

“I am hesitant to visit the doctor unless absolutely necessary”

A qualitative study of delayed care, avoidance of care, and telehealth experiences during the COVID-19 pandemic

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Abstract

The COVID-19 pandemic has disrupted the health care system, resulting in decreased health care utilization. During the pandemic, some patients chose to postpone clinic visits or avoid them altogether while health care providers concurrently scaled back their services. As a result, health care has shifted to a greater reliance on telehealth and virtual care.

This study uses a qualitative descriptive design, focused on providing summaries of participant experiences of health care and telehealth utilization during the COVID-19 pandemic.

Three primary themes emerged during analysis: delayed health care, avoidance of care, and experiences of telehealth. Sub-themes of delayed health care included care delays and scheduling difficulties. Participants reported avoidance of health care due to fear of COVID-19 infection, as well as general changes to care-seeking behaviors. Participants also reported positive experiences with telehealth, with some respondents noting limitations of telehealth systems, such as limitations on procedures and patient-centered monitoring of chronic illness.

Our findings support studies that have found both health care delays and changes in health care utilization patterns during the pandemic. Most importantly, this study expands the literature concerning links between fear of COVID-19 and altered care-seeking behaviors, which is the first study to do so focusing on these concerns in the participants' own words. Finally, while telehealth is promising in preserving continuity of care during pandemics, long-term integration into the health care system is not without challenges, and this study provides insights into how patients experienced telehealth during COVID-19 in their own words.

Data collection, survey design, and research priorities for this study were based on input from ongoing community partnerships.

Keywords: COVID-19, COVID-19 fear, delayed health care, pandemic, telehealth

1. Introduction

The COVID-19 pandemic has disrupted the health care system, resulting in decreased health care utilization. During the pandemic, some patients chose to postpone clinic visits or avoid them altogether while health care providers concurrently scaled back their services.^[1] Reduced access to care during the COVID-19 pandemic has increased emergency department visits for acute issues such as appendicitis, heart attack, and stroke,^[2,3] increased late stage diagnosis and treatment of cancer,^[4] increased adverse maternal health outcomes,^[5] and

delayed diagnosis of chronic conditions, such as diabetes and mental health diagnoses.^[6]

Health care adaptations have been dynamic during the COVID-19 pandemic^[7,8] in response to changing guidelines and policies aimed at preventing health care facilities from becoming overwhelmed.^[9] Telehealth usage increased during the pandemic,^[10] with many encounters shifting to virtual care.^[11] Telehealth has proven to be effective in the treatment of some illnesses while reducing both patient and provider exposure to COVID-19.^[12] Not all patients have positive experiences with telehealth and virtual health care due to some significant

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limitations for patients, such as limited internet access, lack of technological ability, limitations to examinations, and lower quality patient-physician relationships.^[8,13–15]

Several articles have documented the changes in health care during the pandemic. Few articles describe the facilitators and barriers to health care, and even fewer qualitative studies include patient description of changes in health care experience. Understanding the lived experiences of patients provides critical insights, informs process improvement efforts, and aids in the development of programs designed to meet patient needs while increasing access and health equity.^[16,17]

2. Methods

2.1. Study aims

This study aimed to describe patients' health care experiences during the COVID-19 pandemic, including barriers and facilitators to health care access. All study materials and procedures are approved by the University of Arkansas for Medical Sciences Institutional Review Board (IRB #261226).

2.2. Study design and approach

This study uses a qualitative descriptive design, focused on providing summaries of participant experiences and emphasizing the meanings attributed to those experiences^[18,19] related to health care access and telehealth utilization during the COVID-19 pandemic.

2.3. Recruitment, consent, and remuneration

Participants were recruited from six primary care clinics located in rural and urban areas throughout the state of Arkansas, between October 30, 2020 and January 16, 2021. These clinics were chosen to ensure a broad geographical representation in the study sample. Potential participants included active clinic patients with an email address listed in their electronic medical records. Recruitment e-mails describing the purpose of the study and criteria for inclusion were sent to 6092 e-mail addresses. Inclusion criteria for the study included participant verification of being 18 years of age or older and working, living, or receiving health care in Arkansas. Participants were considered ineligible if they did not meet one or more of these criteria. Screening questions documented participants' first and last name, date of birth, street address, and e-mail address. These screening questions were used to identify and remove duplicate records. Participants reviewed consent information and study details at the beginning of the online survey, and consent was documented in Research Electronic Data Capture.^[20] Participants were provided remuneration in the form of a \$20 gift card after completion of the online questionnaire.

