for a friend or other non-relative, caring for a parent or grandparent (PP 18%; 95% CI 7% to 30%) and a spouse or partner (PP 30%; 95% CI 15% to 44%) were associated with increased likelihood of feeling involved by the care recipient.

Caregiver behaviour/wellness outcomes during the COVID-19 pandemic

Compared with having at least a college degree, having less than a college degree was associated with feeling less anxious (PP -15%; 95% CI -25% to -4%). Compared with caregivers aged 18–34 years, caregiver age of 35–64 years was associated with feeling more isolated (PP 9%; 95% CI 01% to 19%). Compared with male gender, female gender was associated with decreased likelihood (PP -13%; 95% CI -24% to -3%) of feeling it has become easier to attend the clinic visit. Compared with low caregiver burden, high caregiver burden was associated with feeling more anxious (PP 12%; 95% CI 3% to 22%), feeling like the caregiver spent less time providing care (PP 13%; 95% CI 4% to 21%) and feeling like it was easier to attend the visit during the pandemic (PP 14%; 95% CI 4% to 24%).

Sensitivity analysis

We conducted sensitivity analyses to determine whether the fully adjusted results were sensitive to caregiver burden, caregiver preparedness or caregiver positivity. In all cases, conclusions did not change, indicating high confidence in the results of the primary exploratory analysis.⁶⁹ In the sensitivity analysis, we found that the relationships between caregiver preparedness or caregiver positivity and both communication and wellness outcomes were stronger than caregiver demographic characteristics. Full sensitivity analyses can be found in online supplemental file E.

Qualitative results

Two-thirds (n=230) of the participants responded to the open-text question asking whether they had a desire to continue to use telemedicine after COVID-19 pandemic restrictions have eased (see [table 3](#) for definitions and sample quotes). Four themes emerged regarding

Table 3 Qualitative themes

Theme name	Definition	Example
Desire to continue using telemedicine		
Convenience	Finding that telemedicine was more convenient than in-person visits	Telemedicine is 'easier than bundling up and traveling to the office.' 'Telemedicine appointments let me be productive during the waiting time, and so far, we find that we wait less for telemedicine visits.'
Contact Minimisation	A desire to minimise exposure to external contacts or germs	'I would rather not expose my family members to the germs of a waiting area.' 'Telemedicine visits are much safer to use, even after restrictions are erased.'
Ease of Technological Use	The finding that the telemedicine technology is easy to use	'Telemedicine visits are much easier when there is lots of information sharing.' 'Telemedicine is very user-friendly.'
Condition Dependent	Desire to continue using telemedicine, based on the condition of the care recipient	'[Telemedicine works well] for the initial screening and determination of the need for an in-office visit.' 'I would love to continue to use telemedicine... I care for both parents who are mobility impaired, so not having to get them in or out of a car helps unless absolutely necessary.'
Desire to return to in-person visits		
Preference	Personal preference for in-person visit instead of telemedicine	'I just like meeting in-person better.' 'Telemedicine is impersonal.'
Logistical Concerns	Logistical problems with telemedicine	'We need pulmonary evaluations that can't be done via telemedicine.' 'I do not trust online visits in case they are recorded or hacked.'

participants who confirmed a desire to continue using telemedicine after COVID-19 restrictions have eased: Convenience, Contact Minimisation, Ease of Technological Use and Condition Dependence. Two themes emerged after analysing the responses for those who indicated a desire to return to in-person visits: Preference and Logistical Concerns.

DISCUSSION AND IMPLICATIONS

Principle findings

This is the first national survey of family caregivers and their experiences of healthcare communication perceived during the COVID-19 pandemic. In our sample, we found that lower educational attainment was associated with decreased odds of experiencing good communication outcomes, though lower education was also associated with lower anxiety related to the COVID-19 pandemic. In our sample, being a caregiver who identified as Hispanic/Latinx was independently associated with feeling less likely to be involved in visit communication by the care recipient's provider. Additionally, smaller proportions of Hispanic/Latinx and black/African American caregivers wished to continue telemedicine after COVID-19 pandemic restrictions eased, though the majority of caregivers in each racial and ethnic group still preferred to continue telemedicine. Even so, our qualitative analysis revealed that telemedicine was convenient and easy to

use; logistical issues like the need for lab testing equipment were the main reasons cited for a desire to return to in-person clinic visits.

Strengths and weaknesses

This study occurred in the summer of 2020, after the broad transition to telemedicine had occurred in the US health system. Due to our use of online panels and social media to recruit members of the general public, it is not possible to create an overall response rate since there is no defined population denominator; additionally, we are unable to compare respondents and non-respondents.⁷⁰ However, by ensuring that our sample approximated the characteristics of well-established national surveys that use probability-based general sampling, we limited the potential impact of selection bias; there is literature that supports the validity of internet panels.⁷¹ Also, while our sample had a higher ratio of male to female than prior studies, we controlled for gender in each model to minimise the potential effect of sampling bias.^{1 8} While this survey included questions about the usual caregiving experience, as well as the experience of caregiving during the pandemic, one challenge is connecting caregiver outcomes prior to the pandemic to their experiences during the pandemic; we are also unaware of what caregivers had access to telemedicine prior to the pandemic. We also asked participants to consider their caregiving during the COVID-19 pandemic but asking about

multiple time points could be confusing for some participants. Finally, the wording of the question on whether caregivers would like to continue using telemedicine could have been confusing for some participants who had not already had a telemedicine visit.

