



CAPTURING THE PATIENT EXPERIENCE DURING THE COVID-19 PANDEMIC

METHODS OF A
LONGITUDINAL
SURVEY

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Introduction

The emergence of the SARS-CoV-2 virus which caused the coronavirus disease 2019 (COVID-19) has had a sudden and profound effect on communities nationwide. Patients with severe or life-threatening chronic conditions faced myriad stresses from losses of economic and psychological support including job loss and difficulties sustaining basic needs, such as housing, food security and access to care.¹ Each of these stressors has the ability to increase financial and psychological strain on patients, caregivers and their families. In addition to the immediate financial and psychological impacts of the COVID-19 pandemic, alterations to the care delivery system challenged patients with chronic and complex illness. Capturing these experiences is key to understanding and mitigating the needs caused, or exacerbated, by the COVID-19 pandemic.

Economic hardships from the COVID-19 pandemic¹ are widespread, affecting nearly every sector of the U.S. population, from college students^{2,3} to the elderly.⁴ There is emerging evidence that the impact is even greater for low-income^{5,6} and minority⁷ populations. For many, these financial hardships are being further exacerbated by the need to managing a chronic, life threatening, or debilitating illness—as the costs associated with many of these diagnoses has already put a financial strain on patients' and their families/caregivers.

The COVID-19 pandemic also had a direct influence on how patients access and pay for care. Many patients have undergone insurance changes due to job loss.⁸ While others have maintained insurance but are experiencing loss of income (due to reduction in hours, tips, or family income) that has affected their ability to pay for premiums, co-pays, and co-insurance. Patients' access to care has been affected by cancellations of non-essential medical procedures by providers,^{9,10} and challenges in transitioning to telehealth.^{11,12} Many patients are at an increased risk of negative outcomes if infected due to their underlying conditions and comorbidities.¹³ This increased risk has impacted patients' personal decisions to delay care due to concerns of contracting the virus.^{14,15}

In pre-pandemic time, safety net services were struggling to meet all the needs of low-income, low-resource patients.¹⁶ Now, in post-pandemic times, we are seeing that the safety net inadequate to meet the growing need, leaving our most vulnerable patients struggling to meet basic housing, nutrition, and healthcare cost needs.¹⁷

This survey project was designed to capture information about the pandemic experiences of patients with chronic and complex conditions to determine how the COVID-19 pandemic and mitigation efforts impacted under resourced patients' physical, emotional and financial wellbeing.

Methods

Based on existing literature and PAF data, it is known that underserved/under-resourced patients face a multitude of challenges related to health care access and affordability.^{18,19,20} We developed a longitudinal survey framework informed by our previous survey work, consultation with a variety of academic partners, and the widely reported challenges presented by the emerging COVID-19 pandemic. Surveys were delivered over a 12-month period in 3 waves (baseline, wave 2, wave 3) approximately 6 months apart. Limited question sets from the baseline survey were asked in each wave, and specific topics of interest (ex: telehealth, vaccine willingness, media trust; employment impact) were added and/or expanded in the second and third surveys.

