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Abstract

The objective of this prospective survey series was to evaluate knowledge and concerns related to the COVID-19 pandemic among individuals with one or more chronic conditions, including cardiometabolic, autoimmune, respiratory and cancer diagnoses. Two surveys were distributed consisting of up to 55 items (March; n=1069) and up to 71 items (April, n=1126), with 24 items repeated from the first survey. Questions focused on healthcare access, barriers and concerns related to the COVID-19 virus. Descriptive analysis evaluated central tendencies, spread, and frequencies of the demographic data, disease states, and survey results within and between the two survey timepoints. Results from 416 individuals (38.9%) on survey 1 and 425 (37.7%) on survey 2 were analyzed. Participants were predominantly female (85%) and white (67%) with 7% residing in rural areas and 69% employed. Respondents reported an average of 2 chronic conditions and 62% would be classified as "at risk" for COVID-19 complications by the CDC. Only 20% reported a conversation about COVID-19 with a healthcare provider, 9% reported anxiety, 35% indicated loneliness. Level of concern about COVID-19 contracting the disease, cost of treatment/complications, medical access, and process of being treated was associated with increased anxiety (p<0.001) and wearing a facemask (p=0.01). Analysis suggests that analyzing concern and its association with health behaviors and anxiety should be a priority for innovative solutions. Insights into how the COVID-19 pandemic is impacting individuals with chronic conditions are imperative to inform tailored interventions to support individuals at higher risk of serious complications and death.

Keywords
COVID-19, coronavirus, patient insights, chronic conditions, healthcare access

Background

Since the World Health Organization declared 2019 novel coronavirus disease (COVID-19) a pandemic on March 11, 2020, rapidly emerging data have provided insight into which populations are at greatest risk for contracting and experiencing serious complications, including death, from the virus. As of July 23, 2020, there have been 15,012,731 confirmed cases and 619,150 deaths worldwide,[1] of which the largest percentage have occurred in the United States with 3,952,273 cases and 142,755 deaths,[2] respectively. From early data emerging from the first COVID-19 epicenter in Wuhan, China,[3] to current data in the US,[4] individuals with pre-existing chronic conditions are among the highest risk for morbidity and mortality. A systematic review[5] of hospitalized individuals with COVID-19 identified hypertension, cardiovascular disease, diabetes mellitus, chronic obstructive pulmonary disease, chronic kidney disease, and cancer as the most frequently observed underlying conditions worldwide. The Centers for Disease

Control and Prevention[6] (CDC) has also identified immunocompromise, obesity, asthma and lung disease among the category of individuals at highest risk for severe illness. The CDC reports that individuals with underlying cardiovascular, metabolic and respiratory conditions are six times more likely to be hospitalized and twelve times more likely to die from COVID-19 than individuals with no reported chronic conditions.[7]

While the potential physical and psychological impact[8] of the pandemic for individuals with chronic conditions is beginning to be documented, related both to quarantine[9] and to uncertainty and anxiety related to elevated risk for complications, an understanding of how individuals with chronic conditions are impacted is still evolving. In addition to concerns about complications of COVID-19, modified access to in-person healthcare due to the need for social distancing to reduce viral spread may result in reduced or delayed access to care for new or underlying conditions, further compounding the health implications

for this population. Understanding the experience of these individuals is pivotal to identify if and how COVID-19 is impacting access to and engagement with healthcare systems, as well as individual health behaviors.

Here we present the results specific to health care access, utilization and concerns from prospective survey data collection at two timepoints, one in March 2020 and one in April 2020, from individuals with one or more chronic conditions. Individuals were recruited from a population who had previously participated in a digital health coaching program for chronic conditions. The survey used both unique and repeated items across the two surveys to gain insight into how COVID-19 is impacting health decisions and care access during this unprecedented pandemic.

Aims

The aim of this descriptive survey study was to evaluate the experience of individuals with pre-existing chronic conditions as it relates to health behaviors, concerns, and healthcare access in the context of COVID-19. In addition, we sought to describe associations between CDC classification of high and standard risk for COVID-19 complications, demographic characteristics, and health behaviors, concerns and access.

Sample & Setting

The sample of survey participants was selected from a patient insights panel associated with a digital health coaching program for individuals with one or more diverse chronic conditions aligned to 4 main categories: cardiometabolic, respiratory, autoimmune and cancer. The panel consists of over 1000 individuals who, after completing the health coaching program, agree to provide patient insights on a variety of monthly health related surveys.