The lack of differences observed for COVID-19 pandemic-related outcomes between urban and rural residents could have been affected by our use of the internet for recruitment; it is unknown whether internet access could have affected the results, though it has been demonstrated that online surveys produce valid and similar results to those administered via posted mail or telephone, which are the most common methods of engaging those in rural areas.⁷² Additionally, caregiver ethnicity was associated with several outcomes in the unadjusted analysis, however, it was only associated with feeling less likely to be involved by the care recipient's provider in the adjusted analysis. Caution is needed when interpreting this finding given the issues of multiple testing comparisons. Given the exploratory nature of this analysis, findings should be contextualised with the number of comparisons made; additionally, while we believe we were thorough, we could have missed some important confounders that might explain these relationships. We considered the potential issues associated with testing across multiple comparisons. While adjusting for multiple comparisons decreases the type 1 error rate, it can inflate the type 2 error rates; this is less ideal for exploratory studies such as ours.⁷³ Common adjustment methods such as the Bonferroni Correction or the Benjamini-Hochberg Procedure are thus less appropriate.^{74 75} Finally, while our items were not psychometrically validated, the questions were adapted from other widely distributed studies like CGUS and FACES.^{1 42}

Comparison with prior work

Our findings support prior research that education is a key factor of quality healthcare communication with caregivers. In our sample, we find that, compared with caregivers with higher educational attainment, caregivers with lower educational attainment had decreased odds of experiencing positive communication outcomes. Prior research has shown lower levels of caregiver educational attainment have been associated with less communication during clinic visits.^{14 21 22} Our findings add to these studies by indicating lower levels of caregiver educational attainment are associated with worse outcomes related to communication during the COVID-19 pandemic, particularly feeling involved by the provider, feeling encouraged to be involved in clinical discussions, feeling like a contributor to discussions and feeling like their questions are being answered. While prior literature has speculated that higher levels of education were associated with lower anxiety early in the pandemic, our results suggest that higher educated populations had more anxiety as the pandemic continued. We hypothesise that this may be due to a greater understanding of severity, risks and

implications of the pandemic, in comparison with caregivers with lower educational attainment.^{12 13}

With regard to caregivers of Hispanic/Latinx ethnicity reporting lower odds of feeling involved by the provider during the COVID-19 pandemic, our findings support those of the largest survey of caregivers in the USA, which found that caregivers who report Hispanic/Latinx ethnicity are less engaged by their providers during non-pandemic times.¹ Prior qualitative data have also found lower provider engagement reported by caregivers of Hispanic/Latinx origin; while not statistically significant, we found that Hispanic/Latinx caregivers also demonstrated lower odds of feeling their questions are being answered. Our findings go beyond the NAC work and the prior qualitative work by demonstrating that this association exists during the COVID-19 pandemic as well as outside of pandemic-related restrictions. These differences in caregiving outcomes by ethnicity could be due to different cultural competencies among providers: when providers are trained to understand, appreciate, and interact with people from other cultures, languages, or belief systems, there is an improvement in health communication quality.^{23 27 28}

Our sample reported slightly higher caregiver preparedness than other published literature could be due to population from which we sampled.^{76 77} One-third of our sample was accounted for by caregivers with an NAC affiliation, a possibly more engaged subset of individuals. However, our sample was similar to published literature in terms of burden,^{78 79} and Positive Aspects of Caregiving Scale scores, and rurality, suggesting it is broadly representative of caregivers.^{80 81} Caregivers in our sample reported providing approximately 3 hours of care per day, suggesting lower recipient illness severity than many caregivers in America; this could contribute to our finding of greater preparedness.¹ Our results also support prior work that has speculated about the association between caregiver burden and caregiving anxiety during the COVID-19 pandemic; we found a statistically significant association between caregiver burden and higher levels of caregiving anxiety.⁸²

In our sensitivity analysis, caregiver preparedness and caregiver positivity were associated with more beneficial outcomes than demographic characteristics. This is important because caregiver preparedness and positivity are modifiable through intervention: a recent systematic review found technological interventions connecting caregivers to information from the clinic visit had beneficial effects on caregiver preparedness and caregiver happiness.⁵⁵ Further research should focus on developing and disseminating interventions to affect preparedness and positivity, in addition to the caregiving benefits proposed in legislation like the RAISE Family Caregiver Act such as subsidised respite care.⁸³