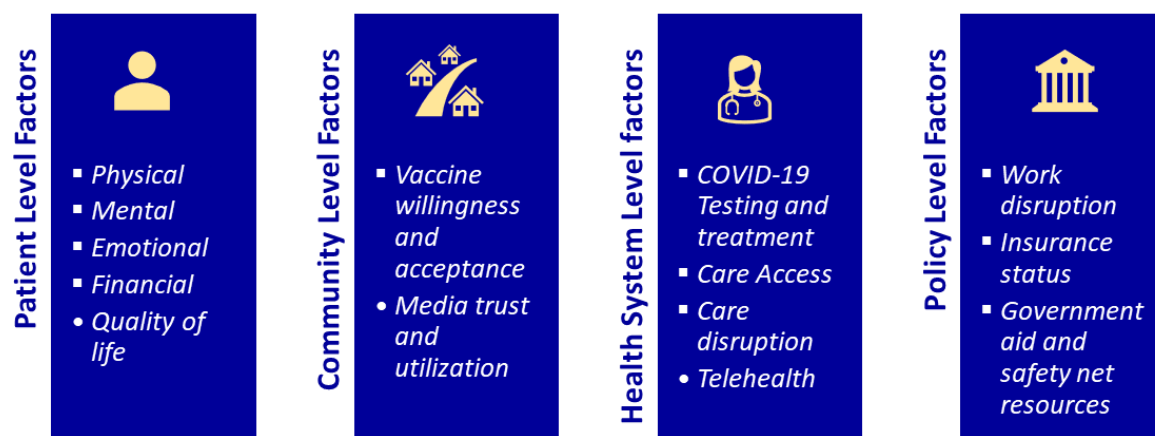
The survey was sent to patients served by PAF in 2019-2020 who were >18 years and opted in to receive communications via email. Patient Advocate Foundation (PAF) is a non-profit organization that serves individuals with serious illnesses nationwide by providing case management, copayment relief, and other

forms of financial aid. Individuals served by PAF include those with limited financial resources, coping with medical disabilities and/or chronic illnesses, residing in geographically isolated or medically underserved areas, and or limited literacy.²¹

Conceptual Framework

Question domains were created based on prior survey work, input from academic colleagues and real time review of issues presenting to patients in the current pandemic climate. As awareness of COVID-19 quickly spread and shutdowns began, PAF clients also began to anecdotally report increases in economic hardship, physical and emotional distress, and disruptions in medical care. Given the potential for future catastrophic downstream outcomes in individuals already under-resourced we also mapped the question domains to individual-, community-, health system- and policy-level factors to assist PAF and our partners in using the resulting information to help drive evidence-based interventions to address pandemic-related effects (Figure 1).

Figure 1: COVID-19 Longitudinal Survey Framework



Survey Question Generation

A multidisciplinary team of internal staff and external experts were mobilized to review the domains and suggested question sets to assess face validity of the survey in capturing the pandemic's impact on patients. Questions were selected from multiple sources including previous PAF surveys, publicly available questions used by news/media polls, questions contributed by content area experts, and validated tools. Where appropriate, new questions were created to capture content specific information.

For the baseline survey, six overarching pandemic-related domains emerged from the review. Longitudinal wave 2 retained most of the previously developed question sets and expanded our exploration of telehealth utilization. Additional questions introduced the topics of vaccine willingness, media trust/mistrust of COVID and vaccine information and provider bias. Wave 3 scaled back or removed some of the baseline question sets (COVID-19 diagnosis impact), expanded the pandemic employment impact section and updated questions about vaccine willingness to those reflecting vaccine acceptance (Figure 2).

PATIENT LEVEL

Physical and mental health: Social distancing has introduced heightened feelings of anxiety and depression amongst members of the general public and these feelings can be heightened in low-income or chronically ill patients already struggling to deal with the challenges of everyday living. While many patients will return to their normal routines after these measures have been lifted, some may have negative health or anxiety experiences.

Indirect health and care needs: Pandemics are not just biological or medical phenomena. They have immense psycho-social implications and affect society at a large. In response many common items (paper products, water, food, over the counter medications) were difficult to obtain either due to overconsumption (hoarding) or lack of access (stores exhausted their inventory). Further exacerbating the problem was the impact of job loss often causing patients to determine when/how they would spend limited funds.

COMMUNITY LEVEL

Vaccine willingness and acceptance: The development of vaccines showing high efficacy against SARS-CoV-2 offered a way to protect against the health effects of the virus. However, public trust in the development of vaccines and the government approval process represented a potential crucial reason for hesitancy to delay or refuse vaccination.

Use and trust of media resources regarding COVID-19 information: Since the beginning of

the COVID-19 pandemic, there has been an abundance of information, with nearly every media channel covering the latest developments. Information channels, both traditional and social media, are sharing vaccine information and may be very influential in swaying public opinion as to whether or not members of the public want to be vaccinated. The content and spread of misinformation may influence risk perception and vaccine hesitancy.