Methods

We conducted an exploratory, descriptive survey study with select repeated measures. Two survey instruments were developed to examine patient perceptions of the COVID-19 virus and its impact on their daily lives, health behaviors and healthcare access. Each survey consisted of internally developed topical questions related to knowledge, attitudes, behaviors and access, 3 demographic questions, and 7 items from validated measures evaluating anxiety, depression and loneliness. Additional demographic data, specifically, gender, age, race and geographic location, is derived from the participant profile in the patient insights database. This data is collected upon enrollment into the patient insights panel and is used for analysis consistent with the terms of agreement for participation in the panel.

Validated measures included the Patient Health Questionnaire-4 (PHQ-4), a validated 4-item questionnaire consisting of a 2-item depression scale (PHQ-2) and the 2-item Generalized Anxiety Disorder (GAD-2) scale, each scored using a 4- point Likert-type response scale, ranging from "not at all" to "nearly every day;"[10] and the Three-Item Loneliness Scale,[11] an ultra-brief scale designed to measure loneliness adapted from the UCLA-R Loneliness Scale.[12]

Survey Instrument 1 (Survey 1) was comprised of up to 55 items (3 demographic, 45 internally developed, 7 validated), and Survey Instrument 2 (Survey 2) was comprised of up to 71 items (3 demographic, 61 internally developed, 7 validated), of which 24 items were repeated between the two surveys. Both surveys contained internally developed items that involved survey logic such that participants may or may not be prompted with additional items based on their responses.

Internally developed items on Survey 1 focused on knowledge of COVID-19, including sources of information and understanding of precautions, as well as their employment accommodations during COVID-19. Internally developed items on Survey 2 focused on the effects of pandemic on the management of chronic conditions, including the use of telehealth services, testing, comfort leaving home and participating in public gatherings. Due to the rapidly evolving context of COVID-19, the internally developed survey items were not validated prior to administration and items differed between the two surveys based on evolving understanding of the virus and its potential impact. Survey questions were aligned to three topical areas: 1) influence of COVID-19 on healthcare access, concerns and behaviors, 2) influence of COVID-19 on work-life conditions and 3) perceptions related to reliability of information sources. This paper focuses specifically on and presents data from items related to healthcare access, concerns and behaviors, for which there were 16 specific items on Survey 1 (4 unique and 12 repeated) and 29 specific items on Survey 2 (17 unique and 12 repeated).

The two surveys were distributed via email invitation to the patient insights panel. Survey 1 was distributed to 1,069 panel members in March 2020 and was open for responses for 6 days, and Survey 2 was distributed to 1,126 panel members in April 2020 and was open for responses for 7 days. Individuals had the option to complete one or both surveys and were remunerated $10 USD for completing Survey 1 and $5 USD for Survey 2.

Data Analysis

Descriptive statistics were used to describe the demographics of the sample and the survey score distribution at both time points. For this analysis,

participants were classified as high or standard risk based on the CDC guidelines in Table 1. Individuals classified as high-risk were compared to the remaining sample across the ordinal and nominal survey questions. Ordinal survey questions included questions pertaining to the level of concern for COVID-19 infections and the financial/economic consequences of precautionary measures, as well as the items related to anxiety, depression and loneliness. The appropriate bivariate test was used to detect significant differences between the two survey time points for the repeated measure items, (Table 5). For this paper, only items specific to healthcare access, concerns and behaviors are presented.

Factor analysis was conducted to create a composite concern variable constructed from the following metrics: contracting the disease, cost of treatment/complications, medical access and process of being treated. All four items were scored on the same 5-point Likert scale from 1 (extremely concerned) to 5 (not concerned at all). All constructs were reverse coded prior to the factor analysis to simplify interpretations of subsequent regression using the concern composite score. Prior to performing the factor analysis, the dataset was assessed for the appropriateness for factor analysis by determining the sampling adequacy and sphericity. There was an appropriate proportion of common variance indicating that the latent constructs may be used to explain the grouping of individual items; therefore, the sample was adequate for factor analysis (KMO=0.79).[14] The correlation between items were verified by Bartlett's test of sphericity, which indicated that the variables were intercorrelated and suited for latent structure identification ($\chi 2$=457.166, df=6, p<0.001).

An unrotated exploratory factor analysis was conducted and resulted in three identified factors, with only the first factor having an eigenvalue of one or greater (1.80). The retained factors accounted for 82.94% of the variation. All 4 items yielded acceptable factor loadings (λ>0.4),[15] resulting in contraction concerns (λ=0.6530), cost of treatment concerns (0.6503), medical access concerns (λ=0.7095) and testing procedure concerns (λ=0.6675) loading on to factor one. Factor 1 showed sufficient internal consistency with Cronbach's alpha values of 0.7847.[16] The latent construct for concern, Factor 1, obtained from the exploratory factor analysis was validated using confirmatory factor analysis (CFA), with maximum

Table 1. Centers for Disease Control and Prevention (CDC)[13] Identified Risk Factors for Severe Illness due to COVID-19