2.4. Study population

A total of 876 survey responses were collected, and 809 of the respondents met the inclusion criteria. However, 34 duplicate records were removed, and 21 responses were removed because no data past the eligibility screener was provided. A total of 754 responses were determined to be unique, non-duplicated responses and are included in the analytical sample. Descriptive demographics of the sample are presented in Table 1, showing frequencies, percentages, and standard deviations.

2.5. Instruments

Data was collected using an online survey with broad, open-ended questions. Participants' experiences of health care during the COVID-19 pandemic were collected by asking participants,

“Please tell us how has COVID-19 affected your overall health care (including ability to see a doctor or other health care provider and your ability to get needed medication)” and “Is there anything else you would like to tell us about how COVID-19 has affected your health care (including ability to see a doctor or other health care provider and your ability to get needed medication)?” In addition to the open-ended questions, survey questions were selected from validated sources, including the Behavioral Risk Factor Surveillance System^[21] and the PhenX Toolkit.^[22]

2.6. Analytic strategy

Survey responses were deidentified prior to analysis. Qualitative descriptive methods were used for the analysis of open-ended questions. The qualitative descriptive approach synthesizes participant experiences and perceptions while retaining the meanings attributed to them.^[23] Open-ended responses were reviewed by the first author who developed the initial codebook. Three additional qualitative researchers reviewed and refined the codebook using an iterative process. Analysis summaries were critically reviewed by the research team to ensure data and illustrative excerpts were categorized within the relevant thematic domain.^[24] The codebook was fully revised three times during analysis to better capture emergent themes. The research team reviewed all data, codebook versions, and excerpts to ensure data reliability, analytic rigor, and data saturation. All responses were coded using MAXQDA (version 2020), a qualitative data analysis tool developed and supported by VERBI software.^[25]

Representative quotes and thematic domains were discussed by the research team, and divergences were resolved using a consensus model. Typed responses are included verbatim, including errors in punctuation, spelling, and capitalization to ensure transparency with respondents' communicative choices. Quotes are organized under individual emergent themes; however, participant comments were multi-faceted, and individual responses often include multiple, interrelated experiences or meanings.

Table 1
Sociodemographics of the sample.

	Frequency	Percentage (%)	S.D.	Range
Age	754	47.38	16.31	18.2–90.6
18–29	112	15.36		
30–49	311	42.66		
50–64	177	24.28		
65+	129	17.70		
Sex	752	.71	.45	0–1
Women	531	70.42		
Men	221	29.31		
Race/ethnicity	747	1.99	.65	1–4
Black/African American	128	17.14		
White	526	70.41		
Other race or multiracial	61	8.17		
Hispanic/Latinx	32	4.28		
Income	620	2.09	1.19	1–4
<\$250K	281	45.32		
\$250K<0\$500K	133	21.45		
\$500K<0\$750K	72	11.61		
>\$750K	134	21.61		
Education	748	2.07	.80	1–3
High school or less	212	28.34		
Some college	265	35.43		
Four-year degree	271	36.23		
Rural-Urban Commuting Area (RUCA)	522	.72	.44	0–1
Non-metropolitan	142	27.20		
Metropolitan	380	72.80		

Note: S.D. = Standard Deviation

3. Results

Descriptive characteristics of the study sample are provided in Table 1. Nearly half (42.66%) of the participants in this sample are between 30 and 49 years of age. Participants were diverse, with 70.41% identifying their race and ethnicity as non-Hispanic White and 17.14% identifying as Black/African American. A majority of the participants identified as women (70.42%) and described their yearly income as \$50,000 per year or less (66.77%). More than a quarter of participants reported their education attainment as a four-year university degree (36.23%). The sample is diverse with regard to race and ethnicity but is over-representative of women compared to the population of Arkansas.¹²⁶¹

Qualitative results are presented in Table 2. Three primary themes emerged from the data. Participants recounted experiences of delayed health care, avoidance of health care, and experiences with telehealth during the COVID-19 pandemic. Experiences of delayed health care includes the extrinsic factors: care delays and scheduling difficulties. Avoidance of health care includes the intrinsic motivators to not seek care during the COVID-19 pandemic, as well as fear of COVID-19 and changed health-seeking behaviors. Finally, participants described both positive experiences and negative experiences with telehealth.