When controlling for various confounders, we found no significant difference in caregiver communication, behaviour or wellness outcomes between urban and rural residents. Previous research has indicated a need to consider

how to address isolation for caregivers during the COVID-19 pandemic and to understand how the shift to telemedicine has impacted rural caregivers.³⁶ Our findings support the use of telemedicine as a tool to combat issues of isolation caused by rurality.⁸⁴ These findings should be placed in context of the lower broadband internet penetration in rural counties, which could impact the ability to comprehensively sample rural residents in this project, though a recent study found that telemedicine use increased significantly among rural populations during 2020 relative to 2012–2019 indicating that many rural residents are using the internet to engage with their healthcare.^{47 85}

While we found that many caregivers prefer telemedicine, about one-quarter would like to return to in-person services. Our exploratory analysis supports previous findings highlighting that the convenience of telemedicine-based visits makes it easier for caregivers to attend visits.^{9 46} Interestingly, we found differences in desire by race and ethnicity that warrant further exploration: Hispanic/Latinx and black/African American caregivers were less enthusiastic about telemedicine than white caregivers. This supports prior literature that found lower desired use of telemedicine among racial and ethnic minority populations during COVID-19, which is speculated to be caused by disparities in digital literacy and a mistrust of digital appointments.⁸⁶ During the COVID-19 pandemic, recent studies have found mixed results regarding the use of telehealth by race or ethnicity. Campos-Castillo and Anthony found that black patients were more likely to use telehealth services than white patients, while Pierce and Stevermer found that patients who identify as black used telehealth less frequently than their non-black counterparts.^{38 39} While our results do not indicate differences in current telemedicine use, we found black/African American and Hispanic/Latinx caregivers were less likely to want to use telemedicine after pandemic restrictions are eased. In our qualitative analysis, we found that the primary reason for caregivers not wanting to continue telemedicine visits was reported as preferential; further work should seek to go beyond our findings and understand the factors associated with the preference for in-person visits.

Caregiver concerns around the logistics of telemedicine, including the privacy or security of online or recorded visits, are similar to the concerns of caregivers raised in prior qualitative studies about remote monitoring technology for caregiving.⁸⁷ The issue of trust in the security of telemedicine technology is important, as a lack of trust in telemedicine is linked to a lack of telemedicine service use.⁸⁸ Lack of trust in telemedicine could be linked to a lack of trust in providers generally, but it has been found that trust can change over time.⁸⁹ Lack of trust in telemedicine could come from a lack of face-to-face communication: building competence, logic, empathy and reliability could improve trust in telemedicine.⁹⁰ Although there were significant differences in the desire to continue with telemedicine, there was very little difference in terms of the association between race and ethnicity and the impact of COVID-19 on communication. The lack of equitable access to digital technologies

could be contributing to lower levels of comfort with telemedicine in racial and ethnic populations.

Meaning of the study

In our exploratory cross-sectional survey, a substantial proportion of caregivers are not experiencing optimal healthcare communication, including those with lower educational attainment and racial/ethnic minorities. One-third of participants are unenthusiastic about continuing telehealth delivery, even more so among minorities, but the majority feel positive towards telehealth. Caregiver demographics have substantial effect on telemedicine-related outcomes: specifically, caregivers with lower educational attainment and from non-white races/ethnicities appear to have lower communication quality and related outcomes.

While telemedicine was rapidly implemented as a response to the COVID-19 pandemic, its use is continuing to grow and it is likely to have a durable effect after pandemic-related restrictions eased.^{38 91} There are concerns that future models of care may expand, rather than address, disparities among underserved or under-represented populations.⁷ Efforts to improve health system design should account for varied education levels, as well as specific concerns of Spanish language and black/African American patients and caregivers, who report higher levels of distrust with the medical system and could need more support in an environment that includes telemedicine.³⁷ One theme that emerged in a qualitative study of 87 patients from racial and ethnic minority groups (including black/African American and Hispanic) was the idea of trust in telemedicine: many participants in the focus groups felt like they could not trust a clinician that was not present in the same room, because they did not know the clinician's credentials, skill or whether the clinician was giving the visit their undivided attention.³⁷ More quantitative work should be done to understand enablers and barriers to telemedicine use in these populations. The inclusion of culturally tailored interventions such as those described above like in-visit translators, communication assistance and cultural competency training for providers can assist with shared decision-making, and patient-centred care in telemedicine will provide higher quality services and communication for all.^{92–94} Further research should explore causes and interventions to address the difference we found in race/ethnicity and educational attainment.

Unanswered questions and future research

There is an urgent need for practices to be more considerate in the engagement of caregivers with low educational attainment and Hispanic/Latinx caregivers. The COVID-19 pandemic has demonstrated that the widespread shift to telemedicine has been well received by caregivers, though one-third are not enthusiastic about expanded use of telemedicine. There are opportunities to redesign health systems, and the redesign process should prioritise addressing racial, ethnic and educational

inequalities through the use of culturally appropriate communication methods.

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