Definitive Increased Risk	Possible Increased Risk
Chronic Kidney Disease (CKD	Asthma (moderate-to-severe)
Chronic obstructive pulmonary disease (COPD)	Cerebrovascular Disease
Immunocompromised from solid organ transplant	Cystic Fibrosis
Obesity (BMI 30 or above)	Hypertension or high blood pressure
Serious heart conditions, including heart failure, coronary artery disease or cardiomyopathies	Immunocompromise (including blood or bone marrow transplant, immune deficiencies, HIV, use of immune weakening medications)
Sickly Cell Disease	Neurologic conditions, including dementia
Type 2 diabetes mellitus	Liver disease
	Pregnancy
	Pulmonary Fibrosis
	Smoking
	Thalassemia
	Type 1 diabetes mellitus

likelihood estimation. The CFA model for concern showed an appropriate goodness of fit ($\chi 2$=460.6, p<0.001), with root mean square error of approximation (RMSEA) of 0.041, comparative fit index (CFI) of 0.997, Tucker–Lewis index (TLI) of 0.991.

A composite concern score was created from averaging a participant's concern level with the four concern items that were validated in the CFA: contracting COVID-19, cost of treatment, medical access and testing procedure. To analyze the relationship between concern and anxiety level, an ordinary least squared regression was conducted. This regression included risk classification and whether a participant felt the COVID-19 pandemic was making it more difficult to manage health conditions, and controlled for demographic differences (age, gender, education, rurality and minority status). Independent logistic regressions were used to evaluate the effect of concern level on the wearing a facemask and self-quarantining, both of which were binary variables. The health behaviors logistic regressions controlled for the same covariates that were included in the ordinary least squared regression. All calculations were completed at the significance level α=.05 and using STATA v16.[17]

Results

The survey was completed by 416 participants (response rate 38.9%) at time point 1 and 425 participants (37.7%) at time point 2. A total of 499 unique individuals participated in the surveys, with 342 (69%) responding at both timepoints. Demographics for participants are presented in Table 2. Survey participants were predominantly female (85% in both surveys) and white (66% in Survey 1 and 68% in Survey 2), residing within the Southeast (59% Survey 1 and 60% Survey 2), and currently employed (67% in Survey 1 and 69% in Survey 2). Respondents reported an average of 2 chronic conditions and 62% would be classified as "high risk" for COVID-19 related complications by the CDC (Table 3). Responses for single survey items are presented in Table 4 (See Appendix) and those related to health and concerns are summarized below.

Survey 1. Specific to this survey were questions related to participants' knowledge of COVID-19. The primary sources of information about preparing for or preventing the spread of COVID-19 reported by participants were the CDC or World Health Organization (WHO) (67.2%), statements from government officials (64.4%), and news channels (47.8%). Only 18.6% (n=67) of all participant, and 20.7% (n=46) of high-risk participants reported having a conversation with their doctor or other healthcare provider about COVID-19. More than half of all participants (53.6%) responded they would receive a vaccination for COVID-19 if one were available, with 39.7% unsure and 6.7% responding they would not. Of

those at high-risk, 56.3% (n=125) responded they would receive a vaccine, 37.8% were unsure and 5.9% would not.

Table 2. Demographics * Information pulled from data previously in Pack Health's database

	Survey 1 (n=416)		Survey 2 (n=425)		Both (n=342)	
	n	(%)	n	(%)	n	(%)
Gender*						
Female	352	(85%)	359	(85%)	293	(86%)
Male	51	(12%)	59	(14%)	43	(13%)
Unknown	13	(3%)	7	(1%)	6	(2%)
Age ranges*						
18-44	121	(30%)	128	(30%)	101	(29%)
45-64	233	(56%)	239	(56%)	190	(56%)
65+	48	(11%)	50	(12%)	44	(12%)
Unknown	14	(3%)	8	(2%)	7	(2%)
Race*						
White	276	(66%)	287	(68%)	232	(68%)
Black	87	(21%)	95	(22%)	72	(21%)
Asian	7	(2%)	5	(1%)	4	(1%)
Other	46	(11%)	38	(9%)	34	(10%)
Employment Status						
Employed	278	(67%)	292	(69%)	230	(67%)
Not employed	138	(33%)	133	(31%)	112	(33%)
Conditions	N=392		N=394		N=320	
Autoimmune	134	(34%)	134	(34%)	116	(36%)
Cancer	58	(15%)	61	16%)	49	(15%)
Cardiometabolic	269	(69%)	273	(69%)	226	(71%)
Respiratory	88	(22%)	93	(24%)	79	(25%)
Other	260	(22%)	262	(67%)	214	(67%)
Region*						
Midwest	55	(13%)	56	(13%)	46	(14%)
Northeast	54	(13%)	56	(13%)	45	(13%)
Southeast	244	(59%)	253	(60%)	203	(59%)
Southwest	19	(5%)	23	(5%)	16	(5%)
West	37	(9%)	35	(8%)	31	(9%)
Unknown	7	(2%)	2	(1%)	1	(0%)