HEALTH SYSTEM LEVEL

Access to COVID-19 testing, treatment, and related costs: Although many state and local health departments quickly mobilized programs to provide free or low-cost screening after the start of the pandemic, confusion around who and where to test persisted. As the pandemic progressed urgent care clinics, pharmacies, and mobile units expanded testing options for patients who were unable to receive testing through their provider. One of the challenges posed by this patchwork system of testing locations was the lack of clarity for how testing (and subsequent treatment) would be reimbursed (insurance) or paid.

POLICY LEVEL

Changes in employment and insurance

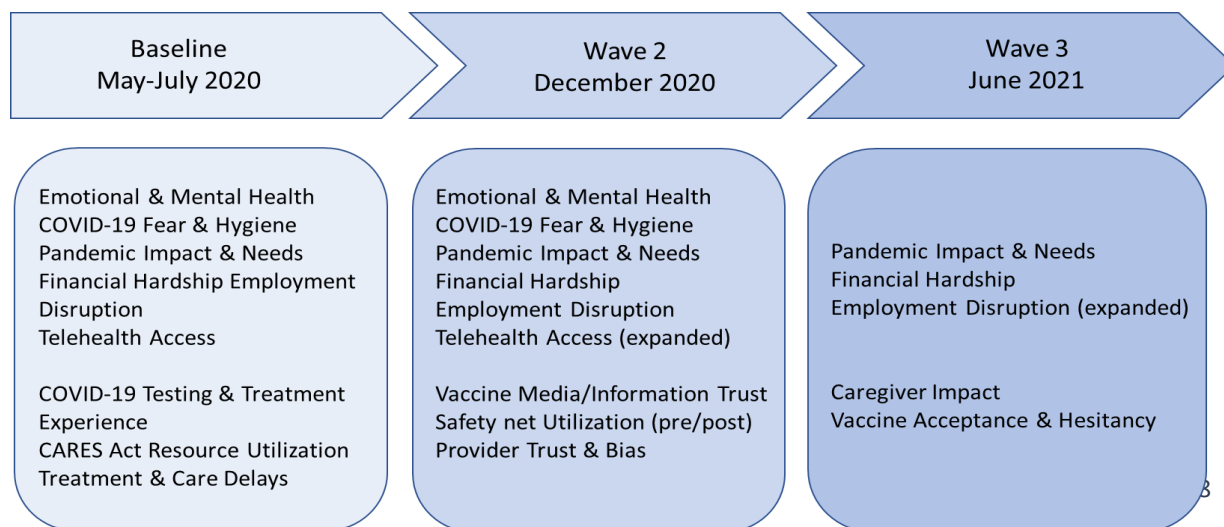
coverage: Regardless of the current or coming health effects of COVID-19 on patients, the pandemic has affected and will likely continue to affect household finances for years to come. Individuals who work for businesses have felt the impact most directly, with furloughs and temporary or permanent job loss. As the economic contraction turns into a longer-term economic recession, high unemployment figures will continue, along with lower wages as more job seekers compete for fewer available jobs. Rising unemployment is expected to significantly alter the health insurance coverage landscape, as millions who lose their jobs (and

Healthcare access issues: The coronavirus pandemic continues to shape patient access to care, with many patients forced to change their care utilization habits. While some of this may be credited to healthcare organizations that had to shutter their doors to non-urgent healthcare, we need to also take into consideration perceived patient trust and safety in healthcare institutions. In addition, recent policy changes during the COVID-19 pandemic have reduced barriers to telehealth access and have promoted the use of telehealth to deliver acute, chronic, primary and specialty care.

their dependents) enroll in Medicaid, purchase Marketplace coverage, or become uninsured.