3.1. Delayed health care

3.1.1. Care delays Delayed health care was reported as a major barrier for participants, and participants described delays in health care as extrinsic factors directly linked to difficulties in gaining access to health care services. One participant recounted that she was “unable to go to primary care for annual exam or dental exam in the beginning of the pandemic.” Several participants reported issues with delayed primary and preventive care for “dental care” and routine or diagnostic procedures (such as “colonoscopies,” “physical therapy,” and “laboratory tests”). Dental care was frequently reported as being cancelled or postponed by providers, with participants stating, “I have not had normal dental checkups.” Participants reported preventive screenings were also disrupted: “I haven’t gotten all of my wellness procedures,” and “I am overdue a colonoscopy.” Not all delayed appointments were for preventive or wellness care, with some participants reporting that major procedures were also delayed by the COVID-19 pandemic. A participant described how her husband's knee replacement surgery was delayed, stating, “My husband has an infected knee replacement [and he was] delayed getting. . . surgery; we now have it scheduled (4 months later).”

3.1.2. Scheduling difficulties Participants described the availability of providers for appointments as the primary reason for delayed care. Participants expressed their concern with delays for potentially life-threatening medical issues. One participant stated, “I found out I have a particularly paralyzed diaphragm. Finding out if that is caused by cancer, nerve damage, heart damage, brain damage, or a tumor has been delayed because my doctor is needed to help with covid.” Another participant described a similar situation, stating, “My doctor was away [...] for two weeks and I had to push an appointment back 3 weeks during an insulin trial period.”

3.2. Avoidance of health care

3.2.1. Fear of COVID-19 Fear was a major theme reported by participants that resulted in a general avoidance of health care and of clinical settings during the COVID-19 pandemic. One participant described avoiding care because they were “scared to go to doctor because I’m scared to catch covid.” Another participant described their health care-seeking behavior during the pandemic: “I am terrified of the interactions so I am putting [seeing my doctor] off.” Another participant shared, “I want

go to the doctors office. I’m very scared of many things but [COVID] beats them all.” Participants also noted that local hospital capacities were a contributing factor to their fear and avoidance of care. One participant stated that he was “afraid to make appointments since hospitals are overwhelmed with covid-19 and [I] don’t want to be infected.”

3.2.2. Changed health-seeking behaviors Participants reported that a fear of exposure to COVID-19 was directly related to decisions to forgo or limit seeking health care, even when symptoms would have otherwise motivated them to health-seeking behaviors. One participant narrated, “Within the last week I was experiencing gut pain that would have taken me to a doctor pre-Covid. I chose to wait it out due to not wanting to be exposed in a doctor's waiting room.” Another participant described forgoing health care: “I avoid going into the doctor so I can avoid contact with other people. I have a severe abscess now because I put off seeing my doctor.” One participant described both avoiding and forgoing care. She stated, “Delayed annual cardiology and echocardiogram appointment by 4 months. I didn’t go to hospital for X-rays of foot injury because I preferred to avoid hospital.” Another participant described avoiding all types of “routine health care (dentist, eye doctor, mammogram, annual gyno visit) to limit my exposure to Covid,” while another noted only avoiding certain kinds of health care, with dental care commonly cited due to a perception of increased risk. One participant stated, “the only healthcare provider I have avoided seeing is a dentist because of the heightened risk of infection.”

3.2.3 Experiences with telehealth The rapid transitions to telehealth affected participants’ experiences of health care both positively and negatively. Some respondents characterized their telehealth experience as generally positive. One participant noted that their health was “better actually since I am doing video appointments.” Another participant cited the lack of exposure to COVID-19 as a positive aspect of their telehealth experiences: “Plus side .. have used Tele-Med appointment .. beats waiting in a room full of sick people.” A similar sentiment was echoed by another participant: “Telehealth appointments have been great. I have no wish to visit a clinic/Doctors office unless it is necessary during this outbreak.”

Not all patient experiences with telehealth appointments were positive. Some participants noted a general negative opinion of telehealth appointments, while others expressed extremely negative opinions of telehealth appointments. One participant stated that she “despised” telehealth. Another participant noted, “telehealth appointments does not seem as personal” when describing her experiences. Other participants stated, “It’s been hard to think about doing tele-health, because I feel like I needed to be in person with the doctor.”