Table 3. Participant Risk for Severe Illness due to COVID-19

	Survey 1 (n=416)		Survey 2 (n=425)		Both (n=342)	
	n	(%)	n	(%)	n	(%)
High Risk	291	(70%)	288	(68%)	239	(70%)
Heart disease	204	(49%)	214	(50%)	177	(52%)
Respiratory Condition	101	(24%)	105	(24%)	91	(26%)
Diabetes	97	(23%)	95	(22%)	85	(25%)
Cancer	58	(14%)	61	(14%)	49	(14%)
BMI>40	67	(16%)	66	(19%)	60	(18%)
Age >65	48	(12%)	50	(12%)	44	(13%)
Low Risk	125	(30%)	136	(32%)	102	(30%)
Number of Risk Factors						
0	125	(30%)	136	(32%)	102	(30%)
1	139	(33%)	133	(31%)	107	(31%)
2	96	(23%)	93	(22%)	78	(23%)
3	40	(9%)	44	(10%)	38	(11%)
4 or more	16	(4%)	19	(5%)	17	(5%)

concerned about the risk of COVID-19 infection for themselves (p = 0.002) but equally concerned about family or friends contracting COVID-19, when compared with the participants with standard risk.

Survey 2. Survey 2 focused on how COVID-19 is impacting management of participants' pre-existing conditions and access to healthcare. Over three fourths (77.4%) of participants reported needing to access healthcare treatment since the pandemic started, of which approximately half (49.5%) had difficulty accessing treatment. The top barriers to accessing care included appointments being canceled or rescheduled (61.3%), healthcare providers not offering elective procedures or new treatments (13.5%) and avoiding healthcare settings due to fear of contracting the virus (13.5%). The COVID-19 pandemic was reported as making it more difficult to manage their chronic condition by 27.4% of participants, most often due to stress (25.9%), the inability to attend appointments (25.9%), and disruptions to their daily routine (18.5%). Accessing medications and medical

supplies was reported as difficult by 13.9% of participants. About three fourths (74.6%) of participants responded that their healthcare provider offered telehealth services. Of those, almost half (40.7%) had already used their providers' telehealth services during the pandemic and the majority (86.8%) reported being pleased with their experience. Only 12.7% of participants with access to telehealth services that have either already used them or plan to use them during the pandemic say they likely will not continue using telehealth after the pandemic.

Repeated Measures. Results from the 12-items that were repeated between the 2 surveys specific to healthcare barriers, access and concerns are presented for all participants, as well as by high or standard risk in Table 5 (See Appendix). Of note, concern about getting infected increased while concerns about finances and job loss decreased over time. There was a 34.5% increase in individuals who reported being concerned about contracting COVID-19 from timepoint 1 to timepoint 2 (p<0.001), with 18.7% of respondents reporting a decreased concern and 46.8% remaining at the same

Table 6. Relationship Between Concern and Anxiety Based on Demographic Variables

Anxiety	B	p
Concern	0.676	<0.001
Pandemic making it more difficult (reference group = not)	1.116	<0.001
CDC High Risk (reference group = standard risk)	0.262	0.221
Age	-0.018	0.028
Gender (reference group = male)	0.036	0.895
Rural (reference group = urban)	-0.086	0.754
Non-white (reference group = white)	-0.580	0.006
Education (reference group = High School/GED)		
Technical or trade school	-0.172	0.763
Some college	-0.154	0.699
Associates degree	-0.292	0.481
Bachelor's degree	0.059	0.874
Postgraduate degree	-0.063	0.868

concern level. Similarly, there was a 33.6% increase in concern about a family member or friend contracting COVID-19, while 22.5% reported decreased concern and 43.9% remained the same. Financial concerns also decreased over time with 40% of the population reporting decreased concern and 21% increased concern. A great number of individuals reported reduced financial concerns related to medical care and buying daily items. The number of individuals who reported having no concerns about access to care increased from Survey 1 (6.4%) to Survey 2 (13.2%), suggesting changes in this area from the start of the pandemic. Related to mental health, individuals considered standard risk had a higher mean anxiety score at timepoint 1 than those in the high-risk group, however there was no significant difference between the anxiety distributions at the two time points. Depression outcomes suggested no significant difference between high and standard risk groups nor any significant change between survey timepoints.