Utilization of CARES Act resources: The Families First Coronavirus Response Act (FFCRA or Act) contained key provisions including (1) paid sick leave (2) insurance coverage of coronavirus testing (3) nutrition assistance (4) unemployment benefits and (5) student loan debt relief. Economic stimulus payments (up to \$1,200) were sent to individuals who met certain financial qualifications based on their 2019/2020 tax filings. Many public and private institutions also developed relief programs for mortgages, car loans, rent, utilities etc.

Figure 2: COVID-19 Longitudinal Survey Series Question Sets



Study Sample & Data Collection

Survey participation was limited to individuals who had previously received at least 1 direct service from PAF, opted in to receive additional PAF communication, provided a valid e-mail address, and were English speaking. Potential respondents were invited to participate in the survey via an automated email from the Qualtrics survey platform.

Each survey (baseline, wave 2, wave 3) was live for a three-week timeframe, and three reminder emails approximately 7 days apart were sent to individuals who had not initiated the survey or had partially completed it. Participation was voluntary and individuals could opt out of receiving survey reminder emails at any time during the data collection periods.

Individual incentives were not provided to respondents for participation. However, participation was incentivized for each survey through random drawings for a limited number of Amazon gift cards (Baseline: 6 -\$25; Wave 2: 4-\$50; Wave 3: 5-\$100). To increase patient engagement, a report with selected aggregate survey results and a message about the upcoming survey was shared with the baseline cohort prior to launching waves 2 and 3. A final summary communication of survey results were also shared with the baseline cohort thanking them for their continued support and to link them to other research and engagement activities.

Results

The survey was disseminated to 115, 114 patients served by PAF from June 2019 – June 2020. The Baseline survey was completed by 4,108 respondents, resulting in a 27% response rate. Wave 2 and 3 was disseminated to those who completed the baseline questionnaire. Wave 2 had a response rate of 44% (1,823/4,108), and Wave 3 had a response rate of 34% (1,401/4,108). Demographic data for patients served, invited cohort, baseline, and wave 2 and 3 respondents are presented in Table 1.

Conclusion

As the coronavirus disease pandemic spread across the United States and protective measures to mitigate its impact were enacted, patients experienced widespread disruptions in daily life. Little was known about the financial and social impact of the COVID-19 pandemic on patients, especially those with a history of healthcare access and affordability challenges. Results of the survey will be used by both internal PAF researchers and collaborating academic partners to explore the experiences of patients and caregivers throughout the

pandemic. Publications utilizing this survey data can be found [here](#).

There are several limitations that impact the generalizability of our findings. We did employ a convenience approach to sampling. While our sample was not intended to be a reflection of the general population, it was drawn entirely from patients who have received PAF services in the past and may not reflect the wider “underserved patient” population. Our online data collection would also disproportionately exclude those with limited access to the internet or comfort with technology. This likely resulted in an underrepresentation of the elderly, the very sick, patients living in rural areas, and patients with extremely low SES.

It is our hope that this longitudinal survey data will continue to be leveraged by direct service providers and researchers looking to understand the constellation of challenges and disruptions caused by the COVID-19 pandemic, as well as the changes in patient reported emotional and financial well-being, attitudes, perceptions, and behaviors through the formative phase of the pandemic.

Table 1: Representation of patients served by PAF in longitudinal COVID-19 surveyⁱ