Other participants reported frustration with the limitations of health care available through telehealth. One participant noted that specific forms of mental health therapy can only be conducted in-person and described her experiences with telehealth: “I have had to switch to Video Conference for my mental health sessions. I am no longer able to have eye movement desensitization and reprocessing therapy for my post-traumatic stress because this requires and in-person session.” Another participant noted, “since my biggest issue is asthma, it is not easy to manage via telehealth.” Diabetes management and monitoring was also reported as being difficult using telehealth systems. Participants noted that “in office visits with my primary care physician are not happening so other tests besides in home glucose are not being performed. Cannot get a current A1c or other test done.”

4. Discussion

This study documents patients’ experiences of health care during the COVID-19 pandemic using qualitative methods.

Participants described the impact of the COVID-19 pandemic on their health care in their own words. From this data, three primary themes emerged: delayed health care, avoidance of health care, and experiences of telehealth. Participants reported their experience with delayed care for primary and preventive care, including routine diagnostic and wellness procedures. This is consistent with the emerging literature on health care delays for primary and preventive care,^[1] dental procedures,^[27] cancer screenings,^[28] obstetric and antenatal care,^[5] colorectal screenings,^[29] dermatology,^[30] and physician-centered diabetes care.^[31] A critical finding of this study is the impact of appointment unavailability on care access. This is supported by previous research on health care rationing during the COVID-19 pandemic.^[32,33]

Within the primary theme of avoidance of health care, participants described fear of COVID-19 infection as the primary reason for changes to their health-seeking behaviors. Participants indicated that fear of COVID-19 influenced health care decision-making about routine/wellness care, preventive care, emergency care, and surgical interventions. This is consistent with studies finding that fear of COVID-19 affects health-seeking behaviors in adults^[34,35] and specifically in special populations, such as parents.^[36] Studies have found that large numbers of COVID-19 deaths were associated with proportional increases in mortality rates from other causes,^[37] and delaying or forgoing care is indicated as a major factor affecting these increases.^[1] Our findings expand on assessments of fear of COVID-19 and provide the first qualitative study of a diverse population that allowed participants to describe their concerns in their own words. Delays in care are especially concerning, as a recent study reported that the high number of COVID-19 deaths was associated with proportional increases in mortality rates from other causes as a secondary effect of the pandemic.^[37] Another recent study indicated delaying and forgoing care is a major factor increasing mortality rates.^[1]

Participants described a range of positive experiences with telehealth such as accommodating their desire to avoid clinical settings and risky contact with other patients or health professionals. These findings are critical in the context of the rapid transitions to telehealth during the COVID-19 pandemic. Our findings are consistent with research which recommends telehealth to avert overwhelming health care capacities during pandemic or disaster conditions,^[12,38] facilitating continuity of care and improving delivery of care during the pandemic.^[39]

Study participants also reported negative experiences with telehealth, citing a lack of personal engagement with their providers and the limitations of contemporary telehealth systems as primary issues. Participants stated that some procedures were impossible to conduct via telehealth modalities of care. These findings are consistent with prior research indicating that the inability to perform physical examinations is a major limitation of current telehealth systems.^[40,41]

5. Limitations and future research

There are some limitations to this study. Digital data collection methodologies allow for a larger number of respondents and greater anonymity for respondents; however, this method for qualitative data capture does not allow for follow-up questions or clarifying probes. This study is also limited by the use of an online survey which may exclude individuals who lack the economic or social resources to navigate the survey. Analysis of this study is limited by the timing of the survey during the second wave of the pandemic. These findings may not fully represent experiences of the pandemic more broadly. Further research is necessary to understand the effects of the pandemic on individual and community access to health care

during large scale disruptions. Additional research is needed to further explore patient experiences with pandemic-adjusted care and especially in exploring the applications of telehealth as it relates to both standards of care and patient satisfaction with health care.

6. Conclusion

This research provides insight into patient experiences with health care during the COVID-19 pandemic. It is imperative to explore barriers and facilitators to patient care during the pandemic, including both the extrinsic and intrinsic factors affecting health behaviors. This study provides insights into the barriers causing delayed or forgone health care.

Additionally, while telehealth is promising in preserving continuity of care during pandemics, long-term integration into the health care system is not without challenges, and this study provides insights into how patients experienced telehealth during COVID-19 in their own words. Going forward, health care leaders and policy makers will be charged with addressing the barriers and benefits of telehealth mentioned in this study, among others, and integrating telehealth into existing health care infrastructure in a medically safe, economically sustainable, and equitable way.

Author contributions

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