Concern Composite. Results related to the relationship between the concern composite and anxiety by demographic variables is presented in Table 6. For every 1 unit increase in concern, anxiety increase by .676 points, on average. Results indicate a statistically significant relationship between concern and anxiety (p<0.001) based on age (p=0.028), race (p=0.006), and the perception that the pandemic is making it harder to manage the individual's health condition (p<0.001). For every year increase in age, anxiety levels decrease by 0.018. Participants identifying as non-white were less anxious compared to those who identified as white. Participants who reported the pandemic is making it more difficult to

manage their health condition were more anxious compared to those who felt the pandemic was not making that management more difficult.

Similarly, the concern composite was compared with self-reported health behaviors across demographic and other variables (Table 7). Results indicate a statistically significant relationship between concern and wearing a facemask based on age (p=0.01) and between concern and self-quarantining by rurality (p=0.02). The level of concern is a significant predictor of wearing a face mask but not of self-quarantining. As the level of concern increases, the odds of wearing a face mask increases by 57% (OR=1.57, p=0.003).

Discussion

Survey findings provide insights into the knowledge and attitudes of individuals with chronic conditions in the context of COVID-19, as well as how the pandemic has impacted their access to healthcare. Because of the increased risk of serious complications, morbidity, and mortality associated with COVID-19 there is a need to both protect individuals with chronic conditions from exposure to COVID-19 while simultaneously ensuring their healthcare needs are met.

Knowledge, attitudes and behaviors related to COVID-19. Results suggest that individuals obtain information about the spread and prevention of COVID-19 from diverse sources. While the majority of participants reported seeking information from the CDC, WHO and government officials, the third most reported source was

Table 7. Relationship Between Concern and Health Behaviors Based on Demographic Variables

	Wearing Facemask		Self-Quarantining	
	Odds Ratio	**p**	**Odds Ratio**	**p**
Concern	1.57	0.003	1.22	0.447
Pandemic making it more difficult (reference group = not)	1.35	0.379	6.16	0.091
CDC High Risk (reference group = standard risk)	1.46	0.47	0.84	0.789
Age	1.01	0.01	1.02	0.485
Gender (reference group = male)	1.54	0.61	3.01	0.07
Rural (reference group = urban)	0.47	0.19	0.19	0.024
Minority (reference group = white)	0.87	0.28		
Education (reference group = High School/GED)				
Technical or trade school	0.33	0.164	0.32	0.463
Some college	1.88	0.311	0.58	0.649
Associate degree	1.39	0.612	0.89	0.93
Bachelor's degree	1.24	0.702	1.46	0.756
Postgraduate degree	1.34	0.61	0.97	0.978

news outlets. Accurate knowledge of the virus, its causes and potential for spread are important, as a survey study in China[18] suggests knowledge is correlated with adoption of prevention behaviors that may reduce transmission of the virus. Though these surveys were conducted earlier in the onset of COVID-19 in the US, the low frequency of reported conversations with a healthcare provider about COVID-19, particularly among individuals at highest risk, suggests the need to implement established evidence-based education about the virus and its implications for individuals at standard and high-risk or to develop materials that address the needs of populations with unique health conditions or social determinants of health that can impact exposure, infection and complications from COVID-19.

Access to healthcare in the context of COVID-19. Reports of inability to access or delayed access to care are consistent with recommendations from professional organizations[19] suggesting how certain tests, procedures and treatments may be spaced out, structured or delayed to support social distancing and reduce transmission of the virus. While these efforts are important measures, the reality of newly diagnosed and pre-existing conditions requires that certain care may not be able to be delayed or that delays may contribute to exacerbations in symptoms, delayed diagnosis and treatment,[20] and potentially poorer health outcomes. Recommendations for the engagement

of solutions, most notably telehealth,[21] are actively being explored and operationalized to ensure individuals are able to engage with healthcare providers in the safety of their own homes. This is true for both mental[22] and physical health needs, both of which have the capacity to be exacerbated by COVID-19 and resulting social isolation. Further, such interventions offer opportunities for leveraging evolving technology to both address emergent healthcare needs during COVID-19, as well as to optimize healthcare access and delivery beyond the pandemic.[23,24]

Anxiety, depression and loneliness in the context of COVID-19. Reviews of existing literature[25] suggest that mental health concerns including depression and anxiety may be associated with the COVID-19 pandemic. Further, studies suggest social isolation is associated with increased risk for cardiovascular death,[26] emphasizing the need for interventions that target reducing social isolation for individuals during COVID-19 and beyond. New instruments[27] are being designed and validated to assess for anxiety specific to COVID-19, which may serve to screen individuals with pre-existing and newly emerging anxiety to identify opportunities for interventions. Appreciating how anxiety, depression and loneliness may uniquely affect individuals with chronic conditions, who may experience higher levels of anxiety and depression during COVID-19 and who may have increased isolation

due to fear of contracting the virus and risk for more severe complications, is important to ensuring that not only physical but also existing and emerging mental health needs are addressed for this vulnerable population.