	Patients Served (N = 103,526)		Panel Invite [^] (n = 16,201)		Baseline (n = 4,213)		Follow-up 1 ^{^^} (n = 1,831)		Follow-up 2 ^{^^} (n = 1,390)	
Participation Rate			16%		26%		43%		33%	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Gender										
<i>Female</i>	58,169	57%	9,926	62%	2,527	60%	1,064	58%	803	58%
<i>Male</i>	44,752	43%	6,200	38%	1,670	40%	762	42%	584	42%
Age Group										
<i>≤18</i>	1,044	1%	67	<1%	24	<1%	15	1%	10	1%
<i>19 – 35</i>	6,723	7%	1,250	8%	220	5%	70	4%	52	4%
<i>36 – 55</i>	20,174	20%	5,464	34%	1,1392	33%	586	32%	414	30%
<i>56 – 75</i>	51,953	51%	8,171	51%	2,319	55%	1,1060	58%	835	60%
<i>>75</i>	21,615	21%	1,138	7%	247	6%	96	5%	76	5%
Race/ Ethnicity										
<i>Caucasian</i>	45,148	60%	8,415	55%	2,396	60%	1,154	66%	864	65%
<i>African American</i>	17,794	24%	4,517	29%	1,007	25%	361	21%	272	20%
<i>Asian</i>	3,204	5%	715	5%	190	5%	79	5%	61	5%
<i>Hispanic</i>	7,051	9%	1,282	8%	309	8%	117	7%	96	7%
<i>Other</i>	1,581	2%	423	3%	105	3%	43	2%	30	2%
Income Group										
<i><\$23,999</i>	39,241	40%	6,224	39%	1,439	35%	597	33%	431	31%
<i>\$24,000 - \$47,999</i>	40,490	41%	6,211	39%	1,763	43%	777	43%	613	45%
<i>\$48,000 - \$71,999</i>	13,629	14%	2,187	14%	623	15%	283	16%	213	16%
<i>\$72,000 - \$95,999</i>	2,567	3%	617	4%	176	4%	79	4%	63	5%
<i>>\$96,000</i>	2,024	2%	527	3%	134	3%	63	3%	49	4%
Employment										
<i>Employed/Self</i>	19,933	22%	4,237	27%	1,022	25%	416	23%	286	21%
<i>Retired</i>	43,520	47%	4,289	27%	1,243	30%	583	33%	442	33%
<i>Disabled</i>	17,751	19%	4,613	29%	1,297	31%	573	32%	475	35%
<i>Unemployed</i>	10,599	11%	2,633	17%	547	13%	208	12%	147	11%
<i>Other</i>	705	1%	66	<1%	11	<1%	4	<1%	3	<1%
Marital Status										
<i>Married</i>	40,811	44%	5,761	36%	1,515	37%	650	36%	489	36%
<i>Single</i>	31,247	34%	5,987	38%	1,542	37%	671	37%	516	38%
<i>Widow/widower</i>	8,824	10%	1,111	7%	260	6%	108	6%	74	5%
<i>Divorced</i>	8,313	9%	2,269	14%	615	15%	266	15%	211	16%
<i>Separated</i>	1,915	2%	603	4%	156	4%	73	4%	46	3%
<i>Domestic Partner</i>	614	1%	157	1%	52	1%	24	1%	22	2%
Household Size										
<i>1</i>	42,728	43%	5,714	36%	1,489	36%	680	38%	519	38%
<i>2</i>	40,613	41%	5,473	34%	1,397	33%	589	33%	467	34%
<i>3</i>	7,677	8%	2,099	13%	566	14%	234	13%	166	12%
<i>4</i>	5,736	6%	2,213	14%	624	15%	277	15%	199	14%
<i>≥5</i>	2,474	2%	489	3%	96	2%	31	2%	27	2%
Region										
<i>Midwest</i>	19,051	19%	2,678	17%	664	16%	297	16%	194	14%
<i>Northeast</i>	14,277	14%	2,222	14%	562	13%	262	14%	198	14%
<i>South</i>	52,128	51%	8,685	54%	2,243	54%	932	51%	730	53%
<i>West</i>	15,845	16%	2,523	16%	720	17%	329	18%	263	19%

ⁱInclusion criteria for panel invite included opting in to receive survey communications from PAF and valid email.

^{^^}Wave 2 and Wave 3 participation was offered to all patients participating in the baseline survey.

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ⁱⁱⁱ Missing or unknown data has been removed from the denominator, and all calculations are based on known data elements. All displayed data is based on closed cases reported to PAF during the referenced time period. Demographic data displayed is based on data contained in Patient Advocate Foundation’s data sources and is held constant across all subsets. Only data contained in these databases is displayed (no survey question data) for continuity and comparison.