The role of concern in health outcomes. The design of a concern composite, while preliminary, provides unique insights into how individuals' level of concerns about aspects of their health and its management during COVID-19 may influence both behaviors and outcomes, including anxiety. The concern composite was derived from alignment of scores on items related to concerns across 4 items: contracting COVID-19, cost of treatment for COVID-19, access to healthcare due to COVID-19 and COVID-19 testing procedures. Because existing models[28] promote the relationship between concern about or perception of risk for adverse health events and motivation for change in health behavior, understanding how concerns about COVID-19 may influence healthcare access and behaviors is pivotal to developing thoughtful and targeted interventions. Here we observed few relationships between level of concern and health behaviors, with concern associated only with mask wearing but not with self-quarantine. While this could be reflective of the relatively early timepoints at which the survey was administered, it could also be the phenomenon of quarantine fatigue, the process by which the practice of self-isolation leads to less sensitivity to the danger of COVID-19 and resulting leniency with respect to protective behaviors (e.g. mask wearing, staying home).[29] A study at The University of Maryland suggests less than 30% of individuals in any state are staying home.[30] Given this data, it is important to consider that concern about contracting the virus may not be sufficient to overcome the want or need to travel outside one's home, due to circumstances ranging from personal preference to in-person work requirements to the need for medical care. In the event staying at home or effective social distancing cannot be adhered to, ensuring the adoption of healthy practices including mask wearing and frequent hand washing are important to reduce viral spread. This is of particular importance as studies increasingly demonstrate the potential for asymptomatic spread.[31]

Study Limitations

This study has several limitations. One limitation was the use of primarily non-validated survey instruments, with the exception of the PHQ-4 and the Three Item Loneliness Scale. Further, the use of unique questions on each survey reflects the development of the surveys as the COVID-19 pandemic and its implications evolved. The exploratory descriptive nature of this data is a limitation but also a reflection of the rapidly evolving circumstances surrounding the virus. Further, the participants were predominantly white, and more than half reside in the southeast US. Given regional variation in responses to and

restrictions related to COVID-19, the responses may reflect this variability of regional practices. Ultimately COVID-19 is an intensely personal human experience in the context of global pandemic, for which unique health needs, social determinants of health, and internalization of the pandemic experience can result in vastly different experiences. Therefore, the insights derived here must be balanced with patient-centered approaches to care for this vulnerable population.

Despite these limitations the study findings provide important insights into the experience of individuals with chronic conditions who are most vulnerable to complications of COVID-19, if infected. The data provide real-world insights into how individuals with chronic conditions are experiencing healthcare access, concerns and barriers during this unprecedented pandemic. Survey questions can be further adapted and implemented in the current context as cases rapidly escalate in the US or may be used as a repeated measures approach to capturing how access, barriers and concerns evolve in the context of endemic COVID-19.

Conclusion

COVID-19 is anticipated to transform the delivery of healthcare globally and in the US. Capturing insights from individuals with chronic conditions, who account for the largest percentage of healthcare utilization in the US and who are concurrently at highest risk for COVID-19 related complications, is imperative to understanding how to optimize systems with the capacity to address care needs both during and beyond a pandemic. This is important to support the health and physical and mental well-being of individuals with chronic conditions in a safe manner, contributing to reduced exposure to and spread of the virus, as well as to decompress demands on healthcare systems, many of which are approaching capacity providing COVID-19 related care. This survey study provides insights into the experience of individuals with chronic conditions, as it relates to their healthcare behaviors, concerns and access during the COVID-19 pandemic. Specifically, it contributes to the literature by elucidating concerns about self or family members contracting COVID-19, barriers to accessing healthcare for underlying chronic conditions, prevalence of anxiety, depression and loneliness and how these data may differ over time and by risk for COVID-19 complications per CDC guidelines. Those at higher risk may have increased concern about contracting the virus which may in turn affect their comfort in seeking healthcare outside their homes. In addition, outcomes suggest that mental health, specifically loneliness which has been correlated with poorer health outcomes, should be a priority for process improvement and research across diverse healthcare settings. The need for innovative, yet scalable solutions to support healthcare needs within home and community-

based settings, including digital health solutions, is pivotal to our capacity to rapidly respond to COVID-19 as it unfolds and to proactively prepare for future shifts in both pandemic and non-pandemic driven healthcare utilization. Insights into how the COVID-19 pandemic is impacting individuals with chronic conditions are imperative to inform tailored interventions to support populations at higher risk of serious complications and death. Now is a pivotal time to leverage the insights, experiences and voices of individuals must vulnerable to COVID-19 and most dependent upon healthcare systems and utilization to create an optimal, patient-centered path forward, supporting the physical and mental health of individuals across diverse settings.

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Appendix

Table 4. Results for Single Survey Items Specific to Health Care Access, Behaviors and Concerns

Survey 1 (March 2020)	
When did you first hear about COVID-19?	
November 2019	42 (10%)
December 2019	89 (21%)
January 2020	140 (34%)
February 2020	101 (24%)
March 2020	44 (2%)
Are there any confirmed cases of COVID-19 in your area?	
Yes	335 (81%)
No	58 (14%)
I do not know	23 (5%)
Have you talked with your doctor or other healthcare providers about COVID-19?	
Yes	87 (21%)
No	329 (79%)
If a vaccine is developed for COVID-19, will you get it?	
Yes	220 (53%)
No	27 (7%)
Maybe	169 (41%)
Survey 2 (April 2020)	
Do you know anyone who has been diagnosed with COVID-19?	
Yes	159 (37%)
No	266 (63%)
Have you been exposed to COVID-19?	
Yes	19 (5%)
No	192 (45%)
I am not sure	214 (50%)
How concerned are you about the process of being tested for COVID-19 (worry about discomfort, cost of testing, etc.)	
Extremely concerned	57 (13%)
Very concerned	50 (12%)
Moderately concerned	99 (23%)
Slightly concerned	95 (22%)
Not concerned at all	124 (29%)
Have you been tested?	
Yes	295 (69%)
No	130 (31%)
Have you experienced symptoms of COVID-19 but have been unable to get a test?	
Yes	16 (4%)
No	395 (96%)
Do you think you would be considered a "high risk" patient if you contracted COVID-19?	
Yes	258 (61%)
No	105 (25%)
I don't know	62 (15%)
Yes, my level of activity has increased a lot	34 (8%)
Yes, my level of activity has increased somewhat	75 (18%)
Yes, my level of activity has decreased a lot	157 (37%)
Yes, my level of activity has decreased somewhat	98 (23%)
No, my activity level has stayed the same	61 (14%)
Have you been forced to choose between utilities, food, medicine, etc. because of COVID-19?	
Yes	35 (8%)
No	390 (92%)

Appendix

Table 4. Results for Single Survey Items Specific to Health Care Access, Behaviors and Concerns (cont'd.)

Do you have access to healthy food during this time?	
Yes	379 (89%)
No	33 (8%)
Have you had difficulty accessing healthcare treatment you need? (i.e. cancelled doctor appointments, clinics closed, etc.)	
Yes	163 (38%)
No	166 (39%)
I have not yet had to get healthcare treatment since the pandemic started	96 (23%)
Have you had difficulty getting your regular medications or medical supplies such as test strips?	
Yes, I had to switch to mail order	11 (3%)
Yes, it takes longer to get my medications/supplies	22 (5%)
Yes, it is more difficult to go to the pharmacy to get my medications/supplies	26 (6%)
No, I have not had any issues getting medications/supplies	298 (70%)
I have not had to order medications since the pandemic started	24 (6%)
I do not take any medications	32 (8%)
Other	12 (3%)
Do you feel the COVID-19 pandemic is making it more difficult to manage your condition?	
Yes	108 (27%)
No	286 (73%)
Do you have access to a patient portal that allows you to view your health information and contact your doctor?	
Yes, and I use it	291 (69%)
Yes, but I do not use it	87 (21%)
No	25 (6%)
I'm not sure	22 (5%)
Does your healthcare provider offer telehealth services?	
Yes	317 (75%)
No	26 (6%)
Unsure	82 (19%)
Do you plan to use telehealth services to communicate with your healthcare provider during this time?	
Yes, and I have already used telehealth services	129 (41%)
No	38 (12%)
I don't know how to use telehealth services	4 (1%)
Yes, but I have not yet used telehealth services	146 (46%)
Do you think having access to telehealth services to communicate with your provider will be helpful during this time?	
Yes	23 (89%)
No	3 (12%)
How would you rate your experience with telemedicine?	
Extremely pleased	74 (57%)
Somewhat pleased	38 (30%)
Neither pleased nor displeased	9 (7%)
Somewhat displeased	8 (6%)
Extremely displeased	0 (0%)
Do you think you will continue to use telemedicine outside of the pandemic?	
Definitely yes	83 (30%)
Probably yes	73 (27%)
Might or might not	84 (31%)
Probably not	30 (11%)
Definitely not	5 (2%)

Appendix

Table 5. Results for Repeated Measure Items

Questions	Survey 1 Responses		Survey 2 Responses		
	n (%)	x̄ (SD)	n	x̄ (SD)	P
How concerned are you about contracting COVID-19 yourself?	416	3.35 (1.15)	425	3.61 (1.13)	< 0.001
Extremely concerned	87 (21%)		120 (28%)		
Very concerned	91 (22%)		106 (25%)		
Moderately concerned	144 (35%)		126 (30%)		
Slightly concerned	70 (17%)		60 (14%)		
Not concerned at all	24 (6%)		13 (3%)		
How concerned are you about friends and family contracting COVID-19?	416	3.75 (1.10)	425	3.96 (1.02)	< 0.001
Extremely concerned	125 (30%)		155 (37%)		
Very concerned	132 (32%)		146 (34%)		
Moderately concerned	102 (25%)		83 (20%)		
Slightly concerned	42 (10%)		33 (8%)		
Not concerned at all	15 (4%)		8 (2%)		
How concerned are you about losing work because of COVID-19?	416	2.51 (1.50)	425	2.45 (1.43)	0.42
Extremely concerned	70 (17%)		59 (14%)		
Very concerned	44 (11%)		45 (11%)		
Moderately concerned	78 (19%)		80 (19%)		
Slightly concerned	60 (14%)		85 (20%)		
Not concerned at all	164 (39%)		156 (37%)		
How concerned are you about financial fallout due to COVID-19?	416	3.64	425	3.40 (1.26)	< 0.001
Extremely concerned	136 (33%)		105 (25%)		
Very concerned	109 (26%)		100 (24%)		
Moderately concerned	87 (21%)		118 (28%)		
Slightly concerned	55 (13%)		63 (15%)		
Not concerned at all	29 (7%)		39 (9%)		
How concerned are you about personal financial issues due to COVID-19 (cost of treatment, complications, etc.)?	416	3.31 (1.34)	425	3.12 (1.31)	0.0029
Extremely concerned	110 (26%)		84 (20%)		
Very concerned	81 (20%)		83 (20%)		
Moderately concerned	100 (24%)		115 (27%)		
Slightly concerned	78 (19%)		86 (20%)		
Not concerned at all	47 (11%)		57 (13%)		
How concerned are you about not being able to get everyday necessities (e.g. food, medicine)?	416	3.39 (1.21)	425	3.06 (1.16)	< 0.001
Extremely concerned	100 (24%)		60 (14%)		
Very concerned	95 (23%)		85 (20%)		
Moderately concerned	114 (27%)		141 (33%)		
Slightly concerned	83 (20%)		102 (24%)		
Not concerned at all	24 (6%)		37 (9%)		
How concerned are you about not being able to access needed medical care?	416	3.38 (1.27)	425	3.1	<0.001
Extremely concerned	102 (25%)		74 (17%)		
Very concerned	100 (24%)		96 (23%)		
Moderately concerned	101 (24%)		111 (26%)		
Slightly concerned	78 (19%)		88 (21%)		
Not concerned at all	35 (8%)		56 (13%)		

Appendix

Table 5. Results for Repeated Measure Items (cont'd.)

Is COVID-19 testing available in your area?	416	425	< 0.001
Yes	101 (24%)	118 (28%)	
No	19 (5%)	13 (3%)	
I do not know	99 (24%)	39 (9%)	
Yes, but only for people that fit a specific criterion	197 (47%)	255 (60%)	
Do you know where to go to get tested for COVID-19?	416	425	0.29
Yes	199 (67%)	295 (69%)	
No	99 (33%)	130 (31%)	
What precautions are you taking to prevent disease?	416	425	
Frequent hand washing	402 (97%)	412 (97%)	0.66
Using hand sanitizer regularly	320 (77%)	335 (79%)	0.30
Avoiding touching others or surfaces	330 (79%)	340 (80%)	0.73
Avoiding touching your face	337 (81%)	321 (76%)	0.017
Wearing facemasks	36 (9%)	315 (74%)	< 0.001
Frequently cleaning your phone or other regularly touched items	260 (63%)	290 (68%)	0.0162
Regularly disinfecting surfaces	299 (72%)	293 (69%)	0.20
Keeping six feet of distance between yourself and others	295 (71%)	395 (93%)	< 0.001
Practicing social distancing (avoiding public places or groups of people)	366 (88%)	394 (93%)	< 0.001
Other	20 (5%)	21 (5%)	0.83
I am not taking any precautions to prevent disease	3 (1%)	2 (1%)	0.57
Are you currently employed? / Were you employed in February 2020?			0.34
Yes	278 (67%)	292 (69%)	
No	138 (33%)	133 (31%)	
Patient Health Questionnaire (PHQ) 4	416	425	
Anxiety	1.74 (1.75)	1.79 (1.76)	0.5834
Depression	1.08	1.31 (1.51)	0.0027
UCLA Loneliness Scale Questions	416	425	< 0.001